Ir J Med Sci (2016) 185:741–744
DOI 10.1007/s11845-015-1290-9

BRIEF REPORT

Identifying palliative care issues in inpatients dying following stroke

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Received: 3 February 2015 / Accepted: 29 March 2015 / Published online: 8 April 2015

Abstract
Background Stroke leads to high mortality and morbidity but often there is a conflict between need for palliative care and avoidance of 'therapeutic nihilism'.
Aims We aimed to elicit the palliative care needs of stroke patients at the end of their lives in our unit with a low overall mortality rate (1 month: 8.8 %, inpatient: 12.9 %).
Methods We identified consecutive stroke patients who died over 2 years. Their clinical records were used for data collection.
Results Of 54 deaths, 33 (61.1 %) were females, mean (SD) age at death was 79.3 ± 12.9 years. 41 (75.9 %) died after first stroke, 9 (16.7 %) were inpatient strokes, 7 (13.0 %) thrombolysed and 7 (13.0 %) had strokes as treatment complication. There were clear statements recorded in 26 (48.1 %) that patients were dying and death was thought to be due primarily to extent of brain injury in 24 (44.4 %). Palliative needs identified included dyspnoea 21 (38.9 %), pain 17 (31.5 %), respiratory secretions 17 (31.5 %), agitation 14 (25.9 %) and psychological distress 1 (1.9 %). Symptoms were due to premorbid diseases in 6 (11.1 %). Palliative care expertise were sought in 13 (24.1 %) and continuous subcutaneous infusion was used in 18 (33.3 %) to control symptoms. 4 (7.4 %) subjects underwent cardiac arrest calls and 9 (16.7 %) deaths occurred in ICU/HDU. The median Stroke–Death interval was 20 days (range 0–389). Do Not Attempt Resuscitation (DNAR) orders were in place in 86.8 % of patients. The median DNAR–Death interval was 7 days (range 0–311) with 7-day DNAR–Death rate of 53.2 % and 30-day of 78.7 % of the total deaths.
Conclusions Dyspnoea, pain and respiratory secretions were identified as the main palliative care needs.

Keywords End-of-life care · Stroke · General palliative care · Specialist palliative care

Introduction

Stroke leads to high mortality and morbidity. In the United Kingdom, 30-day stroke mortality is reported as between 20 and 30 % [1]. It is the third leading cause of death in the western world and the second largest killer world-wide [1]. Most publications with regard to stroke outcome understandably treat death as a concrete or binary outcome; however, the mode of dying following acute stroke varies greatly. People can die from the direct effects of a large or critical brain injury. They can die from the medical complications of the resultant neurological impairment or, because stroke is often the consequence of other medical disease, they can die from coexistent medical problems. Often, when it comes to a final determination of cause of death for official purposes, it is hard to define what contribution each factor makes to the patient's dying other than the overarching diagnosis of 'stroke'.

Prognostication and prediction of stroke outcomes is notoriously difficult [2, 3] and achieving a balance between prematurely ceasing what may be valuable therapy and not prolonging suffering in a situation where an individual's

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life cannot be saved, is at times extremely challenging. Historically stroke specialists have been concerned as to the effect of 'therapeutic nihilism' on outcome and mortality; the expectation of poor outcome becoming a self-fulfilling prophecy. Possibly as a consequence, the evidence base around the palliative care of stroke is extremely limited and this is reflected in the recently published American Stroke Association Guidelines on the Palliative care of stroke [4] concentrated as much on difficulties of prognostication and communication, with little concrete guidance on the process of palliation.

In an effort to greater understanding of the process of dying in stroke we performed a review of the care of consecutive patients who died to evaluate their process of death and identify what palliative care needs were demonstrated. We assessed how these palliative care needs were addressed and aimed to determine if there was evidence of inadequate palliative practice.

Methods

Subjects selection and data collection

We selected consecutive stroke patients who died over 2 years in our University Teaching Hospital. A Hospital In-Patient Enquiry (HIPE) system was used to select all patients who died and had stroke coded as diagnosis. They were then cross-referenced to our local stroke register to make sure that no case was missed. The medical records were reviewed whenever there was discrepancy. St James's Hospital operates both acute and inpatient rehabilitative stroke services and has a low overall mortality rate (1 month: 8.8 %, inpatient: 12.9 %). The service is jointly operated by Neurology and Medicine for the elderly services and has access to all evidence-based therapies for stroke and a specialist palliative care service.

All patient records were evaluated as part of data collection including medical and nursing notes and the Electronic Patient Record. A senior stroke physician with palliative care training examined each set of notes in detail for references to symptomatology, interventions and for Do Not Attempt Resuscitation (DNAR) orders. Where uncertainties arose about causality of death or presence of symptoms, notes were reviewed by a second senior stroke physician with palliative training and a consensus derived. Data were anonymised and collected to a standard proforma through the departmental audit process.

Data analysis

IMB SPSS statistics (version 20) was used for data analysis. Categorical data were presented as frequencies. Continuous data were presented as mean ± standard deviation (SD). To compare the mean age at death with mean age of stroke patients over 1 year, one-way ANOVA welch *t* test was used. Differences between groups was analysed using independent t-tests for quantitative variables and Chi square tests for categorical variables.

Results

Notes on 54 deaths were reviewed [33 females, median (range) age at death 82(33–97) years], demographic details are summarised in Table 1.

Table 1 Demographics of dying inpatients following stroke

Demographics	
Number, *n*	54
Female, *n* (%)	33 (61.1)
Mean age, years (SD)	79.3 (12.9)
Median age, years (range)	82 (33–97)
First stroke, *n* (%)	41 (75.9)
Inpatient strokes, *n* (%)	7 (13.0)
Thrombolysed, *n* (%)	7 (13.0)
Stroke as treatment complication, *n* (%)	7 (13.0)
Clear statement that patient was dying, *n* (%)	26 (48.1)
Cardiorespiratory arrest calls, *n* (%)	4 (7.4)
Deaths in ICU/HDU, *n* (%)	9 (16.7)
Premorbid conditions causing symptoms, *n* (%)	6 (11.1)
Specialist palliative care consultation, *n* (%)	13 (24.1)
Death attributable to	
Brain lesion, *n* (%)	24 (44.4)
Medical complications, *n* (%)	20 (37.0)
Unrelated to stroke, *n* (%)	10 (18.5)
Continuous subcutaneous infusion (syringe driver) use	
Pain, *n* (%)	14 (82.4)
Agitation, *n* (%)	11 (78.6)
Respiratory secretions, *n* (%)	10 (71.4)
Dyspnoea, *n* (%)	10 (47.6)
Specialist palliative care consultation vs. attributable cause of death	
Brain lesion, *n* (%)	5 (20.8)
Ischaemic stroke, *n* (%)	4 (80.0)
Haemorrhagic stroke, *n* (%)	1 (20.0)
Medical complication, *n* (%)	4 (20.0)
Pneumonia, *n* (%)	4 (100.0)
Unrelated to stroke, *n* (%)	4 (40.0)
Lung cancer, *n* (%)	1 (25.0)
Bowel cancer, *n* (%)	1 (25.0)
CCF, *n* (%)	2 (50.0)

ICU intensive care units, *HDU* high dependency unit, *SD* standard deviation, *CCF* congestive cardiac failure

The median interval between Stroke onset and Death was 20 (0–389) days. Females made up a higher proportion of patients who died compared with our overall patient population derived from register data 61.1 vs. 46.4 % ($p = 0.04$, chi square). Patients who died were significantly older on average [Mean (SD): 79.3 (12.9) vs. 70.6 (14.2) years. $p < 0.001$, t test].

Recorded palliative care needs identified were; n (%): pain 17 (31.5 %), respiratory secretions 17 (31.5 %), dyspnoea 21 (38.9 %), agitation 14 (25.9 %), and psychological distress 1 (1.9 %). In terms of palliative care needs, those who died early suffered less dyspnoea and a trend towards fewer other palliative needs versus those who died late.

Continuous subcutaneous infusion (CSCI) was used in 18 (33.3 %) to control symptoms. These infusions contained a combination of Morphine with other agents including Cyclizine, Midazolam, Levomepromazine and Hyoscine Hydrobromide, depending on palliative needs. Patients receiving specialist palliative care consultation were more likely to be placed on a CSCI [12/13 (92.3 %) vs. 6/41 (14.6 %)]. $p < 0.0001$, Fishers Exact test.

Do Not Attempt Resuscitation (DNAR) orders were in place in 86.8 % of patients at time of death. The median interval between DNAR and Death was 7 (0–311) days with 7-day DNAR–Death rate of 53.2 % and 30-day 78.7 % of the total deaths.

There were 24 deaths related directly to stroke, with median (range) length of time from stroke onset to death of 10.5 (0–225) days. Of these, 22 had DNAR orders in place, with median (range) length of time from DNAR to death of 4.0 (0–225) days. Twenty deaths were due to medical complications of stroke with median (range) length of time from stroke onset to death of 60.0 (3–389) days. Of these, 16 had DNAR orders in place, with median (range) length of time from DNAR to death of 11.5 (0–311) days. Ten deaths were due to other medical conditions unrelated to stroke, with median (range) length of time from stroke onset to death of 26.5 (3–285) days. Of these, 9 had DNAR orders in place, with median (range) length of time from DNAR to death of 3.0 (1–36) days.

Discussion

Palliative care needs were common in our stroke population with respiratory symptoms recognised more commonly than pain or psychological distress. The population studied were actively managed by a specialist stroke service and by intensive care services where indicated. The mortality rate for the service is low and rate of interventional care substantial.

Females made up a higher proportion of patients who died compared with our overall stroke patient population derived from register data. In Ireland, report on vital statistics 2006 revealed that females accounted for 60 % of stroke deaths, with 1162 female and 785 male deaths from stroke [5]. In 2013, females accounted for 59 % of stroke deaths, with 1174 female and 827 male deaths from stroke [6]. Morgenstern et al. [7] reported a higher proportion of females constituting 61 % of the 40,346 stroke deaths in Texas. On the other hand, a previous literature review involving France, Germany, Italy, Spain, the UK, and the US reported a higher stroke-attributable mortality in males than females [8].

As a retrospective chart-based study, patients may have suffered symptoms that were not recognised or not recorded. The low rate of recognition of psychological distress is of particular note as is lower than expected prevalence of pain. Hansen et al. [9] reported newly developed pain in 45.8 % of the patients at 6-month follow-up post stroke with more than one pain type in 36.5 % of the patients. Anxiety and depression is experienced by up to 30 % [10] of patients following stroke. Whilst many of our patients may have had reduced levels of consciousness, and clinical staff on the stroke service trained to look for evidence of pain and distress, patients communication difficulties may have contributed to lack of identification of palliative care needs. In a subset of 42 patients dying from stroke in a tertiary hospital and referred to a palliative care team, 93 % on admission [median (range) length of time from admission to death of 12 (4–115) days] and 95 % at first palliative care team visit [median (range) length of time from first palliative care team visit to death of 5 (1–55) days] were reported to have dysphasia or altered level of consciousness that might have led to under recognition and under treatment of symptoms [11]. Respiratory symptoms may be identified more easily in patients unable to communicate.

Overall 35/54 (64.8 %) patients were recognised as having palliative care needs with each palliative care need present in less than 40 % of patients. Holloway et al. [12] reported that patients with stroke who had a palliative care consult were less likely to have traditional symptoms than other common diagnoses over a 3-year period (pain 5.0 %, dyspnoea 4.0 %, depression 3.0 % and nausea 0.0 %). Another study [11] reported dyspnoea behaviour in 81 % and pain in 69 % of dying stroke patients referred to specialist palliative care team. In our study, the longer the patient survived the higher the likelihood of palliative care needs. This could be explained by medical and surgical complications.

The DNAR orders were in place in majority at time of death. A previous study [4] also reported a high number of DNAR orders in stroke patients at time of death. Furthermore, families have reported difficulties about discussions and applicability of DNAR orders [3]. This could be

explained by the uncertainty or difficulties in prognostication in stroke survivors. Most of the patients died earlier which is comparable to another study; Goldacre et al. [13] reported that nearly 70 % of stroke deaths were within 30 days, and 90 % occurred during the initial admission.

Other studies concluded that the specific role of specialist palliative care in the management of stroke patients was unclear [14] and there were gaps in evidence base underpinning stroke care at the end of life [15]. Stevens et al. [16] in a critical review of literature in palliative care in stroke indicated the paucity of data in between provision of palliative care services for patients who die in the acute phase of stroke and for those patients who die late. This paucity in data has not improved greatly in the meantime.

Specialist palliative care advice was sought in 24.1 % of patients. Those, whose cause of death was unrelated to stroke, were likely to be seen by a specialist palliative care team. One study reported 26 % of total stroke deaths benefitting from specialist palliative care team consultation [11]. Gardiner et al. [1] stated the importance of stroke professionals in delivering high-quality palliative and end-of-life care and also appropriate support from specialist palliative care services. Other studies have proposed either bridging the gaps between specialist palliative care and stroke teams without overwhelming specialist palliative care team or deskilling stroke team [16] or partnering with specialist palliative care [17]. It is essential to equip stroke healthcare staff to adjust to sudden changes brought on by stroke [18].

In conclusion, dyspnoea, pain and respiratory secretions were identified as main palliative care needs. Stroke professionals should be in the forefront of providing palliative and end-of-life care. Palliative care needs are complex following stroke and skills in assessing appropriateness and delivering such care are essential. Involvement of specialist palliative care in complex cases is essential. Further research is needed in this field to characterise palliative care needs in dying stroke patients, as this will inform policy and improve outcomes in those with palliative care needs.

Acknowledgments None.

Conflict of interest None.

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