



THE UNIVERSITY *of* EDINBURGH

Edinburgh Research Explorer

Outcomes, experiences and palliative care in major stroke

Citation for published version:

Kendall, M, Cowey, E, Mead, G, Barber, M, McAlpine, CH, Stott, DJ, Boyd, K & Murray, S 2018, 'Outcomes, experiences and palliative care in major stroke: a multicentre, mixed-method, longitudinal study' CMAJ : Canadian Medical Association Journal, vol 190, no. 9, pp. E238-E246. DOI: 10.1503/cmaj.170604

Digital Object Identifier (DOI):

[10.1503/cmaj.170604](https://doi.org/10.1503/cmaj.170604)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Peer reviewed version

Published In:

CMAJ : Canadian Medical Association Journal

General rights

Copyright for the publications made accessible via the Edinburgh Research Explorer is retained by the author(s) and / or other copyright owners and it is a condition of accessing these publications that users recognise and abide by the legal requirements associated with these rights.

Take down policy

The University of Edinburgh has made every reasonable effort to ensure that Edinburgh Research Explorer content complies with UK legislation. If you believe that the public display of this file breaches copyright please contact openaccess@ed.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.



Is palliative care appropriate for all people with major stroke? A multi-centre, mixed-method, longitudinal study of outcomes and experiences

Marilyn Kendall MA, PhD

Senior Research Fellow, Primary Palliative Care Research Group, University of Edinburgh, Usher Institute of Population Health Sciences & Informatics, Medical School, Teviot Place, Edinburgh, EH8 9AG

Eileen Cowey MN, PhD

Lecturer, School of Medicine, Dentistry & Nursing (Nursing & Health Care), University of Glasgow, 59 Oakfield Avenue, Glasgow, G12 8LL

Gillian Mead FRCP, MD

Professor of Stroke and Elderly Care Medicine, Royal Infirmary of Edinburgh, 51 Little France Crescent, Edinburgh, EH16 4SA

Mark Barber MRCP, MD

Consultant, Department of Medicine for the Elderly, Monklands Hospital, Monkscourt Avenue, Airdrie, ML6 OJS

Christine McAlpine FRCP, MRCP

Consultant Stroke Physician, Glasgow Royal Infirmary, Glasgow G4 0SF

David J Stott FRCP, MD

Professor of Geriatric Medicine, Institute of Cardiovascular and Medical Sciences, University of Glasgow, 2nd Floor New Lister Building, Glasgow Royal Infirmary, Glasgow, G4 0SF

Kirsty Boyd MRCGP, FRCP

Honorary Clinical Senior Lecturer, Primary Palliative Care Research Group, University of Edinburgh, The Usher Institute of Population Health Sciences & Informatics, Medical School, Teviot Place, Edinburgh, EH8 9AG

Scott A Murray FRCGP, MD

St. Columba's Hospice Chair of Primary Palliative Care, Primary Palliative Care Research Group, University of Edinburgh, The Usher Institute of Population Health Sciences & Informatics, Medical School, Teviot Place, Edinburgh, EH8 9AG

Correspondence to: Gillian Mead, Professor of Stroke and Elderly Care Medicine, Royal Infirmary of Edinburgh, 51 Little France Crescent, Edinburgh, EH16 4SA

T: 0131 242 6481

E: gillian.mead@ed.ac.uk

Abstract

Background

Case fatality after total anterior circulation stroke (TACS) is high. Our objective was to describe the experiences and needs of patients and carers, and to explore whether, and how, palliative care should be integrated into stroke care.

Methods

Mixed-methods. We recruited a purposive sample of people with TACS from three stroke services, and conducted serial, qualitative interviews with them and their informal and professional carers at six weeks, six months and one year. Interviews were transcribed for thematic and narrative analysis. The Palliative Care Outcome Scale, EuroQol-5D-5L, and Caregiver Strain Index were completed after interviews. A data linkage study of all TACS patients admitted to these services over six months recorded case fatality, place of death and readmissions.

Results

Data linkage (n=219) showed that 57% of TACS patients died within six months. The questionnaires recorded immediate and persistent emotional distress and poor quality of life. We conducted 99 interviews with 34 patients and their informal and professional carers. Patients and carers faced death or a life not worth living. Those who survived felt grief for a former life. Professionals focussed on physical rehabilitation rather than preparation for death or limited recovery. Future planning was challenging. 'Palliative care' had connotations of treatment withdrawal and imminent death.

Interpretation

Major stroke brings likelihood of death but little preparation. Realistic planning with patients and informal carers should be offered, raising the possibility of death or survival with disability. Practising the principles of palliative care is needed, but the term "palliative care" is unhelpful.

Introduction

Stroke is the second-leading global cause of death, accounting for 11% of deaths worldwide.(1, 2) Five year survival is similar to all cancers combined and heart failure.(3) Prognosis is particularly poor for patients with total anterior circulation syndrome (TACS) strokes; i.e. the ‘full house’ of unilateral motor or sensory loss with cortical symptoms (e.g. aphasia or inattention) and homonymous hemianopia.(4) A physical trajectory for patients with severe stroke has been proposed of sudden decline in functional status at stroke onset, and ending in death or survival with long term disability.(5)

Palliative care seeks to support people to live well with deteriorating health until they die, and improves outcomes when introduced early alongside disease-modifying treatment.(6, 7) The World Health Organisation recommends that holistic care for people with *any* life-threatening illness should include the key principles of palliative care.(8) Patients with severe stroke and their informal carers* stand to benefit when their physical, psychological, emotional, spiritual and practical needs are anticipated and addressed.(9-11) Cohort studies and qualitative research in patients with major stroke have identified difficulties with symptom management, communication, family support and proxy decision-making among patients dying with acute stroke.(12-15) However, there is insufficient detail about the immediate and long-term psychological, emotional and spiritual needs of stroke survivors and their informal carers to understand whether, and how, palliative care should be integrated into stroke care. A mixed-methods approach was considered the most appropriate method to explore these dynamic complex issues.(16)

Our objective was to understand patients, informal and professional carers’ experiences, concerns and priorities in the 12 months after TACS stroke and to identify the potential role of palliative care within stroke care, both in hospital and the community.

*The term “informal carer” is used to include family or unpaid carers

Methods

Design

We used a mixed-method approach using a) individual in-depth interviews with patients, informal carers and health/social care professionals, or joint interviews with patient and carer, b) questionnaires if patients and carers were able to complete them, c) data linkage study of all patients with TACS admitted to the three participating stroke units to explore patterns of death. We specifically utilised serial qualitative multi-perspective interviews as this is a robust method for understanding evolving and complex processes.(17) We utilised questionnaires to allow a numeric comparison using standardised measures across the interviewees, and to observe how they might perform serially in a future trial.

Data generation

Qualitative aspects

The qualitative study included TACS patients with a modified Rankin score of 4 or 5. In order to capture a range of experiences, we aimed to recruit a minimum of 10 patients in each of the dichotomous groups of age (70 or over, or less than 70), gender, artificial or oral feeding, right and left hemisphere stroke, significant comorbidity or not, and at least 5 people who were expected to go home. In total, we aimed to recruit around 30 patients because this was expected to achieve saturation, based on our previous experience of serial qualitative interviews in other end-of-life patient groups.(17)

Patients admitted to three stroke units in Scotland, and/or their legally-recognised representative or next of kin, were identified and approached by a clinician or a Scottish Stroke Research Network nurse working in a stroke unit in three Scottish Health Boards between June 2014 and January 2015. We used a recruitment grid to ensure we recruited the required diversity of participants. Consent was obtained from those patients with capacity (using aphasia 'friendly' materials if needed). Proxy consent was obtained for patients with incapacity. Participants were then contacted by a researcher. See box 1 for special considerations we adopted for people deemed not to have capacity.

Two experienced female qualitative researchers (nurse researcher and senior social scientist) undertook the interviews with stroke survivors and/or their informal carer/relative at six weeks, six months and one year.(18) At each time point, participants nominated a key health or social care professional for interview. Patient and relative interviews took place in the hospital ward or in their homes/residential care. Professionals were interviewed at their workplace or by telephone. The interviews took a narrative approach using topic guides which included, for instance with professionals how they perceived “palliative care”. Patients and carers were not asked directly but if they raised the topic of end-of-life care/death/dying this was explored using their terms, and they were asked if they had heard of palliative care, and what they understood it to mean. Interviews lasted 20 to 90 minutes, were digitally recorded and fully transcribed with field notes.(19)

Two lay advisory groups – one from a support group for patients with stroke and their informal carers, and another from a group specifically for people with speech loss regularly discussed emerging findings. An end-of-study focus group of informal carers, stroke clinicians, general practitioners, geriatricians, palliative care specialists, allied health professionals, care home managers and policy-makers, considered emerging recommendations.

Questionnaires

After each interview we mailed patients the EuroQol 5D-5L (quality of life) and the Patient Outcome Score (multi-dimensional needs) and carers the Carer Strain Index (caregiver wellbeing).(20-22).

Data linkage

We obtained Scottish Stroke Care Audit (SSCA) data for all patients with TACS admitted to the three stroke units during the six months of recruitment to the qualitative study. We linked these data with hospital and National Register for Scotland data for the year after the index stroke, to describe temporal patterns of death.

Data Analysis

The qualitative analysis was iterative and ongoing alongside further data generation. It was guided by the research questions, key theoretical concepts in the literature, and assimilated themes arising from the data. We performed thematic and narrative analysis and used a constructivist and interpretivist framework.(19, 23) Principles of grounded theory were used in the sense that data analysis was iterative and guided by emerging themes as well as by the research questions.(24) We were thus open to new ideas or themes as well as being able to situate our findings within the existing theoretical landscape. The interviews with individual patients, carers and professionals were initially coded separately. Then, each set of individual patient's and/or carer's transcripts were analysed over time to identify dynamic changes, generating 29 individual case studies. Next, patient transcripts were analysed together to gather patients' perceptions, informal carer transcripts analysed to examine the carers' perspectives, and health care professional transcripts analysed to gain their perspectives. Finally, all the transcripts (patients', carers' and professionals') from each of the three time points were analysed together to look at issues specific to each point. The insights were integrated with the assistance of NVivo 10 to show common themes and divergent perspectives.(25) We then traced themes across the three data sets to give an in-depth multi-perspective picture of experiences and outcomes.(26)

We triangulated between methods and between the views of the various participant groups to enrich our understanding of the data mainly employing the mixed-methods matrix approach which integrates both qualitative and quantitative data for each participant at the analysis stage of the study.(26) Deviant cases, or accounts of experiences that differed from those commonly reported, were scrutinised to refine our comprehension of emerging narratives.(27) Early in the study, the interviewers (MK, EC) reviewed each other's initial interview transcripts to ensure similarity of interviewing approach. MK coded all the transcripts and met frequently with a principal investigator (SAM) to discuss the emerging findings. The evolving analysis was peer-reviewed by the investigator group at quarterly meetings. We established an audit trail using field notes, recruitment logs, records of meetings and analytical discussions, and made regular reports to the study funder. We used multiple data collection sites to enhance the transferability of our findings and undertook data

linkage to enable a description of the wider study context, in terms of outcomes for a cohort of TACS patients.

Results

Two hundred and nineteen patients with TACS (185 ischaemic stroke (85%); 33 haemorrhagic stroke (15%)) were admitted to the three participating stroke units during the study recruitment period. Six month case fatality was 57% (125 deaths). One year case fatality was 60% (132 deaths); of these deaths 88 (67%) occurred during the first four weeks.

We recruited 34 patients to the qualitative study (Table 1) and performed 99 qualitative interviews (Table 2) over the first year after stroke. Between half and two-thirds of questionnaires were returned; these showed anxiety of family or friends, low self-worth, lack of information, difficulty sharing feelings, and emotional distress (Table 3). See Box 2 for specific details according to specific data sources including data linkage. We present the integrated findings from the three methods.

Experiences and key concerns of patients, informal carers and professionals

A typical trajectory of physical decline with people with TACS is illustrated in Figure 1 based on the findings generated from our mixed-methods. This extends and enriches Creutzfeldt's proposal for a "fourth trajectory"(5). It visualises how the typical physical functioning of patients who have survived the stroke tended to progress during the following 12 months. The percentages of patients surviving at one, two, six and 12 months are also shown. Key quotations are in Box 3.

Phase 1: Sudden illness and acute hospital admission

The sudden unexpected event of major stroke came as a major life crisis. Its life-threatening but unpredictable course posed huge challenges for patients, informal carers and professionals. Although the possibility of dying was clear to all involved, it was rarely voiced. Family members were unsure whether they were 'doing the right

thing' for patients (Q1). Participants faced complex care-planning decisions about resuscitation and feeding interventions (Q2).

Communication with informal carers and amongst staff was often challenging, as circumstances could change rapidly and many patients had lost capacity. Patients and carers expressed "dual narratives"; i.e. the narrative of a good recovery competing with a more realistic account of disability or death. Everyone had thoughts about death, but most patients felt unable to raise these with professionals. When the stroke first occurred, professionals aimed at life-saving treatment unless the patient was clearly dying, so professionals and patients expressed hope for a good recovery, even if death had been mentioned as a possible outcome. This sometimes confused carers (Q3). Staff confessed to be over-optimistic in order to motivate people and encourage participation in physical rehabilitation (Q4).

Many patients and informal carers would have welcomed more support in making decisions and in planning for the future from day one. The focus was on active rehabilitation, recovery, motivation and hope, with much less discussion and preparation for limited recovery. Many professionals gave time and listened and communicated well, but future planning was less evident (Q5&6).

Phase 2: Rehabilitation and transition to the community

Emotional needs and ability to adapt to a radically altered life varied. Some said it was difficult to see life as "*a life worth living*" (Q7).

As in the earlier phase, maintaining a sense of dignity and personhood was central. In rehabilitation wards, where people felt trapped, as they could not be discharged home until their physical abilities improved. Some carers and patients began to suggest that it would have been better if the patient had died, rather than living with severe disability. The sort of life deemed "unacceptable" was subjective; some accepted their disability; others with a better physical recovery felt discontented and grieved for their former life (Q8&9). These carers felt that there was less forward planning than in other illnesses (Q10).

Most patients wished to return home initially, but later realised this was complex, being compounded by pressure on hospital and care home beds (Q11).

Phase 3: living with major stroke in the community

Many people, especially those with aphasia and cognitive impairments, found difficulties in accessing services and equipment. Some felt abandoned and experienced loss of hope and meaning. This was exacerbated once professionals assessed patients as having reached their “plateau”, when many services were withdrawn (Q12). Those who returned to living at home had to adjust to a very different way of life and a home disrupted by hoists, commodes, and boxes of medication (Q13).

Most patients and their informal carers came to appreciate the advantages a good care home offered when they could not manage at home. Although one family member still wanted to take their parent home (Q14). For informal carers a nearby care home with friendly staff that inspired trust was important. Many care homes provided equipment and care that was difficult to achieve at home (Q15). Many informal carers felt that future care planning for both recovery and deterioration would have been helpful (Q16).

A few people died in care homes, where care home staff generally managed discussions and decisions sensitively. However one participant was shocked when the care home GP approached her as she visited her relative and initiated an end of life conversation without any warning (Q17).

Is ‘palliative care’ appropriate for people with major stroke?

Some staff viewed the term ‘palliative care’ as something negative, and applicable only to someone who was clearly dying (Q18 & 19).

Professionals actively sought to offer holistic care to patients and carers, but also struggled with the words ‘palliative care’. Barriers included prognostic uncertainty, although this doctor understood that this may remain, even after introducing a palliative approach (Q20). Professionals spoke about the need for everyone involved in patient care to have the time and ability to communicate effectively, with referrals being made to specialist palliative care only when required (Q21).

One bereaved relative suggested following a routine approach to document preferences (Q22). Using the word insensitively with patients could upset them (Q23). One hospital doctor suggested that the word may best be avoided (Q24).

Discussion

Summary: Patients and their informal carers faced sudden complex decisions, anxiety, distressing symptoms and the likelihood of death. Professionals focused on active physical rehabilitation, recovery, motivation and hope, and took less account of psychological, social and existential needs. Future care planning was difficult because of uncertain prognosis, variable and changing understandings, expectations and coping strategies.(28) Transition home or to a care home brought feelings of abandonment. Some experienced a lack of hope and meaning, and grief for a former life. The term 'palliative care' was equated with 'last-days-of-life' care by health care professionals, patients and family.

Comparison with other studies

Previous studies have identified high case fatality after severe stroke, multiple long-term physical problems, significant emotional distress, prognostic uncertainty, and a sense of abandonment after hospital discharge.(10, 29, 30) Our study confirms and adds richness to these findings, and adds several new insights. Firstly, staff focused on active physical rehabilitation, recovery, motivation and hope, whilst patients and carers felt that they needed more preparation, for, and discussion of, the possibility of death and living with severe disability. The questionnaires documented poor quality of life and multi-dimensional needs, and highlighted anxiety and carer distress throughout. Patients described a degree of suffering consistent with considerable unmet palliative care needs. Secondly, for those patients who survived, there was grief amongst both patients and family for the loss of their previous life, identity and roles; this could be considered as an evolving bereavement process, with some patients and family wondering if death would have been preferable to survival with disability. This evolving process has also been reported in severe head injury and dementia.(31, 32)

Thirdly, patients and professionals found the term 'palliative care' difficult to use, as it was equated with 'end-of-life' care and withdrawal of treatment. This is still true even in people with cancer.(33) This contrasts with how it was defined and recently affirmed by the WHO as active treatment to prevent distress starting from diagnosis of a life-threatening illness (see Box 4).

Strengths and limitations

Strengths included the mixed-methods design, with serial multi-perspective interviews dynamically integrating data from patients, informal and professional carers and rigorous analysis with service user involvement to aid interpretation. For instance the service user involvement explicated the challenges of accessing support when people have aphasia, and the experience of discharge back to the community after a long admission. To promote credibility and generalisability and transferability of the data we sought to find exceptions, then used triangulation (multiple methods of data collection, data sources, researchers or theories), to obtain a high level of concordance in category development. We adopted a relatively large longitudinal multi-site interview study to enable prolonged engagement in the field and used a varied sample to ensure that a range of perspectives were explored.

Limitations included that we recruited patients from Scotland only, some patients participated in only one interview because of loss to follow-up or death (though we performed several bereavement interviews with informal carers), and the sample was all white British. No formal training in palliative care had occurred in any of the stroke units, although some online learning was available: this is likely to be the case in most facilities internationally.

Conclusion and future directions

A realistic model of care would be to prepare for survival, decline or death, balancing "hoping for the best" with "preparing for the worst."(5) This palliative approach more often occurs for patients with progressive cancer and increasingly for people with non-malignant conditions such as heart, lung and renal failure and frailty.(34) Shared decision-making and individualised care is crucial.(30, 35-37) Staff need to be supported and trained in talking openly and honestly about the possibility of death or survival with severe disability, particularly in the acute setting

where the majority of deaths occur. Models of bereavement support might help professionals to facilitate both the more traditional restoration-orientated approaches to rehabilitation and loss-orientated rehabilitation that allows people to express and work through devastating life changes.(38) The principles of palliative care should be embedded within stroke services, but the term 'palliative care' should currently be avoided or reframed because of the implications of abandonment rather than a positive approach to care.(33, 39) Some specific recommendations are offered in Box 5.

Acknowledgements: We are grateful to all patients, informal and professional carers, and clinical colleagues who identified participants, and to members of the lay advisory groups for their involvement throughout the study. We thank the Scottish Stroke Research Network for support with patient recruitment, and Sian Nowell, National Service Scotland, for conducting the data linkage. Heather Goodare, who cares for her husband with a stroke commented on an earlier draft of this article.

Contributorship: GM, MK, EC, MB, CM, DS & SAM conceived the study and contributed to its design. GM and MK prepared the application for ethics approval and the patient information leaflets. MK led the study and undertook data collection and initial analysis with EC. All authors were involved in the interpretation of the data and reviewing the early and final drafts.

Funding: This study was funded by the Chief Scientist Office, grant number CZH/4/1033. The funder played no part in undertaking the research apart from funding it.

Ethics: Ethical approval was obtained from Scotland A Research Ethics Committee (reference 14/SS/0060) and the Caldicott Guardian for the data linkage study. Governance approval was conferred by the local NHS Research & Development services.

Data Sharing: Further data may be available from GM.

References

1. Mozaffarian D, Benjamin EJ, Go AS, Arnett DK, Blaha MJ, Cushman M, et al. Heart Disease and Stroke Statistics—2015 Update. A Report From the American Heart Association. 2014.
2. National End of Life Care Intelligence Network. Deaths from cardiovascular diseases: implications for end of life care in England February 2013 [Last accessed 6th February 2017]. Available from: http://www.endoflifecare-intelligence.org.uk/resources/publications/deaths_from_cardiovascular_diseases.
3. Askoxylakis V, Thieke C, Pleger ST, Most P, Tanner J, Lindel K, et al. Long-term survival of cancer patients compared to heart failure and stroke: a systematic review. *BMC Cancer*. 2010;10:105.
4. Bamford J, Sandercock P, Dennis M, Burn J, Warlow C. Classification and natural history of clinically identifiable subtypes of cerebral infarction. *The Lancet*. 1991;337(8756):1521-6.
5. Creutzfeldt CJ, Longstreth WT, Holloway RG. Predicting decline and survival in severe acute brain injury: the fourth trajectory. *BMJ*. 2015;351:h3904.
6. Tassinari D, Drudi F, Monterubbianesi MC, Stocchi L, Ferioli I, Marzaloni A, et al. Early Palliative Care in Advanced Oncologic and Non-Oncologic Chronic Diseases: A Systematic Review of Literature. *Rev Recent Clin Trials*. 2016;11(1):63-71.
7. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010;340:c1345.
8. WHO. Definition of Palliative Care. 2013. Available from: <http://www.who.int/cancer/palliative/definition/en/>.
9. Addington-Hall J, Lay M, Altmann D, McCarthy M. Symptom control, communication with health professionals, and hospital care of stroke patients in the last year of life as reported by surviving family, friends, and officials. *Stroke*. 1995;26(12):2242-8.
10. Burton CR, Payne S, Addington-Hall J, Jones A. The palliative care needs of acute stroke patients: a prospective study of hospital admissions. *Age Ageing*. 2010;39(5):554-9.
11. Eriksson H, Milberg A, Hjelm K, Friedrichsen M. End of Life Care for Patients Dying of Stroke: A Comparative Registry Study of Stroke and Cancer. *PLoS One*. 2016;11(2):e0147694.
12. Alonso A, Ebert AD, Dörr D, Buchheidt D, Hennerici MG, Szabo K. End-of-life decisions in acute stroke patients: an observational cohort study. *BMC Palliative Care*. 2016;15(1):38.
13. Payne S, Burton C, Addington-Hall J, Jones A. End-of-life issues in acute stroke care: a qualitative study of the experiences and preferences of patients and families. *Palliative Medicine*. 2010;24(2):146-53.
14. de Boer ME, Depla M, Wojtkowiak J, Visser MC, Widdershoven GA, Francke AL, et al. Life-and-death decision-making in the acute phase after a severe stroke: Interviews with relatives. *Palliative Medicine*. 2015;29(5):451-7.
15. Cowey E, Smith LN, Stott DJ, McAlpine CH, Mead GE, Barber M, et al. Impact of a clinical pathway on end-of-life care following stroke: a mixed methods study. *Palliative Medicine*. 2015;29.
16. Rowan M, Huston P. Qualitative research articles: information for authors and peer reviewers. *CMAJ: Canadian Medical Association Journal*. 1997;157(10):1442-6.
17. Murray SA, Kendall M, Carduff E, Worth A, Harris FM, Lloyd A, et al. Use of serial qualitative interviews to understand patients' evolving experiences and needs. *BMJ*. 2009;339:b3702.
18. Kendall M, Murray SA, Carduff E, Worth A, Harris F, Lloyd A, et al. Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs. *BMJ*. 2009;339:b4122.
19. Charon R. *Narrative Medicine: Honoring the Stories of Illness*. USA: Oxford University Press; 2008.
20. Herdman M, Gudex C, Lloyd A, Janssen M, Kind P, Parkin D, et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). *Quality of Life Research*. 2011;20(10):1727-36.
21. Cicely Saunders Institute. Palliative Care Outcome Scale (POS) 2012 [Last accessed 24th May 2017]. Available from: <http://pos-pal.org/>.
22. Robinson BC. Validation of a Caregiver Strain Index. *J Gerontol*. 1983;38(3):344-8.
23. Riessman CK. *Narrative Methods for the Human Sciences*. London: Sage Publications; 2008.
24. Bryant A, Charmaz K. *The SAGE handbook of grounded theory*. London; Thousand Oaks, Ca; New Delhi; Singapore: SAGE Publications Ltd; 2007.
25. NVivo qualitative data analysis software. QSR International Pty Ltd. Version 10 2010. Available from: http://www.qsrinternational.com/products_nvivo.aspx.
26. O' Cathain A, Murphy E, Nicholl J. Three techniques for integrating data in mixed methods studies. *BMJ*. 2010;341.
27. Ziebland S, McPherson A. Making sense of qualitative data analysis: an introduction with illustrations from DIPEX (personal experiences of health and illness). *Med Educ*. 2006;40(5):405-14.
28. Murray S, Boyd K, Sheikh A. Palliative care in chronic illnesses: we need to move from prognostic paralysis to active total care. *BMJ*. 2005;330:611 - 12.

29. Holloway RG, Benesch CG, Burgin WS, Zentner JB. Prognosis and decision making in severe stroke. *JAMA*. 2005;294.
30. Braun LT, Grady KL, Kutner JS, Adler E, Berlinger N, Boss R, et al. Palliative Care and Cardiovascular Disease and Stroke. A Policy Statement From the American Heart Association/American Stroke Association. 2016.
31. Headway (the brain injury association). [Last accessed 17/07/2017]. Available from: <https://www.headway.org.uk/news/national-news/coping-with-grief-after-brain-injury/>.
32. Alzheimer Scotland. [Last accessed 17/07/2017]. Available from: http://www.alzscot.org/information_and_resources/information_sheet/1788_loss_and_bereavement_in_people_with_dementia.
33. Zimmermann C, Swami N, Krzyzanowska M, Leighl N, Rydall A, Rodin G, et al. Perceptions of palliative care among patients with advanced cancer and their caregivers. *Canadian Medical Association Journal*. 2016;188(10).
34. Kimbell B, Boyd K, Kendall M, Iredale J, Murray SA. Managing uncertainty in advanced liver disease: a qualitative, multiperspective, serial interview study. *BMJ Open*. 2015;5(11):e009241.
35. Murray SA, Kendall M, Mitchell G, Moine S, Amblàs-Novellas J, Boyd K. Palliative care from diagnosis to death. *BMJ*. 2017;356.
36. Oliver D, Domenico Borasio G, Caraceni A, de Visser M, Grisold W, Lorenzl S, et al. Palliative care in chronic and progressive neurological disease: summary of a consensus review. *European Journal of Palliative Care*. 2016;23(5):232-5.
37. Royal College of Physicians. National clinical guideline for stroke: Prepared by the Intercollegiate Stroke Working Party. Fifth Edition, London 2016. Available from: <https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-%281%29.aspx>.
38. Stroebe M, Schut H. The dual process model of coping with bereavement: rationale and description. *Death Studies*. 1999;23(3):197-224.
39. CAPC. [Last accessed 18/07/2017]. Available from: <https://www.capc.org/about/palliative-care/>.