Development of a Poststroke Checklist to Standardize Follow-up Care for Stroke Survivors

Ian Philp, MD,* Michael Brainin, MD,† Marion F. Walker, PhD,‡ Anthony B. Ward, MD,§ Patrick Gillard, PharmD,‖ Alan L. Shields, PhD,¶ and Bo Norrving, MD, PhD,# on behalf of the Global Stroke Community Advisory Panel**

Background: Long-term care for stroke survivors is fragmented and lacks an evidence-based, easy-to-use tool to identify persistent long-term problems among stroke survivors and streamline referral for treatment. We sought to develop a poststroke checklist (PSC) to help health care professionals identify poststroke problems amenable to treatment and subsequent referral. *Methods:* An instrument development team, supported by measurement experts, international stroke experts, and poststroke care stakeholders, was created to develop a long-term PSC. A list of long-term poststroke problem areas was generated by an international, multidisciplinary group of stroke experts, the Global Stroke Community Advisory Panel. Using Delphi methods, a consensus was reached on which problem areas on the list were most important and relevant to include in a PSC. The instrument development team concurrently created the actual checklist, which provided example language about how to ask about poststroke problem areas and linked patient responses to a specific referral process. *Results:* Eleven long-term poststroke problem areas were rated highly and consistently among stroke experts participating in the Delphi process (n = 12): secondary prevention, activities of daily living, mobility, spasticity, pain, incontinence, communication, mood, cognition, life after stroke, and relationship with caregiver. These problem areas were included in the long-term PSC. *Conclusions:* The PSC was developed to be a brief and easy-to-use tool, intended to facilitate a standardized approach for health care providers to identify long-term problems in stroke survivors and to facilitate appropriate referrals for treatment. **Key Words:** Stroke—long-term care—stroke rehabilitation—continuity of patient care—assessment of health care needs—referral and consultation—quality of life.

From the *South Warwickshire Foundation National Health Service Trust, Warwick, United Kingdom; †Department of Clinical Neurosciences and Preventive Medicine, Danube University Krems, Krems, Austria; ‡Division of Rehabilitation and Ageing, University of Nottingham, Medical School, Nottingham, United Kingdom; §University Hospital of North Staffordshire, Haywood Hospital, Stoke on Trent, United Kingdom; ‖Allergan Inc, Global Health Outcomes Strategy and Research, Irvine, California; ¶Adelphi Values, Patient Reported Outcomes, Boston, Massachusetts; and #Department of Clinical Sciences, Section of Neurology, Lund University, Lund, Sweden.

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**Panel members: L. Abetz, S. Blackburn, C. Chen, C. Diener, G. Donnan, P. Duncan, A. Esquenazi, P. Fayad, G. Francisco, D. Good, G. Graham, B. Kissela, D. Leys, J. Olver, J. Stokes, K. Sunnerhagen, T. Wein, J. Wissel, and R. Zorowitz.

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Address correspondence to Ian Philp, MD, South Warwickshire Foundation National Health Service Trust, Lakin Road, Warwick CV345BW United Kingdom. E-mail: ian.philp@warwick.ac.uk.

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As the second leading cause of death and one of the leading contributors to adult disability worldwide, stroke poses a significant personal, social, and financial global burden.[1,2] Stroke survivors can experience long-term problems at different points in their recovery, and these will affect their quality of life for up to 5 years poststroke[3,4] and possibly longer.[5] Stroke survivors may experience impairments, such as memory loss,[6] pain,[7] spasticity,[8] fatigue,[9] urinary incontinence,[10,11] cognitive impairment,[12] communication disorders[13], and disability and activity limitations, such as social isolation,[14] emotional change,[15] reduced physical functioning (eg, mobility and performing activities of daily living [ADLs]),[16] and impact on the stroke survivor and caregiver relationship.[17-20] These long-term problems affect a considerable percentage of stroke survivors. One review demonstrated that approximately 33% of stroke survivors did not feel prepared to manage their problems upon discharge from acute-stroke treatment and, over the long term, between 18%-46% experienced social problems and between 19%-62% experienced emotional problems.[3] The impact of these long-term problems are significant and contribute to an overall decrease in quality of life among many stroke survivors.[14,21]

Compounding the long-term problems stroke survivors experience is the fragmentation of the health care delivery system following the acute and subacute phases of stroke treatment.[22] This is unfortunate, as about 50% of stroke survivors report unmet needs (eg, incontinence, emotional problems, mobility, pain, and speaking problems). Patients likely seeing health care providers for long-term problems also regularly report unmet needs.[23] Despite the perceived need for rehabilitation after discharge, many stroke survivors will not receive a rehabilitation review or additional therapeutic contact.[3]

The prevalence of long-term poststroke problems, often unidentified or untreated although potentially amenable to effective interventions, and the common fragmentation of health care systems[22] indicate a need for a comprehensive stroke strategy to facilitate long-term management for stroke survivors. In the United Kingdom, the National Stroke Strategy recommends that clinical assessments be carried out 6 and 12 months poststroke and annually thereafter.[24] The Australian stroke guidelines recommend that stroke survivors have regular and ongoing review by a member of a stroke team, including at least 1 specialist medical review, with an initial review within 3 months, and again at 6 and 12 months postdischarge.[25] In the United States, primary care physicians have 140 quality care indicators covering general aspects of poststroke management, although most are not implemented into clinical practice.[26] The World Health Organization has also called for research into the barriers and opportunities for providing poststroke management in low- and middle-income regions in the world.[27] Despite these strategies, guidelines, and recommendations, there is a lack of systems and tools that can enable health care providers to actively identify opportunities for intervention and manage referral to appropriate services. The practice of long-term care for stroke survivors lacks an evidence-based and easy-to-use tool that can both identify long-term problems among stroke survivors and facilitate their referral from primary/community-based care to appropriate specialist management. The development, adoption, and implementation of such a tool can help fulfill the promise of an improved research effort into understanding long-term stroke problems and help meet the long-term health needs of stroke survivors.

This paper describes the development of the poststroke checklist (PSC), designed to be an easy-to-use tool to assist health care professionals in identifying treatable poststroke problems and facilitate referral for care. The goal in developing the PSC is to improve the standard of long-term management provided to stroke survivors, and to improve their quality of life.

Methods

Consistent with good instrument development practices,[28,29] the PSC was developed with the following principles in mind: (1) to be simple and easy to use by health care professionals in primary care settings at 6 and 12 months poststroke and annually thereafter; (2) to focus on problem areas where evidence-based data support the effectiveness of interventions to improve outcomes; and (3) to focus on areas where an intervention has the largest impact on a stroke survivor's quality of life. Consistent with these principles, the PSC was developed over the course of 4 steps (detailed below) and tailored in preparation for an initial pilot within the United Kingdom health care system.

Step 1: Specifying Long-Term Poststroke Problems

The first step in developing the PSC was to create an all-inclusive list of long-term poststroke problems. The rationale for generating this initial list was to ensure that all facets of stroke recovery were considered for inclusion in the final PSC. This list was generated by an international and multidisciplinary group of experts, the Global Stroke Community Advisory Panel (GSCAP), and then cross-referenced with the International Classification of Functioning, Disability, and Health.[30] GSCAP consists of 21 stroke experts and represents 9 countries: Australia (n = 2), Austria (n = 1), Canada (n = 1), France (n = 1), Germany (n = 2), Singapore (n = 1), Sweden (n = 2), the United Kingdom (n = 3), and the United States (n = 8). The 6 specialty areas represented were stroke neurology (n = 9), neurorehabilitation (n = 4), physical medicine and rehabilitation (n = 5), and 1 each from occupational therapy, physical therapy, and care of the elderly.