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Core Outcome Measures for Palliative and End-of-Life Research After Severe Stroke

Mixed-Method Delphi Study

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BACKGROUND AND PURPOSE: Stroke is the second commonest cause of death worldwide and a leading cause of severe disability, yet there are no published trials of palliative care in stroke. To design and evaluate palliative care interventions for people with stroke, researchers need to know what measurable outcomes matter most to patients and families, stroke professionals, and other service providers.

METHODS: A multidisciplinary steering group of professionals and laypeople managed the study. We synthesized recommendations from respected United Kingdom and international consensus documents to generate a list of outcome domains and then performed a rapid scoping literature review to identify potential outcome measures for use in future trials of palliative care after stroke. We then completed a 3-round, online Delphi survey of professionals, and service users to build consensus about outcome domains and outcome measures. Finally, we held a stakeholder workshop to review and finalize this consensus.

RESULTS: We generated a list of 36 different outcome domains from 4 key policy documents. The rapid scoping review identified 43 potential outcome measures that were used to create a shortlist of 16 measures. The 36 outcome domains and 16 measures were presented to a Delphi panel of diverse healthcare professionals and lay service users. Of 48 panelists invited to take part, 28 completed all 3 rounds. Shared decision-making and quality of life were selected as the most important outcome domains for future trials of palliative care in stroke. Additional comments highlighted the need for outcomes to be feasible, measurable, and relevant beyond the initial, acute phase of stroke. The stakeholder workshop endorsed these results.

CONCLUSIONS: Future trials of palliative care after stroke should include pragmatic outcome measures, applicable to the evolving patient and family experiences after stroke and be inclusive of shared decision-making and quality of life.

GRAPHIC ABSTRACT: An online [graphic abstract](#) is available for this article.

Key Words: cause of death ■ consensus ■ decision making ■ quality of life ■ palliative care ■ stroke

Stroke is a major cause of death and disability, with 5.5 million deaths worldwide attributed to stroke in 2016.¹ Case fatality for severe stroke in the United Kingdom is about 50% at 6 months, and 90% of deaths occur in acute hospitals.^{2,3} Integrating a palliative

care approach into management of people with severe stroke is appropriate, whether patients die in the acute phase or survive with ongoing disabilities and reduced life expectancy.⁴ The 2020 International Association for Hospice and Palliative Care consensus definition states:

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Nonstandard Abbreviations and Acronyms

COMET	Core Outcome Measures in Effectiveness Trials
CREDES	Conducting and Reporting Delphi Studies

“Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.”⁵ The American Heart Association/American Stroke Association 2014 guidelines state that “palliative care should be available to all patients with serious or life-threatening stroke and their families throughout the entire course of the illness.”⁶ Potential benefits of a wider palliative care approach include improving quality of life as well as care of the dying, reducing health-related suffering, and person-centered care that minimizes use of costly interventions with low benefit or potential harms.^{4,7,8}

For 20 years, the World Health Organization has highlighted quality of life as a core outcome of palliative care achieved by early identification and impeccable assessment and treatment of pain and other problems: physical, psychosocial, and spiritual.⁹ There are no published randomized trials of palliative care in stroke. Given the high case fatality in severe stroke, such trials are essential. Trials of palliative care for severe stroke require robust outcome measures that capture what matters to patients, their families, and professionals. However, systematic reviews of outcomes in palliative and end-of-life care have not included people with stroke who are likely to have different needs from those with commonly studied conditions such as cancer.^{10,11} The International Consortium for Health Outcomes Measurement (www.ICHOM.org) and COMET (Core Outcome Measures in Effectiveness Trials; www.comet-initiative.org) have no information about appropriate outcome measures for palliative care in people with stroke. However, qualitative studies have shown the need to understand patient and carer experiences and address their unmet needs.^{3,12–15}

The aim of this study was to identify a set of outcome domains and outcome measures for use in clinical trials of palliative and end-of-life care in stroke. The term outcome domain refers to a measurable aspect of a condition that matters to patients, family caregivers, and clinicians. Outcome measure refers to a specific tool to evaluate or assess the effects of an intervention.¹⁶

METHODS

The study was managed by a multidisciplinary steering group with 15 members, including the project lead (G.E.M.), researcher

(B.M.), and 2 bereaved carers of people who died after severe stroke. These 2 patient-public involvement representatives provided important insights throughout the whole study from concept to dissemination. The data that support the findings of this study are available from the corresponding author upon reasonable request. This was a mixed-method, Delphi study consisting of 4 stages.

1. Collation and synthesis of potential outcome domains from consensus documents and national guidelines in palliative care.
2. A rapid scoping literature review of recent trials and interventions in severe stroke and palliative care to identify candidate outcome measures.
3. A Delphi survey with a panel of healthcare professionals from stroke services and palliative care along with lay members who had personal experiences of stroke to generate consensus about the most important outcome domains and measures for a future trial.
4. An end-of-study workshop involving the steering group, key stakeholders, and Delphi panelists to finalize consensus recommendations.

Outcome Domains

Four expert sources were identified and used for potential outcome domains: World Health Organization definition of palliative care, US National Consensus Project Clinical Practice Guidelines for Quality Palliative Care Guidelines,¹⁷ UK National Institute for Clinical Excellence quality statements for palliative and end-of-life care,¹⁸ and results of a consensus-workshop on outcome domains for palliative care from the 2016 European Association of Palliative Care meeting.¹⁹ Outcome domains extracted by the researcher were agreed upon by the project lead. A synthesized list for the Delphi survey was agreed upon by the project steering group.

Rapid Scoping Literature

We constructed a rapid scoping review by combining the Preferred Reporting Items for Systematic Reviews and Meta-Analyses–ScR (Scoping Review) protocol²⁰ with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses protocol for rapid reviews.²¹ A scoping review “identifies knowledge gaps, sets research agendas, and identifies implications for decision-making.”²² A rapid review streamlines or omits specific methods to produce evidence for stakeholders in a resource-efficient manner.²¹ Our scoping review used rapid methodology and aimed to identify diverse study types in a short time frame.²²

The steering group advised restricting the search to publications since January 1, 2015, from one major database for peer-reviewed evidence (Medline), and one gray literature source, Google Scholar. The Cochrane Palliative Care database and COMET databases were also searched without date restrictions to look for potential outcome measures. We included primary research, audits, reviews, and service evaluations that reported outcome measures. We excluded studies where the abstract or full text was not available and non-English publications. The short time frame of the project meant that full-text articles not available from the university library or personal subscriptions were excluded (Data I in the [Data Supplement](#); search terms and restrictions)

Delphi Survey

A Delphi survey is frequently used for building consensus among professionals, service users, and key stakeholders.^{23–26} We aimed to complete 3 rounds and recruit at least 23 panelists; this is sufficient to provide stability of results and was feasible within available resources.²⁷ We tried to recruit a substantial number of service users to achieve a broad mix of expertise. We used the CREDES (Conducting and Reporting Delphi Studies) reporting guidelines for conducting a Delphi study in palliative care.²⁸

We conducted the Delphi via Joint Information Systems Committee Online Surveys, hosted in the United Kingdom and compliant with European Union General Data Protection Rules (<https://www.onlinesurveys.ac.uk/>). Test versions were piloted by steering group members and refined to address any accessibility or logic issues. Survey data were stored on a secure University server. We recruited panelists from professional contacts of the steering group, internet searches for experts, our existing links with public-patient involvement groups, requests to national professional networks, voluntary organizations including stroke charities, and by posting on the Cochrane Task Exchange (<https://taskexchange.cochrane.org/>). Professionals and service users identified themselves as experts in palliative care, stroke, or both.

We addressed attrition by sending reminder emails to late responders and keeping time between rounds short. The survey pages had indicators showing progress and an option to save and return. Help buttons provided additional information. The text density was minimized to improve accessibility and readability, with images and formatting used to highlight key content. At round 3, panelists were offered a £25 (\$US dollar 35) retail voucher if they completed the survey.

The Delphi utilized an iterative process with the importance of outcome domains and the usefulness of outcome measures rated on 5-point scales. The consensus level for agreement was set at 75% of respondents who completed each rating. If 75% of respondents scored an item as 1 to 2 on a 5-point scale, consensus for lack of importance or usefulness was reached. Conversely, if 75% of respondents scored an item as 4 to 5 on a 5-point scale that item had consensus for importance or usefulness. After each round, any item achieving consensus for lack of usefulness or importance was removed. In the second and third rounds, and panelists received the scores from previous rounds. At the end of a round, if 50% of items reached the consensus level of 75% for usefulness or importance, the rating task for the next round was changed to ranking: ranking required panelists to pick a top 5 ordering them from first to fifth. Panelists could add free-text comments during each Delphi round which were analyzed thematically.

Stakeholder Meeting

On March 4, 2020, a face-to-face participatory meeting in Edinburgh involved the steering group, key stakeholders identified by the steering group, and available Delphi panelists. Outputs from the Delphi were presented for discussion and review to reach a final consensus inclusive of multiple perspectives.

Ethical Review

The local National Health Service ethics committee decided this project did not require formal ethical review.

RESULTS

Outcome Domains

From the 4 expert consensus sources, 33 individual outcome domains were extracted and grouped into 9 broad domains adapted from the domains listed in the US National Consensus Project.

Rapid Scoping Review

The database searches identified 817 titles. After duplicates were removed, 720 remained. The project researcher conducted initial screening with review by the project lead of 100 randomly chosen papers. This retrieved 80 full-text articles and 45 of them met the inclusion criteria (Figure I and Data II in the [Data Supplement](#)). We found no completed clinical trials of palliative care in severe stroke published since 2015 or in the 2 databases; COMET and Cochrane Pain, Palliative and Supportive Care. One protocol for trial of a person-centered intervention for informal carers/caregivers of stroke survivors (Organising Support for Carers of Stroke Survivors [OSCARSS]) has been published since.²⁹ The steering group reviewed reports and helped assess interrater reliability. A data extraction table was created, but quality assessment using a risk of bias tool was not considered relevant or appropriate. Of the 45 included studies, 15 were randomized controlled trials: 13 in stroke and 2 in palliative care. In addition, 8 trial protocols were included: 7 from stroke and 1 from palliative care. The remainder were other quantitative studies, 2 systematic reviews, 1 qualitative study, and 1 mixed-method study. The studies were predominantly stroke-based: 32 stroke, 13 palliative care, and 1 combined.

Outcome measures were extracted from the literature review data by the researcher with input from the project lead. A list of preexisting tools and other outcome measures was produced. The project steering group reviewed the list to generate a consensus set of measures suitable to present to a Delphi panel. A total of 43 outcome measures were extracted including 23 existing tools developed independently of the study which reported them (Data I in the [Data Supplement](#)).

The 33 outcome domains and 43 outcome measures were presented to the steering group on July 17, 2019. The group retained all 33 domains and shortlisted 16 outcome measures. The group added 3 further outcome domains based on their expertise in stroke or palliative care: “The length of time between admission to hospital and discharge to the community,” “The length of time between admission to hospital and death,” and “Looking back, did you achieve the outcome that you hoped to achieve?” Outcome domains listed in the same domain grouping were displayed together in the survey (Data III in the [Data Supplement](#)).

Delphi Results

Recruitment and Retention

Eighty-nine people were invited to participate in the Delphi panel; 48 agreed but 1 withdrew before the survey was circulated. Round 1 was completed by 35 out of 47 (75%), round 2 by 30 (64%), and round 3 by 28 (60%). The overall retention rate was 60%. Table 1 shows the experience/expertise in stroke or palliative care of the panelists. Seven respondents stated that they had personal experience of caring for a family member with stroke: of these one identified as a stroke professional. Of the 6 lay respondents, 5 had experience of caring for someone who died from a severe stroke, and 1 currently cared for a major stroke survivor. Five lay respondents completed all 3 rounds. One respondent who identified as a stroke survivor without professional experience in stroke or palliative care completed all 3 rounds. In total, 7 people with personal but not professional experience in stroke or palliative care (lay respondents) started the Delphi, and 6 completed it: a higher retention rate than those who identified their expertise as professionals.

Outcome Domains

In the first Delphi round, 31 of the 36 domains were rated as "important" to "very important" by at least 75% of the panelists (Table I in the [Data Supplement](#)). This was higher than expected and exceeded the threshold to move from rating to ranking. We selected the 12 outcome domains that had been rated "important" or "very important" by 97% or more of the panelists. In round 2, panelists selected a top 5 from the 12 domains presented. We then assigned points: 5 points for first place, down to 1 point for fifth place. A total score was calculated. This approach mirrored the nominal group technique used in the European Association of Palliative Care consensus workshop.¹⁹ For the third round, we removed 5 outcome domains scoring under 20, leaving 7 domains to be ranked by panelists (Table 2).

The final ranking from round 3 is shown in order of priority.

1. Shared decision-making between professionals, patients, and family members.

Table 1. Delphi Panelist Recruitment, Retention, and Experience

No. of individuals	Invited	Completed		
		Round 1	Round 2	Round 3
	47	35	30	28
Areas of expertise/experience				
Stroke—professional		25	23	21
Palliative care—professional		17	15	13
Stroke—personal experience		7	5	5
Palliative care—personal experience		5	3	3

2. Distress around fear of dying or living with severe disability the patient is feeling.
3. Whether the patient feels that they are being treated and valued as a person.
4. Amount of distress treatment for stroke causes the patient.
5. Patient and family perceptions of the quality and appropriateness of care.
6. Patient's ability to understand and respond to communication from others.
7. Amount of pain a patient has.

Outcome Measures

In round 1, none of the 16 outcome measures were rated as 4 or 5 ("useful" or "very useful") by at least 75% of panelists so all went through to the next round. In free-text comments and emails to the project team, some panelists said they did not know the measures well enough to make an informed judgment. For round 2, panelists were presented with the same outcome measures along with the round 1 results for each measure. In this second round, 2 of the 16 outcome measures reached consensus level for usefulness: the Distress Thermometer and CollaboRATE. Seven outcome measures were not rated as "useful" or "very useful" by at least 50% of the panel so we removed these for the third round. Nine outcome measures were presented to panelists in round 3, again with results from previous rounds. In the final round, 4 outcome measures were rated "useful" or "very useful" by 75% of panelists; CollaborRATE (shared decision-making), then EQ-5D-5L (quality of life), the Integrated Palliative Outcome Scale (<https://pos-pal.org/>), and the Distress Thermometer (Table II in the [Data Supplement](#)).

A total of 212 free-text comments from the Delphi panelists (123 from professionals and 41 from service users) were received and analyzed. Two major themes emerged: the need for simple, quick measures and difficulty finding a tool that is relevant beyond the initial, acute phase of stroke.

Stakeholder Meeting

Eight steering group members and 6 Delphi panelists attended. There was agreement about the top 3 outcome measures. Six outcome domains that did not progress from round 1 were considered important to patients and families:

- Physical and emotional impact of being an informal carer.
- Social isolation of patient and/or family member(s) due to the stroke.
- Family perceptions of quality of care for a person in their last days of life.
- Whether the patient's wishes were sought and followed.
- Patient's ability to communicate using language.
- Patient's own perception of their quality of life.

Table 2. Delphi Rounds 2 and 3—Ranking of Outcome Domains by Panelists

Outcome domain	Round 2 score*	Round 3 score*†
Shared decision-making between professionals, the patient, and family members	86	73
How much distress around fear of dying or living with severe disability the patient is feeling	55	56
Whether the patient feels that they are being treated and valued as a person	53	45
Patient and family perception of the quality and appropriateness of care provided	41	39
Patient's ability to understand and respond to communication from others	25	12
Amount of distress that treatment for stroke causes the patient	25	39
Amount of pain a patient has	22	12
How anxious or depressed the patient is	18	...
How well the information needs of the patient and family members are being met	17	...
Amount of functional ability a patient has	11	...
Impact of the illness on the relationship between a patient and their family	4	...
How much difficulty a patient has with swallowing (dysphagia)	3	...

*Each panelist chose the top 5 most important outcome domains and scored these out of 5.

†Round 3 had 7 domains.

Domains relating to patient and family quality of life are addressed by the recommended outcome measures but other approaches may need to be included.

DISCUSSION

This study aimed to build consensus on important outcome domains and outcome measures for future trials of palliative and end-of-life care in stroke by integrating a rapid review of published literature with expert discussion using a Delphi process with professionals and lay representatives. The study findings demonstrated the importance of measuring shared decision-making and quality of life for future trials of palliative care in severe stroke. This reflects complex choices about treatment and care options in the acute phase of stroke where interventions may increase survival but leave people with major disability. Shared decision-making is central to high-quality healthcare but stroke brings additional challenges to patient participation including sudden illness, impaired communication, lack of capacity, and proxy (substitute) decision-making.^{13,30} The devastating impact of severe stroke on the lives of patients and families globally is evident.³¹ Both decision making and quality of life evolve over a stroke illness trajectory so measures for patients and proxy (substitute) decision-makers suited to early and later phases were highlighted by our panelists and key stakeholders.

There are several strengths to this study. We searched both the stroke and the palliative care literature. Two bereaved carers of people who died after a stroke were involved throughout the project from inception to publication. Lay people and those with experience of major stroke were included in the Delphi study, and all but one of them completed the 3 rounds. These lived experiences of end-of-life care after stroke improved the validity and relevance of our results. The final round of the Delphi still

had 28 panelists more than the minimum target of 23 specified in the Delphi methodology.

There are some limitations. Most of the Delphi panelists were United Kingdom based because we want to initially develop a palliative care intervention for the United Kingdom. However, many aspects of clinical decision-making in stroke care are generalizable to other countries and health systems, and we reference relevant international work. A majority of Delphi panelists were professionals, although we tried hard to maximize public-patient involvement and involved 7 laypeople. Participants in the Delphi were not asked to disclose protected characteristics, such as gender, ethnicity, or race, so this study was not able to address cultural context and diversity among professionals, patients, and family caregivers. This is an important consideration for palliative care delivery and future research.³² Some panelists were not familiar with all of the outcome measures so it was difficult to gauge how confident they were in their scoring. Conversely, the very high level of agreement over the importance of so many of the outcome domains in round 1 of the Delphi meant that there was no principled way of assessing the cutoff point for inclusion in round 2. Therefore, in our stakeholder workshop, we discussed the outcomes that had not progressed through the Delphi and included those confirmed by laypeople who attended. Had the Delphi panel included more laypeople, those excluded outcomes might have been rated higher.

The most important domain was shared decision-making, and the proposed outcome measure was CollaborATE, a 3-question measure of shared decision-making in accessible language that can be completed by patients and family members. It has been used mainly in primary care and outpatient settings.³³ A systematic review of instruments to measure the process of shared decision-making recommended use of measures with good content validity and inter-rater reliability suited to the aim

of the study, the perspectives to be assessed, and the resources available.³⁴ Alternative outcome measures that include proxy (substitute) decision-making are, therefore, likely to be needed in the context of serious acute illness, such as severe, life-threatening stroke.^{14,35}

The other top outcome domains included distress around fear of death or major disability after stroke, effects of stroke treatment on patients, treating patients as individuals, quality of care, and effective communication. The EQ-5D-5L quality of life measure can be completed by patients and families,³⁶ as can the Integrated Palliative Outcomes Scale. It is a patient-reported outcome measure designed to capture physical, psychological, social, practical, and spiritual/existential concerns. Both were rated highly as outcome measures and are already used extensively in the United Kingdom and internationally. The Distress Thermometer³⁷ complements the visual analog scale within the EQ-5D-5L. There is an established Stroke Specific Quality of Life tool designed for stroke survivors not identified by panelists.³⁸ Going forward, the complexities associated with shared decision-making in serious acute illness, and the specific challenges associated with delivering person-centered treatment and care after stroke need to be considered fully in designing palliative care intervention studies. It is likely that a group of measures including those for proxy (substitute) decision-makers is required.

CONCLUSIONS

Shared decision-making and quality of life are the most important outcomes to measure in future trials of palliative care interventions after severe stroke. Interventions to improve shared decision-making and address the key outcome domains we have identified now need to be developed and tested in randomized controlled trials.

ARTICLE INFORMATION

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wrote the first article draft. All authors reviewed and revised drafts and approved the final submitted manuscript. Drs Mead, Mason, and Boyd are guarantors. The corresponding author attests that all listed authors meet authorship criteria and no others are omitted.

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Disclosures

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Supplemental Materials

Online Data I–III
Online Figure I
Online Tables I–II

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