Palliative Care and Stroke

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Abstract
There have been significant advances in the prevention and management of stroke over the last few decades. Despite these important developments, stroke, both in the acute and chronic phases, remains a major cause of morbidity and mortality. The value of integrating palliative care principles and practices into stroke care management is being increasingly recognized across a range of domains including symptom management, assistance with complex decision-making, discharge planning, and end-of-life care. This chapter will explore the logistics, benefits, complexities, and challenges associated with the evolving relationship between stroke and palliative care services.
1 Introduction

There have been significant advances in the acute treatment and rehabilitation of stroke over the last few decades. Contributing factors include improved early detection/recognition, timely hospital presentation, the use of thrombolytic and endovascular therapies, early initiation of rehabilitation, and the introduction of organized stroke care. Ongoing improvements in stroke prevention, treatment, and rehabilitation are crucial as stroke prevalence is expected to increase with the aging population. The lifetime risk of having a stroke has been reported to be approximately one in five for females and one in six for males (Mozaffarian et al. 2015) although this figure was calculated from a predominantly Caucasian cohort within the United States and may therefore not be easily generalizable. Stroke incidence varies between countries and is influenced by a range of health, cultural, geopolitical, and socioeconomic factors. Globally the burden of stroke is increasing as measured by the absolute number of people affected, stroke survivors, and disability-adjusted life years lost (Feigin et al. 2014). Much of this burden is seen in low- to middle-income countries.

Strokes constitute a heterogeneous group of conditions which can be described by mechanism and/or location of injury. Approximately 80–85% of strokes are ischemic in nature, with the remainder being either intracerebral hemorrhage (ICH) or subarachnoid hemorrhage (SAH). ICH generally occurs following arterial wall rupture in vessels weakened by chronic hypertension while SAH typically follows aneurysmal rupture within the circle of Willis or trauma (Simmons and Parks 2008). Ischemic subtypes include thrombotic strokes due to occlusive arterial atherosclerotic disease, embolic strokes which are typically cardiac in origin, and lacunar infarcts which occur following the occlusion of the small arteries that supply deep brain structures. Broadly speaking the extent of injury or damage associated with a stroke will depend upon the blood vessels involved and the areas and extent of brain affected.

The most important factor in the initial management of acute stroke is time. The sooner a stroke is recognized and treatment commenced, the better the outcome is likely to be. Another key factor in optimizing chance of recovery is venue of care. There is clear evidence that patients who are managed in a designated stroke center or unit with a specialist multidisciplinary team do better than patients managed elsewhere. In a Cochrane review of 28 trials and 5855 participants which compared stroke care unit (SCU) care with alternative care, SCU was associated with significant reductions in the odds of death, dependency, and/or institutionalized care (Stroke Unit Trialists’ Collaboration 2013). The benefits of management within a SCU have been demonstrated for all subtypes of ischemic strokes (Smith et al. 2010a) as well as for ICH (Langhorne et al. 2013).

After initial cardiorespiratory stabilization, immediate stroke management is individualized according to a range of factors including type and severity of stroke, presence of contraindications, medical comorbidities, and patient and family wishes. Following an ischemic stroke in appropriate patients who do not have contraindications, the initial goal is to provide intravenous (IV) thrombolytic therapy as quickly as possible. The provision of a single dose of IV recombinant tissue plasminogen activator (IV rt-PA) within 4.5 h of the commencement of symptoms has been associated with a substantially improved chance of independent function at 3 months post stroke (Maldonado et al. 2014). The use of endovascular therapies following ischemic stroke is an area of ongoing research and development. Therapies under this umbrella include endovascular thrombolysis, thrombectomy, and stent retriever technology. It has been suggested that these approaches may provide superior recanalization in situations such as proximal vessel occlusion when systemic thrombolysis may be less efficacious although until recently results from randomized trials were mixed. Two recently published trials however, both of which were stopped early due to efficacy, have shown significant improvements in functional outcome (Campbell et al. 2015; Goyal et al. 2015) as well as mortality (Goyal et al. 2015) for the combination of
endovascular thrombectomy and IV rt-PA compared to IV rt-PA alone, in ischemic stroke with proximal cerebral arterial occlusion.

The management of ICH involves acute stabilization including management of blood glucose and temperature, careful blood pressure control, quality nursing care, prevention of complications, early rehabilitation, and prevention of recurrent hemorrhage (Hemphill et al. 2015). Time is again crucial as it is common for deterioration to occur in the period soon after an ICH. While the benefits of surgical removal of hemorrhage for most supratentorial ICH have not been proven, prompt surgical management is recommended for patients with a cerebellar ICH who are deteriorating neurologically or have brain stem compression (Simmons and Parks 2008; Hemphill et al. 2015). Emergent therapies under investigation in ICH include minimally invasive surgical techniques and the use of biological neuroprotective agents.

Despite advances in prevention, acute treatment, and rehabilitation, stroke remains a prominent cause of morbidity and mortality worldwide. It is a major cause of disability in the United States where up to a third of patients require admission to a long-term care facility following stroke (Mozaffarian et al. 2015). A range of psychological and physical sequelae have been reported by stroke survivors including anxiety and depression, pain syndromes, and communication difficulties. Not surprisingly high levels of distress and caregiver burden are also common among relatives and loved ones. The ideal model for managing the important physical and psychosocial needs of stroke survivors and their families is yet to be established, and it is not clear where palliative care services sit in this paradigm.

While mortality rates vary internationally and have decreased over the last 20 years (Feigin et al. 2014), stroke remains the second commonest cause of death worldwide (World Health Organization 2014). A range of important and diverse needs have been reported by dying patients and their families including symptom management, psychosocial support and assistance with prognostication, treatment decision-making, and future planning. The utilization of palliative care principles and practices would seem appropriate in meeting these needs, and there is increasing recognition, including from international guidelines, of the importance of integrating palliative care into stroke care (National Stroke Foundation 2010; Holloway et al. 2014; Casaubon et al. 2016; Intercollegiate Stroke Working Group 2016). However a range of challenges to effective integration have also been identified from both a stroke and palliative care perspective. The aim of this chapter is to explore the relationship between stroke services and palliative care in both the acute and longer-term setting. The current level of involvement and proposed models of integration will be discussed as well as some of the common palliative care needs and issues identified by patients, families, and health professionals. It is hoped this will provide a contemporaneous overview of the current situation and highlight some important areas for future thought, research, and investment.

2 Palliative Care and Acute Stroke

There is growing recognition that some patients and families following an acute stroke have needs that will be best met by integrating palliative care philosophies and practices into their stroke management.

2.1 Palliative Care Recognition Within International Stroke Guidelines

There is increasing recognition of the relevance of palliative care principles for some patients following a stroke within published international stroke guidelines. While the depth and breadth of information varies across guidelines, there is general agreement concerning the importance of high-quality end-of-life care within stroke services and some support for palliative care throughout the stroke care trajectory.

In a comprehensive scientific statement from the American Heart Association/American Stroke...
Association, Holloway and colleagues explored the dynamics, logistics, and complexities associated with palliative and end-of-life care in stroke (Holloway et al. 2014). The authors advocate for the availability of palliative care for all patients and their families following a severe or life-threatening stroke, throughout the disease course. In their proposed model, the management of most palliative care problems would be carried out by the stroke service multidisciplinary team with specialist palliative care services available for secondary consultation in situations of heightened complexity. Importantly, the authors provide evidence-based recommendations and guidance to aid implementation, including practical education regarding communication skills, goal setting, and symptom assessment and management.

The Canadian Stroke Best Practice Recommendations emphasize the importance of fostering palliative care expertise within stroke centers (Casaubon et al. 2016). The guidelines make a distinction between palliative care and end-of-life care noting that palliative care can occur in combination with life-prolonging therapies and is not reserved only for those who are imminently dying. A palliative approach is suggested in the setting of catastrophic stroke or multiple comorbidities in order to support both patient and family. Replicating the recommendations of Holloway and colleagues (2014), the guidelines make clear that the stroke service multidisciplinary team should have the appropriate palliative care skills to support dying stroke patients but also that there be access to specialist expertise. Specific indications for specialist palliative care referral include the management of unstable symptoms and assistance with decision-making and with managing complex family and psychosocial dynamics. Recommendations are also made in relation to Advance Care Planning (ACP), specifically that stroke survivors, their families, and caregivers should be supported to participate in it.

In Australia, the 2010 Clinical Guidelines for Stroke Management recommend that all patients dying following a stroke have access to care that is aligned with palliative care principles and practices (National Stroke Foundation 2010). This includes consideration of physical, psychosocial, spiritual, and cultural needs as well as guidance with prognostication and the diagnosis of dying in deteriorating patients or those following a severe stroke. The guidelines note that in many less complex situations, this care will be provided by stroke service staff, and these staff will require ongoing education and support in relation to end-of-life care. The importance of clear and timely communication between stroke services, patients, and families is stressed, and family meetings are suggested as an appropriate forum for these discussions.

The 2016 fifth edition of the UK National Clinical Guideline for Stroke include, among their key recommendations, the proposition that multidisciplinary stroke teams should consider high-quality end-of-life care as a core component of their work (Intercollegiate Stroke Working Group 2016). The need for enhanced education and support for stroke service staff in palliative care principles is emphasized, as is access to specialist palliative care and the opportunity for timely transfer to home if this is the desirable outcome. Among changes from the previous iteration, the 2016 guidelines caution against imposing burdensome restrictions upon patients dying from stroke with particular mention made about the pragmatic management of impaired swallowing and oral intake at end of life. The guidelines acknowledge the range of physical and psychological stressors that can occur following a large stroke and propose that the appropriate management of these problems can help ameliorate distress for patients and their families at end of life.

When considered together, a number of common themes are evident across the guidelines. These include:

- General support for palliative care principles as key components of stroke care.
- Recognition of the presence of multidimensional symptom issues for many patients and their families following a large stroke.
- The importance of clear and ongoing communication between stroke services, patients, and families particularly in relation to issues such as prognostication, goals of care, and management.
- Support for a service model in which the multidisciplinary stroke team provides the majority
of palliative and end-of-life care with secondary support available from specialist palliative care services.

### 2.2 Integration of Stroke and Palliative Care

Although integrating palliative care and acute stroke services is considered important for patients, families, and health professionals alike, how this integration might actually take place is under-researched and not without its challenges. Establishing the palliative care needs of stroke patients and their families is a crucial first step in an integrated approach; however data addressing this question are limited and little is known about how these needs might change over time (Stevens et al. 2007).

Potential methods to assess palliative care needs might include triggers built into existing stroke care pathways – simple bedside prompts or more formal targeted needs assessment tools. Creutzfeldt and colleagues (2015) showed that the use of a simple four-question “palliative care needs checklist” during neurology ward rounds was an effective prompt for recognizing and meeting patient and family needs. Questions in the checklist addressed the presence of distressing symptoms, how the patient and family were coping, and whether the goals of care or treatment approach needed to be modified. Burton and colleagues (2010) used the Sheffield Profile for Assessment and Referral for Care (SPARC) tool to identify high levels of palliative care needs in a prospective study of 191 consecutive stroke admissions to two UK hospitals. The SPARC was developed to screen patients with a range of advanced diseases for specialist palliative care (SPC) referral and incorporates five domains covering physical, psychosocial, spiritual, and functional issues. The authors concluded that the use of the SPARC tool particularly in more disabled stroke patients provided a valuable trigger for staff to consider a range of palliative care issues.

In some ways acute stroke and palliative care might not be considered particularly compatible. The acute stroke environment is one of high-intensity neuro-restorative care with an emphasis on survival, while palliative care is commonly considered more meditative in approach with less concern placed upon survival and more on quality of life. Challenges in introducing palliative care into general stroke management are highlighted by qualitative studies in which stroke unit staff have questioned the juxtaposition of a simultaneous curative focused and palliative approach (Gardiner et al. 2013) and have viewed palliative care as being predominantly about end-of-life care and representative of failure of stroke management (Burton and Payne 2012). Beyond the acute stroke phase, categorizing a patient as “palliative” has been identified as a barrier to combining rehabilitation and palliative care (Burton and Payne 2012).

Traditional palliative care models developed predominantly for patients with malignant diseases may not be easily transferrable to stroke. With its typically sudden onset and decidedly unpredictable clinical course, stroke may behave differently to many cancers or other chronic non-malignant conditions in which palliative care is commonly involved. Such differences were highlighted by a study of 544 patients admitted to a tertiary SCU that found more than 50% of the 87 patients who died had been completely independent and well immediately prior to their stroke (Eastman et al. 2013). Caregivers of stroke survivors have also been noted to have different needs when compared to those of patients with cancer. They are typically older and frailer and as a result may lack important support and social networks (Stevens et al. 2007).

Despite a current lack of clarity concerning the characteristics and function of palliative care within acute stroke services (Burton and Payne 2012), there does appear to be general acceptance of a pragmatic service model in which the multidisciplinary stroke team provides the majority of palliative and end-of-life care with secondary support available from SPC (Holloway et al. 2014; Creutzfeldt et al. 2015; Casaubon et al. 2016). SPC services are also ideally placed to provide the necessary education, training, and support to enable the provision of high-quality nonspecialist
2.3 Specialist Palliative Care Utilization in Acute Stroke: A Review of the Current Literature

Data quantifying the level of SPC involvement in stroke are limited and predominantly focused on inpatient consultation services. While variability is seen between health organizations internationally, there is evidence to suggest that the overall uptake of palliative care services for patients following an acute stroke is increasing. In a large cross-sectional study investigating palliative care utilization in nontraumatic intracerebral hemorrhage (ICH), Murthy and colleagues (2016) analyzed admissions to over 1000 American hospitals using the National Inpatient Sample, the largest inpatient health database in the United States. Of the 311,217 included admissions, 32,159 (10.3%) received palliative care, with a substantial annual increase in palliative care involvement seen (4.3% in 2007 to 16.2% in 2011). In an analysis of administrative data of 4894 patients who died within 30 days of an ischemic stroke, 23% of all patients were enrolled in hospice for end-of-life care, a threefold increase from previously reported rates (duPreez et al. 2008).

A small amount of research has explored predictors for SPC involvement in patients following stroke as well as differences between referred and non-referred patients. The influence of both socio-demographic and clinical factors on referral patterns has been reported with data typically obtained from either large administrative dataset analyses or retrospective cohort studies.

In an analysis of palliative care involvement for patients following nontraumatic ICH (Murthy et al. 2016), significant predictors for palliative care involvement included ICH severity, associated comorbidities, female gender, advanced age, hospital location, and ethnicity. Several of these factors were also predictors for hospice utilization in 4894 patients who died within 30 days of an ischemic stroke (duPreez et al. 2008). Predictors which increased the likelihood of hospice utilization included older age, female gender, dementia,
Caucasian descent, and hospital length of stay greater than 3 days. Mechanical ventilation, gastrostomy, and uncomplicated diabetes mellitus as a comorbidity correlated with decreased hospice enrolment.

Holloway and colleagues (2010) reviewed all patients referred to an inpatient palliative care consultation service within a large US teaching hospital over a 3-year period. Compared to patients with cancer or common nonmalignant diagnoses including chronic obstructive pulmonary disease (COPD), stroke patients tended to be more functionally impaired, less likely to have decision-making capacity, and were more likely to die in the hospital. For the 1551 stroke patients analyzed during the study period, 6.5% received palliative care consultation. Stroke patients seen by the palliative care service were older, stayed longer in the hospital, and were more likely to be discharged to hospice. However, the majority of stroke patients who died or were discharged to hospice were not seen by SPC.

In an Australian review of 544 admissions over a single year to a metropolitan, tertiary SCU, just over 11% of patients were referred to SPC (Eastman et al. 2013). The predominant reason for referral was end-of-life care, and a number of predictors for referral were identified. These included female gender, older age, increased disability pre stroke, ICH, and living alone or in a residential aged care facility prior to stroke. Sixteen per cent of all SCU admissions died during the review period with just over half seen by the palliative care team. This is approximately double the rate reported from both Swiss and Irish stroke services where only 26% and 24%, respectively, of deceased stroke patients received palliative care consultation (Mazzocato et al. 2010; Ntlholang et al. 2016). Stroke patients referred to the Australian SPC who died during the admission were older, more disabled, and had a significantly longer length of stay than those not referred. In contrast to the total SCU population, the proportion of patients with an ICH was higher in deceased stroke patients who did not receive palliative care consultation (50% vs. 37%). This in combination with the significantly shorter median survival of non-referred patients (2.5 days vs. 6 days) supports previous observations that stroke service staff are generally comfortable managing clearly terminal patients (Rogers and Addington-Hall 2005).

In a retrospective review of 54 consecutive deaths on an Irish teaching hospital stroke service over a 2-year period, several differences were found between patients referred and not referred to SPC (Ntlholang et al. 2016). Those patients whose cause of death was judged to be unrelated to their stroke were more likely to be seen by the SPC team. These patients also had a longer median time between stroke and death, again supporting the notion that stroke unit staff are more comfortable managing the palliative care needs of patients who die soon after a severe stroke, and less so in those who survive longer.

Taken together these data suggest that referrals to SPC, particularly to inpatient consultation services, following acute stroke are increasing. This may reflect increased recognition of the benefits associated with palliative care in areas such as symptom management, complex end-of-life decision-making, and communication. Referral to SPC is influenced by a range of clinical, sociodemographic, and health service factors, but not surprisingly stroke patients referred to palliative care tended to be older, frailer, and sicker. Importantly the majority of stroke patients, including those who were severely disabled or died, were not referred to SPC. While epidemiological data regarding referral rates and predictors are useful for service provision and planning, they do not answer important questions such as whether all patients with complex needs who would benefit from SPC input are currently being referred or whether non-referred “less complex” stroke patients are receiving timely and appropriate non-specialist palliative care (Stevens et al. 2007). This represents an area for ongoing research.

2.4 Shared Stroke and Palliative Care Issues in the Acute Setting

2.4.1 Prognostication

The prediction and communication of prognosis is an important but inherently difficult part of stroke
care. Given the majority of patients will survive a stroke, prognostication is relevant to all stages of stroke care from initial acute presentation to post-acute recovery and finally to rehabilitation and/or discharge. Accurate prognostication provides a road map to guide treatment decision-making and allows patients and families to plan for the future. Inaccurate prognostication runs the risk of depriving some patients of the best chance of recovery while exposing others to burdensome treatments that may only prolong suffering. In essence, prognostication attempts to provide some degree of certainty while being at the same time inherently uncertain. In a qualitative study that examined patient and family members’ perspectives of acute stroke care, honest discussions around prognosis despite uncertainty were valued by relatives even when it was predicted that prognosis might be poor (Payne et al. 2010).

Studies investigating prognosis following stroke have tended to focus on mortality more than functional outcome or recovery. Numerous clinical, sociodemographic, and institutional predictors for mortality have been identified, with stroke severity and older age generally reported to have the strongest associations (Smith et al. 2010b). The National Institutes of Health Stroke Scale (NIHSS) provides a quantification of stroke severity and is a highly reliable predictor of mortality after stroke both on its own and in combination with other variables (Smith et al. 2010b; Frontera et al. 2015). It is a 15-item validated bedside assessment tool which incorporates testing of consciousness, language, sensation, and motor function.

Stroke type itself is also a strong predictor of mortality. This is illustrated by a Danish study of 39,484 hospitalized stroke patients in which intracerebral hemorrhage (ICH) was associated with a fourfold increased risk of dying compared to ischemic events in the immediate post-stroke period (Andersen et al. 2009). Interestingly the difference in mortality between the two stroke types progressively decreased over time until at 3 months, stroke type no longer correlated with mortality. Temporal differences in the factors associated with mortality have also been reported after ischemic stroke. In a Canadian study of 3631 patients following ischemic strokes, stroke severity was found to be a significant predictor of mortality at all time points, while clinician experience was only significant at seven and 30 days and age and medical comorbidities only significantly associated with 30-day and 1-year mortality (Saposnik et al. 2008).

Numerous multivariate prediction models for outcome and mortality following stroke are available although the quality and clinical utility of these models varies (Holloway et al. 2014). Examples include the Hunt-Hess scale for subarachnoid hemorrhage and the ICH score which incorporates Glasgow Coma Scale, ICH volume, intraventricular hemorrhage, age, and site of ICH origin. ICH scores of three or greater have been reported to have a sensitivity and specificity approaching 80% and 90%, respectively, for mortality following ICH (Simmons and Parks 2008).

The applicability of prognostic models to the real world is related in part to the commonality of the variables included and also by the sample from which the data are drawn. Prediction models, for example, generated using data from cohorts with high numbers of clinical trial participants or only patients managed in specialized stroke centers may not be easily applicable to a broader, community-based stroke population. Similarly models that include clinical information from imaging modalities that are not widely available may also lack generalizability.

One particular concern raised by a number of stroke researchers when considering mortality prediction models is the concept of “withdrawal bias.” It is argued that because current models have incorporated patients who either never commenced or had life-sustaining therapies withdrawn, there is a potential bias toward mortality (or treatment withdrawal) as well as difficulty in establishing the true effect (positive or otherwise) of these therapies following severe stroke. This is likely to be particularly relevant for stroke types with poor prognosis such as ICH. Given this the importance for clinicians to understand the strengths and limitations of these models, when using them to establish and communicate prognosis to patients and families, has been highlighted (Holloway et al. 2014; Frontera et al. 2015).
may be particularly the case when considering instigating or transitioning to end-of-life care.

Prognostication based upon clinician experience and expertise is an alternative to a model-based approach. Unlike fixed mathematically generated models, clinicians have the advantage of being able to consider an individualized range of factors and adjust their estimations in real time. Clinician-based estimates however may vary considerably between individuals and be influenced by both optimistic and pessimistic judgements (Holloway et al. 2014; Frontera et al. 2015). The involvement of the multidisciplinary team and utilization of a second opinion (including from SPC) have been suggested as ways to overcome some of the issues with clinician-based estimates.

Despite the inherent difficulties associated with prognostication, the importance of providing patients and their families with a sense of the future cannot be underestimated. This is likely to be best achieved using a combination of clinician acumen and evidence-based estimation models individualized to each patient and their unique characteristics.

### 2.4.2 Limitations of Treatment

The majority of deaths after stroke follow either the limitation, cessation, or foregoing of potentially life-prolonging therapies (Kelly et al. 2012; Holloway et al. 2014; Creutzfeldt et al. 2015; Alonso et al. 2016). In the United States, up to 60% of all stroke deaths follow the removal of mechanical ventilation (Holloway et al. 2014) although this rate is likely to be different in other countries. Decision-making regarding limitations of treatment in acute stroke is complex as it needs to incorporate a range of patient, sociocultural, and clinical factors including autonomy, patient and family wishes, and prognostication. Additionally in the acute phase when uncertainty is high, management decisions need to be made quickly so as to maximize the chances of injury reversal and potential recovery. The acute stroke setting has been described as a “fast-paced, chaotic environment wrought with hope and disappointment, relief and anxiety” (Creutzfeldt et al. 2015), and therefore it is hardly surprising that decision-making in this setting is challenging. Complicating the situation further, many patients have impaired communication as a consequence of their stroke, meaning the responsibility for these complex and often life-and-death decisions will involve family and loved ones.

Treatment limitations can take numerous forms and may alter over time. In the acute setting, they may include decisions regarding thrombolytic and/or endovascular therapy or aggressive resuscitative approaches such as cardiorespiratory resuscitation or mechanical ventilation. In some patients, particularly the more elderly, frail, or those following a severe stroke, the decision to take a palliative approach with an emphasis on comfort might be taken at the outset. This might involve, among other things, the foregoing or withdrawal of antibiotic therapy, hydration, or supplementary feeding. In the majority of circumstances, these discussions and decisions will not involve SPC but be undertaken by members of the stroke team or emergency department. Relatives of stroke patients have reported experiencing discomfort when they felt excluded from the decision-making process, overly responsible for the decisions made (Cowey et al. 2015), or when participating in discussions if they knew do-not-resuscitate (DNR) orders had already been made by the medical team (Payne et al. 2010). This highlights the importance of mutual, shared decision-making between clinicians, patients, and families. The importance of good communication skills underpinned by an awareness of palliative care practice and philosophy has been advocated as a valuable component of both neurology practice and training (Holloway et al. 2014; Creutzfeldt et al. 2015).

The impact of treatment limitations on acute stroke outcomes has been fairly extensively studied with particular interest in the effect of early DNR orders (and other limitations) on stroke mortality. A number of papers have shown an association between DNR orders and increased mortality in both ICH and ischemic stroke independent of other established mortality predictors (Zahuranec et al. 2007; Holloway et al. 2014; Parry-Jones et al. 2016). In a study of 270 non-traumatic ICH, the presence of early treatment limitations (defined as DNR orders alone or in
combination with early withdrawal and/or early deferral of other life-sustaining therapies) was associated with a twofold increase in mortality independent of a range of established predictors including age, Glasgow Coma Scale score, and ICH volume (Zahuranec et al. 2007). It has been suggested that the association between DNR orders and early mortality following stroke (and ICH in particular) represents a “self-fulfilling prophecy” whereby the prediction of poor prognosis leads to limitations of care which ultimately produce a poor prognosis. Accordingly, and in the absence of clear advance care directives, caution is advised about making early treatment limitations decisions in the immediate post-stroke period.

Following the acute stroke phase, ongoing consideration of treatment goals is influenced by the evolving clinical picture, patient and family wishes, and expectations in relation to recovery. This can be a time of significant uncertainty for patients, families, and clinicians and one in which decision-making can become more complex with emphasis on factors such as prognosis, potential withdrawal of life-prolonging therapies, and discharge planning (Rogers et al. 2005; Eastman et al. 2013). Decisions around the withdrawal of hydration and nutrition can be particularly challenging and were recorded as a source of conflict in nearly half of all interactions between family members and staff in a study of 104 patients who died in a Canadian SCU (Blacquiere et al. 2009). Assistance with this complex decision-making and communication is a common reason for SPC involvement following stroke and is valued by other health professionals. In one study, stroke staff noted that the benefits of access to SPC in these complex scenarios included “reassurance” and “support for decision-making” (Burton and Payne 2012).

For relatives of patients who have had a severe stroke, acting as a surrogate decision-maker can be a two-edged sword. On the one hand, feeling sufficiently involved in decision-making is a predictor of high satisfaction with end-of-life care for bereaved relatives of stroke patients (Young et al. 2009). On the other, when relatives have reflected upon their experiences as surrogates for patients who had suffered severe strokes, a number of conflicts and struggles were described (de Boer et al. 2015). These include the strain of making decisions under time pressure, feeling unprepared or underqualified to speak for their relative, and dealing with uncertainty and change. Despite differences in the experiences reported between interviewees, there was an overall tendency for surrogates to follow medical advice, highlighting again the importance of patient- and family-centered communication in this setting.

Longer-term positive and negative consequences have been reported for surrogates involved in making treatment decisions for others (not specific to stroke). In a systematic review (Wendler and Rid 2011) which included 2854 surrogates across 40 quantitative and qualitative studies, nine papers found that being involved in decision-making had beneficial effects for some surrogates. Importantly however up to a third of surrogates reported negative emotional consequences associated with making decisions for their loved one including stress, guilt, and doubt about whether they had done the right thing. These negative emotions were typically sustained for months and sometimes years which has important implications for bereavement services. Feeling confident they were following a treatment plan consistent with patient preferences seemed to mitigate some of the emotional burden on surrogates, perhaps highlighting the value of Advance Care Directives as a way of planning for future health care.

2.4.3 Symptom Burden Following Acute Stroke

The recognition and appropriate management of both physical and psychological symptoms has been highlighted as an unmet need for patients and their families following acute stroke (Addington-Hall et al. 1995; Stevens et al. 2007; Burton and Payne 2012). While published literature is limited, symptom burden has been reported in between 65% and 98% of dying stroke patients. A broad range of physical symptoms have been reported with varying frequency in patients following an acute stroke including fatigue, nausea, restlessness, and issues with urination and
defecation. Pain has been variably described with reported prevalence rates of between 30% and 70% (Addington-Hall et al. 1995; Mazzocato et al. 2010; Ntlholang et al. 2016; Eriksson et al. 2016).

There is evidence that psychological distress is common in patients following an acute stroke, although differences in prevalence are noted in the limited available published literature. Psychological distress, including anxiety, dysthymia, and loneliness, was found to be present in almost half of 191 consecutive stroke admissions in one UK study (Burton et al. 2010) and in 25% of dying stroke patients referred to a Swiss palliative care consultation service (Mazzocato et al. 2010). By contrast, in a separate review of 54 consecutive deaths in an Irish specialist stroke service, psychological distress was reported in only one patient (Ntlholang et al. 2016). Investigating the palliative care needs of patients following an acute stroke, Burton and colleagues (2010) found that while spiritual or religious concerns were low, up to 25% of patients were worried about death and dying. Additionally, many were concerned about ongoing dependence and disability and the impact this might have on their loved ones. About a quarter felt that their care needs would exceed the capabilities of their families creating the potential for additional distress and even disharmony in an already emotionally fraught time.

The importance of considering the psychological impact of stroke upon patients and families was highlighted in a study investigating bereaved family members’ satisfaction with the care provided to patients palliated after ischemic stroke (Blacquiere et al. 2013). While overall satisfaction with palliative care was high, lower satisfaction rates were reported for treatment of anxiety and depression and for the level of emotional support provided to families. The impact of stroke upon loved ones and families is frequently profound, in large part due to the abrupt change in function and cognition often associated with stroke. In the longer term, a number of adverse outcomes have been identified in stroke caregivers including mental health issues, worsening physical health, and financial burden (van Heugten et al. 2006; Carod-Artal and Egido 2009). This potential for longer-term adverse sequelae adds further weight to the importance of considering the psychosocial needs of stroke patients and their families in the acute phase.

While variability in symptom burden following acute stroke has been reported, respiratory symptoms including dyspnea and secretions appear to be particularly prevalent. This is likely to be due, at least in part, to their demonstrability when compared to less visibly obvious symptoms such as pain and anxiety. In one prospective cohort study of 22 patients admitted to a SCU and felt likely to die within 3 months of admission, all of the 20 patients who subsequently died experienced respiratory symptoms during their last hours of life (Rogers and Addington-Hall 2005). Respiratory secretions or “death rattle” were recorded in just over 60% of 1626 dying stroke patients in a Swedish database review (Eriksson et al. 2016), and dyspnea was the commonest recorded symptom in 54 consecutive patients who died in an Irish hospital stroke service (Ntlholang et al. 2016) and in 81% of stroke patients referred to a Swiss palliative care consultation team (Mazzocato et al. 2010). The potential difficulty of managing dyspnea in dying patients was highlighted in this study as only 48% of patients were felt to be free from dyspnea during their last 48 h of life (compared to 81% who were assessed as being free from pain).

Using data from the Swedish Register of Palliative Care, Eriksson and colleagues (2016) compared the prevalence of six symptoms (pain, “death rattle,” dyspnea, anxiety, confusion, and nausea) between 1626 patients who died following a stroke and 1626 patients dying from cancer. Interesting differences in symptom prevalence, awareness, and management were noted between the groups. While all symptoms were present in the stroke group (nausea 7.6%, confusion 7.9%, dyspnea 16.3%, anxiety 18.9%, pain 42.7%, and “death rattles” 60.7%) when compared with their matched counterparts with cancer, stroke patients were significantly more likely to experience “death rattles” but less likely to experience any of the other five symptoms. Importantly however, staff caring for stroke patients were significantly less likely to know whether a patient suffered
from any of the target symptoms compared to staff caring for patients with malignant disease. It might be anticipated that this difference was related to higher rates of reduced consciousness in dying stroke patients; however this does not seem to have been the case as the ability to self-determine until the last days of life was equivalent between groups (73.3\% of stroke patients, 74.3\% in cancer). In keeping with the differences seen in symptom prevalence and staff awareness of symptoms, stroke patients were significantly more likely to have as-required medications charted for “death rattle” but less likely to have them for pain, nausea, or anxiety. Overall this study highlights the potential differences in palliative care needs between dying stroke and cancer patients and lends support to individualized approaches rather than assuming that one model of care will fit all. Crucially it also reinforces the importance of stroke service staff being appropriately educated and supported in the provision of general palliative care.

The considerable variability in symptom prevalence seen in the published literature is likely due to a range of factors including communication and consciousness impairment and inconsistent symptom assessment. Additionally accurate quantification of symptom burden for patients following an acute stroke is hampered at least in part by the fact that most studies addressing the question have been retrospective reviews of precollected data. Further prospective longitudinal research is required to expand the currently limited dataset addressing this question and to guide the development of appropriate interventions and approaches to meet the important needs of patients and their families.

2.4.4 End-of-Life Care and Dying Following Acute Stroke

The recognition or diagnosis of dying is complicated and largely arbitrary. Difficulties identifying the time point at which end-of-life care (EOLC) might be initiated are commonly reported by stroke care staff (Burton and Payne 2012; Gardiner et al. 2013; Cowey et al. 2015) leading to potential under- or overtreatment and delay in providing palliative and end-of-life care. A large contributor to this difficulty is the commonality between many of the features associated with dying and those seen in patients following a severe stroke who may subsequently recover. A range of factors have been used to identify dying stroke patients including stroke characteristics (including subtype and severity), clinical course (in particular the lack of meaningful recovery or ongoing deterioration), and physiological parameters (such as altered breathing patterns) (Cowey et al. 2015). In a study of patients who died in a stroke unit, disturbed consciousness, early dysphagia, and large supratentorial strokes were indications for initiation of EOLC (Alonso et al. 2016). In a separate mixed-methods study involving 23 Scottish stroke unit health professionals, over a quarter reported using intuition (at least in part) to recognize dying (Cowey et al. 2015).

The responsibility for decision-making regarding commencement of EOLC for hospitalized stroke patients has generally rested with the SCU medical team, although the importance of input and insight from other members of the multidisciplinary team cannot be underestimated. As we have seen due to the nature of stroke presentation and management, SPC services are infrequently and reactively involved in this process typically at times of increased complexity or significant uncertainty. Involvement of family members in decision-making around end-of-life care is important but not without its problems particularly if there is discordance between relatives and healthcare professionals (Rogers and Addington-Hall 2005). Feeding patients after a severe stroke has been highlighted as an area where motivations and opinions may differ between family members and staff. Rogers and Addington-Hall (2005) noted that while relatives and stroke unit staff shared the common motivation of wanting to avoid prolongation of suffering, stroke unit staff were also concerned about the patient starving or having their chance of recovery impinged due to lack of nutrition. Despite these difficulties family involvement allows a unique perspective on the patient and their place in the world and has been shown to be a predictor of high satisfaction with EOLC. As for all other areas of stroke care, the importance of clear,
unambiguous, empathic, and effective communication cannot be overstated.

Two distinct patterns of dying following an acute stroke have been described, namely, a rapid, sudden death or prolonged dying. A prolonged dying phase can be particularly difficult for family members, and this is likely to be exacerbated if there was expectation of a quick death, they had not been informed of the possibility of prolonged dying, and in the setting of severe dysphagia (Cowey et al. 2015). Not surprisingly the transition from recovery-focused care to EOLC can be challenging for family members with feelings of isolation and abandonment reported (Payne et al. 2010). However when death is considered likely, the most important things identified by relatives and stroke unit staff alike are the avoidance of distress and the maintenance of comfort and dignity (Rogers and Addington-Hall 2005; Payne et al. 2010).

End-of-life care (EOLC) pathways have been used to guide and optimize multidisciplinary, holistic care for dying patients and their families including following stroke. In this setting EOLC pathways aim to cover not only physical symptoms but also psychological, spiritual, and cultural considerations, desired place of care, and after-death management. The Liverpool Care Pathway (LCP) is an example of an EOLC pathway which has been used worldwide in both malignant and nonmalignant conditions. Recently the LCP has attracted considerable media attention and controversy in part due to concerns about its perceived overapplication at times, the inappropriate denial of nutrition and hydration in some cases, and deficits in communication with patients and families about its use. A subsequent UK government-commissioned independent review, while acknowledging the principles underpinning the LCP, expressed among a range of concerns that it was too frequently used as a “tick-box” exercise and recommended that it be progressively phased out and replaced by individualized care plans (Neuberger et al. 2013).

There is limited evidence addressing the use of EOLC pathways following severe stroke with available data seeming to be generally supportive of their use. The Australian Clinical Guidelines for Stroke Management in a small section devoted to palliative care include a recommendation that pathways for stroke palliative care can be used to improve the care of people dying following a stroke but acknowledge that evidence to support this recommendation is weak (National Stroke Foundation 2010). Very little is known about the quantitative impact of EOLC pathways on care parameters following severe stroke although improvements in both documentation and clinical practice were observed in a small retrospective audit pre- and post the implementation of the LCP on a 12-bed stroke unit (Jack et al. 2004). Examples of the changes in clinical practice seen included increases in the discontinuation of inappropriate medications (from 40% to 100%), in the charting of subcutaneous medications (from 20% to 85%), and in the assessment of religious needs. While these results appear promising, they need to be interpreted cautiously given the retrospective study design and small sample size.

Two qualitative studies have addressed the perceptions of healthcare professionals regarding the use of the LCP in English and Scottish stroke units (Gardiner et al. 2013; Cowey et al. 2015). In general satisfaction has been reported with its use, with staff in one study suggesting that the LCP was a core element of high-quality palliative care (Gardiner et al. 2013). Surveyed family members were also generally satisfied with LCP-based care although tended to be more concerned with adequate control of problems rather than whether an EOLC pathway was used (Cowey et al. 2015). Importantly family members were able to influence EOLC including when the LCP was used. This meant that management plans, including components such as the ongoing provision of parenteral hydration, were adapted to incorporate their wishes. This negotiated mutual pragmatism is perhaps what Neuberger and colleagues (2013) were envisaging when they recommended the replacement of the LCP with individualized care plans. Interestingly while both of these studies undertook their qualitative data collection prior to the 2013 independent LCP review, the paper by Cowey and colleagues (2015) was published subsequent to it. In their conclusions, the authors acknowledged the withdrawal of the LCP in the
UK but noted that it continued to be used world-
wide. They reiterated that in their study, family
members were more concerned with distressing
stroke-related problems than the LCP. In a suc-
cinct summary encapsulating the complexity of
EOLC following stroke, they concluded that
“such problems are enduring in nature and remain
as clinical challenges whether end-of-life care
pathways are used or not.”

3 Palliative Care in the Post-
Stroke Phase

The last couple of decades have seen emerging
recognition of the role palliative care can play
beyond end of life. Earlier involvement in
advanced malignant disease, for example, has
been demonstrated to lead to improvements in
symptom burden, quality of life, and psychologi-
ical well-being. Increased awareness of the sub-
stantive symptom burden and distress associated
with a range of noncancer conditions, including
chronic respiratory, renal, and neurological disor-
ders, has highlighted the benefits of multi-
disciplinary palliative care in symptom
management, complex decision-making, and
care facilitation. In stroke while there is a devel-
oping evidence base for palliative care in the acute
phase, the picture is much less clear for the post-
stroke period. This is worthy of further consider-
ation because as previously discussed the majority
of patients will ultimately survive an acute stroke.

For those people who survive their initial
stroke, the focus of most clinical programs and
the literature has understandably been on second-
ary prevention and stroke rehabilitation. Accord-
ingly there is comparatively little published data
evaluating the involvement or potential role of
palliative care services in post-stroke care. While
data examining palliative care in this setting are
limited, there is evidence of a range of often
under-recognized symptoms and morbidity in
patients, families, and caregivers following
stroke.

The symptoms and issues experienced by
patients and their caregivers in the chronic post-
stroke phase will be familiar to many palliative
care clinicians. They can include pain, depression,
functional disability, seizures, bladder and bowel
dysfunction, and caregiver stress/fatigue. While
these symptoms are likely to share similarities
with those seen in patients with cancer, end-
organ failure, and/or neurological degenerative
disorders, they may also display features unique
to stroke. For example, the immediate onset of
profound change in physical and cognitive func-
tion that often accompanies acute stroke contrasts
with the subacute development of illness and dis-
ability in other malignant and nonmalignant con-
ditions. Additionally the management of
symptom burden in an environment where patient
survival might be measured in years rather than
weeks or months is outside the traditional skill set
of many palliative care clinicians.

In some ways the chronic post-stroke period
might be considered analogous to cancer survi-
vorship as both may share features of ongoing
symptoms in the context of likely long-term sur-
vival. The role of palliative care in cancer survi-
vorship, while variable worldwide, remains
relatively undefined, debatably appropriate, and
influenced by a broad range of clinical and struc-
tural factors including limitations in clinician
experience, workforce issues, and funding
models. It seems likely that involvement in the
post-stroke phase will provide palliative care, at
both a clinician and organizational level, with
similar challenges regarding clinical appropriaten-
ness and service provision.

3.1 Pain Syndromes

The most common types of pain reported in stroke
survivors are central post-stroke pain, hemiplegic
shoulder pain, painful spasticity, musculoskeletal
pain, and tension-type headache (Creutzfeldt et al.
2012). Accurate pain assessment following stroke
can be challenging due to the consequent commu-
nication deficits that may include dysphasia and
dysarthria and/or changes in consciousness that
occur in some stroke survivors.
3.1.1 Central Post-Stroke Pain

Central post-stroke pain (CPSP) is a neuropathic pain syndrome that is both highly distressing and frequently refractory to treatment. Sometimes referred to as Dejerine-Roussy syndrome, it was first described in 1906 (Vartiainen et al. 2016). There is variability in the reported rates of CPSP development among stroke survivors as well as concerns that it may be under-recognized. In an Italian population-based study which included 1494 post-stroke patients, symptoms and sensory changes consistent with CPSP were present in 11% of stroke survivors (Raffaeli et al. 2013). Other authors have reported prevalence rates of between 3% and 8% when all stroke survivors are considered (Vartiainen et al. 2016) and up to 35% in those with specific thalamic lesions. While the pathogenesis of CPSP is not well established, postulated mechanisms for development include hyperexcitability of injured sensory networks, changes in central inhibitory mechanisms, or central nervous system neurotransmitter imbalances. The varying incidence and prevalence of CPSP is explained by the unclear etiology of this pain syndrome as well as the lack of universally accepted diagnostic criteria. The diagnosis of CPSP requires the exclusion of pain caused by joint contracture, peripheral nerve disorders, and spasticity.

The pain of CPSP may be spontaneous or evoked. Spontaneous pain can occur either continuously or intermittently, while evoked pain is typically precipitated by stimuli such as touch, movement, stress, or temperature change (Creutzfeldt et al. 2012; Vartiainen et al. 2016). Sensory abnormalities such as alldynia, dysesthesia, paresthesia, and hyperalgesia are common features (Creutzfeldt et al. 2012; Raffaeli et al. 2013). The pain is typically experienced within the area of sensory impairment and usually at the point of maximal deficit. Spinothalamic abnormalities such as temperature-sensory abnormality are frequently described. CPSP may develop at any time from immediately to years after a stroke; however onset most commonly occurs at 3–6 months (Raffaeli et al. 2013).

Management of CPSP is challenging as there is a paucity of evidence to guide practice. Optimal management is likely to be best achieved by utilizing a combination of pharmacological and non-pharmacological treatment approaches. A range of pharmacological agents have been trialed in the management of CPSP with a particular focus on antidepressants and anticonvulsants. The efficacy and tolerability of these agents has varied across trials. Amitriptyline at a final dose of 75 mg daily was associated with significant improvements in pain when compared to placebo in a small double-blind, placebo-controlled crossover study conducted in 15 nondepressed patients (Leigon and Boivie 1989). Importantly there was little in the way of adverse effect associated with amitriptyline. No statistically significant benefit was seen for carbamazepine (at doses of up to 800 mg/day) in the same study.

In terms of other agents, there is some evidence of benefit from both case series and a controlled trial for lamotrigine; however, there is limited evidence for gabapentin and none for opioids (Frese et al. 2006). The efficacy and safety of pregabalin in the management of CPSP was assessed in a double-blind, placebo-controlled randomized trial in 219 patients. The mean dose of pregabalin received was 356.8 mg, and after 13 weeks, pain had improved in both treatment arms (pregabalin baseline pain score 6.5, end-point pain score 4.9; placebo baseline pain score 6.3, end-point pain score 5.0); however there was no significant difference between the groups. Pregabalin was associated with improvements in sleep and anxiety in the study; however, more than 50% of patients in the pregabalin group reported some adverse effects (compared to 23% in the placebo group), with dizziness and somnolence being most common (Kim et al. 2011).

Non-pharmacological therapies including cognitive behavioral therapy and stimulation therapies including transcutaneous electrical nerve stimulation and acupuncture have been described in small case series; however, controlled trial evidence is lacking. Surgical pain therapies such as rhizotomy, sympathectomy, cordotomy, and deep brain stimulation have not been formally evaluated for the treatment of CPSP and should be considered only in the context of approved clinical trials.
3.1.2 Hemiplegic Shoulder Pain

Hemiplegic shoulder pain (HSP) is the most common post-stroke pain, occurring in 11–83% of patients (Creutzfeldt et al. 2012). The prevalence of HSP increases with worsening motor impairment. HSP occurs as a consequence of joint subluxation and sensory and motor deficits. Careful attention to joint positioning in hemiplegic patients and physical therapies are the mainstay of treatment, with some emerging data for intra-articular steroid injections and intramuscular injections of botulinum toxin-A. Analgesia with anti-inflammatory medications, paracetamol, and topical heat or ice and soft-tissue massage can also assist with initial pain management.

3.1.3 Spasticity and Musculoskeletal Pain

Pain due to contractures, pressure areas, and spasticity are best prevented through the use of physical and rehabilitative therapies, body positioning, and range of motion exercises. Baclofen and dantrolene are used for post-stroke spasticity; however, their side effects including sedation, confusion, and dizziness can limit their use. Botulinum toxin can be used, particularly in upper-limb spasticity, to improve functional outcome (Creutzfeldt et al. 2012).

3.2 Post-Stroke Depression

Depression is part of a constellation of neuropsychiatric disorders that are recognized to be associated with stroke. Estimates of the frequency of post-stroke depression (PSD) vary due to the heterogeneity of assessment and reporting approaches; however, a recent meta-analysis which included 61 studies and over 25,000 people found a frequency for PSD of 31% out to 5 years post stroke (Hackett and Pickles 2014). PSD onset can occur at any time following a stroke, with a prospective, longitudinal study of over 200 patients, observing rates of PSD to be relatively stable across a range of time points from 1 month to 18 months post stroke (De Ryck et al. 2014). Stroke severity and the resultant degree of physical and functional disability are the strongest predictors of post-stroke depression, with other recognized predictors including cognitive impairment, dysphasias and aphasia, apraxia, and pre-morbid history of depression or anxiety (De Ryck et al. 2014; Robinson and Jorge 2016). Evidence for the impact of social support and stroke lesion location upon PSD is conflicting; however, there are reports of association between left frontal and left basal ganglia lesions and PSD (Robinson and Jorge 2016).

Post-stroke depression is associated with increased mortality, poorer engagement in rehabilitation, decreased quality of life, and social isolation (Creutzfeldt et al. 2012; De Ryck et al. 2014; Robinson and Jorge 2016). An independent and direct association exists between depression severity and functional impairment although this relationship is likely to be reciprocal in many cases. The increased mortality associated with PSD has been reported to be due to greater cardiovascular mortality, with PSD associated disruptions in autonomic nervous system function postulated as a potential explanatory mechanism (Robinson and Jorge 2016).

A number of double-blind, placebo-controlled treatment trials for PSD have been undertaken using both tricyclic antidepressants and selective-serotonin uptake inhibitors (SSRI) since 1984 (Robinson and Jorge 2016). Although sample numbers were generally small across the trials, most reported improvements in depression scores when compared to placebo. A meta-analysis that included 17 trials (13 using pharmacological agents and 4 psychotherapy) and 1655 patients (Hackett et al. 2008) found that pharmacotherapy conferred a small but significant benefit in treating depression and reducing depressive symptoms; however, this was coupled with an increase in adverse effects. No evidence of benefit was demonstrated for psychotherapy; however, other studies have reported positive outcomes for brief psychosocial interventions (including psychoeducation and family support) when combined with antidepressants (Robinson and Jorge 2016). The impacts of antidepressant medications on physical and functional outcomes are less well described (Creutzfeldt et al. 2012); however, improvements in motor, cognitive, and functional
capacity have been demonstrated (Robinson and Jorge 2016). There is emerging evidence that pharmacotherapy (in particular SSRIs) may have a preventative role in PSD as well as interesting data, suggesting antidepressants might improve stroke survival independent of either successful depression treatment or the presence of depression in the first place (Robinson and Jorge 2016).

3.3 Quality of Life

Of patients who survive 30 days following acute stroke, half will die within 5 years, and of the survivors, approximately 30% will remain disabled, with 14% requiring institutional care (Hankey et al. 2002). Quality of life (QOL) while difficult to define and inherently subjective in nature is generally considered to be a multidimensional construct incorporating multiple broad domains including physical, social, and mental. Recognition of the potential impact of stroke upon QOL has seen the development of a number of stroke-specific health-related QOL scales in recent years. These scales include specific factors relevant to stroke patients including vision and language impairments, with examples being the Stroke Impact Scale and the Burden of Stroke Scale (Carod-Artal and Egido 2009).

A wide range of factors have been shown to impair QOL following stroke including dependency in activities of daily living (ADL), motor dysfunction, aphasia, presence of depression, CPSP, sexual dysfunction, and limited social supports (Carod-Artal et al. 2000; Choi-Kwon et al. 2006; Carod-Artal and Egido 2009). Reductions in QOL have been described by stroke survivors with differing levels of functional impairment from the profoundly disabled to those who regained independence in ADL function but did not get back to premorbid functional levels and in others who were not able to return to work. A Korean study that examined influences on QOL in 151 first-time stroke patients found that ADL dependency, CPSP, depression, and lower socioeconomic status were all important explanatory factors for lower QOL 3 years post stroke (Choi-Kwon et al. 2006). Although variation exists in the literature stroke type, lesion location, age, and gender have not consistently been associated with lower QOL (Choi-Kwon et al. 2006) although there is some evidence to suggest females have lower QOL following stroke than men (Carod-Artal et al. 2000; Carod-Artal and Egido 2009).

Importantly recognition of the negative influence of a broad range of factors upon QOL highlights the need for close attention to be paid to these things in the post-stroke period. In particular, vigilance when it comes to the assessment and treatment of depression and pain and rehabilitative efforts focused on maximizing functional outcomes and independence are crucial components in the preservation of QOL for patients following a stroke.

3.4 Caregiver Issues

While patients after stroke confront a myriad of issues, caregivers are also confronted with a new and often devastatingly different world. This is often exacerbated by the sudden onset of change which necessitates the rapid acquisition of new knowledge, skills, and acceptance of changed circumstances. This contrasts other more chronic illnesses where disease progression is typically gradual and predictable, allowing caregivers greater opportunity for adjustment and adaptation. Cognitive deficits including perceptual and language change along with motor deficits and functional dependency add additional complexity to the caregiver role. Additionally many caregivers are themselves elderly with their own health problems and often contracting social and support networks.

Worsening physical health, lower QOL, high levels of stress and mood disorder, social isolation, and financial burden have all been reported by stroke caregivers (van Heugten et al. 2006; Carod-Artal and Egido 2009). Anxiety and depression are common with rates of depression estimated to be upward of 25%. Given the recognized high levels of burden among stroke caregivers and the crucial role they play in supporting patients at home, increasing attention is being paid to assessing and managing stroke caregiver needs.
Importantly despite the clear challenges that the caregiver role can bring, evidence suggests that many stroke caregivers still experience increased appreciation of life and role fulfillment.

A lack of attention to caregivers in established stroke guidelines prompted the development of evidence-based clinical practice guidelines specific to stroke caregivers in the Netherlands in the mid-2000s (van Heugten et al. 2006). These guidelines cover a range of topics including risk factors for caregiver burden, approaches to assessing burden, and possible caregiver interventions. Factors identified as predictive of increased caregiver burden include both patient characteristics (particularly limited functional capacity and significant cognitive impairment) and caregiver factors including preexisting psychological ill-health.

The impact of interventions upon stroke caregivers has been evaluated across a number of studies with varying degrees of benefit reported. Interventions identified to provide at least some improvement in caregiver wellbeing include the provision of information, social and practical supports, training in the caregiver role, attention to mental health issues, and counseling (Kalra et al. 2004; van Heugten et al. 2006). Clinicians have a key role to play in preparing caregivers for their role. In retrospective surveys of bereaved caregivers, satisfaction with care following a stroke is positively correlated with involvement of doctors and nurses who are knowledgeable about stroke, clinicians being open to discussing fears and concerns, and caregivers being involved in decision-making processes (Young et al. 2009).

While after-stroke care largely focuses on secondary prevention and rehabilitation, it is clear that symptoms and complex care needs including pain syndromes, depression, impaired quality of life, functional impairment, and caregiver issues are highly prevalent following stroke. These are all things familiar to multidisciplinary palliative care clinicians, who accordingly are conceivably well positioned to address them utilizing expertise and experience drawn from other chronic diseases, as well as collaboration with colleagues from stroke and rehabilitation teams.

4 Conclusions/Summary

Despite significant advances in prevention, recognition, and treatment, stroke remains a major cause of morbidity and mortality worldwide. The value of integrating palliative care principles and practices into stroke management is being increasingly recognized particularly in relation to issues such as symptom management, complex decision-making, and establishment of goals of care. Ongoing research is required addressing not only these important patient and family needs but also the theoretical basis, clinical requirements, and departmental structures required for successful integration. In the acute phase, the majority of palliative care is currently and likely to continue to be undertaken by members of the stroke team with secondary support available from specialist palliative care services on an as-needed basis. Additionally specialist palliative care is ideally placed to provide the necessary education and guidance to ensure the provision of high-quality care.

The role of palliative care in the more chronic post-stroke phase is less clear with little published data addressing the question. There is clear evidence of significant symptom burden, reduced quality of life, and caregiver distress for patients and their families in this period, and these are all things familiar to multidisciplinary palliative care teams. In many ways palliative care clinicians are well placed to take a lead role in the management of many of these problems although their chronicity is likely to impose clinical, organizational, and workforce challenges upon the profession.

The ongoing success of the integration of palliative care and stroke services will be contingent on a number of factors, not least of which being buy-in from both specialties. For palliative care this will perhaps require a conscious shift away from the cancer-related models and ideologies of the past and an acknowledgement that adaption, conciliation, and collaboration will be crucial in moving forward. This is relevant not just for stroke but also other nonmalignant diseases and the ever-changing cancer landscape. In essence this is the challenge for modern palliative care and the next generation of specialists.
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