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From Prevention to Nursing Home Care: A Comprehensive National Audit of Stroke Care.

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From Prevention To Nursing Home Care – A Comprehensive National Audit of Stroke Care

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Short title

A Comprehensive National Audit of Stroke Care

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Abstract

Background

Many countries are developing national audits of stroke care. However, these typically focus on stroke care from acute event to hospital discharge rather than the full spectrum from prevention to long-term care. **We report on a comprehensive national audit of stroke care in the community and hospitals in the Republic of Ireland.** The findings provide insights into the wider needs of people with stroke and their families; a basis for developing stroke-appropriate health strategies; and a global model for the evaluation of stroke services.

Methods

Six national surveys were completed: general practitioners (prevention and primary care); hospital organisational and clinical audit of 2,570 consecutive stroke admissions (acute and hospital care); allied health professionals and public health nurses (discharge to community care); nursing homes (needs of patients discharged to long-term care); and patient and carers (post-hospital phase of rehabilitation and ongoing care).

Results

The audit identified substantial deficits in a number of areas including primary prevention; emergency assessment/investigation and treatment in hospital; discharge planning; rehabilitation and ongoing secondary prevention; and communication with patients and families. There was a lack of coordination and communication between the acute and community services, with a dearth of therapy services in both home and nursing home settings.

Conclusion

This multi-faceted national stroke audit facilitated multiple perspectives on the continuum of stroke prevention and care. An overall synthesis of surveys supports the development of a multidisciplinary perspective in planning development of comprehensive stroke services at the national level, and may

assist in regional and global development of stroke strategies.

Introduction

Stroke is a disease of enormous global significance: it is a major cause of death and disability, and the commonest form of acquired major physical disability in adult life, but it is also the second most common cause of dementia. Stroke requires an uncommon breadth of skills for prevention and management, combining elements of neurosciences, cardiovascular medicine, geriatric medicine, general internal medicine, rehabilitation, and public health, while fusing chronic disease management with the treatment of potentially devastating acute events (1).

Services for stroke are under-developed in most countries (2). A number of countries have conducted national audits. Most focus on the segment of stroke care from acute event to discharge from hospital rather than on the full spectrum from prevention to long-term care (3). While acute care is clearly important, research to support policy and service development also needs to consider prevention, after-care and support of stroke survivors. A substantial proportion of those affected by stroke are left with residual disability (4) and an important minority require nursing home care (5). However, secondary prevention, rehabilitation and ongoing support receive variable attention after discharge from hospital.

We report on a comprehensive national audit of services for stroke in the community and hospital settings, which we believe to be the first of its kind. It provides insights into the wider needs of people with stroke and their families, while also providing a basis for developing public health and preventive strategies appropriate to stroke. Such a model could provide a useful template for stroke policy evaluation internationally.

Professional and advocacy support for stroke in the Republic of Ireland has been concentrated in the Council on Stroke of the Irish Heart Foundation. Founded in 1997, the Council comprises representatives from organisations representing the major medical disciplines involved with stroke care

(geriatricians [who, as in certain European countries, play a prominent role in the provision of stroke services]), neurologists, rehabilitationists, vascular surgeons, public health specialists, family doctors, nurses (hospital, public health), allied health professionals (physiotherapy, occupational therapy, speech and language therapy, clinical nutrition, clinical psychology and social work) and the patient's advocacy group, the Volunteer Stroke Scheme. The Council oversaw this first national stroke audit (6-11).

The aim was to conduct a comprehensive national audit of stroke care in the community and hospitals in the Republic of Ireland. This was achieved by completing six separate surveys and by drawing conclusions based on complementary information across surveys. Where possible, audit systems used in the UK's Sentinel Audit (12) and Healthcare Commission survey of stroke (13) were used to provide an opportunity for comparison of relative, as well as absolute, levels of achievement of recommended standards of care. Some aspects of the study have been published in report (14), paper (15, 16) and abstract form. However, the overall picture presents an important holistic perspective, which may be useful in developing a comprehensive national profile of stroke care in other countries.

Materials and Methods

General Practitioner (GP) Survey – A national survey of randomly selected GPs was completed using a questionnaire developed for general practice in the UK (15). Participation was invited by postal survey. A telephone reminder followed at two weeks. Of a target sample of 484 GPs, 36 were ineligible and 204 responded (response rate = 46%).

Public Health Nurse (PHN) and Allied Health Professional (AHP) Survey - senior managers for services for people with disabilities and for older people for the four health regions of the Republic of Ireland were interviewed (N=7). They nominated AHP and PHN managers for more discipline-specific semi-

structured interviews (N=25). Managers then nominated frontline staff to provide a profile of stroke care (N=43 survey responses).

Hospital Organisational Study – All public hospitals providing acute stroke services participated in senior team executive interviews using a questionnaire based on the UK Sentinel Audit (N=37 hospitals: interviews with chief executive and senior nursing, medical and therapy representatives).

Hospital Clinical Audit – All public hospitals providing acute stroke services and participating in the national hospital information system - Hospital In-Patient Enquiry Scheme (HIPE) - provided access to medical charts (N=36 hospitals). The audit of clinical aspects of stroke care involved a retrospective review of 2,570 clinical case notes for a selected sample of patients in these 36 hospitals. The audit sample included consecutive discharged cases with a primary diagnosis of stroke (ICD 10 codes: I61, I63 and I64 including subcategories) during a specified six-month period in 2005. Local chart auditors were identified and underwent training. The audit proforma used was adapted from the Royal College of Physicians London (United Kingdom) (RCPUK) Sentinel Stroke Audit 2006 Clinical Audit Proforma.

Patient/Carer Survey - This survey investigated current health status and experiences of stroke services of patients with stroke and their carers following discharge from hospital. The sample was identified through four representative hospitals regionally. Patients who were discharged to home and were either a short time (6-12 months) or a longer time (24-36 months) post-discharge were contacted. They were stratified by age and gender to capture potentially different service needs and experiences. A total of 139 patients and 72 nominated carers (55% and 71% response rate respectively) participated in home interviews. Four questionnaires were developed for this survey: a patient questionnaire; a carer questionnaire; a proxy questionnaire for use where a patient was unable/unwilling to take part, but was happy for a relative to take part on his/her behalf; and a carer questionnaire for use

where the person with stroke died following discharge from hospital. The patient survey included the Vulnerable Elders Survey (VES) (17), Hospital Anxiety and Depression Scales (HADS), (18), Barthel Index (19), an index of access to services arising from the Irish Health and Social Services for Older People (HeSSOP) survey (20), and a measure of access and quality of care from the UK Healthcare Commission National Patient Survey of Stroke Care (13). The carers were surveyed with the VES, HADS, and a carer satisfaction with community stroke care questionnaire (21).

Nursing Home Survey - A national interview survey investigated experiences of nursing home proprietors, staff and patients in randomly selected nursing homes, stratified by geographic location (N=60; 20 in Dublin and 40 outside the Dublin area) (16). The content of the nursing home manager questionnaire comprised questions relating to nursing home profile; number of residents affected by stroke, number of residents who sustained a stroke since admission to the nursing home, access to treatment and services, and the specific challenges in providing optimal care for residents with stroke. For each resident with stroke, nursing home managers were questioned about level of dependency (including communication and swallowing difficulty, and cognitive impairment) and risk of falls.

Table 1 presents the timeline and key data from each subsection of the audit.

Research ethics approval for all projects was provided by the Royal College of Surgeons in Ireland's Research Ethics Committee and the National Hospitals' Office of the Health Service Executive.

Results

1) Primary Care and Primary/Secondary Prevention of Stroke

There was little or no organised system of care for the prevention and management of stroke in primary care in Ireland. Almost 35% of GPs were in practices involved in HeartWatch (a coronary heart disease chronic disease management programme) and these were more likely to engage in evidence-

based prevention and risk assessment activities relating to stroke, except for surveillance of atrial fibrillation and warfarin protocols (Table 2). A minority of GPs (14%) reported that they had a stroke register. A majority of GPs (86%) reported that they were not sent information in relation to stroke patients immediately prior to hospital discharge. Information provided by the hospital following patient discharge with stroke typically concerned medications and diagnostic test results, stroke type and severity. Almost two thirds of GPs (64%) reported that they received notification from the hospital indicating the point at which the patient was fully discharged from hospital, namely the patient had no further outpatient visits. Most GPs (87%) believed that the availability of existing rehabilitation services was inadequate for their stroke patient population. Just over two-thirds of GPs (68%) had stroke patients who were residing in nursing homes.

2) Public Health Nurse / Allied Health Professional Survey

Managerial: Across the four regions, there was no designated co-ordinator or formal structured system for stroke service provision in Ireland. Stroke was managed as part of a generic workload and there were no existing service plans for stroke. All managers highlighted the need for a national strategy for stroke. A recurring issue was that of inadequate staff resources and of significant variability in the availability of specialist staff, resulting in considerable inequity in relation to service access. Special attention was also drawn to the lack of age-appropriate services for stroke. A shortage of rehabilitation services for those under 65 years was noted and, in some regions, it was described as non-existent. The discrepancy between acute care and continuing care was also highlighted nationally, with resources to ensure adequate transition from acute to community care identified as a distinct unmet need. Managers described the characteristics of an ideal stroke service in Ireland as comprehensive, fully integrated, seamless between hospital and community care, amply resourced, and with a clear national structure for responsibility.

Frontline staff: Communication from hospitals to community health professionals prior to stroke patient discharge was described as very variable and generally very poor. A stroke register did not exist in any region. Lack of designated stroke co-ordinators and dedicated stroke teams were seen as major impediments to appropriate levels of rehabilitation for stroke patients discharged to the community. There was no rehabilitation programme for patients with stroke in many areas, with treatment described as fragmented. The duration of input from physiotherapy was between 6 and 12 weeks for most areas. Access to occupational therapy was more limited, and for certain disciplines - speech and language therapy, clinical nutrition and psychology – services were non-existent in the community in most regions. Across regions, it was reported that there were no – or very little – dedicated services available for under 65's who had suffered a stroke. Thus, for example, situations arose where people in their 50's with stroke were not entitled to rehabilitation or home care supports and, as a result, were placed in nursing homes indefinitely.

Access to the few established specialist rehabilitation units was very limited, frequently involving long waiting times. Where patients with stroke required long-term management, follow-up of patients was described as frequently sporadic. Resources and workload were cited as the primary reasons for being unable to guarantee this long-term management, in addition to limited interdisciplinary services and short-term respite care.

3) Organizational audit of hospitals: Only one Irish hospital (of 37) had a fully resourced stroke unit (i.e. 3% compared with 91% of UK hospitals) (13), while a minority of acute hospitals (n=5), had developed a stroke specialist unit which, although not meeting all the criteria for a Stroke Unit (22), were sufficiently developed to facilitate later development to proper stroke unit status. It is expected that progress in this area will be examined objectively in any future repeat national audit of stroke care in Ireland. There were only

12 designated stroke unit beds nationally, a ratio of 0.03 beds per stroke patient (UK ratio 0.82 beds) (Table 3) (12). 30% of hospitals did not have routine access to CT scanning within 48 hours of stroke, and 41% had access to emergency MR scanning. Provision of thrombolysis was virtually nonexistent (1% of Irish stroke patients received thrombolysis). Only 16% of Irish hospitals had TIA services.

Only one third of hospitals could identify a lead consultant physician with responsibility for stroke care. Furthermore, only five had protected consultant physician time for stroke care by having committed sessions. There were only five clinical nurse specialists and two clinical specialist therapists working in stroke care nationally. Multidisciplinary team availability was very limited with services from some disciplines relatively more frequently available (e.g. occupational therapy, physiotherapy) and others almost non-existent (e.g. clinical psychology, social work). The majority of hospitals (23 of 37) had submitted service plans for stroke service development.

5) *Clinical audit of hospital care:* The majority of patients were admitted to an acute hospital on the day of their stroke (71%) (Table 4). However, the proportion getting to hospital within two hours of stroke was only 5%. There were considerable deficiencies in timely access to assessment and intervention, particularly notable for speech and language therapy (SLT) services. A formal SLT swallow assessment within 72 hours of admission happened for only 25% of Irish patients. A formal SLT communication assessment within 7 days occurred for 29% of Irish patients. Access to physiotherapy and occupational therapy was also limited, with 43% of patients assessed by a physiotherapist within 72 hours of admission and 22% assessed by an occupational therapist within seven days of admission. Irish patients were moderately-severely disabled at discharge with only 28% assessed as independent in activities of daily living on discharge from hospital (39% in the UK).

Generic lifestyle factors to promote secondary prevention following stroke, i.e., smoking cessation, physical activity, diet and alcohol management, were documented as having been discussed with the patient in only a small proportion of cases. Documented hospital chart evidence of staff discussion of stroke diagnosis and prognosis with patients and/or families was low at 22% and 18% respectively. Hospital-initiated assessment of carers' needs post-discharge was evident from hospital charts for only a quarter of Irish patients (24%). Similarly, there was little documented evidence that the skills required to manage stroke patients at home were taught to carers (12% in Ireland, 71% in the UK). In the UK, 60% of patients had a home visit linked to discharge to identify needs and to support patients and carers. Only 7% of Irish patients had a home visit linked to discharge to identify needs post discharge

5) Patient and carer survey: A majority of patients (62%) had no significant disability at the time of the survey. However, just over a quarter had moderate (14%) or severe (12%) levels of disability. and 57% were rated as 'vulnerable' using the VES. Three in four patients (78%) believed they attended hospital as soon as necessary but almost half (44%) reported delays in processing through Emergency Departments. Patients and carers also identified major deficits in the provision of information, support and services during and following discharge from hospital. Carers reported receiving little information about what to expect when the patient came home and little or no information about services or entitlements that might be available to them. In this situation of limited community services, carers reported that they needed to become 'expert' in managing the patient at home in the context of little or no support from health professionals. One in ten of these carers could themselves be classified as at risk of health problems. These were almost exclusively women, most of whom were over 65 years old.

6) *Nursing home survey:* Nursing home managers described lack of coordination and communication between health professionals in the acute services, the community and nursing homes. They reported a dearth of physiotherapy, occupational therapy and speech and language therapy for residents with stroke. There was a concern that nursing home residents were particularly 'invisible' in terms of rehabilitation needs. In terms of service provision very little distinction could be seen between public and private nursing homes.

Discussion

This multi-stage study demonstrated the feasibility of a national audit of stroke care covering all major stages of the patient journey, and engaged all of the key personnel involved with stroke. This is important in terms of supporting similar comprehensive audits in other countries and generating strategies and policies that recognize the preventive and chronic disease aspects of stroke that are hugely important to patients, society and practitioners. The study overall identified substantial deficits in national stroke policy; primary prevention; emergency assessment, investigation and treatment in hospital; discharge planning; rehabilitation and ongoing secondary prevention; support of stroke survivors in nursing homes and, through all of this, communication with patients and families. These findings will be a major cause of concern for people with stroke, their families, and for health professionals and the community more widely. Results highlight the need for major investment in stroke services in Ireland and the areas in which this is most needed. One advantage of this multi-faceted form of stroke audit is that it allows for multiple perspectives on all aspects of the continuum of stroke prevention and care. For example, the evaluation of patients and carers, GPs and hospital providers on access to hospital, as well as communication and discharge, highlighted aspects of stroke care which functioned reasonably well and areas that were lacking. Equally, the perspectives on communication between services identified a lack of planning, coordination, and leadership, which were as prominent as major deficits

identified in availability of personnel for stroke rehabilitation and support in the community and nursing homes.

While time, financial and data protection constraints did not allow for direct audit linkages between services, as has been attempted for patient surveys and hospital audit in the UK (13), the overall synthesis of the almost synchronous audits allowed for the development of a broad perspective to support planning national development of comprehensive stroke services. In particular these perspectives led to a strong recommendation for the development of the role of a regional coordinator for stroke services, with responsibilities for overseeing preventive, community and hospital services (14). This represents an overt expansion of the role of coordinator of stroke services recommended in the WHO's Helsingborg Declaration on Stroke Strategies (23), a post that seemed more circumscribed to hospital-based services. Equally, an emphasis on the chronic aspects of stroke prevention and care can find support through liaison with public health, and it is encouraging that stroke has been adopted subsequently as one of the main areas of focus for the national public health programme on chronic disease in Ireland (24).

This work had a number of limitations and caution must be exercised in the direct comparison with neighbouring clinical audits owing to the different methods of identification of stroke patients (prospectively in UK, retrospectively Irish audit). Other limitations include time, self-selected sampling and potential for bias in recruitment of respondents. A national stroke programme is currently underway (2010-2015) and the main priorities for development include stroke unit care, stroke networks and coordinated rehabilitation. The use of repeated cycles of national audits of hospital-based stroke care has been shown to be associated with improvements in the degree and quality of stroke care (25, 26, 27). It is a major moral imperative to professionals in stroke care to ensure that we can extend our scope of attention to the full continuum of the experience of stroke, and to ensure an equal level of scrutiny in the development of quality standards and

mechanisms of regular audit for all aspects of prevention and care of this complex and burdensome syndrome.

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Conflict of interest

Frances Horgan – none to declare.

Hannah McGee – Professor McGee chaired the Irish Department of Health and Children’s Working Group from 2008-2010 to develop the National Cardiovascular Health Policy 2010-2019.

Anne Hickey – none to declare.

David L Whitford – none to declare.

Sean Murphy – Advisory Board Sanofi-Aventis and Boehringer Ingelheim.

Maeve Royston – none to declare.

Seamus Cowman - none to declare.

Emer Shelley – none to declare.

Ronan Conroy – none to declare.

Miriam Wiley – none to declare.

Desmond O’Neill – none to declare.

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Table 1 Timeline and key data from each subsection of the audits

Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	Dataset
Hospital Organisational Audit																			37 hospitals
Hospital Clinical Audit																			2570 charts
Community Audit - GP																			204 surveys
Community Audit – PHN / AHP																			7 regional managers 25 PHN/AHP managers 43 frontline PHN/AHP staff
Community Audit - Patient/Carer																			139 patient 72 carer interviews
Community Audit - Nursing Home																			60 nursing homes

Start date - Month 1 - March 2006
End date - Month 18 - August 2007
GP – General Practitioner
PHN – Public Health Nurse
AHP – Allied Health Professional

Table 2 Relationships between being part of HeartWatch (national chronic diseases management scheme for cardiac conditions) and stroke service related variables (N=210)

	HeartWatch	Non HeartWatch	χ^2	df	p
	%	%			
Has a register of patients with hypertension	46%	22%	10.6	1	.001
Has conducted audit of patients with HTN within last 2 years	17%	2%	12.5	1	<.001
Screens routinely AF	44%	66%	7.5	1	<.01
Has register AF patients	30%	10%	10.9	1	.001
Has referral for warfarin anticoagulation guidelines	23%	43%	6.5	1	<.05
Runs a warfarin clinic	47%	31%	4.3	1	<.05
Register of patients with diabetes	73%	41%	15.7	1	<.001
Runs a diabetes clinic	38%	18%	7.6	1	<.01
Has conducted audit of patients with diabetes in the last 2 years	30%	17%	3.9	1	<.05
Runs general healthy lifestyle clinics	20%	7%	5.2	1	<.05
Runs smoking cessation clinics	14%	4%	4.3	1	<.05
Has a stroke register	23%	8%	6.5	1	<.05
Computerised Stroke register	88%	48%	4.7	1	<.05

Note: The Continuity Correction value is reported, as this compensates for any overestimate of the chi-square value when used with a 2 by 2 table.

Percentages based on 201 GPs missing data varied between 1 and 10 GPs.

HTN Hypertension AF Atrial fibrillation

Table 3
 Comparison of key areas between Ireland and Sentinel audit
(Organisational Stroke Audit)

	Ireland 2006	UK 2002	UK 2004	UK 2006
Stroke unit	3%	73%	79%	91%
Rapid transfer to hospital	3%	NA	4%	12%
Routine thrombolysis	0%*	NA	NA	18%
Neurovascular clinic	16%	NA	65%	78%
Mobile stroke team	14%	NA	23%	29%
Early support discharge team	0%	NA	14%	22%
Specialised community team	0%	NA	25%	32%
Consultant with responsibility for stroke care	32%	80%	90%	98%

NA = Not available

Table 4
Key standards and indicators of stroke care INASC versus Sentinel (**Clinical Audit**)

Key standards	INASC	Sentinel	Sentinel
% Compliance with indicator		2004	2006
<i>Patients</i>	<i>(N=2173)</i>	<i>(N=8697)</i>	<i>(N=13625)</i>
	%	%	%
Q1.2iii Brain scan within 24 hours	40	59	42
Q1.7 Treated on a stroke unit during their stay	2	46	62
Q1.9 > 50% stay on a stroke unit	1	40	54
Q3.1 Screened for swallow within 24 hours	26	63	66
Q3.3 Aspirin started by 48 hours	45	68	71
Q3.5 Physiotherapy assessment within 72 hours of admission	43	63	71
Q4.2 Occupational therapy assessment within 7 days of admission	22	57	68
Q5.1 Weighed at least once during admission	41	52	57
Q5.3 Mood assessed by discharge	28	47	55
Q6.3 On anti-thrombotic therapy by discharge	85	95	100
Q5.5 Rehabilitation goals agreed by MDT	22	68	76
Q7.4 Home visit performed by discharge	7	69	63
Average for 12 indicators	30	61	65