Two Decades of Integrated Stroke Services in the Netherlands

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47.1 About Stroke

Worldwide, stroke remains the second leading cause of death and the second leading cause of 'disability adjusted life years' (GBD 2019). The prevalence of stroke is expected to increase due to a growing and ageing population and due to lower stroke case fatality rates associated with better acute ischaemic stroke care and improved recurrent stroke prevention strategies addressing metabolic and behavioural factors (GBD 2019). Ischaemic stroke occurs when the blood supply to part of the brain is interrupted or reduced, preventing brain tissue from getting oxygen and nutrients. Less frequently, cerebral haemorrhages occur with similar, often devastating results. Early action and effective treatments can reduce brain damage, complications and disabilities. Recovery after stroke mainly occurs within the first six months. Stroke patients can experience long-term difficulties in terms of quality of life, social reintegration, life satisfaction and emotional functioning, including depression and anxiety (van Eeden et al. 2015). After stroke, about 70% of patients are discharged from hospital back home, 20% are referred to rehabilitation centres or nursing homes and about 10% die within 30 days (KNCN 2012).

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47.2 Integrated Patient-Centred Stroke Care

Effective treatment and management of stroke require seamless integration across the healthcare and social care interface (KNCN 2012). Cooperation and collaboration between professionals, patients and caregivers is needed to deliver patient-centred care, to align healthcare services, to decrease repeated assessments, incomplete or conflicting information about the patient's health status and to reduce duplications in supervision and multiple transaction costs (WHO 2016). However, different barriers reported in academic literature seem to hinder the formation and development of such collaboration, such as barriers related to administration and regulation, funding, (inter-) organisational domain, service delivery and clinical practices (Auschra 2018). From patients' perspectives, quality of stroke care in the Netherlands could be improved by better collaboration between involved professionals, by provision of tailor-made and timely information and by better preparation of transition from hospital to home care (Harteraad 2018).

47.3 Towards Integrated Stroke Services

Integration of primary and hospital services has been the subject of health policy in The Netherlands since the 1990s. Several initiatives focused on the implementation or the investigation of transmural care. Transmural care was defined as care attuned to the needs of the patient, provided on the basis of cooperation and coordination between general and specialised caregivers with shared overall responsibility and the specification of delegated responsibilities (van der Linden et al. 2001). For stroke, first studies on shared care—this concept overlaps the concept of transmural care—appeared early 2000. In the Netherlands, benefits of shared stroke care six months after stroke were: higher patient satisfaction, higher portion of patients back home, and less volume of home care (Rosendal et al. 2002). Improvement of quality of shared stroke care was also the aim of a national improvement project that started in 2002. Based on the Breakthrough Series (IHI 1995) teams from 23 regions aimed to make 'breakthrough' improvements (Kilo 1998) on specific topics in integrated stroke care. Significantly better results in health outcomes and interprofessional collaboration were attained (Minkman et al. 2005). The 'sense of urgency' for continuous improvement of integrated stroke care was set. Following this, more registered integrated stroke services emerged. Regional networks of service providers, such as hospitals, geriatric and medical rehabilitation centres, skilled nursing facilities, and primary care providers started to work together in an organised way (Huijsman and Rash 2005). These networks were led by a steering board with representatives—professionals and managers—of involved organisations. Needed were professionals and managers with the ability to create collaboration and cooperation across professions and organisations, that are comfortable with distributing responsibilities, and that thoroughly understand the stroke service (Miller and Stein 2020). One professional within the stroke service was appointed as

coordinator. Within the stroke service, the aim was to work together to provide multidisciplinary, coordinated care through organised patient transfers and protocols. In addition, the ambition was to make continuous improvements on collaboration and cooperation of stroke care.

47.4 Dutch Knowledge Network of Stroke Services

In 2006, the Dutch Knowledge network of stroke services (KNCN) was founded to support all stroke services in the Netherlands in their mission to improve the coordination, cooperation and quality of the multidisciplinary integrated stroke care in the region. In 2006, 21 stroke services participated; this increased to 44 in 2009. In 2012 and 2019, 72 and 52 stroke services were member of KNCN. A decline in participating stroke services took place after 2014 due to the changed role of KNCN in the national Benchmark stroke care and discontinuing of financial support, and due to the merging of some stroke services. Still, in 2019, about 90% of all hospitals participated with their regional stroke service in KNCN. Coordinators of the stroke services were appointed for approximately one day a week on average (Table 47.1). Most coordinators are specialised stroke nurses, appointed at the hospital. These coordinators participate in the main learning network of KNCN. Important skills of coordinators include networking, organising meetings with professionals and organisations, supporting the exchange or exchanging of (new) knowledge, collecting data on quality of care, promoting or making agreements on collaboration, reflecting on current practice and stimulating quality improvement. Within the learning network, coordinators and the office of KNCN share and collect 'best practices', guidelines and studies on specific topics in

Table 47.1 Characteristic of stroke services, in 2012, 2015 and 2019 (KNCN 2019a)

	2012	2015	2019
Existence (median year)	9	12	15
Involved organisations (median *n*)	5	6	7
Volume of stroke patients, previous year (median *n*)	364	450	499
Professional roles of members in working groups			
• Healthcare professionals only	4%	0%	0%
• Managers only	13%	17%	30%
• Both	70%	78%	66%
• Not applicable	13%	5%	4%
Coordinator of stroke service			
• Appointed (% yes)	92%	100%	93%
• Working hours per week (median)	8	8	8
Formal agreements on cooperation (% yes)	81%	81%	82%
Regular meetings with steering group (% yes)	77%	91%	74%

(integrated) stroke care. An online toolbox with this information is available for all coordinators. This also includes an online forum where coordinators can communicate with each other. Each year, national meeting days with all coordinators are planned in spring and autumn. In addition, educational courses on specific topics, such as 'creating good collaboration within the stroke services' are organised. In addition, a national one-day congress for all participants in the stroke services is organised. About 400 professionals and patients attend the congress.

In the past years, KNCN supported several activities focused on quality measurement and quality improvement of integrated stroke care. These were as follows:

1. Benchmark of quality indicators on stroke care

Inspired by the 'Helsingborg declaration' (Kjellström et al. 2007), all stroke services started to register the multidisciplinary care of stroke patients on a regional level. In 2006, data on 5 indicators were collected; in 2014 this was extended to 12 indicators. These indicators, based on Dutch evidence-based guidelines, contained performance indicators as well as outcome measures. The office of KNCN was responsible for data collection and provision of performance reports to the coordinators of the stroke services. In 2014, KNCN joined the Dutch Institute for Clinical Auditing to initiate a new benchmark that registered stroke care on patient level (instead of a regional level). Between 2014 and 2016, a pilot with the registry of additional indicators, including patient-reported outcome measures, in the stroke care chain was performed (Oemrawsingh et al. 2019). In 2016, the Netherlands Society of Neurology took over the governance of the audit. Due to the high registration burden of the audit and the developments in acute stroke care treatment, the primary focus of the benchmark shifted towards the acute treatment of acute ischaemic stroke. Funding for the audit was ensured by 'Zorgverzekeraars Nederland' (i.e. the umbrella organisation of nine health insurers in the Netherlands) (Kuhrij et al. 2018). Stroke service coordinators share their experiences and best practices to improve data collection of the registry and the performance on indicators at the national meetings of the learning network. From 2005 until now, many quality indicators in Dutch stroke care revealed favourable trends. The overall 30-day mortality rates (in-hospital and post-discharge) declined for both ischaemic and haemorrhagic stroke (RIVM 2014). The intravenous thrombolysis rates (IVT rate: portion of stroke patients receiving IVT within 4.5 h after onset of ischaemic stroke) more than doubled and a large decline in mean 'door-to-needle-time' took place (DNT: the time between arrival at the emergency room until administering a thrombolytic agent. This should be less than 45 min) (Scherf et al. 2016; Kuhrij et al. 2018) (Fig. 47.1).

2. Healthcare standard integrated stroke care

In 2011, together with professional and patient organisations, KNCN started with the development of the healthcare standard for integrated stroke care (KNCN 2012). The aim of the healthcare standard was to optimise the quality of care for people

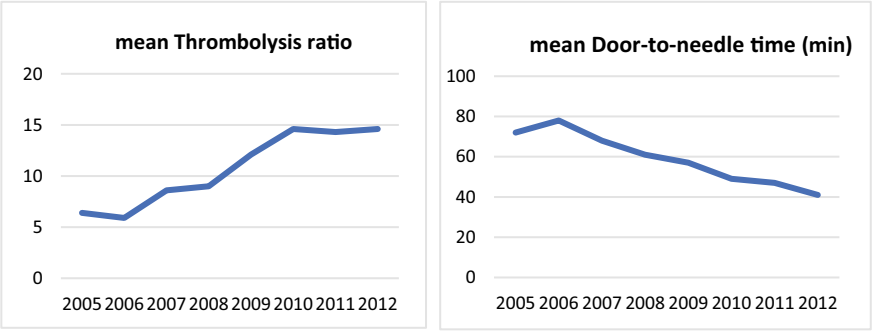

Fig. 47.1 Trend of two quality indicators in Benchmark stroke care, 2005–2012

with stroke by formulating the principal requirements of good integrated stroke care in terms of services and organisational structures necessary for long-term disease management. Two versions of the healthcare standard were made; one for professionals and one for patients and their caregivers. Following this, an implementation project with the patient version of the healthcare standard integrated stroke care was executed in three stroke services, and recommendations for implementation were formulated and spread among all stroke services (Hersenletsel.nl et al. 2014).

3. Knowledge broker network of professionals

Creation of healthcare standards, collaboration agreements or protocols are insufficient to bring about the cooperation between healthcare professionals that is needed for quality improvement. Therefore, in 2011 a knowledge broker network started, to help organisations of stroke services to make improvements on specific topics or to implement innovation. Each year, approximately 45 organisations and

Table 47.2 Cycle of yearly activities in the KNCN knowledge broker network (KNCN 2019b)

March	Training 'Project management'
April	Formulation of the project: aim of implementation, plan of activities Regional meeting with the learning collaborative
May	Follow-up training 'Project management'
June	Baseline measurement of goals
September	Start-up of the implementation project During the project: sharing experiences and lessons with each other (forum, toolbox)
November	Regional meeting with the learning collaborative
February, next year	Final measurement of goals and final report with lessons learnt

120 knowledge brokers participate in the network. During one year, an implementation or innovation project is conducted in order to achieve quality improvements in the organisation (Table 47.2). Support is given from other participants in the knowledge broker network. Most knowledge brokers are therapists (physiotherapist, language and speech therapist or occupational therapist) or nurses.

4. Self-evaluation tool on integrated stroke care

In 2012, 2015 and 2019, all participating stroke services received a digital web-based self-evaluation validated questionnaire to evaluate the performance and development of the stroke service. The questionnaire included questions on the execution of 97 activities of integrated stroke care, with dichotomous answering: completed yes or no. The questionnaire is based on the Development model for Integrated Care (Minkman et al. 2009) that consists of 9 clusters (Table 47.3). Participation was voluntary, and the response rate varied from 93 to 86% (KNCN 2019a). All coordinators were asked to fill out one questionnaire for their stroke service. Over the past seven years, an increase of integrated activities within the stroke services was found. Stroke services seem to have worked actively on realising integrated care for patients. Two clusters 'Interprofessional teamwork' and 'Allocation of roles and tasks' were best implemented compared to the other seven (KNCN 2019a). The coordinators received a benchmark report of the total group (anonymously reported) and an individual report. The coordinators were stimulated to discuss the results with the steering group and working groups of the stroke service, and to define an action plan for further improvements.

5. Development of an audit instrument

In 2016, a project group of KNCN developed a peer-to-peer audit instrument in order to provide a tool for the stroke service to improve quality of collaboration, education and stroke care. The audit instrument consists of the self-evaluation tool,

Table 47.3 Completed activities within the nine clusters of development model of integrated care (KNCN 2019a)

	2012 (%)	2015 (%)	2019 (%)
Interprofessional teamwork	86	93	89
Roles and tasks	72	89	86
Client-centredness	59	71	72
Commitment	59	76	70
Transparent entrepreneurship	50	65	67
Results focused learning	59	67	67
Quality care	54	66	62
Delivery system	54	68	60
Performance management	52	67	58

the indicators of the benchmark stroke care and the recommendations of recent guidelines on stroke care. An independent audit team with trained coordinators of other stroke services investigates how recommendations for good practice are applied in daily practice. First, the audit team reviews documents on structure: workforce, agreements and guidelines. In addition, the team visits the organisations of the stroke service and interviews some healthcare professionals in order to evaluate the process of care. The audited stroke service receives a final report with results and recommendations for improvement. Participation in the audit is voluntary and stroke services have to pay a fee. Each year, approximately 8 stroke services are audited.

6. Project on quality of care: Screening for impairment at home

Regular detection of problems in discharged stroke patients is necessary. In the years following a stroke, a significant proportion of patients deals with several problems, e.g. problems with participation, energy, mood, mobility and intimacy. Sometimes these complaints worsen over time. In addition, caregivers often express health problems such as fatigue and depressive symptoms. Various screening instruments are used in general practice or home care to identify problems (Barthel, EQ5D, CSI), but most of these questionnaires are aimed at a certain area of functioning in daily life. Therefore, between 2016 and 2017, a working group of KNCN developed a practical tool with limited questions for the systematic mapping of problems in the home situation. The tool could be used by different types of

Table 47.4 Screening of problems after stroke (KNCN 2016)[a]

Theme	Questions
Household	How is it going with the housekeeping, care for yourself and care for the family? What kind of support do you need?
Activities	In what way could you still do your activities, such as hobbies, work, trips?
Tiredness	Do you experience tiredness or are you fatigue?
Emotions	Does it ever happen that you are gloomy, anxious or emotional? Could you share about this?
Concentration	Have you ever been forgetful? Or are you struggling with concentration? Or with doing two things at a time?
Communication	How easy is it for you to speak with someone or to understand someone, or to read a book?
Other problems	Do you experience other physical problems (swallowing, sleeping, pain, dizziness)?
Intimacy (usually not in 1st conversation)	And how's that with lovemaking or intimacy?
Caregiver burden (*for the caregiver)*	How's your partner doing now? (change of character and above topics) How do you experience the care for your partner? Are you overloaded?

[a]For healthcare professionals in home care. To be used 3–4 times (first year), 1–2 times later on

professionals involved in health and social care for stroke patients (Table 47.4). The tool could also be part of the regular consultation of cardiovascular prevention by general practitioners and practice nurses.

7. Project on patient-centred care: Shared decision making

Stroke patients face several decisions about treatment options and the setting in which care takes place. An optimal process of shared decision making is required in order to make integrated stroke care person-centred. However, the context-sensitive nature of the challenges in integrated stroke care calls for research to facilitate the implementation of shared decision making. In 2017, a two-year implementation programme started in five stroke services. The shared decision implementation programme consisted of training for healthcare professionals, tailored support, development of decision aids and a social map of local stroke care. Involved healthcare professionals indicated it is feasible to implement shared decision making in integrated stroke care. Several well-known implementation activities could improve shared decision making in stroke care. Special attention should be given to the following activities: (1) the appointment of knowledge brokers, (2) agreements between healthcare professionals on roles and responsibilities for specific decision points in the integrated stroke care chain and (3) the timely investigation of patient's preferences in the care process—preferably before starting treatment through discussions in a multidisciplinary meeting (Voogdt-Pruis et al. 2019).

47.5 Improvement of Dutch Integrated Stroke Care: A Never-Ending Story

Two decades of integrated stroke care have led to remarkable improvement in Dutch stroke care (Lackland et al. 2014):

- Stroke units in hospitals and integrated stroke services have been created on a large scale.
- Stroke diagnostics have been improved through the prompt use of imaging devices.
- Active treatments for intravenous or endovascular clot removal.
- Intensive attention for secondary prevention (antiplatelet treatment, cholesterol lowering, carotid surgery or stenting, lifestyle interventions)
- More attention is devoted to the prevention of complications (such as pneumonia, urinary tract infections, deep vein thrombosis, acute coronary syndrome, heart failure, digestive problems and hip fractures) and to rapid rehabilitation.

Though major steps have been set in improving care for Dutch stroke patients in the last two decades, there will always and continuously be room for improvements. Future developments for regional stroke services might encompass consolidation of

the stroke service with similar regional networks in order to provide integrated care for a wider range of acquired brain or vascular diseases in the region.

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