Canadian Stroke
Best Practices

CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

Acute Stroke Management Evidence Tables

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Section 10: Advance Care Planning

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Acute Stroke Management Writing Group and in collaboration with the
Canadian Stroke Consortium

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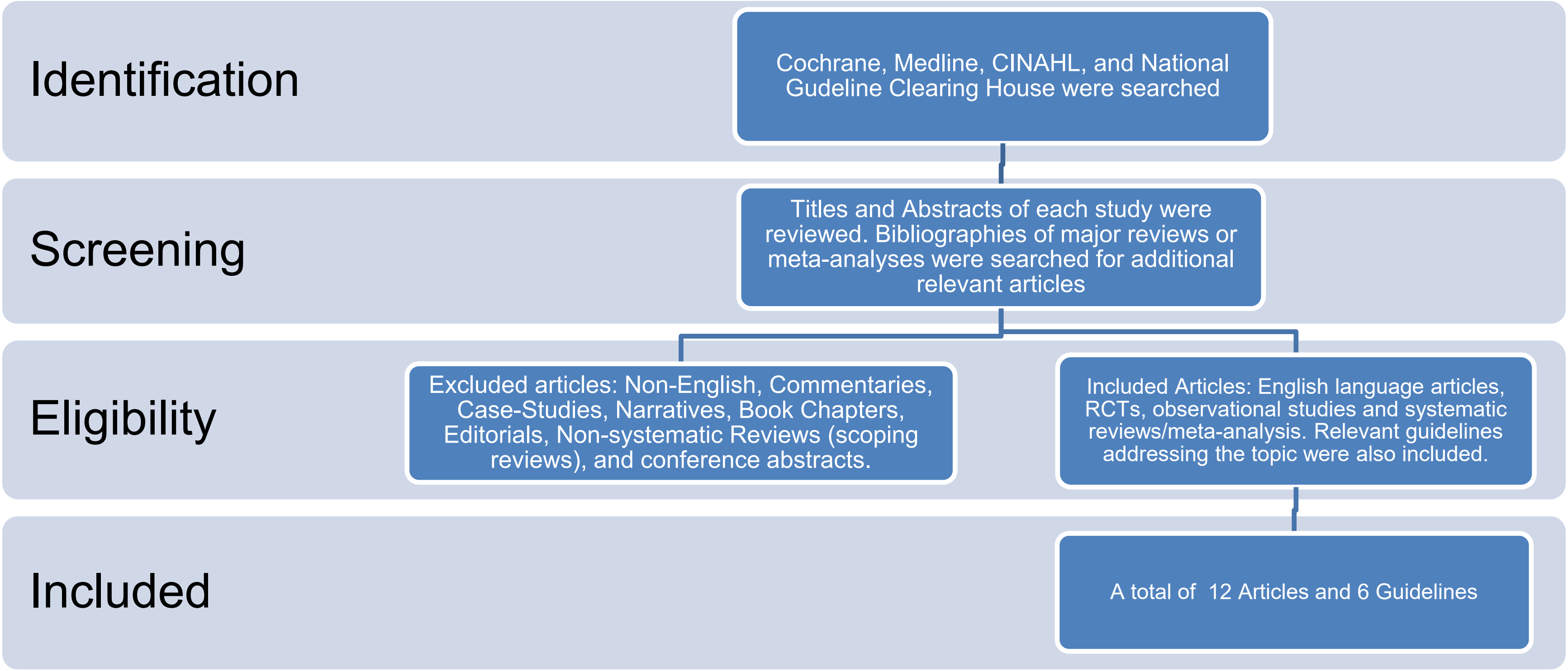
Search Strategy



Pubmed, EMBASE and the Cochrane Database were search using the terms ("Stroke" and "end-of-life" or "advance care planning"). Titles and abstract of each article were reviewed for relevance. Bibliographies were reviewed to find additional relevant articles. Articles were excluded if they were: non-English, commentaries, case-studies, narrative, book chapters, editorials, non-systematic review, or conference abstracts. Additional searches for relevant best practice guidelines were completed and included in a separate section of the review. A total of 12 articles and 6 guidelines were included and were separated into separate categories designed to answer specific questions.

Published Guidelines

Guideline	Recommendations
McKenzie, E., & Couillard, P. **Choosing Wisely: Canadian Neurological Society recommendations for advance care planning.** ***Canadian Journal of Neurological Sciences / Journal Canadien Des Sciences Neurologiques,* 2022; 1-14.**	1. Don't wait for your patient to bring up ACP, initiate the conversation. 2. For patients with progressive illness that could impact cognition, initiate ACP conversations as early in the disease course as possible. 3. Encourage family and care partner involvement in ACP. 4. Use clear, direct language when discussing prognosis. 5. Use standardized, specific language to document ACP conversations. 6. Don't recommend or initiate aggressive care without establishing prognosis, preferences and goals of care. 7. Revisit advance care plans regularly and whenever there is significant change in a patient's status. 8. Patients who enquire about Medical Assistance in Dying should receive comprehensive information about care options.
Intercollegiate Stroke Working Party. National clinical guideline for stroke, 5th edition. London: Royal College of Physicians, 2016.	People with stroke with limited life expectancy, and their family where appropriate, should be offered advance care planning, with access to community palliative care services when needed.
Registered Nurses' Association of Ontario (RNAO). Stroke assessment across the continuum of care 2011 supplement. Toronto (ON): Registered Nurses' Association of Ontario (RNAO); 2011 Aug. 42 p.	Advanced Care Planning Recommendation 4.1 Nurses in collaboration with the interprofessional team will assess and support clients (family/substitute decision maker [SDM]) to make informed decisions that are consistent with their beliefs, values and preferences to ensure client wishes are known and incorporated into the plan of care (includes advanced, palliative and end of life care planning). (Level of Evidence = IV)
American Medical Directors Association (AMDA). Stroke management in the long-term care setting. Columbia (MD): American Medical Directors Association (AMDA); 2011. 46 p.	Develop and implement an interdisciplinary treatment plan that treats stroke complications. When the assessment identifies complications of stroke, implement appropriate curative, restorative, or palliative treatment on the basis of a shared decision that reflects the patient's wishes and treatment goals.
Royal College of Physicians, British Geriatrics Society, Royal College of	Detailed recommendations were made within the following categories: When and with whom should I be considering ACP discussions?

Guideline	Recommendations
Nursing, Royal College of Psychiatrists, Royal College of General Practitioners, British Society of Rehabilitation Medicine, Alzheimer's Society, Help the Aged and the National Council for Palliative Care. Advance care planning. RCP Concise Guidance for Good Practice No. 12. February 2009.	The discussion Will ACP work? Individuals with progressive cognitive impairment Recommendations for training and implementation of ACP
National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care. 2nd ed. Pittsburgh (PA): National Consensus Project for Quality Palliative Care; 2009. 80 p.	Domain 1: Structure and Processes of Care Guideline 1.1 The timely plan of care is based on a comprehensive interdisciplinary assessment of the patient and family. Guideline 1.2 The care plan is based on the identified and expressed preferences, values, goals, and needs of patient and family and is developed with professional guidance and support for decision making. Guideline 1.3 An interdisciplinary team provides services to the patient and family consistent with the care plan. In addition to nursing, medicine, and social work, other therapeutic disciplines with important assessment of patients and families include physical therapists, occupational therapists, speech and language pathologists, nutritionists, psychologists, chaplains, and nursing assistants. For pediatrics, this should include child-life specialists. Complementary and alternative therapies may be included. Guideline 1.4 The use of appropriately trained and supervised volunteers within the interdisciplinary team is strongly encouraged. Guideline 1.5 Support for education and training is available to the interdisciplinary team. Guideline 1.6 In its commitment to quality assessment and performance improvement, the palliative care program develops, implements, and maintains an ongoing data driven process that reflects the complexity of the organization and focuses on palliative care outcomes. Guideline 1.7 The palliative care program recognizes the emotional impact on the palliative care team of providing care to patients with life-threatening illnesses and their families. Guideline 1.8 Palliative care programs should have a relationship with one or more hospices and other community resources in order to ensure continuity of the highest-quality palliative care across the illness trajectory. Guideline 1.9 The physical environment in which care is provided should meet the preferences, needs, and circumstances of the patient and family to the extent possible. Domain 2: Physical Aspects of Care Guideline 2.1 Pain, other symptoms, and side effects are managed based upon the best available evidence, with attention to disease-specific pain and symptoms, which is skillfully and systematically applied. Domain 3: Psychological and Psychiatric Aspects of Care

Guideline	Recommendations
	Guideline 3.1 Psychological status is assessed and managed based upon the best available evidence, which is skillfully and systematically applied. When necessary, psychiatric issues are addressed and treated. Guideline 3.2 A grief and bereavement program is available to patients and families, based on the assessed need for services. Domain 4: Social Aspects of Care Guideline 4.1 Comprehensive interdisciplinary assessment identifies the social needs of patients and their families, and a care plan is developed to respond to these needs as effectively as possible. Domain 5: Spiritual, Religious and Existential Aspects of Care Guideline 5.1 Spiritual and existential dimensions are assessed and responded to based upon the best available evidence, which is skillfully and systematically applied. Domain 6: Cultural Aspects of Care Guideline 6.1 The palliative care program assesses and attempts to meet the needs of the patient, family, and community in a culturally sensitive manner. Domain 7: Care of the Imminently Dying Patient Guideline 7.1 Signs and symptoms of impending death are recognized and communicated in developmentally appropriate language for children and patients with cognitive disabilities with respect to family preferences. Care appropriate for this phase of illness is provided to patient and family. Guideline 7.2 Postdeath care is delivered in a respectful manner. Cultural and religious practices particular to the postdeath period are assessed and documented. Care of the body postdeath is delivered with respect to these practices, as well as in accordance to both organizational practice and local law. Guideline 7.3 A postdeath bereavement plan is activated. An interdisciplinary team member is assigned to the family in the postdeath period to help with religious practices, funeral arrangements, and burial planning. Domain 8: Ethical and Legal Aspects of Care Guideline 8.1 The patient's goals, preferences and choices are respected within the limits of applicable state and federal law, within current accepted standards of medical care, and form the basis for the plan of care. Guideline 8.2 The palliative care program is aware of and addresses the complex ethical issues arising in the care of persons with life-threatening debilitating illness. Guideline 8.3 The palliative care program is knowledgeable about legal and regulatory aspects of palliative care.

Evidence Table

Knowledge of Advance Care Planning Among the General Public

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Teixeira et al. 2015 **Canada** **Survey**	NA	1,021 Canadians, aged ≥18 years, randomly sampled from the general population. 48% were male, a plurality of participants was aged 45-54 years (33%) and were from Ontario (32%)	5 questions related to advance care planning (ACP) were posed using a short online survey: 1) had they ever heard of the term 'ACP'; 2) had they ever had a discussion with a family or friend or 3) a healthcare provider regarding healthcare treatments' preferences in the event that they would become too ill or too injured to speak for themselves; 4) had they written an ACP; and 5) if they had designated a person to be their healthcare decision maker in the event of incapacity. Associations between knowledge of ACP and 6 variables was also examined (age, sex, education, income, children living in household, born in Canada)	**Primary outcome:** Number of participants familiar with aspects of ACP	160 participants (16%) were familiar with the term ACP 530 participants (52%) had discussions with friends and family members regarding ACP 105 participants (10%) had discussions with healthcare professionals regarding ACP 204 participants (20%) had written an ACP 479 participants (47%) have a substitute decision maker. Increasing age was the only factor that was associated all 5 ACP outcomes.

Advance Care Planning

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Johnson et al. 2019 **USA** **Survey**	NA	219 patients attending an outpatient stroke clinic a median of 5 months following (any) stroke. Mean age was 60 years, 46% were women. 68% were ischemic stroke, 14% ICH. Median NIHSS score was 4.	Patients completed the Planning After Stroke Survival survey, designed to explore the prevalence, experiences, and influencing factors around goals-of-care and advance care planning (ACP) conversations	**Primary outcome:** Completion of advanced directive (AD), as reported by the patient, predictors of AD	Response was 78%. 45% of respondents reported having completed AD, 20% were unsure. Most patients (n=155; 73%) reported having previously discussed ACP with a physician. 123 (58%) patients were interested in having additional ACP conversations with their stroke doctor. 28 (53%) patients stated that they did not wish to discuss ACP with their stroke doctor, over half of whom (28/53; 53%) had already completed ADs. Predictors of completing ADs included age (≥65 years, white race, milder poststroke disability (mRS score ≤1), having previously discussed ACP with a physician and discussing risk of stroke recurrence.
Green et al. 2014 **Canada** **Qualitative study**	NA	14 patients ≥18 years, recruited from an acute stroke unit and 2 rehabilitation units ≤12 weeks previously; and 4 healthcare professionals (HCP) (3 nurses and 1 social worker). Patients with aphasia and cognitive impairment, were excluded.	Participant observation and semi-structured interviews were used to gather information related to the communication processes regrading advance care planning between patients and HCPs, using grounded theory methodology.	**Primary outcome:** Key themes related to why/why not participants engaged in the ACP process.	1. Lack of perceived urgency by participants about the need for ACP, many of whom felt the physician and/or family members would make decisions in accordance with their wishes; another aspect was the patients' lack of information from HCPs regarding the severity of their stroke. In the rehabilitation phase, the focus was recovery. 2. Lack of initiation by HCPs to discuss issues around ACP. 3. HCPs expressed hesitation about initiating discussions related to ACP, and uncertainty as the best timing for such discussions. There was also a lack of awareness as to what ACP is, and thought it was outside their scope of practice. 4. Confusing ACP with advance directives, designation of care and living wills

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Qureshi et al. 2013 **USA** **Retrospective study**	NA	28 patients who were admitted to a comprehensive stroke study over a 12-month period with ischemic stroke or ICH and those with advanced care directives at the time of admission	A total of 28 treatment decision items were selected and categorized in three groups of decision making according to complexity and risk: i) routine complexity which included interventions that are done routinely and did not require informed consent (e.g., fever or hyperglycemia management); ii) moderate complexity that did not always require informed, but did require some discussion with family members (e.g., thrombolytic therapy or institution of intubation and mechanical ventilation); and iii) high complexity, requiring informed consent (e.g., craniectomy or hematoma evacuation). A summary of each patient's case, including a copy of the patient's advanced healthcare directives (ACD) were reviewed and rated independently by 6 stroke physicians. Each rater indicated that they would or would not offer a therapeutic option. The review was performed	**Primary outcome:** The proportion of treatment withheld and the percentage agreement to treat per patient for each of the items.	The decision to withhold treatment in all 3 treatment complexity categories was similar among raters, regardless of their knowledge of an ACD. One exception was intensive care monitoring where the treatment was withheld in 32% of patients with ACD vs. 8% without ACD. In routine complexity treatment decisions, the percentage agreement among raters as to whether to offer a specific treatment varied from 75%-100% in the presence of ACD and 78%-100% in their absence. In moderate complexity treatment decisions, the percentage agreement among raters as to whether to offer a specific treatment varied from 68%-79% in the presence of ACD and 67%-86% in their absence. In high-complexity treatment decisions, the percentage agreement among raters as to whether to offer a specific treatment varied from 74%-80% in the presence of ACD and 71%-85% in their absence. Treatment decisions were not influenced by the presence of ACDs.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			twice by each rater one month apart, once with knowledge of the ACP and once without.		
Heyland et al. 2013 **Canada** **Prospective Study**	NA	278 patients with advanced pulmonary, cardiac, or liver disease, metastatic cancer, were ≥80 years of age and admitted for an acute condition, or were not expected to survive 6 months. 225 family members of patients meeting the above criteria were also included.	Participating patients and family members were interviewed 2-5 days following admission. Medical records were reviewed immediately following the interview to identify any documentation of issues related to end-of-life care.	**Primary outcome:** Selected domains from the Canadian Health Care Evaluation Project (CANHELP) Questionnaire.	Prior to hospitalization, 76.3% of patients reported that they had considered end of life care, 73.3% had formally named a surrogate decision maker, and 47.9% had completed an advance care plan. Most patients (61.2%) expressed a preference for comfort care or a mix of comfort care and medical care that excluded resuscitation. Only 11.9% preferred life-prolonging care. For the 199 patients that expressed end-of-life care preferences and had a documented goals-of-care order, documented preferences crudely corresponded to the patient's stated preferences in 30.2% of cases. Lowest levels of satisfaction on the CANHELP Questionnaire were reported to be related to discussions of the location of end-of-life care and what to expect during end-of-life care.
Pearlman et al. 2000 **USA** **Prospective study**	NA	A convenience sample of 342 participants from 7 groups (younger and older well adults; persons with chronic illness, terminal cancer, AIDS; stroke survivors with residual impairments (n=45); and nursing home residents.	Treatment preferences (antibiotics, long-term mechanical ventilation (with tracheostomy), long-term hemodialysis, long-term jejunal tube feeding, short-term mechanical ventilation, and CPR) and health status data (functional status, depression, and personal experience with mechanical ventilation, CPR, dialysis, coma, severe memory loss, and paralysis) were collected during in person interviews.	**Primary outcome:** % of participants willingness to accept/forgo the 6 treatments (antibiotics, short-term ventilation, CPR, long-term dialysis, long-term tube feeding and long-term mechanical ventilation). Summary scores.	Overall, participants chose to forego invasive or long-term treatments more often than less invasive, short-term treatments, and chose to forego treatments more often in seriously impaired health states (coma, and to a lesser extent severe dementia and severe stroke) than they did in their current health state. **For the subgroup of stroke survivors:** Current health state: the percentage of participants who chose to forgo the 6 treatments ranged from 5% (antibiotics) to 60% (long-term mechanical ventilation) Severe stroke: in this scenario, the percentage of participants who chose to forgo the 6 treatments ranged from 30% (antibiotics) to 80% (long-term mechanical ventilation)

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
			Responses were elicited for each participant's current health state and three hypothetical health states representing severe dementia, permanent coma, and severe stroke. A 6-point summary scale was developed (0-6) as an indicator of a patients' willingness to accept all 6 treatments. Lower scores indicated greater likelihood to accept treatment.		Permanent coma: this health state was associated with the highest percentages of persons choosing to forgo treatment, ranging from 60% (antibiotics) to 80% (long-term mechanical ventilation). Summary scores for the different health states were 1.9 (current health), 3.5 (severe stroke), 2.9 (severe dementia) and 4.3 (permanent coma)

Interventions Associated with Advance Care Planning

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Kirchhoff et al. 2012 **USA** **RCT**	CA: ☑ Blinding: Patient ☒ Assessor ☒ ITT: ☒	313 patients (and their surrogate decision makers) with congestive heart failure or end-stage renal disease who were expected to experience serious complication or death within 2 years.	Participants and their surrogates were randomized to receive a patient-centered advance care planning intervention (n=160) or care as usual (n=153). The intervention involved a 60-90-minute interview with a trained facilitator that involved discussion of disease-specific end-of-life care issues and options. The facilitator also assisted in documenting treatment preferences.	**Primary outcome:** The Statement of Treatment Preferences (STP) was used to document patient preferences. For patients who died during the study period, telephone interviews with surrogates and medical records were used to identify end-of-life care received.	Of the 313 patients enrolled in the study, 110 died within the study period. 26% of these individuals required a surrogate decision maker at the end-of-life. 1 patient in the intervention group and 3 in the control group received care at the end-of-life that was contrary to their wishes for reasons other than medical futility. With respect to resuscitation preferences, fewer patients in the intervention group received care that was contrary to their wishes (1/62) than patients in the usual care group (6/48); however, between group comparisons were not significant.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Detering et al. 2010 **Australia** **RCT**	CA: ☑ Blinding: Patient ☒ Assessor ☒ ITT: ☑	309 patients' ≥ 80 years of age who were admitted to internal medicine, cardiology, or respiratory medicine. Patients who were not competent, who had an existing advance care plan, or who were expected to die or be discharged within 24 hours were excluded. 35.5% of those assessed were eligible for inclusion	Participants were randomized to receive formal advance care planning from a trained facilitator (n=154) or care as usual (n=155). The intervention was based on the Respecting Patient Choices model which involves reflection on goals, values, and beliefs, documentation of future health care wishes, and appointment of a surrogate decision maker. Participants in the control group only received advance care planning if it was specifically requested.	**Primary Outcome:** The proportion of deceased participants whose end-of-life wishes were respected. **Secondary Outcomes:** Patient satisfaction of hospital stay (5-item survey) and the impact of death on a surviving family member (Impact of Events Scale and Hospital Anxiety and Depression Scale). Assessments were conducted 3 and 6 months after enrollment. For those who died during the 6-month study period, a final follow-up was conducted with a family member 3 month following the death.	Of the 154 participants randomized to the intervention group, 108 completed a formal advance care plan, including end-of-life health care wishes and/or appointment of a surrogate. By the end of the study period, 56 participants were deceased (29 in the intervention group and 27 in the control group). Of those who died, end-of life wishes were significantly more likely to be known and respected for participants in the intervention group as compared to those in the control group (86% vs. 30%, $p<0.01$). Following the death of a relative, family members of those in the intervention group reported significantly less anxiety and depression and more satisfaction with the quality of their relative's death, as compared to control group family members (all at $p<0.05$).
Grimaldo et al. 2001 **USA** **RCT**	CA: ☑ Blinding: Patient ☒ Assessor ☒ ITT: ☒	200 elective surgery patients' ≥65 years of age attending an anesthesia preoperative evaluation clinic. 65% of eligible patients agreed to participate in the study.	Participants were randomized to receive the advance care planning intervention (n=99) or care as usual (n=99). The intervention consisted of a single 5-10-minute information session focusing on issues such as designation of surrogate decision-makers and end-of-life care.	Outcomes included a questionnaire (with items concerning advance care planning, quality of communication, and treatment preferences) and the SF-36. Assessments were conducted before and after the intervention.	Preoperatively, 70% of participants in the intervention group and 61% of participants in the control group had discussed end-of-life- care wishes with a family member. Post-operatively, an additional 15% of those who had received the intervention reported having discussed end-of-life care with a loved one, as compared to an additional 8% in the control group ($p<0.05$). Dropouts: 10 in the intervention group and 3 in the control group.

Advance Care Planning Regarding Thrombolysis and Endovascular Therapy

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Flatharta et al. 2015 **Ireland** **Cross sectional survey**	NA	121 inpatients and outpatients attending geriatric and stroke services at a single hospital with at least one stroke risk factor. Patients who would not be candidates for thrombolysis treatment in a real-life situation, were excluded.	Two scenarios for potential treatment with t-PA were presented: presentation within 3 hours and 3-4.5 hours of symptom onset. Risks and benefits of treatment were explained. Participants were asked to decide whether they would decide to have or not have the treatment if they were faced with the decision in real life. Participants were also asked if they would like for their choice to be documented in their medical notes (instead of having it recorded anonymously for research purposes) and in the event that they did have a stroke and couldn't speak for themselves, if they would prefer to have a close family member make the decision regarding treatment, or if they would prefer to have it be left to the treating physician	Proportion of patients opting for treatment in both scenarios.	108 participants (89.3%) opted to receive thrombolysis within 3 hours. 100 participants (82.6%) opted to receive thrombolysis within 3-4.5 hours. 98 participants (81.0%) opted to receive thrombolysis in both scenarios. 11 participants (9.1%) opted not to receive thrombolysis in either scenario. Participants who agreed to treatment were more likely to have had a previous stroke or TIA and were more likely to want their decision documented in their medical chart. The majority of participants indicated that the doctor should decide whether they should receive treatment with thrombolysis.

Advanced Directives

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Liu et al. 2017 **USA** **Retrospective study**	NA	206 patients with neurological conditions referred to a palliative care service at a single institution from 2010-2014. Mean age was 70 years, 54% were women.	Chart review examining symptoms, prognosis, goals of care, discharge planning, and advance directives	**Secondary outcome:** Number of patients with advanced directives in place.	72% of patients were unable to communicate at the time of consultation. The diagnosis of 49% of patients referred to the service was stroke. 61 patients (30%) had advanced directives in place at the time of admission to hospital, including a living will (7%) medical durable power of attorney (4%) while 19% had both a living will and MDPOA. At the time of palliative care consultation, 130 patients (63%) had advanced directives, which increased to 190 (92%) after consolation.
Silveira et al. 2010 **USA** **Retrospective study**	NA	3,476 persons aged ≥60 years included in the Health and Retirement Study who died between 2000-2006, for whom a proxy had completed an exit interview after the participant's death, within 24 months. Mean age at death was 80.5 year, 53% were female.	Data was collected regarding whether the subject had completed a living will or durable power of attorney (DPOA) for health care, maintained decision-making capacity, or needed decision making at the end of life. For subjects who needed decision making, data were collected on the decisions made and on the person who made them. Predictors of and preferences for all care possible, limited care and comfort care, were examined	**Primary outcome:** Need for proxy end-of-life decision making and concordance of preferences in advanced directives with care received.	25.6% of decedents had cerebrovascular disease at the time of death. Most proxy respondents were adult children or spouses. 70.3% of decedents who required decision-making in the last few days of life, lacked decision-making capacity. Among them, 67.5% had an advance directive, 6.8% had a living will only, 21.3% had appointed a DPOA for medical decision-making and 39.4% had prepared both a living will and appointed a DPOA for healthcare decisions. Living wills and DPOA were completed a median of 20 and 19 months prior to death, respectively. Among decedents who had living wills, 1.9% had requested all care possible, 92.7% had requested limited care, and 96.2% had requested comfort care. 83.2% of decedents who requested limited care and 97.1% who requested comfort care received care consistent with their preferences. Incapacitated subjects who had prepared a living

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
					will (regardless of preferences) were less likely to receive all treatment possible (adjusted OR= 0.33, 95% CI 0.19 to 0.56) and more likely to receive limited treatment (adjusted OR=1.79, 95% CI, 1.28 to 2.50) than decedents without a living will. Living wills were associated with increased odds of receiving comfort care (adjusted OR=2.59, 95% CI 1.06 to 6.31). Decedents who had assigned a DPOA were less likely to die in a hospital or receive all care possible compared with those who had not assigned a DPOA.

Abbreviations

CA: concealed allocation	ITT: intention-to-treat	CI: confidence interval
OR: odds ratio		

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