Chapter 4

Care after hip fracture and stroke in Sweden

The degree to which a health system routinely provides high quality health care after a stroke or hip fracture directly reflects its capacity to provide a complex and tailored array of health and social care services in the face of sudden and unexpected disability.

This chapter assesses how well Swedish health care meets such a challenge. Sweden's national standards for stroke care, and in particular its monitoring framework, are amongst the most detailed and extensive in the world. In contrast, quality initiatives for care after hip fracture are less advanced – no national standards or guidelines for care exist. For both conditions, however, the quality architecture is predominantly concerned with the acute phase of care – there is a distinct lack of guidance or quality monitoring for on-going care once a patient has been discharged, which is happening earlier and earlier in the patient pathway.

There are a number of ways in which Sweden can strengthen the quality of health and social care provided after a stroke or hip fracture. These include developing joint health and social care standards and guidelines, ensuring that quality monitoring frameworks reflect changes in how services are organised and provided, using community rehabilitation resources more effectively and devoting particular attention to secondary prevention.

The statistical data for Israel are supplied by and under the responsibility of the relevant Israeli authorities. The use of such data by the OECD is without prejudice to the status of the Golan Heights, East Jerusalem and Israeli settlements in the West Bank under the terms of international law.

4.1. Introduction

The final chapter in this quality review examines the quality of care after stroke and hip fracture. Both conditions represent a sudden and unexpected loss of health, independence and well-being and will trigger a complex set of health and social care needs. These must be met in a timely, co-ordinated and personalised manner if an individual is to regain as much of her former functional ability as possible. The chapter places particular emphasis on post-acute care after hospital discharge. This is in order to complement earlier chapters on Sweden's general quality architecture, on primary care and on long-term care, each of which had a particular emphasis on care for the elderly. This chapter can be seen as a case-study which seeks to illustrate the issues raised in earlier chapters.

4.2. The burden of stroke and hip fracture in Sweden

In 20 years' time, one in four of the Swedish population will be aged over 65. Although most of these individuals will be healthy, increasing numbers of strokes and hip fractures imply an ever greater burden on health and social care services going forward. Hence, high quality services which meet people's needs are important. Efficiency is also important, and it is known that high quality care, that is effective, free from errors and patient-centered reduces costs in the long term.

The degree to which a health system routinely provides high quality health care after a hip fracture or stroke is a good index of how well a system can respond in an effective, safe and personalised way to a sudden and unexpected change in an individual's demand for health and social care. This is one of the greatest challenges that health and social care systems face, whether at local service level or national strategic level.

Stroke, although decreasing in incidence, remains a significant burden on the Swedish health system as well as wider society

About 30 000 patients in Sweden suffer a stroke annually, of which an estimated 23 000 are first-ever events. As Figure 4.1 shows, age-standardised rates of hospital discharge for stroke, a measure of incidence, are slowly declining in Sweden but remain significantly higher than some other countries. Declining incidence in high income countries is a well-recognised phenomenon, due to better management of risk factors such as high blood pressure and reduced smoking (WHO, 2004). Nevertheless, ageing populations means that the absolute burden of ill-health and disability caused by stroke may not decline substantially.

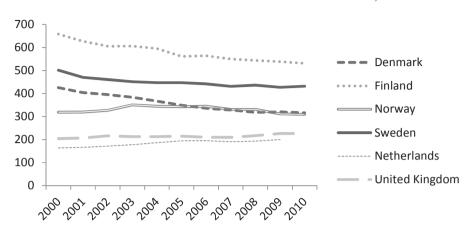


Figure 4.1. Age-standardised discharge rates per 100 000 population for cerebrovascular diseases in selected OECD countries, 2000-10

Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Stroke is the third leading cause of death in Sweden. For those who survive, about half are left with some degree of physical or cognitive impairment and may need substantial support to manage tasks of daily life, from both professional caregivers and family or friends (di Carlo, 2009). After a period of intensive hospital-based care, aiming to minimise neurological damage as rapidly and as far as possible, recovery most often begins with a phase of rehabilitation. Together, stroke care consumes more bed days in Sweden than any other somatic condition – around a million per year in the hospital sector and substantially more in nursing or assisted-living facilities.

In recent estimations, Sweden spends 2% of total health care expenditure on cerebrovascular disease (in line with the EU average); non-health care costs are estimated to include SEK 1 500 million (EUR 180 million) on production losses and SEK 1 400 million (EUR 167 million) on informal care (Nichols et al., 2012). The total estimated cost of stroke to society in Sweden has been estimated at SEK 14 billion (EUR 1.5 billion) per year (Socialstyrelsen, 2011).

In contrast, the incidence of hip fracture in Sweden shows little sign of decline and is amongst the highest in the world

As Figure 4.2 shows, age-standardised hospital discharge rates for fractured neck of femur are higher in Scandinavian countries than elsewhere in Europe. Even amongst Scandinavian neighbours, however, Sweden has a relatively high incidence of hip fracture. This has been observed in other international comparisons (Ström et al., 2011) and may be due to reduced sun exposure at northern latitudes, which supports the body in synthesising vitamin D and thereby adequately mineralising bone. Detailed analysis of the national trend in incidence rates undertaken by Nilson et al. (2013) finds that incidence rates have decreased for all age- and sex-specific groups, with the largest changes in the younger age groups and among women. The absolute number of hip fractures among the elderly in Sweden, however, has largely remained constant over recent decades.

350
300
250
200
150
100
Sweden
Netherlands
United Kingdom

Figure 4.2. Age-standardised discharge per 100 000 population for fracture of femur in selected OECD countries, 2000-10

Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

2000 2001 2002 2003 2004 2005 2006 2007 2008 2009 2010

Approximately 85% of all hip fractures occur in individuals aged ×65 years (Braithwaite et al., 2003). Between 18% and 33% of older hip fracture patients die within one year of their fracture. Amongst survivors, however, fractures of the hip are associated with a greater loss of independence, morbidity and mortality than any other type of fracture (Boonen and Singer, 2008). Many of those living independently before their fracture do not return to their pre-fracture level of independent living a year after fracture, including the ability to walk without assistance (Magaziner et al., 2003).

In Sweden, annual health care costs associated with fractures are estimated at SEK 5 639 million (EUR 610 million), four-fifths of which is accounted for by hip fractures – around 3% of the total health care costs. Most costs are due to community care (66% of the total annual cost), followed by medical care costs (31%), informal care

(2%) and indirect costs (1%). Including lost productivity and quality of life costs increases costs by around three-fold (Bergström et al., 2007)

4.3. Characteristics of high quality care after stroke or hip fracture

Although this chapter looks specifically at the quality of health care in Sweden *after* the acute hospital phase for these two conditions. focussing on rehabilitation and secondary prevention, the importance of other phases of care should be mentioned. The first few hours of hospital care, when diagnosis, risk stratification and stabilisation are undertaken, are critical to minimise the extent of irreversible damage. Equally important, however, is primary prevention to prevent strokes and hip fractures from happening in the first place: management of blood pressure, lipids, smoking, overweight and diabetic or prediabetic states in the case of stroke; and reducing the risk of falls and managing osteoporosis in the case of hip fracture.

Rehabilitation should start early, be individualised, multidisciplinary and goal oriented

Once the acute phase of a stroke or hip fracture is no longer evolving, the rehabilitative phase of care can begin, aiming to restore as fully as possible the patient's ability to move, self-care, communicate and participate in society. Legg et al. (2007) pooling results from several studies in a systematic review of occupational therapy after a stroke report a relatively low "number needed to treat" (NNT)¹ for this particular form of therapy – around ten – to avoid deterioration or dependency in the activities of daily living. Similarly, Halbert et al. (2007) find that the NNT after hip fracture to avoid death or disability is 24.

Individualised and goal-oriented rehabilitation is self-evidently necessary, given patients will differ in the severity of their stroke or fracture, their prior level of function, their support network and dependents, and their goals. Rehabilitation needs should be assessed quickly and rehabilitation should start as soon as the patient is medically stable and physically and cognitively able to participate. Evidence and several international guidelines emphasise the need for a team of specialists to be involved, including a rehabilitation physician, specialist rehabilitation nurse, physiotherapist, occupational therapist and social worker (Mak et al., 2010; Cameron et al., 2005; Halbert et al., 2007). In the case of stroke, input from a speech and language therapist may also be necessary. It is well recognised that depression and anxiety may follow stroke and that support from a clinical psychologist can be beneficial. Using data from the Swedish quality register for hip fracture (described in more detail in Section 4.4), Hommel et al. (2012) demonstrate that anxiety about returning home and resuming usual activities is also prevalent in this patient group.

It is important to note that the mere presence of multiple rehabilitation specialists should not be assumed to lead to effective care. Indeed, one systematic review of rehabilitation after hip fracture found weak or conflicting evidence for the benefit of multidisciplinary care (Chudyk et al., 2009). Similarly, care pathways –which are often established in an attempt to effectively integrated multidisciplinary care- may have a limited role beyond the acute phase. A systematic review of their benefit after stroke found that, although integrated care pathways appear useful for goal-setting, the variable and unpredictable trajectories of patients' recovery during rehabilitation renders their utility less evident (Allen and Rixson, 2008). Multiple specialists must co-ordinate effectively to identify and meet a patient's individual and evolving needs. To maximise the effectiveness of this complex array of services working together, the Stroke Unit Triallist's Collaboration suggest that co-ordination is achieved via five key factors, namely: weekly team meetings, nursing integrated into multidisciplinary team, carers routinely involved in rehabilitation and team meetings, provision of carer information and training and support for staff to develop a specialist interest in rehabilitation (Cochrane Database of Systematic Reviews, 2007).

Early supported discharge may have benefits in selected patients

Rehabilitation most often takes place on the acute hospital ward or on rehabilitation units. Recently, however, interest has developed of offering patients with relatively mild loss of function the possibility of early discharge from the acute setting with continued rehabilitation at home. To be eligible for early discharge, patients should meet minimum criteria such as being medically stable, cognitively able to continue with rehabilitation and able to mobilise short distances safely, such as moving from the bed to a chair without assistance. A specialist multidisciplinary team should take on-going responsibility for the patient's recovery and ensure adequate, regular face to face contact until the agreed rehabilitation goals have been met.

There is increasing evidence that rehabilitation in a person's own home is associated with greater patient satisfaction and as good or better functional recovery. Langhorne et al. (2007) in a systematic review of randomised trials of early supported discharge after a stroke finds reduced odds of death or dependency equivalent to five fewer

such outcomes per 100 patients treated. Chudyk et al. (2009) in a systematic review of hip fracture rehabilitation practices finds supportive evidence for improved recovery in patients offered rehabilitation in their own home. Notably, there was also some evidence that this need not be resource intensive – in one study: three face-to-face contacts a week were as effective as six.

Home rehabilitation services may be more difficult to organise in rural areas, however, and it remains unclear which components of multidisciplinary rehabilitation are most determinant of effective care. It is also important to note that home based services have not been shown to be cost-saving, both within the specific setting of Swedish post-stroke services (Von Koch et al., 2001) and for a mix of medical and surgical conditions in elderly patients more broadly (Shepperd et al., 2001).

Effective secondary prevention is necessary to prevent recurrent strokes or fractures

Amongst stroke patients, the risk of a further stroke is around 30% at five years, around nine times higher than the general population; the risk of other cardiovascular events such as a heart attack is also greatly increased (Burn et al., 1994; Touze et al., 2005). Recurrent events are more likely to be fatal than a patient's first stroke (Rothwell, 2005). Several interventions, however, have been shown to be effective in reducing the risk of further cardiovascular events, including aspirin. medications to lower blood pressure and cholesterol, dietary modification and exercise. Hackam et al. (2007) model the combined effect of these interventions and estimate that at least four fifths of these recurrent events could be prevented (or, at the very least, delayed) over five years, assuming additive effects and patient compliance. Even greater risk reductions were additional therapy to be included such as smoking cessation, glycaemic control and anticoagulation in appropriate patients.

Likewise, around 10% of individuals with a hip fracture will go on to have another fracture, usually within a few years of the first, equivalent to a risk some ten times higher than the general population, (Eliot-Gibson et al., 2004; George and Patel, 2000). A number of studies have demonstrated the efficacy of agents such bisphosphonates, raloxifine, strontium or teriparatide in reducing the risk of a second fracture (NICE, 2011) and there is increasing consensus that they should be offered to patients who have suffered a hip fracture and in whom bone fragility has been documented upon further investigation. Similarly, interventions to prevent falls such as medication review, home modification, balance work and exercise and other risk reduction measures have also been shown to be both effective and cost-effective (Frick et al., 2010; Haines et al., 2004).

Hence identifying and treating underlying diagnoses such as elevated blood pressure or lipids, smoking, overweight and diabetic or pre-diabetic states in patients after a stroke, and osteoporosis or a tendency to falling in patients after a hip fracture is an essential element of high quality care. Identification and management is likely to be shared across primary and secondary care, however many national health systems, including Sweden's, increasingly expect primary care services to take on full responsibility for the long-term management of these conditions. The extent to which the primary care system in Sweden is currently equipped to meet these challenges is assessed in Chapter 2.

4.4. Quality initiatives and related outcomes in Sweden

Stroke care benefits from particularly ambitious national quality initiatives

In 2005, Socialstyrelsen published national guidelines on care for patients after a stroke (these were updated in 2009 and another update is planned for 2015). Part of a small set of about ten disease-focussed national guidelines, they are intended to support local and regional authorities in the prioritisation, resource allocation and organisation of stroke care and to support doctors and patients in making individual treatment decisions, according to the best available evidence adapted to the Swedish context.

The greater part of these guidelines focus on management of the acute phase of care, although one section is dedicated to post-acute care and rehabilitation. Of note, this section seeks to ensure individually tailored rehabilitation, stating that it is reasonable to discharge patients with mild to moderate symptoms from hospital earlier than normal provided that specialist multidisciplinary rehabilitation is available in the home, whilst patients with more severe strokes or with complex pre-stroke co-morbidities should not be offered early discharge.

Sweden also has an extensive set of Quality Registers monitoring the patterns and outcomes of care as described in Chapter 1. *Riks-Stroke*, the Quality Register for Stroke Care, was the first stroke register in the world to be established on a national basis, in 1994. It

covers all Swedish hospitals admitting patients with a stroke and seeks to provide a comprehensive picture of the patterns of care and of quality; over 90% of first-ever strokes currently enter the Register (Asplund et al., 2011). The Register includes a wide range of patient reported measures, alongside clinical and process indicators, tracking patient outcomes for up to a year after their stroke and achieving an 80% follow-up rate. Examples of indicators include the proportion of patients admitted to a specialist stroke unit as opposed to a general medical ward or the proportion of patients reporting that their rehabilitation and home care needs were fully met, at three months and one year after their stroke. Detailed feedback is reported to each participating hospital and peer comparisons, disaggregated down to county and to hospital level, are published for public scrutiny (see Figure 4.5 for example).

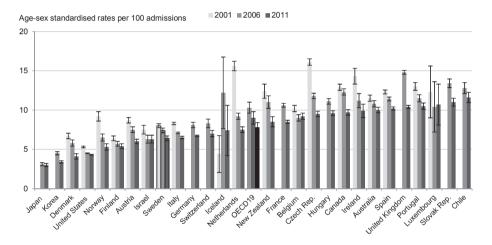
From its inception. Riks-Stroke was designed to be used as a quality improvement tool, with significant effort made to translate registry data into information which can be used, by planners. physicians and patients to seek improvements in stroke care. A recent advance along these lines was Socialstyrelsen's publication of the first national assessment of the quality and efficiency of stroke care in 2011, with a particular focus on the co-ordination of care between municipalities and county councils (Socialstyrelsen, 2011). The report brings together multiple data sources on efficiency and quality, combining data from Riks-Stroke, social care registers, prescribing databases and additional specialised surveys to providers, in an attempt a comprehensive assessment of the quality of stroke care.

Such extensive quality architecture, comprising national guidelines, a long-established and far-reaching national quality register and national strategic performance reviews, has few parallels elsewhere Sweden is one of very few countries to have developed a such comprehensive quality improvement process (comprising all elements of the Plan Do Study Act cycle) at national level. Other countries with comparable quality architecture in place are the United Kingdom, Canada and Australia: aspects of their comparative performance is set out below.

Outcomes for acute stroke services are better than OECD averages, but fall slightly short of Nordic comparators

The most recent in-hospital 30 day fatality rates from stroke in Sweden are significantly better than many other OECD countries but, as Figure 4.3 shows, reductions in fatality have been modest compared to most other countries and Nordic comparators significantly outperform Sweden.

Figure 4.3. Reduction in admission based (same hospital) case-fatality within 30 days after admission for ischemic stroke, 2001-11 or nearest year



Note: Rates age-sex standardised to 2005 OECD population (45+). 95% confidence intervals represented by H.

Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Sweden's relatively modest gains in the national survival rate over recent years will to some extent be related to the wide regional variation in fatality rates, differing by just over 50% in the case of women (Figure 4.4). Such differences may be due to differences in quality of care, differences in case-mix severity not captured by age standardisation or differences in the geographic accessibility of emergency care. Nevertheless, over 95% of patients, however, report being satisfied or highly satisfied with their quality of care during the acute hospital phase, with very modest regional variation (range from 93.9% to 98.5%).

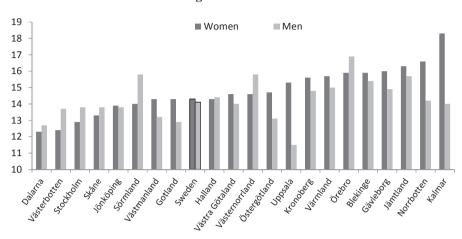


Figure 4.4. 28-day case fatality rates for first ever stroke, hospitalised patients, age-standardised

Source: SALAR and Socialstyrelsen (2012), "Quality and Efficiency in Swedish Health Care: Regional Comparisons 2012", Swedish Association of Local Authorities and Regions and Swedish National Board of Health and Welfare, Stockholm.

The few indicators of post-acute care that exist suggest that quality of care falls after discharge

Although data relevant to on-going care after discharge from hospital (the focus of this chapter) is sparse, one indication comes from a corollary of the patient satisfaction rates reported above, namely the proportion of patients reporting that their rehabilitation needs had been met 12 months after the acute phase. Rates are low: only 57.4% nationally in 2010, with almost a two-fold difference across county councils as shown in Figure 4.5. The dispersion is more modest if Jämtland county, a clear outlier, is excluded, nevertheless in all counties, more than a third of patients report dissatisfaction with their rehabilitation programme.

Part of the explanation for these low satisfaction rates, and the significant regional variation, may be due to differences in how responsibilities are shared between county councils and municipalities. Part may also be due to unrealistic expectations of what rehabilitation should or could achieve, these figures should nevertheless prompt consideration of the reasons for an apparent dichotomy between the quality of acute hospital care and the quality of care after discharge. Much of this is likely to come down to the challenge of providing an array of community based services. There are reports that some patients and carers find rehabilitative care uncoordinated and fragmented and the recent proliferation of providers resulting from the choice and competition reforms confusing, an issue that was explored in detail in Chapter 2 on primary care. Likewise, the relative absence of guidelines, standards and monitoring frameworks for community based care compared to hospital care is likely to be an important explanatory factor, as explored more fully in Chapters 1 and 3.

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Figure 4.5. Percentage of patients reporting that their rehabilitation needs had been met 12 months after the acute phase, 2010

Source: SALAR and Socialstyrelsen (2012), "Quality and Efficiency in Swedish Health Care: Regional Comparisons 2012", Swedish Association of Local Authorities and Regions and Swedish National Board of Health and Welfare, Stockholm.

A related – possibly more objective – indicator of the quality of rehabilitation concerns the proportion of patients returning to paid work after a stroke. In Sweden, this is around 31% (all ages), with an almost two-fold variation across county councils, as shown in Figure 4.6. Reassuringly, however, Sweden's average rate of return to work is broadly similar to that seen elsewhere. A study of 2 874 patients between 1995-2004 from a well-known research-focussed stroke register based in London, for example, reported that 35% of survivors had returned to work at one year (Busch et al., 2009).

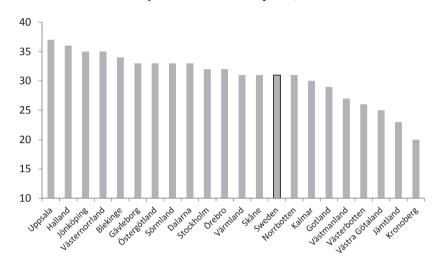


Figure 4.6. Proportion of patients returning to paid work after a stroke one year after the acute phase, 2011

Source: Riks-Stroke (2011). Arsrapport 2011. The Swedish Stroke Register, available at www.riks-stroke.org/content/analyser/RS arsrapport 2011.pdf (accessed on 14 Oct. 2013).

The quality architecture surrounding care after hip fracture is less developed

In contrast to care for patients after a stroke, there are no Socialstyrelsen guidelines to support care for hip fracture. Whilst considered osteoporosis is in the national guideline musculoskeletal diseases, this focuses on the assessment and management of fracture risk, and care after hip fracture is not considered. Neither has there been a comprehensive national assessment and strategic review of the efficiency and quality of care after hip fracture, comparable to Socialstyrelsen's 2011 publication on stroke.

Lack of national guidelines does not indicate a lack, however, of local initiatives. Indeed, in terms of care pathways specified at servicelevel. Sweden appears to be a world leader. In a systematic review evaluating their impact internationally, Leigheb et al. (2012) identified 15 studies, five of which were from Sweden (others were from Canada, the United Kingdom, the United States and China). Furthermore, the Swedish evaluations were unique in looking at process measures to do with post-hospital care (it was found that using a care pathway brought about discharge planning meetings and contact with a social worker significantly sooner, Olsson et al., 2007). Nevertheless, a linked study notes that, even in Sweden, care pathways remain relatively unknown (Olsson et al., 2009).

An important point of similarity between the two clinical areas is, however, the existence of a long-established and pioneering Quality Register. *Rikshöft,* or the Swedish National Hip Fracture Register, dates back to 1988 and was intended to complement pre-existing registers on hip and knee replacement procedures. *Rikshöft* went beyond these procedure-focussed registers, however, and collected information about the patient including level of functioning and social circumstances. The register's annual report publishes clinical observations such as fracture type, method of operation as well as outcomes such as walking ability and living accommodation at four months, disaggregated by age band, gender, region and hospital.

From its inception, Rikshöft has had an academic focus. Over 160 peer reviewed studies published using data contained within the register since the 1990s: these largely focus on pre-hospital and hospital aspects of care such as comparison of outcomes associated with different surgical techniques or acute service designs. Hommel et al. (2008), for example, study the impact of a new clinical pathway for hip fracture introduced at the University Hospital in Lund and find that surgery performed within 24 hours was significantly associated with reduced length of stay (p<0.001) and that mortality was significantly higher among medically fit patients in whom surgery was delayed for non-clinical reasons compared with patients with no delay (p<0.001). One example of a direct impact on clinical practice is *Rikshöft*'s identification of poorly performing brands of hip prosthesis. This translated into new clinical policy that eliminated their use, with estimated resultant savings of SEK 1 billion (EUR 100 million, USD 130 million) over seven years (Kurtz et al., 2007). Although studies include examination of the published effects multidisciplinary care (e.g. Hommel et al., 2003) and the effects of hospital care over the longer term (e.g. Samuelsson et al., 2008), no studies directly examine the quality or effect of post-hospital care, the focus of this chapter.

The mere existence of a national hip fracture registry, especially one so well established, distinguishes Sweden vis-à-vis its peers few other OECD countries have one. Norway established a hip fracture register in 2005; in the United Kingdom, the National Hip Fracture Database was launched in 2007 (building on a Scottish national audit dating back to 1999). Canada has published national guidelines but lacks a national audit of care, although regional initiatives are

underway. Similarly, Australia and New Zealand are moving toward a shared registry, beginning with voluntarily participating centres.

The European Union used Rikshöft as a template to develop the Standardised Audit of Hip Fractures in Europe (SAHFE) project in 1996, aiming to promote Europe-wide benchmarking of care and to disseminate best practice. SAHFE data is drawn from voluntarily participating hospitals and is not derived from national audits. Various studies comparing outcomes in different countries have been published although all, again, focus on the acute phase of care. Valaviciene et al. (2012), for example, comparing Sweden and Lithuania, report that Swedish patients reported significantly better self-care, felt less pain and discomfort, and had fewer symptoms of anxiety and depression at four month follow-up.

Acute care after hip fracture in Sweden is efficient and of high quality

Data from Rikshöft demonstrates that surgery on hip fractures almost always performed within 24 hours of admission. Mobilisation is also quick, usually the next day, and pain is well controlled. It is reported that discharges are rarely delayed for administrative reasons (such as lack of capacity in, or co-ordination with, the community sector), although this information is not routinely published. In terms of the timeliness of surgery. Sweden is in a small set of countries performing particularly well compared to other OECD countries. achieving rates of surgery performed within 48 hours of over 90% (along with Denmark, the Netherlands and Iceland according to the latest OECD Health Statistics). There has also been a steady increase in the number of hip fractures managed with full or partial hip replacement (which is more resource intensive but leads to better results than pinning) in certain patient groups.

Although Rikshöft data show no difference in waiting time to operation by age or by gender, a more than two-fold difference is apparent across regions, as Figure 4.7 shows:

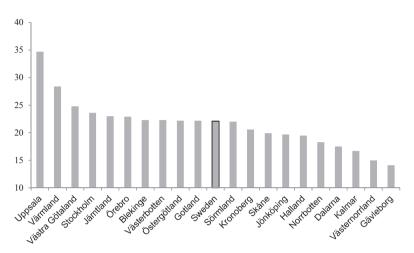


Figure 4.7. Waiting time in hours for operation after arrival at hospital by region, women

Source: Rikshöft (2011), *Årsrapport 2011*. Swedish National Registry of Hip Fracture Care. Available at http://rikshoft.se/wp-content/uploads/2013/07/arsrapport2011.pdf (accessed on 14 Oct. 2013).

As for stroke, little is known about post-acute care for hip fracture patients

Rikshöft publishes little data on the patterns or quality of care after the acute hospital phase. One indicator relates to patients' place of dwelling upon discharge from hospital. For patients living independently before a hip fracture, returning to their own home will presumably be a priority for most. The likelihood of returning home depends on patients' age and functional ability prior to the fracture, but also on the availability and effectiveness of rehabilitation – both early on in the acute hospital setting as well as in the community after discharge.

As Figure 4.8 shows, immediately after the acute hospital phase, the majority of hip fracture patients are discharged to a rehabilitation unit (35%), to their own home (30%) or to institutional care (18%). At four months, 59% are living in their own home and 23% in institutional care. These figures appear in line with the few international comparators that are available, although caution around direct comparison is necessary given the need to adjust for age and prior functional status. Data from the Scottish hip fracture register, for example, shows that 94% of 50-64 year-olds and 77% of 75-89 year-olds (living in their own home before fracture) were living

in their own home four months after their fracture, with 1% and 8% respectively in institutional care and 2% and 10% on a rehabilitation ward (Holt et al., 2008).

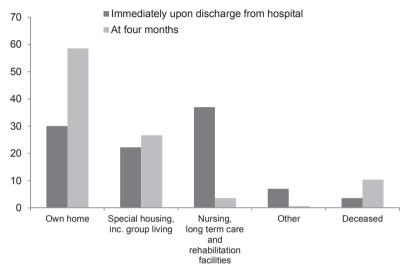


Figure 4.8. Place of dwelling after hip fracture

Source: Rikshöft (2011), Årsrapport 2011. Swedish National Registry of Hip Fracture Care. Available at http://rikshoft.se/wp-content/uploads/2013/07/arsrapport2011.pdf (accessed on 14 Oct. 2013).

A related indicator concerns patients' mobility. There has been a small increase in the proportion of people walking fully independently (that is outdoors without assistance) over the lifetime of the register and is currently around 40%, for all ages, as shown in Figure 4.9. This figure is in line with international comparators. Data from the Scottish hip fracture register, for example, shows that 41% of 50-64 year-olds and 22% of 75-89 year-olds able to walk unaided and unaccompanied before fracture were able to walk unaided and unaccompanied four months after their fracture (Holt et al., 2008).

Of note, Rikshöft does not contain any patient reported outcome measures in the way that Riks-Stroke does. It does not, for example, ask whether patients feel satisfied that their rehabilitation needs have been met. This is in contrast to registers elsewhere. In the United Kingdom, for example, national audit data indicates that 74% of patients after hip fracture report feeling fully satisfied that their rehabilitation needs have been met at three months (Royal College of

Physicians, 2010), although this varies between 42-98% across hospitals. Studies with internationally comparable data on the quality of rehabilitative care are lacking.

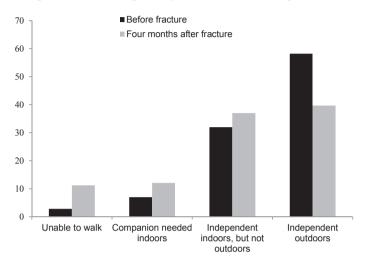


Figure 4.9. Walking ability before and after hip fracture

Source: Rikshöft (2011), *Årsrapport 2011*. Swedish National Registry of Hip Fracture Care. Available at http://rikshoft.se/wp-content/uploads/2013/07/arsrapport2011.pdf (accessed on 14 Oct. 2013).

4.5. The pathway of care after stroke or hip fracture in Sweden

Significant primary prevention efforts are made to reduce the incidence of first stroke or hip fracture

As noted earlier in the opening paragraphs of the chapter, the incidence of stroke in Sweden – as indicated by hospital discharge rates – is falling, thought to be due to better management of primary risk factors. Figure 4.10 demonstrates how Sweden has a relatively low adult obesity rate, one of the major cardiovascular risk factors, amongst OECD countries and with only a modest increase in prevalence over the past decade. Smoking prevalence, at 14%, is the lowest amongst OECD countries. Although consumption of smokeless tobacco (snus) is common in Sweden, this has a much less adverse cardiovascular risk profile than smoking (Hansson et al., 2009).

Primary preventive efforts are especially important for hip fracture, given Sweden's northern latitude. The country has a long history of implanting falls prevention programmes and is a leader of the international research agenda in this field. Multidisciplinary community based interventions have been shown to be particularly effective. A local campaign involving elderly residents, pharmacists, opticians, shoe retailers, and fitness centres in Södertälie, for example, was associated with a 17% reduction in falls in men and women aged over 55 (Larsson et al., 2010).

% of population aged 15 years and over = 2000 ■ 2011 30 20 10

Figure 4.10. Prevalence of obesity among adults in OECD countries. 2000 and 2011 or nearest year

1. Data are based on measurements rather than self-reported height and weight.

Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Most stroke and hip fracture patients are cared for in specialist units and enter a dedicated care pathway

In 2011, 89.1% of patients with stroke were admitted to a stroke unit at some point in the acute phase (see Figure 4.11). Around three quarters of patients were directly admitted to a stroke unit or intensive care unit after arriving at the hospital. Furthermore, in a specially conducted survey in 2010, it was reported that 15 of 76 hospitals had routines for immediately transporting stroke patients from the ambulance to the radiology department for a CT-scan (Socialstyrelsen, 2011).

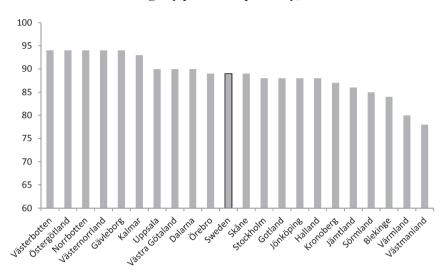


Figure 4.11. Percentage of stroke patients admitted to a designated stroke unit during any part of hospital stay, 2011

Source: SALAR and Socialstyrelsen (2012), "Quality and Efficiency in Swedish Health Care: Regional Comparisons 2012", Swedish Association of Local Authorities and Regions and Swedish National Board of Health and Welfare, Stockholm.

Parallel data for hip fracture patients, relating to the proportion of this group admitted on a specialist care pathway, is not available.

Patients are leaving hospital earlier and more is being asked of municipality-led health care

As discussed in preceding chapters, there is an increasingly acute element to the care that municipalities are being asked to provide. Figures 4.12 and 4.13 show how length of hospital stay has decreased over recent years for both stroke and hip fracture, from an already low baseline compared to other countries. Although part of this reduction may be explained by quicker and more effective treatment, a significant driver is the expectation, on the part of both patients and administrators, that more care be delivered outside the hospital. Indeed, Sweden was a pioneer of the early supported discharge model described in Section 4.3. In the case of hip fracture, patients' discharge destinations were discussed in detail in Section 4.4 – the majority are discharged to a rehabilitation unit (35%), to their own home (30%) or to institutional care (18%). All of these sites fall under municipality responsibility.

45 40 Denmark 35 Finland 30 France 25 20 Netherlands 15 Sweden 10 United Kingdom 5 2003 2004 2005 2006 2007 2008 2009 2010

Figure 4.12. Trends in length of stay after stroke

Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

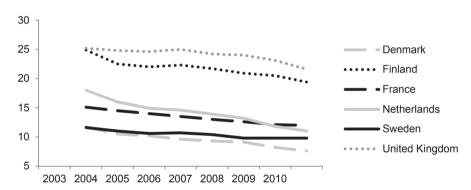


Figure 4.13. Trends in length of stay after hip fracture

Source: OECD Health Statistics 2013, OECD Publishing, Paris, http://dx.doi.org/10.1787/health-data-en.

Once discharged, patients who have suffered a stroke or hip fracture are likely to need a complex array of on-going services to restore their independence and functioning as far as possible. These will include some or all of the following: physiotherapy, to help with strength, balance and mobility; occupational therapy, to help with safe management of the tasks of daily living such as washing, dressing and preparing meals; speech and language therapy, to help with communication and, in some cases, swallowing; clinical psychology, to help with any psychological sequelae such as anxiety or depression; social services, to help with access to appropriate benefits, accommodation and employment; and medical and nursing care to provide clinical care. The needs of each individual will be unique and will not be constant over time, hence it is essential, both from a patient-centered and system-centered point of view, that services are provided in an co-ordinated and responsive manner, to ensure that needs are met and that services are not duplicated, delayed or take contrary approaches.

It is not always clear, however, for both hip fracture and stroke patients, that municipalities are adequately equipped to manage patients coming out of hospital earlier and earlier. Although generally well resourced, there are reports of deficiencies in both the skill-mix of municipality staff, and the care processes they use, in relation to meeting patients' needs upon discharge from hospital. Regarding skill-mix, there are fewer stroke specialist nurses in the community compared to other long-term conditions, such as diabetes. Specialist nurses have a particularly critical role to play in co-ordinating patients' care after discharge, identifying and managing early signs of deterioration and avoiding readmission, and providing reassurance to patients and their families. Currently, the professionals with whom discharged patients are likely to have the most extensive contact are home care staff. These carers have basic nursing education, but lack specific training in rehabilitation.

There is a requirement that municipalities identify the frail elderly and other residents in need of rehabilitation and develop an individualised care plan for each of them. Defining who these patients are and the level of detail in each plan is reported to be inconsistent, however, across municipalities. Similarly, prior to leaving hospital, multidisciplinary discharge planning meetings involving municipality services are mandated to happen for every patient requiring on-going care in the community. Again, there is inconsistency in identifying these individuals, in the multidisciplinary professionals attending the meeting and in the depth and detail of discharge planning that occurs. As noted earlier, this may be due to regional variation in how responsibilities for post-discharge care are shared between county councils and municipalities.

Secondary prevention is of low quality in Sweden

As noted earlier, secondary prevention must be seen as a central element of care and rehabilitation after a stroke or hip fracture. In the case of stroke, the steady downward trend in the rate of hospital readmission after a stroke (from around 11% readmitted within a year in 1994 to around 9% in 2008) suggests that the quality of secondary prevention is improving in Sweden. There is evidence, however,

which indicates that specific aspects of secondary prevention are poor, particularly once the patient leaves the hospital setting.

Upon discharge, *Riks-Stroke* reports that 92.0% of patients with an ischaemic stroke are on an antiplatelet or antithrombotic agent such as aspirin or warfarin (Riks-Stroke, 2012). This rate is amongst the best in the world and compares well with rates reported in other countries. such as 89% in the United Kingdom's national audit (RCP, 2011) or 91% in Canada's (CSN, 2011). Other indicators of secondary prevention, such as the proportion of patients leaving hospital on antihypertensive or lipid lowering medication also compare well against international peers.

On-going care after the hospital episode, however, appears to present a problem. Data from Riks-Stroke demonstrates that three months from discharge from hospital, around one in six patients have had no contact with a physician or specialist nurse, with substantial variation across counties. Even for those in whom secondary preventive treatment is started. Glader et al. (2010) have shown that use evidence-based secondary preventive medications such as aspirin, statins to reduce blood cholesterol and blood pressure lowering medications falls to 60% of Swedish patients or fewer, two years after a stroke. This is despite the fact that national guidelines call for regular review, at least yearly, of risk factor management.

Although Riks-Stroke does not collect information on clinical outcomes related to secondary prevention, an indication of their likely impact comes from Sweden's quality register for heart disease. This register finds that only around one in six patients (range 0-40%) managed by hospital outpatient clinics after a heart attack simultaneously achieve the four goals of systolic blood pressure being less that 140mmHg, total cholesterol being less than 2.5 mmol/L, stopping smoking and enrolling in a physical training programme (the figure amongst patients managed by primary care physicians is unknown) (range 0-40%). There is no reason to assume that risk factor management amongst stroke patients would be any better.

Secondary prevention after a hip fracture is also inadequate. In Sweden, less than one in six patients nationwide are on preventive treatment six to twelve months after a fracture (with treatment rates across counties varying from 7% to 22%), far short of the 60-70% rate that most scientific studies conclude is necessary, taking into account those with and without osteoporosis (Socialsytrelesen, 2012).

Secondary prevention of hip fracture is known to be poor in other countries. A relatively recent systematic review of 37 studies (ElliotGibson et al., 2004) reported a median rate of osteoporosis investigation in patients who had sustained a fragility fracture was 11% (0.5-32%), with only very small numbers of patients, around 10%, going on to receive treatment with calcium, vitamin D or bisphosphonates to prevent further weakening of their bones. Estimations by Ström et al. (2011), however, place Sweden in a more unfavourable light: Sweden's osteoporosis "treatment gap" for women, that is the difference between the number of women that epidemiological data suggest need treatment and the number of women that sales data suggests are receiving treatment, is 71% for women, compared to 19% in Spain, 41% in France, 56% in the United Kingdom, 60% in Italy and 75% for Germany. Of note, the "treatment gap" counts women in need of either primary or secondary prevention.

4.6. Achieving better quality care after stroke and hip fracture

Developing joint health and social care guidelines or standards should be considered

As described in earlier chapters, Sweden recently set out its broad national vision on health and social care for the elderly. Detail is lacking, however, for discrete clinical areas. The absence of clinical guidelines for hip fracture care is an obvious deficiency, which should be addressed with some urgency given the substantial individual and public health burden that hip fractures cause, and the complexity of health and social care demanded after the acute event. Even where guidelines exist, as in the case of stroke, there is a case for revisiting them to ensure that they fully encompass the breadth of care and services that a patient will make use of.

Currently, joint health and social care guidelines only exist for dementia, alcohol or substance abuse and schizophrenia. The case for jointly developed health and social care guidelines in the case of stroke or hip fracture is no less strong. Sweden should also consider going beyond guidelines to set out minimum quality standards that encompass both health and social care. Although defining standards may signal a departure from Sweden's traditional supportive rather than directive governance model, it fits with broader trends within the health and social care landscape and is a necessary response to public demands for the consistent and transparent assurance of the quality of care.

In some cases, the needed guidelines or standards can be easily identified: guidance around discharge planning, for example, should specify more clearly who should be present, the level of detail in the

discharge plan and the timeframe, given the inconsistency in discharge planning referred to earlier. In other cases, the novelty and rapid innovation in how health and social care services are provided means that evidence of what works best may be not be plentiful. Here, it may be an option for guidelines to showcase what appears to have worked well in some settings rather than be prescriptive. Given the strong local character of governance and administrative arrangements in Sweden, national guidelines should always allow for local innovation. Equally importantly, guidelines should emphasise responsiveness to user feedback as a particular priority, given the historical tendency for municipalities to be relatively slowly responsive to this type of information, as described in Chapter 1.

Better frameworks for monitoring the quality of on-going care outside the hospital setting are needed

Having achieved a clearer definition of what constitutes good quality community care after stroke or hip fracture, emphasising closer working between health and social care services, a framework can be developed to monitor implementation. The difficulties here should not be underestimated – quality assessment of community care is a nascent area and no country has yet developed a comprehensive monitoring framework for health care delivered outside traditional settings (that is, hospitals and primary health care). Patient reported measures are likely to be key, and should be as fully developed as possible, whilst acknowledging the difficulties of asking patients and carers questions that are simultaneously comprehensible to them and actionable to service providers.

Sweden's pioneering quality registers form the starting point for strengthening the monitoring framework. Some strengthening could be identified from monitoring frameworks in other countries: England's Care Quality Commission, for example, disaggregates rehabilitation into several areas (such as occupational therapy, speech therapy, assistance with returning to work). Although costs (including the time and good will of the respondent) are implied with each additional question or level of detail added to a quality register, it is essential to ensure that they are as relevant and informative as possible.

Frameworks for monitoring quality need to keep abreast of changes in how services are provided; in Sweden's case it is particularly important, for example, that quality monitoring is sensitive to the service changes brought about by the choice and competition reforms. Dedicated patient surveys may be the best means to monitor the impact of changes in service configuration, rather than quality registers. Nevertheless, quality registers can usefully include high-level measures of whether services meet patients' needs. *Riks-Stroke* includes a patient-reported measure on whether rehabilitation needs have been fulfilled at three months and one year. This data is not collected as part of *Rikshöft* yet is highly relevant information, particularly in the context of recent organisational shifts in the provision and responsibilities of care.

The quality architecture around stroke and hip fracture, and other similar conditions, should be made more equal

Despite stroke and hip fracture being broadly comparable in terms of incidence rates, the depth and breadth of care needs that they trigger, the relatively advanced evidence bases setting out optimal care and the marked regional variation within Sweden regarding process and outcome measures, the quality architecture around the two conditions is rather unequal. As described earlier, stroke care, for example, benefits from national clinical guidelines and a national performance report from the National Board of Health and Welfare, bringing together diverse data sources and making strategic recommendations for future service development. There are no equivalent guidelines or national performance report for care after hip fracture. The contents of the two quality registers also differ, that for stroke including patient satisfaction measures as noted above, which are not included in the hip fracture quality register.

Reasons for these differences lie in the distinct historical trajectories that quality improvement initiatives for each area, largely led by clinical professionals working in the field, have taken. While this bottom-up approach has some advantages, including freedom to innovate and develop initiatives that best meet specific needs, it is also an illustration of the inconsistent approach taken to quality assessment, assurance and improvement in Sweden. This could now benefit from greater standardisation at a national level. The need to take a standard approach to quality in clinical domains such as stroke and hip fracture is particularly important because the pathway of care for these conditions crosses several boundaries (that between primary and secondary health care and between health and social care in particular) and is central to Sweden's ambition to achieve better integrated care.

Formulating a more consistent quality approach to distinct clinical areas will require the Swedish authorities, in association with

professional and patient groups, to set out the quality architecture it wishes to see in place for each area. This may include minimum quality standards, joint health and social care guidelines, quality registers that include patient experiences, regular national strategic reviews and so on. Special attention should be paid to assuring quality for the frailest elderly and ensuring that any risk of fragmented care engendered by choice and competition reforms are minimised. Frameworks set out at national level should not restrict local freedom to establish additional quality architecture and must fully embrace the reality of multiple alternative providers and an expanding market place of health and social care solutions

Local innovation should continue to be supported and good practices disseminated

Nationally determined guidelines, quality standards monitoring frameworks need not stifle local innovation to develop solutions that best meet local needs. There are several examples of innovative working by municipalities that might benefit from wider roll-out. Many of these involve pro-active risk stratification of discharged patients and instigation of appropriate preventive care. A local initiative that telephoned discharged patients a day, and a week, after discharge reduced readmission rates by 30-40%, for example, and another in which a geriatrician and two nurses looked at the case notes of all readmitted patients, identifying and managing what they felt to be avoidable root causes of readmission, was reported to have led to significant reductions in admissions and lengths of stay in the following year.

Broader, systemic reforms may also play a role, particularly for less complex patients needing less tailored care. In Stockholm County a bundled payment initiative, for example, offered providers of elective hip and knee replacements a fixed price that included a prepaid premium for rehabilitation and post-operative complications. including readmission (a form of "bundled payment"). Perhaps expectedly, length of stay reduced, and throughput and productivity increased; more surprisingly, scheduled follow-up visits increased, as providers instituted more pro-active care to reduce risk of more costly complications. Patients were found to prefer this system and quality registers showed better care.

It is important that the impact of innovations such as these are robustly evaluated and learning shared with other municipalities. With regards to bundled payment initiatives, for example, there issues to resolve around the fact that the split between county councils and municipalities complicates whole-pathway reimbursement and results monitoring and that bundled payment models entail the risk that responsibility for a patient's care is not continuous, but contracted to end at a certain point. Choice and competition between multiple providers may also entail a risk of increasingly fragmented care, and this should form a particular focus of any evaluation.

At present it does not always appear to be the case that innovations shown to be successful in one area are trialled elsewhere. The Swedish authorities need to develop better mechanisms to enable contact and exchange between municipalities. This might best be organised on a county by county basis as a first step, with a central co-ordinating agency such as SALAR developing guidelines around which parties should be invited, which responsibilities need to be identified and how they might be shared out. It would seem particularly important to invite local universities to participate in these exchange fora, to support the evaluation of new projects. Inviting partners from local industry may also be valuable to advise on the diffusion of innovation.

Secondary prevention needs particular attention

Although Sweden has historically preferred to avoid use of centrally determined standards to direct locally provided services, one area where more directive guidance could be of use would be around secondary prevention. Clear responsibilities for ensuring effective secondary prevention need to be assigned. In theory, secondary prevention can be managed either through hospital out-patient clinics or through primary care, but given the trend to shift care outside the hospital setting as much as possible and the need to situate secondary preventive efforts in the context of a patient's complete medical record and medication history, it seems more sensible that the task should be taken up by primary care. The importance of an identified co-ordinator is brought out in work by The International Osteoporosis Foundation (a group of independent, not-for-profit national osteoporosis societies working with a committee of scientific advisors and corporate advisors) who, reviewing systems for secondary prevention of fracture internationally, found that two-thirds of such systems employed a dedicated co-ordinator who acts as the link between the orthopaedic team, the osteoporosis and falls services, the patient and the primary physician (known as "Fracture Liaison Services" "Osteoporosis Co-ordinator Programs" for example).

Having clarified responsibilities, more effective secondary prevention could be achieved by setting out standards or guidelines for

secondary prevention after cardiovascular events and fragility fractures at any site. Guidelines should also be published in a format understandable to patients and patient-oriented decision aids (setting out risks and benefits visually, for example) should also be considered. Adequate monitoring of secondary prevention should be ensured, either by including additional data points within the relevant quality registers or ensuring appropriate data linkage with other sources such as prescribing databases. Targeted and time-limited financial incentives may be appropriate to support implementation. In the United Kingdom a financial incentive to stimulate assessment of bone health and assessment of the risk of falls is thought responsible for the fact that 86% of patients now receive both bone protection medication. such as calcium and vitamin D preparations, as well as an assessment of their risk of falling by the time of discharge, and a further 8% either one of these two (NHFD, 2012).

Thought should also be given to improving primary prevention. The reason for a patient's fall, for example, is not entered in the hip fracture register; hence it cannot be used to inform preventive work at a public health level. Of particular note, possible linkage between this Register and Senior Alert should be explored, since there is promising evidence of Senior Alert's impact on reducing use of medications associated with impaired orientation and increased risk of falling. More broadly, as mentioned in Chapter 1, there is huge potential to get a deeper understanding of the quality of system care for elderly patients with multiple long-term conditions by overcoming the legal and technical impediments to cross-linking patients' data in multiple registers.

Sweden has an international role to play in benchmarking and improving health and social care

At country level, little is known about the quality of post-acute care. This is not for lack of evidence on what should be offered or what might be measurable – in terms of rehabilitation, secondary prevention and psychological support – and seems paradoxical given that the widely observed trend for an ever shorter acute phase of care, matched with a commensurate increase in what is being asked of post-acute services based in the community. Instead, this lack of knowledge is probably due to community services' inexperience with the culture of efficiency measures, quality monitoring and public accountability.

Beyond national systems, frameworks for the international comparison of post-acute care are even less well developed. The few national indicators of post-acute care that exist do not map easily onto one another to facilitate benchmarking. This becomes evident in the clear gap in international comparative efforts such as the OECD Health Care Quality Indicator project: this contains a well-established set of indicators of acute hospital care, of primary care for chronic diseases and of long-term residential care, but no indicators which pertain to post-acute care based in the community, which can be so strongly determinant of patients' recovery and quality of life.

Sweden has an opportunity to contribute here, given its long established efforts and pioneering ambitions. Efforts are underway to establish an international minimum dataset to compare the quality of stroke care – in which Sweden is involved – and the same should be done for care after hip fracture. The benefits to Swedish health care would be immediate since it is currently very difficult to comprehensively benchmark the quality of Swedish care against that of other countries.

4.7. Conclusions

Sweden is well experienced in using many approaches to encourage high quality health care, including guidelines, monitoring frameworks and powerful use of incentives such as Open Comparison or targeted financial bonuses. Regarding stroke care, Sweden has extensive quality architecture in place at a national level, comprising all stages of the Plan Do Study Act cycle. Quality architecture is less extensive for care after a hip fracture (lacking, in particular, national guidelines and any comprehensive strategic performance review) but is nevertheless far ahead of most other countries given the existence of *Rikshöft* and the extensive use made of its data in improving the efficiency and quality of care. As a general point, however, nearly all elements of the quality architecture for both clinical areas concerns hospital care – guidelines and monitoring frameworks only superficially address post-acute care, if at all.

This is clearly regrettable given the importance of post-acute care in determining the functional recovery of stroke and hip fracture patients. Furthermore, given Sweden's recent reforms to shift increasing responsibility for this phase of care to municipal authorities, which previously had had only limited responsibilities in the health domain, the need to quality assure post-acute health and social care is particularly pressing. Little is known about the patterns or quality of

on-going care after hospital discharge. This is the case not just in Sweden, but internationally, which precludes a convincing assessment of the comparative performance of this sector of Sweden's health care system. Addressing this deficit is self-evidently necessary. Rather than leaving the assessment there, however, a number of further recommendations can be made by identifying gaps or weaknesses in the quality architecture that exists. These include developing joint health and social care standards and guidelines, ensuring that quality monitoring frameworks reflect changes in how services are organised and provided, using community rehabilitation resources more imaginatively and effectively and devoting particular attention to secondary prevention and palliative care.

These recommendations should be extended to other clinical areas beyond stroke and hip fracture. Although these two conditions are paradigmatic causes of sudden and unexpected disability, requiring a complex and tailored array of health and social care services to restore the patient as fully as possible to her prior level of health. opportunities should be sought to apply the underlying principles of quality assurance and improvement to other clinical areas such as care after other fractures, heart attack, major surgery, external injury or during the care of debilitating illnesses which may have an unpredictable course, such as multiple sclerosis. In parallel, there is a need to avoid a myopic view which focusses exclusively on post-acute clinical care. Care should be seen as part of a continuous pathway, in which primary prevention is also fundamentally important, and which is holistic, addressing the importance of high quality housing over the longer term for example, rather than just immediate clinical and social care concerns.

Note

1. Number needed to treat (NNT) is a measure of the effectiveness of an intervention and refers to the number of patients that need to receive the intervention in order to prevent one adverse outcome.

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