



ADVANCE CARE PLANNING AFTER STROKE

An interventional pilot study exploring the delivery of advanced care planning to stroke survivors

Melanie Malpass

BSPath, MHIthSc (Stroke Speciality)
Senior Speech Pathologist
Aged Care and Rehabilitation Taree



Health
Hunter New England
Local Health Network



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Acknowledgements

This project was supported by the NSW Health Education and Training Institute (HETI) through the Rural Research Capacity Building Program.

The author wishes to express her gratitude and sincere appreciation to the following people who have been essential to the completion of this project:

Kerith Duncanson and David Schmidt, Rural Research Capacity Building Program Officers, Health Education and Training Institute (HETI) – for their wonderful support, encouragement, patience and advice throughout completion of this research.

Dr Heidi Janssen, Research Associate and Conjoint Lecturer, Hunter Stroke Service, University of Newcastle and Hunter Medical Research Institute – your ongoing advice, support and mentoring has been invaluable.

Hunter Stroke Service, particularly Louise Jordan (Manager) and Dr Di Marsden (Manager, Professional Development and Education) for your greatly appreciated support and funding to complete this project and further improve my research skills.

Aged Care and Rehabilitation Service Taree, especially Jo Varley (Health Service Manager) and Murray Hair (Allied Health Manager) – for your positivity and support of my participation in the Rural Research Capacity Building Program.

The staff at Wingham Rehabilitation Hospital, for their collegial support and assistance with data collection for this project.

Abbreviations

- Advance Care Planning (ACP)
- Functional Independence Measure (FIM)
- Hospital Anxiety and Depression Scale (HADS)
- Human Research Ethics Committee (HREC)
- Montreal Cognitive Assessment (MOCA)
- Modified Rankin Scale (MRS)
- Personal Wellbeing Index - Adult (PWI-A)
- Western Aphasia Battery (WAB)

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Abstract

Aim

One third of patients with stroke will die within a year, however their wishes for treatment are commonly unknown. Advance care planning (ACP) can facilitate appropriate treatment and reduce low value healthcare. The best method for delivering ACP in stroke is unknown. This study aimed to determine if face to face ACP compared to usual care could improve documentation, communication and awareness of stroke survivor wishes around end of life care. The impact of conducting face to face ACP upon patient mood and wellbeing was also assessed.

Method

An interventional pilot study with non-randomised control was conducted in a rural rehabilitation unit. Twenty one participants were recruited and allocated to control (n=12) or intervention (n = 9) conditions using time sampling methods, over four months each. The control received usual ACP practices and the intervention received a face to face ACP session during their admission. Primary outcomes of communication and documentation of patient wishes were assessed using the Advance Care Planning Audit Questionnaire. Mood was assessed using the Hospital Anxiety and Depression Scale, and wellbeing with the Personal Wellbeing Index for Adults. Data was analysed with independent samples t-tests for continuous variables, Fisher's Exact Test for categorical variables and Mann Whitney U for non-parametric variables.

Results

Groups were comparable for baseline and stroke related characteristics. There was a statistically significant difference in patient reported (p=0.001) and documented (p<0.001) ACP, along with communication with health providers about previous ACP (p<0.001), personal values (p<0.001) and life sustaining treatments (p<0.001). There was no significant difference in anxiety (p=0.986), depression (p=0.179) or wellbeing (p=0.101) between groups.

Conclusion

The delivery of face to face ACP with stroke survivors was more effective in achieving documentation, communication and awareness of end of life wishes compared to usual care. The process did not have adverse effects upon depression, anxiety or wellbeing.

Implications

This study showed that face to face ACP is both acceptable and feasible during rehabilitation for stroke survivors. This could ultimately improve awareness and clinical documentation around the future care wishes, ensuring that end of life care is valuable and patient centred. This pilot study will inform the intervention of the larger Plan, Assess, Understand Survival: After Stroke study.

Keywords Advance Care Planning, Stroke, Palliative Care, Affect, Communication, Documentation, Wellbeing



Executive Summary

Background

In Australia, a third of patients who suffer from stroke will die within a year (1). There is a high burden of care associated with stroke and those who survive are at increased risk of re-presenting to hospital with life threatening complications. The use of Advance Care Planning (ACP) can significantly reduce unwarranted, low value healthcare and ensure that personal values and dignity are maintained(2).

In hospital records ACP is frequently absent (3, 4) and the burden of decision making falls upon family, friends and health providers. Exploration of engagement barriers to ACP in stroke indicates that these can range from lack of understanding and urgency to a desire to focus upon recovery rather than decline (5). The best method of ACP delivery and the personal impacts of the process upon stroke patients is currently unknown.

Context

This study was carried out at a small rural rehabilitation hospital in Wingham, on the Lower Mid North Coast of the Hunter New England Local Health District. Patients in rural areas admitted with stroke have poorer health outcomes and are more likely to die in hospital than their metropolitan counterparts (6), yet

are also less likely to access services where ACP is traditionally accessible. It is therefore important to address the best mechanisms of ACP not only in stroke specific populations, but also in rural areas.

Approach

An interventional pilot study with non-randomised control group was conducted to determine if face to face ACP with stroke survivors was more effective than usual care in achieving documentation, awareness and communication of end of life wishes. The impact upon mood and wellbeing was also assessed. This study included a developmental phase with surveys to stroke survivors and clinicians used to explore the essential elements of ACP, and the acceptability of using telehealth to include significant others in the ACP process. Participants admitted to rehabilitation after a recent stroke were screened for eligibility and invited to participate in the study. Participants admitted between May to September 2016 were allocated to a usual care group, and those admitted from October 2016 to February 2017 received a face to face ACP intervention. Quantitative data was collected from file audits and outcome measures auditing patient reported ACP, mood and wellbeing.

Results

This pilot study highlighted several key findings which have implications for the delivery of ACP in stroke. In summary:

- Face to face sessions were significantly more effective in achieving patient reported ($p=0.001$) and documented ACP ($p<0.001$), along with communication about personal values ($p<0.001$) and life sustaining treatments ($p<0.001$) with health providers.
- There was no significant impact on legal nomination of a decision maker ($p=0.673$) or consideration of life sustaining treatments ($p=0.104$) as many patients had already engaged in these elements.
- There was no significant difference in anxiety ($p=0.986$), depression ($p=0.179$) or wellbeing ($p=0.101$) for those who received face to face ACP versus usual care.
- Stroke survivors and clinicians identified differing ACP elements considered to be of high importance.
- Stroke survivors frequently (77.8%) declined the involvement significant others in face to face ACP sessions.
- Ongoing barriers to the use of telehealth were identified by clinicians and the

technology was available but not utilised during this study.

Further Research

Extend to include qualitative component

The addition of a future qualitative component to this study would provide insight into patient barriers around including of significant others in the ACP process.

Replicate with larger sample size

It is recommended that the next stage of this study include a larger sample size to determine if results can be maintained in the larger stroke population and across multiple sites. Applicability of findings to patients suffering from health conditions of a similar profile may also be considered (for example, traumatic brain injury).

Publication

This report will be publicly available on the HETI website and distributed to relevant stroke professionals. Data will be used to inform the education component of the larger Plan, Assess, Understand Survival: After Stroke Service. Research papers will be submitted to appropriate journals for potential publication.

Conclusion and Implications

Face to face Advance Care Planning is effective with stroke survivors.

In comparison with usual care practices, a single face to face session achieved dramatically improved documentation, communication and awareness around future care wishes.

Advanced Care Planning did not have negative emotional impacts.

The completion of an Advance Care Plan during inpatient rehabilitation appeared to be acceptable to stroke survivors and was not detrimental to mood or wellbeing.

Communication and cognitive deficits did not prevent involvement in Advance Care Planning.

Stroke survivors with deficits in language, speech and cognition could participate in Advance Care Planning, provided that comprehensive assessment was undertaken by a multidisciplinary stroke team.

Stroke survivors and clinicians may value different elements of an Advance Care Plan.

Differences between medical versus value based approaches to end of life decision making should be considered in Advanced Care Planning documentation.

Further exploration into engagement barriers for involving significant others is warranted.

This may help to improve future advance care planning processes within and beyond stroke populations.

Introduction

Stroke is one of the largest killers and a leading cause of permanent disability in Australia. In 2015 Australians suffered from one stroke every 10 minutes and the number of people suffering from the devastating impacts of stroke is predicted to increase in the years to come (7).

The diagnosis and management of stroke is improving with significant advances made in preventative and restorative treatments. Despite these advances, 12% of stroke patients will die in the first week after stroke, 19% in the first month and a third in the first year (1). It is also recognized that approximately 40% of patients who suffer from a first stroke, will go on to have another potentially life threatening stroke event within 10 years (8).

Australia's National Stroke Foundation recommends that a palliative approach be integrated into the care of patients dying after a stroke (9). Despite these recommendations, little information is

available to inform what such care should be like for stroke patients and their families, and how this should best be incorporated into health practice (9).

For those patients who survive an initial stroke event but remain at risk of future complication, the use of Advance Care Planning is a vital component to ensuring that care is consistent with the individuals' wishes and values. There has been limited exploration into the mechanisms through which Advance Care Planning can be best implemented in stroke populations and the impacts that this may have on patients recovering from a devastating and unexpected life event.

This report describes an interventional pilot study aiming to explore the essential elements of advance care planning, the most effective mechanisms of delivery and the personal and emotional impacts of completing an advance care plan after a stroke.



Background

Why is Advance Care Planning Important?

Advance Care Planning (ACP) is a process of communication between patients, their significant others and health providers to understand, discuss and plan ahead for future healthcare management. There are many models of ACP currently in use however the core elements of this process commonly include; consideration for medical interventions, personal values, involvement of family and friends, and individual preferences around care in the event of chronic or life threatening illness (2). This process is particularly important in delivering care that respects personal values, maintains dignity and reduces low value healthcare in the dying patient.

Advance Care Planning is particularly relevant for patients who may be frail and elderly, have chronic disease or multiple health issues that may increase the risk of medical complication and death. Stroke is often sudden and unexpected, resulting in the provision of hospital care and rapid decision making for patients who have not previously considered their wishes. As stroke is not only unanticipated but fatal to approximately a third of patients within 12 months (1) of the initial event, this is a vital population to target for future ACP.

End of Life Care in Stroke

Research regarding the end of life care needs of stroke survivors and their families is sparse. Studies exploring the challenges of providing emergency care in stroke indicate that the wishes of patients regarding the use of life prolonging interventions such as resuscitation and artificial nutrition are often unknown (10). This makes it difficult for health professionals and families to make these decisions urgently, and to be consistent with the personal values of each patient. The limited existing literature around the family experience of death of a loved one after stroke indicates a need for improved communication with health service providers (11), and a more collaborative approach for decision making during end of life care (12).

Health providers report an absence of core values around palliation in stroke, difficulty integrating acute with palliative care and in early identification of the palliative patient (13). Due to lack of a coordinated approach, specialist palliative care service providers are not routinely involved with patients who have suffered from a stroke (14). There is also a noted absence of common practice in the cessation of medical interventions and the provision of appropriate symptom management to improve the comfort of the dying stroke

patient (15). The combination of these factors make it difficult for health service providers to decide when and how to transition from providing acute or rehabilitative care to palliation, and to deliver care consistent with individual values.

What are the current barriers for Advance Care Planning in stroke?

The prevalence of ACP in stroke populations has not been specifically measured, however there has been assessment of comparable populations. Evaluation of the medical records of acute elderly and general rehabilitation inpatients show a complete absence of ACP (3, 4). Similarly, patients with chronic long term conditions have reported experiencing some elements of care planning in their health service contacts, but the absence of a structured, in-depth process or comprehensive record of this information (16).

Engagement barriers for stroke survivors participating in ACP have been identified and include; a perceived lack of urgency to plan for future decline, poor communication with health providers and a lack of understanding around ACP (4). The timing of ACP discussion is also an identified barrier, as many patients wish to maintain a focus upon recovery (5). Similarly health providers report barriers to engaging in ACP, which commonly include discomfort with discussing end of life and uncertainty around roles and responsibilities (5).

There are many challenges identified around the delivery, timing and documentation of ACP however when appropriately completed ACP is recognized as both effective in meeting patient end of life preferences, and positively impacting quality end of life care (17, 18).

Advance Care Planning in rural stroke populations

The importance of ACP is heightened for patients treated for stroke in rural hospitals, as this group has poorer health outcomes, greater odds of dying in hospital and a higher dependency after discharge (6). Rural stroke survivors are at a higher risk of complication yet are identified as having less access to health services where ACP may be traditionally discussed, such as specialist palliative care or via regular consultations with a general medical practitioner (19). This group is therefore less likely to present to hospital with a documented ACP which has potential to result in delivery of unwarranted interventions that are against patient wishes and cause unnecessary harm.

ACP with rural and remote stroke survivors may be hindered by geographic isolation which limits involvement of significant others in decision making alongside health providers. The importance of the role of family in end of life care has been emphasized (12), as these individuals are often asked to make complex and emotionally difficult health decisions when their loved one is unable.

The use of Telehealth as a mechanism to connect patients, families and clinical teams for advanced care planning post stroke has not yet been explored. To address the issue of geographic isolation projects involving Telehealth are currently underway in the Australian palliative care field. For example, the Decision Assist Project is one which aims to connect aged care nurses and general practitioners to specialist services to assist with palliative symptom management. Telehealth could be considered as a feasible option to include significant others in ACP decision making in cases where they would typically be excluded.

The best format and delivery of Advance Care Planning

In order to capture those patients who survive an initial stroke but remain at risk of death or complication due to chronic illness, ACP should be an important part of post stroke service delivery. There is currently no consistent and clear format for ACP delivery reflected in the literature, and there are no specific recommendations for stroke populations.

consider how ACP could be best delivered and what aspects of this planning are important for patients, significant others and health providers.

Pilot research in Australia has indicated that face to face ACP interviews with elderly inpatients appear to be a feasible and acceptable mechanism to commence discussion around end of life preferences (4). The literature regarding the best timing for ACP remains conflicted however exploratory research has indicated that hospitalised patients have higher engagement in ACP than patients in other settings, reflected by increased readiness and knowledge (20). Specifically tailored ACP research and resources are required to determine how to best facilitate this process in a range of unique clinical settings, and particularly those in rural and remote areas.

Objectives



The primary objectives of this study were to assess the impact of face to face Advance Care Planning with stroke survivors compared to usual care on:

1. Documentation, communication and awareness of future medical and end of life care wishes.
2. Mood and wellbeing.



The secondary objectives were to determine the essential elements of a stroke specific Advance Care Plan and the potential to include Telehealth in this process.

Methods

Design

This interventional pilot study with non-randomised control had two phases;

1) Developmental: which explored the essential elements of ACP and the acceptability of using Telehealth in this process.

2) Interventional: assessing the effectiveness of delivery and the personal and emotional impacts of completing ACP during inpatient stroke rehabilitation.

Sample Size Calculation

A sample size of 30 participants was targeted to explore the research question in this pilot study. This was based upon study time constraints and the number of patients annually admitted to the unit.

Setting

The study was conducted at Wingham Hospital, a 16 bed rural rehabilitation unit located within the Hunter New England Local Health District. This site has an average of 39 stroke admissions annually (reported from Australian Rehabilitation Outcomes Centre data 2013-2015).

Participants

Developmental Phase

To inform the ACP intervention and possible use of Telehealth, exploratory data was collected from two groups who

were separate from intervention subjects:

Stroke Survivors: Identified from Wingham Hospital admissions data of all strokes in 2015, with quota sampling utilised to include mild, moderate and severe stroke severity groups.

Clinical Staff: All staff working at the primary study site and local stroke unit.

Intervention Phase

After the developmental phase, participants were recruited based upon current admission to rehabilitation unit.

Inclusion Criteria

- Adult patients ≥ 18 years admitted for rehabilitation after a stroke.
- Stroke onset ≤ 16 weeks ago.

Exclusion Criteria

- Severe impairment of cognition assessed as <10 on the Montreal Cognitive Assessment (MOCA).
- Severe impairment of language function assessed as <25 on the Western Aphasia Battery (WAB).
- Pre-morbid conditions or medical complications which impact capacity for decision making (for example, dementia, reduced consciousness).
- Patients determined by the multidisciplinary team as not having decision making capacity.

Assessment of Eligibility

The study was conducted from May 2016 to February 2017. The lead researcher reviewed all stroke survivors admitted for rehabilitation at the unit for eligibility.

Recruitment and Consent

Patients were admitted per routine procedure and identified for eligibility. Patients were invited to participate by a member of staff not providing direct clinical care, using a recruitment script. A participant information handout was provided and time was given for patients to consider the study information and ask questions. An aphasia friendly consent process was also developed and utilised for patients presenting with language impairment. Following consent via the written form or aphasia friendly process, patients were allocated to a control or intervention group.

Time sampling methods were utilised with group allocation depending on the timing of admission (Control Group: May 2016 – September 2016, Intervention: October 2016 – February 2017). This sampling methodology was employed to prevent any contamination of the intervention between groups in a small, shared ward environment and was time-limited by the study completion date of March 2017.

If patients chose not to participate, routine care was provided and there was no disadvantage as there is no current best practice evidence for ACP in stroke.

Interventions

Patients recruited to the intervention phase of the study were allocated to two groups:

- The control group received standard site ACP procedures which may have included a Hunter New England Local Health District Resuscitation Order and Advance Care Form completed at the discretion of the Chief Medical Officer/Care Coordinator.
- The intervention group received standard site procedures in addition to a face to face ACP session of approximately 30 minutes in duration with the lead researcher. During this session participants discussed and could complete the ACP Toolkit, which was created during the study's developmental phase.

Clinical Documentation of ACP

Consent was obtained from the intervention group participants to include a copy of the completed ACP toolkit in their medical records. The original document was given to participants as a record of the discussion, and to prompt conversation with family and their general practitioner. Participants were made aware that their ACP could change at any time, and was not a formal legal document. In the event of requiring further medical or legal clarification, participants were linked with the site medical team or local legal advisors.

Ethical ACP for the Control Group

Participants recruited to the control group could access the intervention following completion of data collection if desired. This was explained in the participant information statement and accessible by informing the lead researcher.

Involvement of Significant Others

All participants who completed an ACP were encouraged to indicate any significant others they would like to be present at the face to face session. Telehealth resources were made available to include any relatives and friends unable to be personally present.

Emotional Wellbeing and Support

All participants were monitored for significant changes in mood during the study. Abnormal scores (>8) on the Hospital Anxiety and Depression Scale, or emotional distress were followed up by the site Social Worker. In the event of evident distress, data collection and the intervention was to be ceased.

Outcomes

Developmental Phase (Secondary Aims)

- 1) To explore the elements that stroke survivors and clinicians feel are important to include in ACP.
- 2) To determine if the use of Telehealth is feasible for involving geographically removed significant others in the ACP process.

Intervention Phase (Primary)

- 1) To assess the impact of delivering face to face ACP to stroke survivors upon documentation, communication and awareness of patient preferences around end of life care, compared with usual care.

- 2) To determine the effect of face to face ACP on patient mood, compared with usual care.

- 3) To determine effect of face to face ACP on patient wellbeing, compared with usual care.

Data Collection

Developmental Phase

Data was obtained from the stroke survivor group via mailed paper surveys with return addressed and stamped envelopes. The clinician group received surveys via email link to select survey. Separate surveys were developed and tailored to each group (appendices 1 and 2). Survey questions focused on the important elements of ACP and determining the feasibility of using Telehealth technology to maximise inclusion of significant others in the intervention. A combination of multiple choice, 5 point Likert scale and open ended responses were included.

Developmental phase data was utilised to develop the ACP Toolkit for the intervention. The data was also used to gain a better understanding of current practices and attitudes to Telehealth use with ACP.

Intervention Phase

At recruitment the baseline demographic data of all participants was collected via file audit and included; gender, age, aboriginality, living arrangements, stroke type, FIM, pre stroke and discharge MRS, cognition and communication.

Primary outcome measures were collected 7 (+/- 2) days prior to hospital discharge in both the control and intervention groups. Measures included:

- Participant report of ACP experiences was measured using the modified Advanced Care Planning Audit Questionnaire (21),
- Evidence of a documented advance care plan collected with a medical record audit (present/absent),
- Personal well-being measured by the Personal Wellbeing Index for Adults (PWI-A),
- Mood measured by the Hospital Anxiety and Depression Scale (HADS).

Data Analysis

Developmental phase data and eligibility screening was captured via select survey online, with coded results exported into excel for descriptive data analysis. Interventional phase data was collected via paper forms and then de-identified and coded into an excel spreadsheet by the lead researcher. Data was exported from excel and analysed in SPSS V22.

The characteristics of participants were analysed to confirm similarity between the control and intervention groups. Independent t-tests were utilised for continuous variables and Fisher's Exact Test for categorical variables. Descriptive comparison of participant data with National Stroke Audit Rehabilitation Services Report (22) was undertaken to establish clinical similarity of the study group with the wider stroke population.

The primary ACP outcome was measured with seven dichotomous (yes/no) responses on the Advanced Care Planning Audit Questionnaire. The eighth item was excluded from analysis as this was an open-ended question asking for suggestions about improving ACP, however participants instead made more general suggestions for the unit. For comparison between groups, Fisher's Exact Test was used for each item, and chosen due to the small sample size along with expected variables <5. A p-value of $p < 0.05$ indicated a statistically significant difference in the described elements of ACP between groups.

A dichotomous (present/absent) measure of documented ACP in participant medical records was collected to support questionnaire data, and similarly analysed with Fisher's Exact Test.

The measure of Total Subjective Wellbeing was calculated by taking a mean of the seven domain scores of the PWI-A, as per the scoring guide. Scores of anxiety and depression were yielded from the HADS record a score of 0-21 (0-7 Normal, 8-10 Borderline, 11-21 Abnormal). For comparison between groups, independent t-tests were used with equal or unequal variance determined by Levene's Test.

Ethical Approval

Approval was given by the Hunter New England Local Health District Human Research Ethics Committee, No: 15/12/16/4.05 on 11th March 2016. The Site Specific Assessment, No: SSA/16/HNE/83 was granted 23rd March 2016.

Patient Flow

Developmental Phase

Thirty paper surveys were distributed via post to stroke survivors who were identified from hospital admission data. Quota sampling was used to include stroke survivors from mild (n=10), moderate (n=12) and severe (n=8) groups.

Email surveys were circulated to 40 staff across two sites, consisting of Allied Health, Nursing and Medical clinicians.

Intervention Phase

Twenty-five potential participants were identified during the study period and screened for eligibility. Of the 23 identified as eligible, 21 consented to participate (see *figure 1, patient flow*). The primary reason for exclusion was the presence of severe language or cognitive deficit preventing sufficient decision making capacity for ethical inclusion in the study (n=2). Stroke survivors who declined to participate provided the reasoning of maintain a recovery focus or not wishing to consider the possibility of future illness.

Numbers Analysed

Developmental Phase

Of the 30 surveys distributed to stroke

survivors, 12 were returned, a response rate of 35%. Responses were coded by the lead researcher into excel. Fifteen email surveys were returned via select survey from clinicians across two sites, a response rate of 37.5%. Four sets of survey data were excluded due to multiple missing fields, with 11 full sets exported into excel for descriptive analysis.

Intervention Phase

The sample (table 1) included full data sets from 21 participants, with 12 allocated to usual care conditions and 9 allocated to receive a face to face ACP intervention (*figure 1*). The primary and secondary outcomes were measured by analysing data from the 12 control and 9 intervention participants, with no further exclusions.

Demographic Patient Data

There were no statistically significant differences between groups in demographic or stroke characteristics. The average disability level was slight to moderate, with an average MRS of 2.54 for both groups. On average participants displayed a mild degree of cognitive impairment with an average MOCA of 21.3. Both groups included participants with communication impairment (*figures 4 and 5*).

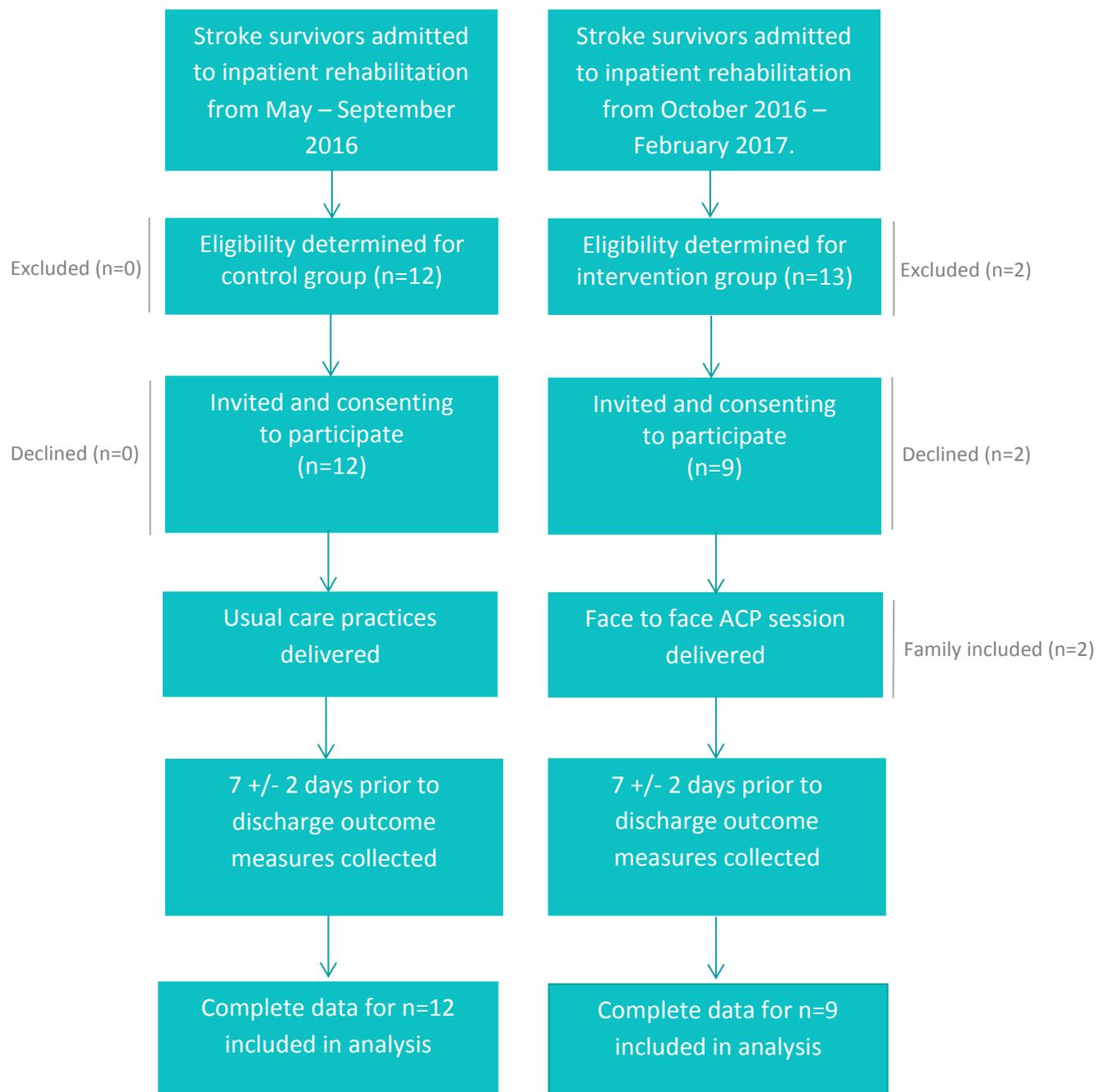


Figure 1: Patient flow chart for the intervention phase of the Advance Care Planning in stroke study.

Developmental Phase

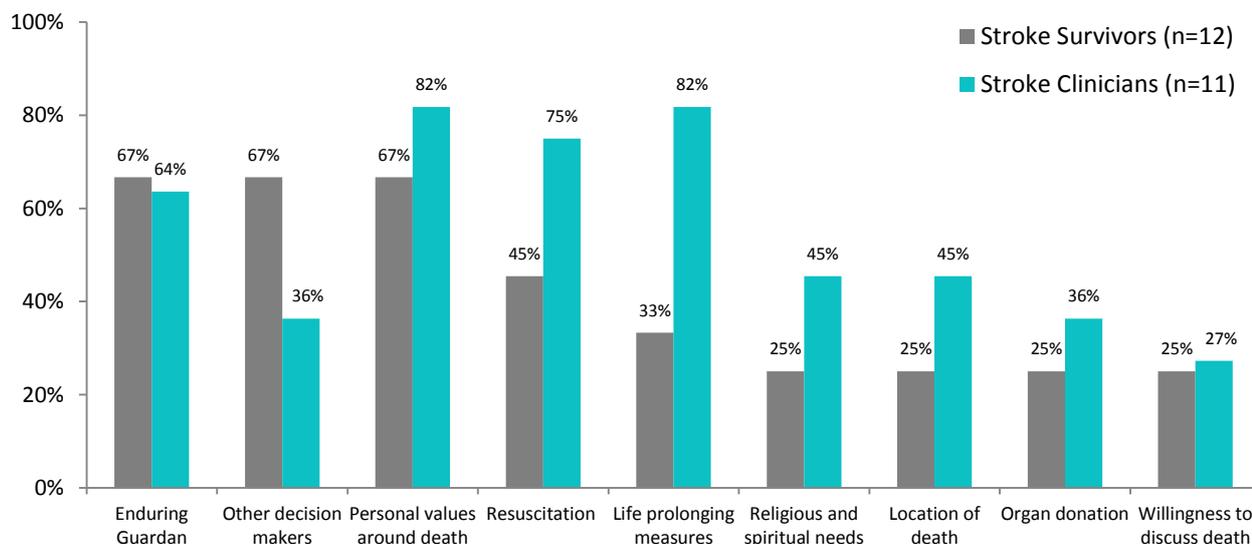


Figure 2: Elements of Advance Care Planning rated very important, by clinician and stroke survivor groups from surveys in the Advance Care Planning after stroke study.

Exploratory data revealed mixed responses from clinicians and stroke survivors in relation to the importance of various elements of ACP. The items rated very important did however highlight greatly differing responses between the two groups.

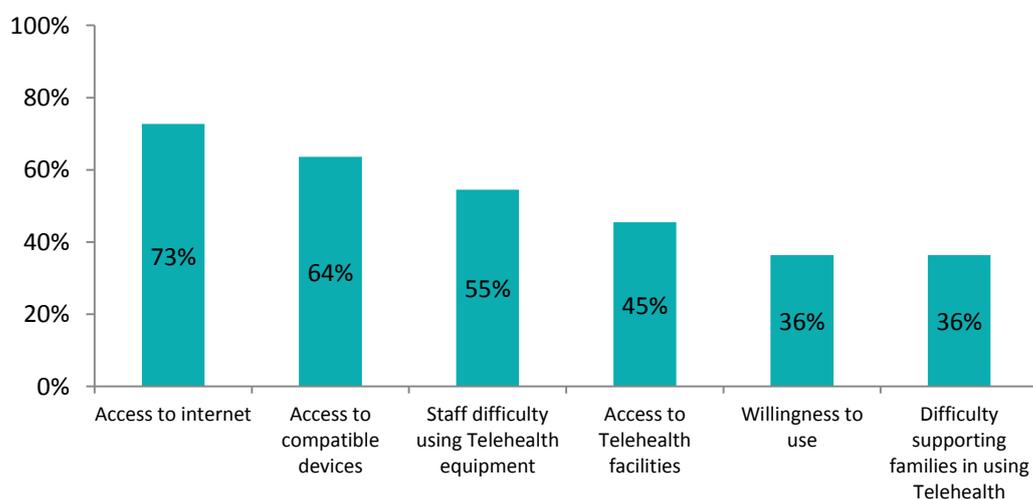


Figure 3: Clinician identified barriers to the use of Telehealth in ACP, from surveys in the Advance Care Planning after stroke study.

Thirty-three percent of stroke survivors felt that Telehealth could be a useful for involving significant others in ACP. In contrast 54.5% stroke clinicians felt Telehealth could be a useful inclusion but also reported a range of barriers to uptake (Figure 3).

Intervention Phase

Table 1

Patient characteristics in the Advance Care Planning after stroke study

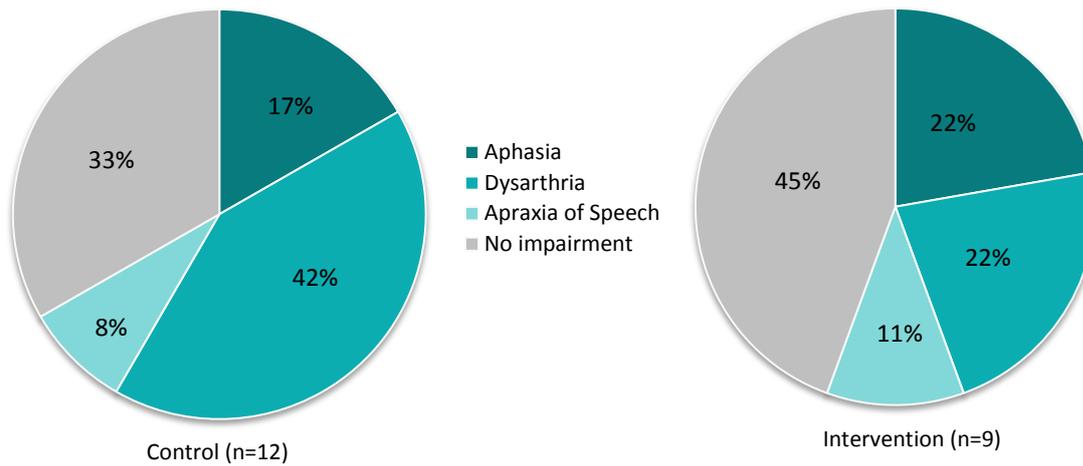
Variable	Total (n=21)	Usual Care (Control n=12)	Face to Face ACP (Intervention n=9)	P-Value
Demographic				
Age: mean (SD)	74.43 (SD 10.97)	73.25 (SD 11.38)	76 (10.86)	p=0.583
Female % *	38 (8)	25 (3)	56 (5)	p=0.203
Stroke Characteristics				
Hemisphere of stroke: % left *	48 (10)	42 (5)	56 (5)	p=0.670
Communication Impairment % *	62 (13)	67 (8)	56 (5)	p=0.673
Pre-Morbid Disability (mean MRS) [∞]	0 (IQR 0-1)	0 (IQR 0-0.25)	0 (IQR 0-1)	P=0.393
Disability at Discharge (mean MRS) [∞]	3 (IQR 2-3)	3 (IQR 2-3)	3 (IQR 2-3)	p=0.620
Cognition (mean MOCA) ^λ	21.3 (SD 4.97)	20.91 (SD 6.24)	21.91 (SD 2.14)	p=0.631
Functional Independence (mean FIM)	101 (SD 13.66)	104.08 (SD 11.59)	96.89 (15.77)	p=0.242

^λ 3 participants with missing MOCA data due to aphasia impacting validity, 1 control and 2 intervention.

* Fisher's Exact Test, all others independent t-test.

[∞] Mann Whitney U Test used for ordinal, abnormally distributed data.

For comparison to the wider stroke population; the reported mean age across Australia is 76 (IQR 66-84), 44% of patients are female and 30% have diagnosed aphasia. The median FIM score at discharge is 105 nationally (22).



Figures 4 and 5: Communication impairment by participant group within the Advance Care Planning after stroke study

Table 2

Advanced Care Planning Audit Questionnaire by group during the Advance Care Planning after stroke study

Variable	Usual Care (n=12)	Face to Face ACP (n=9)	Total (n=21)
Advance Care Planning Audit Questionnaire	Yes (frequency, %)	Yes (frequency, %)	p-value
Participant reported a documented Advance Care Plan	3 (25)	9 (100)	p=0.001
Participant reported being asked if they had a previous Advance Care Plan on this admission	1 (8.3)	8 (88.9)	P<0.001
Participant reported being asked about their values around future healthcare treatment on this admission	1 (8.3)	9 (100)	P<0.001
Participant formally designated a health decision maker (enduring guardian)	8 (66.7)	5 (55.6)	p=0.673
Patient has considered types of life sustaining treatment they would/would not want	8 (66.7)	9 (100)	p=0.104
Participant reported being asked about preferences for life sustaining treatment on this admission	0 (0)	9 (100)	P<0.001
Participant reported information provided about supports available in the event of life threatening illness.	2 (16.7)	0 (0)	p=0.486

Table 3

Documentation of Advance Care Plan in medical record in usual care versus intervention groups of the Advance Care Planning after stroke study.

Variable	Usual Care (n=12)	Face to Face ACP (n=12)	Total (n=21)
Medical Record Audit	ACP present (frequency, %)	ACP present (frequency, %)	p-value
Documented Advance Care Plan in medical file	0 (0)	9 (100)	P<0.001

Table 3

Mood and wellbeing in usual care versus intervention groups of the Advance Care Planning after stroke study.

Variable	Usual Care (n=12)	Face to Face ACP (n=9)	Total (n=21)
Hospital Anxiety and Depression Scale	Mean (SD)	Mean (SD)	p-value
Anxiety	5.08 (3.55)	5.11 (3.59)	p=0.986
Depression*	2.33 (1.97)	4.44 (4.07)	p=0.179
Personal Wellbeing Index - Adult	Mean (SD)	Mean (SD)	p-value
Total Subjective Well-being Score	77.14 (9.04)	84.76 (11.23)	p=0.101

* Independent samples t-test with equal variances not assumed as significant difference found on Levene's Test. All other items have equal variance assumed.

Discussion

This pilot study was the first to the author's knowledge to explore the mechanisms of ACP delivery in a stroke specific population and to consider the impacts that this process may have upon stroke survivors. The results from 21 participants demonstrate that the delivery of face to face ACP was significantly more effective than usual care in achieving clear documentation, awareness and communication of end of life wishes. There was no significant change in formal nomination of decision makers or consideration of life sustaining treatments, as many participants had previously engaged in these elements. The ACP process with stroke survivors during inpatient rehabilitation did not significantly impact anxiety, depression or wellbeing.

Results support existing literature which describes an absence of comprehensive ACP discussion and documentation during usual inpatient care (3, 4). Although more than 60% of patients in usual care conditions had considered their own wishes for the future, written documentation of this prior to hospital admission was uncommon and very few patients were asked about their wishes as part of routine admission procedures. The delivery of a one-off, 30 minute intervention guided by a paper based ACP toolkit considerably increased documentation, discussion and awareness of future care wishes between stroke

survivors and health service providers.

Previous literature has addressed the engagement barriers for ACP in stroke populations including the concept of a recovery focus during rehabilitation (5). This concept was echoed in the reasons for declining for a small (n=2) number of participants within this study. The priorities and focus of stroke survivors during rehabilitation in combination with the emotional impacts of a life changing event were essential to consider in the timing and anticipation of possible adverse impacts of an ACP intervention. Within this study the delivery of the ACP intervention did not significantly impact anxiety or depression in stroke survivors. Similarly, there was no significant difference in subjective wellbeing for those who received the intervention. The absence of negative impacts upon mood and wellbeing suggest that timing delivery of ACP prior to discharge from rehabilitation is acceptable and not harmful to stroke survivors.

This pilot study is one of few to include people with communication impairments, including aphasia – a population often excluded from both ACP and broader stroke research. On a practical level this study demonstrates that people with communication impairments can be included in ACP, with the use of appropriately targeted resources and following comprehensive input from a

multidisciplinary stroke team. Participants within this study also presented with a mild degree of cognitive impairment post stroke and were successfully included, after having careful consideration of cognitive function versus decision making capacity from the stroke team. This suggests that the presence of cognitive change post stroke is not an automatic reason for exclusion from ACP.

The developmental phase of this study examined the values of stroke survivors and clinicians around ACP to develop a holistic toolkit. Descriptive data from surveys exploring the essential elements of ACP indicated differing values between stroke survivors and clinicians. Clinicians placed higher importance upon the interventional elements of end of life care such as cardiopulmonary resuscitation (CPR) and life prolonging measures, whilst stroke survivors rated formal and other nominated decision makers as important elements. This difference may reflect a lack of patient understanding around life prolonging measures such as CPR or that stroke survivors place greater value on others making decisions about interventions delivered at the end of their life. It is also therefore possible that the content of ACP offered to patients may impact engagement, as many of the existing documents focus upon specific medical interventions which may not be well explained or understood. Both groups rated personal values around death and disability with high importance therefore the ACP toolkit developed for this study was value based to provide a guide for medical intervention.

Secondary aim (ii) of the study was to explore the acceptability of using Telehealth technology to involve significant others in the ACP intervention. Approximately a third of stroke survivors felt that this technology may be useful to use with ACP. Just over half of stroke clinicians felt telehealth could be useful within ACP however identified multiple barriers to uptake. As a result of this finding, Telehealth was not built into the intervention but was still offered to participants. Despite the availability of the technology, telehealth use was declined by all nine intervention participants.

Within this pilot study the intervention group were invited to include family or friends in face to face ACP sessions. It is a point of interest that only two participants, both of whom were aphasic chose to include significant others. The remaining participants indicated that they wished to attend the session alone and acknowledged that the topic matter would be confronting or uncomfortable to discuss with family present. All participants took written copies of their completed ACP to share with family or store in an accessible location should they become unwell. This observation within the study may warrant further exploration via a qualitative research methodology to explore the reasons for excluding family from the process, despite results from the developmental phase indicating that having nominated decision makers was very important to stroke survivors.

Strengths and Limitations

The strengths of this study are that it is the first to consider the ACP processes specifically tailored to a stroke population including the impact of the process itself upon patients. The study provides insight into the practical elements of delivering ACP in stroke. Despite the small sample, there were strong effect sizes demonstrated for the outcomes of ACP documentation, discussion and communication of end of life wishes with no adverse effects for those included in the intervention. These results suggest that further exploration with a larger sample size is warranted. This pilot will therefore be used to inform the intervention of the ongoing, larger Plan, Assess, Understand Survival: After Stroke (PAUSe) study which is being conducted across Hunter New England Local Health District in 2017-18.

This pilot study is limited by its small sample size and subsequently a participant group who may not represent that larger stroke population. The mean age of 74.43 years across groups is comparable with the national age of 76 years. Although the result was not significant, there was a higher proportion of females and lower functional independence in the intervention group compared to the control and national averages. Gender based differences in both the approach used and reaction to an ACP discussion should be considered, along with the possibility that ACP could be more acceptable in patients with less functional independence.

There are methodological limitations to this study due to the inability to randomise because of the study environment and potential for bias due to the absence of blinding during the data collection and analysis processes.

Conclusion

This study demonstrated that face to face Advance Care Planning with stroke survivors using a tailored toolkit had a significant effect upon documentation, awareness and engagement in communication with health providers around end of life wishes. This was evident from both medical record audits of Advance Care Plan documentation and questionnaire responses from stroke survivors around Advance Care Planning processes.

This study is the first to consider the personal impacts of completing an Advance Care Plan as an inpatient and after a traumatic stroke event. It demonstrated that a direct intervention did not significantly impact the anxiety and depression levels or perceived personal wellbeing of stroke survivors when delivered prior to discharge home from rehabilitation. This period of recovery therefore appears to be an acceptable time to capture the future wishes of those patients at risk of both life threatening complications and representation to hospital.

The improved delivery and processes around Advance Care Planning will ultimately lead to better awareness of the wishes of stroke survivors around end of life care, and thus facilitate the delivery of valuable, patient centred healthcare.



Recommendations

- Face to face advance care planning should be delivered to stroke survivors as this improves documentation, awareness and communication about end of life wishes with health providers.
- The completion of an Advance Care Plan during inpatient rehabilitation is acceptable and without significant emotional impact to stroke survivors.
- Engagement with consumer groups should be maintained regarding the content of Advance Care Planning documentation to ensure relevance outside of a medical framework and to best maximise engagement.
- Education and training should be offered to all clinical staff to improve confidence and skill in facilitating a discussion around end of life care wishes with stroke survivors.
- Stroke survivors with cognitive and communication impairments are able to participate in the ACP process after assessment of capacity by a skilled, multidisciplinary team.
- Replication of this pilot study with a larger sample size is warranted.

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Appendix 1: Developmental Phase Clinician Survey

Advanced Care Planning After Stroke

This project is a sub-study of PAUSE: After Stroke. It is a pilot, pre-post study aiming to explore the effect that delivering face to face advanced care planning sessions to stroke survivors and their significant others in the subacute phase post stroke has upon; determination of advanced care wishes, documentation, patient well-being and mood. The study will also test the feasibility of Telehealth as a medium to better involve family and carers in advanced care planning.

As a clinician identified as having a role or interest in the provision of stroke care, you are invited to take part in an anonymous, self-administered survey which should take no longer than 10 minutes. This survey is seeking clinician input on the most important elements of advanced care planning which help to deliver better end of life care for patients dying post stroke.

We are interested in your views about information needed to manage a dying patient who has had a stroke. Please indicate how important each of the following issues are by circling a number for each item below.

	Very Important	Important	So-So	Less Important	Not Important
Resuscitation Status	1	2	3	4	5
Preferences for life prolonging measures (eg. enteral feeding, dialysis)	1	2	3	4	5
Enduring Guardian and Power of Attorney	1	2	3	4	5
Other nominated decision makers	1	2	3	4	5
Personal values of the patient around death or disability (eg. Would not want to bear permanent conditions such as inability to speak, incontinence, loss of independence)	1	2	3	4	5
Religious and spiritual requests of the patient and family	1	2	3	4	5
Wishes for location of death (eg. hospital, home)	1	2	3	4	5
Organ donation	1	2	3	4	5
Patient's desire/willingness to talk about death	1	2	3	4	5

Are there any important elements that have not been noted above? Please describe:

We are also interested in your views about the best time to ask patients who are not imminently dying to consider advanced care planning after a stroke.

- During the acute hospital admission (first 1-2 weeks after stroke)
- During rehabilitation admission (first 2-8 weeks after stroke)
- Following return home
- Other: *Please State* _____

Who do you feel should be responsible for initiating advanced care planning? Tick all that apply

- Medical Team Social Worker Nursing
- Allied Health Stroke Coordinator Nursing Unit Manager
- Palliative Care Staff For team management

How do you feel advanced care planning is best delivered? Tick one box

- Face to face between patient and health professional
- Face to face with patient, family and health professional
- Team meeting with patient and family
- By general practitioner with patient in the community
- By giving patient written paperwork to complete
- Other (please state): _____

Do you feel that Telehealth could be used to better involve family and friends of patients in advanced care planning alongside health providers?

- Yes No

Why?

If available, do you feel you would personally use Telehealth to involve family and friends of patients in decision making for advanced care planning and/or end of life management?

- Yes No

Why?

What do you believe could be the barriers to using Telehealth as a method to better involve family and friends of patients in advanced care planning? *Tick all that apply*

- Lack of access to compatible devices for relatives
- Lack of internet access to facilitate video conferencing for relatives
- Staff unwilling to use this technology
- Access issues to Telehealth equipment for staff
- Difficulty supporting relatives in setting up/installing Telehealth software
- Staff difficulty using Telehealth equipment
- Other, please state:

Do you have any further comments to add?

Thank you for taking the time to complete this survey

Appendix 2: Developmental Phase Patient Survey

Advanced Care Planning After Stroke

The Hunter Stroke and Hunter New England Health Service are currently conducting a study exploring the effects of delivering advanced care planning to stroke survivors. This area is being explored because we recognise that people have poorer health after a stroke.

Advanced care planning is a process where you are asked to think about your wishes for future medical care, should a serious or life threatening event occur. This helps health services and also family and friends to understand and carry out your wishes.

As a survivor of stroke, we feel your input is extremely valuable in helping us decide what aspects of advanced care planning are important. You are invited to complete this self-administered survey which is likely to take no longer than 10 minutes.

We are interested in your views about what information you feel is important for health providers and your family to know if caring for you. Please circle the number that indicates how important you feel each piece of information is.

	Very Important	Important	So-So	Less Important	Not Important
Feelings about resuscitation	1	2	3	4	5
Preferences for life prolonging measures (eg. Dialysis, feeding tubes)	1	2	3	4	5
Enduring Guardian and Power of Attorney	1	2	3	4	5
Important people to make decisions	1	2	3	4	5
Knowing my personal values around death or disability (eg. Would not want to bear permanent conditions such as inability to speak, incontinence, loss of independence)	1	2	3	4	5
Religious and spiritual requests of the person and family	1	2	3	4	5
My wishes for location of passing (eg. hospital, home)	1	2	3	4	5
Organ donation	1	2	3	4	5
My willingness to talk about death	1	2	3	4	5

Are there any important things that have not been noted above? Please describe:

Do you have an advanced care plan?

- Yes No

If yes, was this in place before your stroke?

- Yes No

Who did you make your advanced care plan with?

- General Practitioner Solicitor Privately with Family
- Staff while in hospital Other: _____

In our study we are going to ask stroke survivors and their families/carers to meet and discuss advanced care planning. Based upon your experience, when do you feel would be the best time to have this discussion?

- During the acute hospital admission (first 1-2 weeks after stroke)
- During rehabilitation admission (first 2-8 weeks after stroke)
- Following return home
- Other, please describe: _____

How important do you think it is for health providers to involve family and friends of patients in advanced care planning? Please circle one number

Very Important	Important	So-So	Less Important	Not Important
1	2	3	4	5

The next section of the survey is about Telehealth. This is the term used for connecting health providers, patients and families/carers on a live video call. This is usually done using computers, tablet computers or mobile phones with cameras. It is particularly helpful when family and friends live a long way from hospitals and cannot travel.

Do you feel that Telehealth could be used to better involve family and friends of patients in advanced care planning alongside health providers?

Yes No

Why? _____

Do you feel it would have been useful to use Telehealth to involve your family with decision making while you were in hospital after the stroke?

Yes No

Why? _____

Do you live in a rural or remote area?

Yes No

Do you find it difficult to travel to hospitals or health services?

Yes No

What type of technology do you have access to at home? *Tick as many options as apply to you*

- | | |
|--|--|
| <input type="checkbox"/> Computer | <input type="checkbox"/> Laptop |
| <input type="checkbox"/> Tablet (eg. iPad) | <input type="checkbox"/> Mobile phone (able to video call) |
| <input type="checkbox"/> Smart television | <input type="checkbox"/> Other _____ |

Do you have access to the internet at home?

Yes No

Do you have any further comments to add?

Thank you for taking the time to complete this survey.

Appendix 3: Advance Care Planning Toolkit

Advance Care Planning Kit

Version 1, 11/10/2016

- The advance care planning toolkit has been created to help people think and talk about their wishes for future care.
- You have been given this toolkit because you recently suffered from a stroke. Many people find that after a stroke they start to think seriously about their life and what type of medical care they might want in the future.
- Making an advance care plan is important for everyone, no matter what their age or how well they are.
- It can be difficult to think and talk about all of the decisions you and your family might face in the future. It is impossible to cover all of this in one document and your wishes could change.
- This kit is designed to help you understand and share your personal values and wishes with your loved ones. This can make it easier for your family, friends and health providers to give you treatment that considers what is important to you.

Name:

Date:

How to use the toolkit

This kit will take you through a series of questions and steps to help you think about your values and wishes around medical care, particularly for life threatening illnesses. It will also help guide you in letting your family and friends know about your wishes.

This kit can be completed on your own, or with help from a health professional. You might like a family member to be present while you complete this kit, or to share your decisions with them once you are home. It is designed to be completed over a period of time so you can think about each step. This may be as fast or slow as you wish.

Remember that just like your wishes, this document can be changed at any time. It is designed to help conversations about end of life wishes become easier and more open.

Step One: What is important to you?

Life can be unpredictable. Think about this scenario:

- One day when you are going about your normal business, you start to feel strange. Suddenly your arm and leg stop moving. You cannot stand up or lift your arm to reach the phone. You try to call for help but cannot talk properly. You are admitted to hospital as you have had a severe stroke.
Does the hospital know who to call? Does anyone know what your wishes are for healthcare? Who will make those decisions?
- A few days later the hospital are worried because you are not able to eat and drink properly. The doctor thinks that you need a feeding tube inserted but this can be uncomfortable and distressing. Your family is asked to make the decision.
Who will decide this? What happens if your family members disagree?
How do they know this is the right choice for you?
- You have suffered from a severe stroke and the health team do not think that you will recover enough to live safely at home, even with help. They recommend that you need to move to an Aged Care facility. Your thinking and ability to make decisions has been affected by your stroke. You insist that your son needs to quit his job to be your full time carer at your home. Is this what you would have wanted for your son before you had your stroke? Who would decide where you live if you do not have decision making capacity? Where would you want to go?

Step One: What is important to you?

The first part of the toolkit will help you to consider what is important to you in life. This section can help health providers, family and friends to understand more about your personal values and wishes. Please think about and answer these questions:

What gives meaning to my life?

This might include things like: being part of my community, spending time with family, practicing my faith, being physically active, doing hobbies or enjoying a busy social life.

Step One: What is important to you?

What do I value most about my physical ability?

Choose any of these that are important to you and add other comments if you would like.

- | | |
|---|---|
| <input type="checkbox"/> Being able to be active | <input type="checkbox"/> Being able to do my hobbies |
| <input type="checkbox"/> Being able to live independently | <input type="checkbox"/> Being able to care for my loved ones |
| <input type="checkbox"/> Being able to do my job | <input type="checkbox"/> Being able to draw or write |
| <input type="checkbox"/> Other: _____ | |

What do I value most about my mental ability?

Choose any of these that are important to you and add other comments if you would like.

- | | |
|---|--|
| <input type="checkbox"/> Being able to recognise others | <input type="checkbox"/> Being able to communicate |
| <input type="checkbox"/> Being able to make my own decisions | <input type="checkbox"/> Being able to understand others |
| <input type="checkbox"/> Being free from anxiety and depression | <input type="checkbox"/> Being able to read |
| <input type="checkbox"/> Other: _____ | |

What would I be UNABLE TO BEAR if my life were prolonged?

- | | |
|---|---|
| <input type="checkbox"/> Being unable to communicate | <input type="checkbox"/> Being unable to eat or drink |
| <input type="checkbox"/> Losing control of my bodily functions | <input type="checkbox"/> Being a burden to others |
| <input type="checkbox"/> Losing my privacy and dignity | <input type="checkbox"/> Being in constant pain |
| <input type="checkbox"/> Being kept alive by machines when I have no chance of recovery | |
| <input type="checkbox"/> Other: _____ | |

Step One: What is important to you?

Talking about death

Which of these options apply best to you?

- I am frightened of death and do not want to think about it happening to me or my loved ones. I would not want to be told if I was dying.
- Dying is a fact of life. You just have to deal with it when it happens. I hope that I can talk about it with loved ones and others before my time comes.
- Dying is a natural part of life. I am comfortable discussing death and dying with my loved ones and others. I want to be prepared for when my time comes

When I think about dying, the things that worry me most are:

Choose any of these that are important to you and add other comments if you would like.

- Being in pain
- Having trouble breathing
- Being alone
- Loss of dignity
- Not having my affairs in order
- Not being able to say goodbye
- Other: _____

If my time for natural dying was nearing, I would feel more peaceful by:

Choose any of these that are important to you and add other comments if you would like.

- Being at home
- Being in hospital/hospice
- Having friends and family near
- Having pets near
- Having spiritual support
- Having specific photos or music
- Other: _____

Step One: What is important to you?

My spiritual and religious care requests would be:



It is important that the people caring for me know:

You can write down anything that is important for others to understand in caring for and supporting you.



You have now completed the first part of the toolkit. The next step will provide you with information about common medical treatments, and help you think more about what specific things you may or may not want.

Before moving on to the next section you might like to take some time to think over, or reflect on Step One.

Step Two: Thinking about medical treatments

There are so many treatments used in hospitals and emergency situations to prolong life. It can be confusing to understand the many medical interventions that you or your family might be asked about in the event of life threatening illness. The list below will describe and help you understand some common medical and legal terms.

Active Interventional Treatment is the term given to providing medical care that improves, sustains or prolongs life. This might include things like: Use of medications, CPR, feeding tubes, breathing support, medical testing and rehabilitation.

Comfort or palliative Measures are treatments that aim to make you comfortable but do not keep you alive or cure an illness. In serious illness, people with palliative measures often live as long as people with interventional treatment

CPR or cardiopulmonary resuscitation is an emergency procedure used to restart your heart and breathing. CPR typically involves mouth to mouth breathing and hard compressions of your chest. Electric shocks might also be used to restart your heart. CPR does not work well for people who have serious health problems or who are frail or who are 70+ years.

Dialysis is carried out by connecting to a machine that cleans your blood if your kidneys are not properly functioning.

Enduring Guardian is a person legally appointed by you to make your medical and lifestyle decisions for you, in the event you are unable.

Feeding tube is used to deliver food directly to your stomach via your nose or a surgical hole in your abdomen. Feeding tubes are commonly used for people who cannot safely swallow or are unable to eat due to damage or problems that affect the throat. Feeding tubes can be temporary (used for a short time) or permanent (used for life).

Hospice is a homely environment set up to provide end of life care for people with life threatening illness and their families. These units are often connected to aged care facilities or hospitals. Hospices are not available at all hospitals.

Intravenous (or IV) is the delivery of medications or water via a needle in your hand or arm.

Life Support is a group of procedures to keep a person artificially alive. It might include a breathing machine, feeding tubes, dialysis and/or CPR.

Palliative Care is the term given to specialist care of people who are dying. This care usually involves treating symptoms to give comfort, providing physical care and providing spiritual and psychological support to a person and their family.

Power of Attorney is a person legally designated by you to handle your financial affairs, in the event you are not able.

Symptom Management refers to treating signs of being sick or that are uncomfortable. For example pain, nausea, fever.

Ventilator is a machine that is used to assist breathing when a person is unable to breathe on their own.

Step Two: Thinking about medical treatments

Please answer the following questions by ticking the box that best applies. The questions will help you to consider treatments that you would want if you became critically ill, **with little chance of recovery.**

I want to receive medical care indefinitely, no matter how uncomfortable.

Strongly Disagree Disagree Neutral Agree Strongly Agree

I will tolerate pain and discomfort if it extends my life.

Strongly Disagree Disagree Neutral Agree Strongly Agree

I want invasive treatment (tubes and machines) if it prolongs my life.

Strongly Disagree Disagree Neutral Agree Strongly Agree

I want my wishes followed completely, even if they are different to what others think.

Strongly Disagree Disagree Neutral Agree Strongly Agree

I want my loved ones to follow my wishes, even if it makes them uncomfortable.

Strongly Disagree Disagree Neutral Agree Strongly Agree

Step Two: Thinking about medical treatments

I want to know all of the details about my condition and treatment, even if this is confronting.

Strongly Disagree Disagree Neutral Agree Strongly Agree

I want my loved ones to know everything about my health.

Strongly Disagree Disagree Neutral Agree Strongly Agree

If my time of death arrives I want to be surrounded by family and friends.

Strongly Disagree Disagree Neutral Agree Strongly Agree

Think about the role you would like your family to play.

Do you think your loved ones have any idea of what you would want, or do they have no idea?

Great job, you have now completed step 2 of the booklet. The next part will focus on nominating a family member or friend as your decision maker.

Step Three: My Substitute Decision Maker

In this step we would like you to consider someone who is important in your life, who you would trust to make decisions about your health and life if you were unable. This person might be a husband or wife, adult child or a close friend.

It is important to consider:

- If this person can best represent and follow your wishes.
- If this person can communicate well with doctors and health professionals.
- How well this person can cope with stress and make good decisions under pressure.
- If this person would be available to make decisions for you.

If you already have appointed an enduring guardian, their details should be added here as they are your legally authorised decision maker.

The person I want to be involved in making medical decisions for me is:

Full name

Address

Phone number

Email

Relationship to me

You might also like to consider making arrangements with your solicitor to put in place a legal Power of Attorney and Enduring Guardian.

Step Four: Who will you talk to?

Well done! You have completed your Advance Care Plan and it is time to share this information with your preferred decision maker, loved ones and health providers. These conversations can sometimes be difficult but they will help everyone who is important to you in understanding your wishes.

At present, who is most important to speak to about your wishes?

- Substitute decision maker
- Partner/spouse
- Child/children
- Mother
- Father
- Carer
- Doctor
- Friend
- Religious or spiritual leader

Other: _____

What are the three most important things you need to say?

Is there anything else you need to do to prepare for the conversation?

Step Four: Who will you talk to?

Later on, there may be other important people in your life that you would like to share your wishes with.

Who else would you like to share your wishes with?

- Substitute decision maker
- Partner/spouse
- Child/children
- Mother
- Father
- Carer
- Doctor
- Friend
- Religious or spiritual leader

Other: _____

When would be the best time to talk to these people?

- As soon as I get home
- Before I get sick again
- The next time my children visit
- At the next family gathering
- Before the next holiday
- Other: _____

Where would be a good location to have the conversation?

- At the dining table
- In the car
- At a restaurant
- On a walk
- At our place of worship
- Other: _____

Step Four: How to share your wishes

A discussion with your loved ones about your future wishes can be difficult. Here are some ideas to help you introduce the topic and include the most important parts for you.

Here are some suggestions on how to start the conversation...

“I have been thinking about the future. Will you help by listening to me?”

“ Even though I am feeling okay now, I have been thinking about the future and want to prepare myself”

“ During my time in hospital I have thought about what I would want to happen if I got very sick or was dying. I wonder what your wishes for me would be?”

“ I have answered some questions about my future health care. I want you to see these”

“ I was thinking about what happened to _____ and it made me realise....”

Key points to talk about

You might like to tick these off as you discuss them

- What are your concerns about your health and if you were at the last phase of your life?
- If you were at the last phase of your life, what would be most important to you?
- What affairs are important to get in order and for your loved ones to know about?
- Who would you want to be involved in your care and to make decisions for you?
- Would you want to make your own care decisions or let doctors do what they feel is best for you?
- If you were dying, where would you want to be and who (including pets) would you want with you?
- Are there any treatments you would or would not want?
- Are there any milestones you would really like to be there for?
(for example: arrival of grandchildren, a special birthday, an anniversary)
- Are there any family disagreements or tensions you are concerned about?
- If you were very unwell, would you want your care to change from curative to just making you comfortable?

Some important things to remember...

- Advance care planning and death can be really difficult topics for some people to discuss. Your loved ones might need a bit of time to think about things.
- People can have very different values around death. It is really important that we don't judge each other on what we think is 'good' and 'bad'.
- Be patient with your loved ones.
- Nothing is set in stone – you or your loved ones can change your minds at any time.
- Even though this conversation might be difficult, it is extremely valuable.
- You don't need to discuss everything all at once. There will be many conversations over time.

You have done a wonderful job in completing this booklet and discussing your wishes with your loved ones. This is a step towards making sure you have the best possible quality and say in your own life and health care.

We hope you will encourage others to also get the conversation started about end of life wishes.

This tool has been adapted from a range of sources including:
NSW Health Advance Care Plan
The Conversation Project <http://theconversationproject.org/>
Speak Up Canada <http://www.advancecareplanning.ca/>

Appendix 4: Advance Care Planning Audit Questionnaire

ADVANCED CARE PLANNING AFTER STROKE

Patient Advanced Care Planning Questionnaire

An advanced care plan is a written document that describes your wishes for future medical care if you become very sick or a life threatening event occurs. It might include your wishes around medical procedures like resuscitation and organ donation. It might describe the conditions under which you might not want to be treated such as if you are unable to eat, talk, walk or be independent. Advanced Care Plans also take into account things that are important to you, such as remaining at home, spirituality or people (or pets) who you would want by your side.

Since this hospital admission:	Response (circle)
1. Do you have an advance directive or living will or some other written document describing the medical treatments you would want (or not want) in the event you are unable to communicate for yourself as a result of a life threatening health problem?	Yes No
2. Were you asked if you had prior discussions or written documents about your advanced care plan?	Yes No
3. Has a health professional asked what is important to you as you consider health care decisions at this stage of your life?	Yes No
4. Have you formally designated someone you trust (e.g. Power of Attorney for Health) to represent your wishes concerning medical treatment decisions in the event you are not able to do so?	Yes No
5. Have you ever considered or thought about what kinds of life-sustaining treatments you would want or not want in the event your physical health deteriorated?	Yes No
6. Has a health professional talked to you about whether to use or not to use life-sustaining treatments in the event of a life-threatening illness?	Yes No
7. Has a member of the health care team provided information about supportive care services such as palliative and spiritual care that may be helpful in the event of a life-threatening illness?	Yes No
8. What could we have done differently to improve the process of making a decision about medical treatments to sustain life the event your condition deteriorated?	Open ended (see below)

Do you have any further comments you would like to add?



Final Report March 2017
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Health Education and Training Institute, Rural and Remote Portfolio

Melanie Malpass

BSPath, MHIthSc (Stroke Speciality)

Senior Speech Pathologist

Aged Care and Rehabilitation Service

Suite 2, 57-61 Albert St Taree NSW, 2430

Melanie.Malpass@hnehealth.nsw.gov.au