

Specialized Long-Term Care for Severe Acquired Brain Injury in the Netherlands: Organizing Nationwide Networks



Kitty H.M. Jurrius PhD^{*}, Willemijn S. van Erp MD, PhD, Jan C.M. Lavrijsen MD, PhD, Raymond T.C.M. Koopmans MD, PhD

Department of Primary and Community Care, Radboud University Medical Center, Nijmegen, The Netherlands

ABSTRACT

Long-term care for people with severe acquired brain injury in the Netherlands was historically fragmented, resulting in unmet needs and variation in care quality. In 2019, a government-funded program established nationwide expert networks for low-prevalence, high-complexity conditions, including prolonged disorders of consciousness and acquired brain injury with complex neuropsychiatric symptoms (acquired brain injury+). These networks integrate specialized care pathways, multidisciplinary expertise centers, education, consultation, and practice-oriented research through a central knowledge infrastructure. Early experience suggests improved coordination, knowledge dissemination, and access to specialized care. This model offers a transferable framework for strengthening equitable, high-quality long-term care for complex neurological populations.

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Introduction: the Challenge of Severe Acquired Brain Injury

Every year, millions of people worldwide sustain acquired brain injury (ABI),¹ defined as any brain injury occurring after birth. Its severity can be defined by acute clinical characteristics, such as coma duration or radiological findings, and/or by functional outcome at follow-up.² Severe ABI (sABI) is a life-altering condition associated with profound cognitive, behavioral, and functional impairments. It often requires lifelong, specialized care beyond the scope of hospital or standard rehabilitation services. Until recently, patients with sABI in the Netherlands were invariably admitted to long-term care (LTC) facilities with insufficient ABI expertise, resulting in unmet needs, professional strain, and variation in care quality.³

Before 2019, Dutch LTC for individuals with sABI was fragmented. After hospital or rehabilitation discharge, patients resided in general nursing homes or community-based settings lacking appropriate rehabilitation and specialized expertise for challenges, such as behavioral dysregulation, prolonged disorders of consciousness (PDOC), and high dependency. Families often felt abandoned, whereas professionals struggled without structured clinical guidance. This resulted in inequities, with quality shaped more by local availability and reimbursement mechanisms than by patient needs. Expertise was concentrated in isolated centers and insufficiently shared. The absence of a coordinated national approach limited insight into outcomes and reduced system efficiency. Health care workers, scientists, and

experience experts called for sustainable improvement through long-term commitment to expertise development and integrated knowledge dissemination.⁴

New Approach: LTC Expert Networks for Low-Prevalence, High-Complexity Target Groups

In 2019, the Dutch government launched a nationwide program to improve LTC for 7 low-prevalence, high-complexity conditions: Korsakoff syndrome; Huntington's disease; multiple sclerosis; sABI with complex neuropsychiatric symptoms (ABI+); PDOC; psychiatric conditions at an older age; and dementia and very severe distress behavior.

While these patient groups are small in number, their needs are highly specialized and often unmet by existing services, resulting in significant individual and societal impact. Inspired by academic networks that, through close cooperation with care practice, advance knowledge and improve care,⁵ 7 new networks were established that centralize expertise and promote the systematic dissemination of knowledge through collaboration between academic institutions, health care professionals, and patient organizations.⁶ Since the start of the program in 2019, these networks have evolved into structures that comprise a central knowledge center and national and regional expertise centers, supporting multidisciplinary teamwork, professional development, and integrated research. The overarching aim is to ensure equitable, high-quality LTC by reducing knowledge deficits and standardizing care delivery.

Implementation: The Dutch Model Applied to sABI

This article outlines the Dutch expert LTC model for (1) individuals with PDOC and (2) individuals with ABI and complex neuropsychiatric symptoms (ABI+). Across both groups, the care timeline follows a common sequence—from acute care to neurorehabilitation—after

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^{*} Address correspondence to Kitty H.M. Jurrius, PhD, Department of Primary and Community Care, Radboud University Medical Center, PO Box 9101, Nijmegen 6500 HB, The Netherlands.

E-mail address: kitty.jurrius@radboudumc.nl (K.H.M. Jurrius).

which patients either enter the regular LTC needs-assessment process or, in highly complex cases, follow a dedicated special-case procedure supported by the national expert network.

LTC for PDOC

PDOC include unresponsive wakefulness syndrome (reflexive only) and minimally conscious state (limited awareness without functional communication).⁷ Patients with minimal or absent signs of consciousness require prolonged, specialized care. Inadequate PDOC care has major consequences, from misdiagnosis rates up to 41% and unrealized recovery potential to continuation of life-sustaining treatment even when meaningful recovery is unlikely. To address this, the Expertise Network for Severe Acquired Brain Injury (EENncoma: “One after coma”) established a national PDOC care pathway in 2019.⁸ A mobile team of experts provides on-site consultation during the hospital phase, enabling timely referral to specialized post-acute care. Patients who do not regain consciousness within 14 weeks of early intensive neurorehabilitation may be referred to prolonged intensive neurorehabilitation, lasting up to 24 months and delivered in 3 specialized nursing homes led by elderly care physicians with PDOC expertise. Throughout early intensive neurorehabilitation and prolonged intensive neurorehabilitation, goal-directed neurorehabilitation is combined with personalized decision-making and advanced care planning. Before this structured pathway was introduced, ca. 30 patients with PDOC entered chronic LTC yearly. This has now fallen to fewer than 10, with remaining cases directed to accredited LTC expertise centers or supported in generic LTC or home care by the expert team.

The national PDOC knowledge center coordinates the expert team, facilitates research, maintains care registration, and develops care programs, competency profiles, education, and knowledge products, such as the digital PDOC roadmap.⁸ Priority research themes include diagnostic and prognostic accuracy, family collaboration, sensory integration, advanced care planning, and tracheostomy management. Approximately 100 new patients with PDOC benefit annually from this structured continuum of care.

LTC for sABI With Complex Neuropsychiatric Symptoms (ABI+)

Adults with ABI and severe neuropsychiatric symptoms—referred to as the ABI+ population—form a second highly complex sABI subgroup. ABI+ includes individuals with chronic brain injury and co-occurring problems, such as behavioral dysregulation, limited insight, and severe dependency, often compounded by impaired social networks and reduced self-direction. A small proportion of patients exhibit behaviors posing substantial safety risks; specialized secure facilities are being developed to accommodate their needs.

The ABI+ Knowledge Center developed Samen Wegen (Joint Weighing), a structured assessment instrument of 14 items that supports expert teams in identifying ABI+ clients and determining eligibility for admission to the 14 specialized expertise centers. The network also created training modules for LTC professionals and contributed to national competency profiles, now embedded in the “*Handreiking Goede Zorg ABI+*” (Guideline for Quality Care in ABI+). A comprehensive handbook provides evidence-informed tools for high-quality daily care.⁹

Priority research themes include early recognition, ethical dilemmas in care planning, appropriate behavioral support environments, family involvement, and transitions between settings. The network conducts practice-oriented research to strengthen evidence-based practice, interprofessional collaboration, and sustainable care structures.

Evaluation

Dutch knowledge centers have sparked substantial progress in appropriate LTC for small populations with highly complex and impactful conditions. Since 2019, they have strengthened organizational structures, expanded collaboration, and produced practice-oriented knowledge products that support professional development and multidisciplinary work. Stakeholders report improved knowledge exchange, greater visibility of the centers, and growing alignment between research, practice, and patient representation. Remaining challenges relate primarily to administrative burden, integration of specialized knowledge into vocational and higher-education curricula, and implementation of the networks’ impact. Formal evaluations have highlighted the need for strong coordination, clear long-term strategic planning, and accessibility of outputs, alongside continued attention to meaningful client participation.¹⁰

Comment

Expert networks for sABI continue to strengthen Dutch LTC by embedding research, specialized expertise, and professional support within nationwide care pathways. An expertise-driven knowledge center, funded by the government at €470,000 per network annually, remains essential for these small but highly complex populations. Close integration across care phases promotes smoother transitions and reduces the risk of clients being lost between systems, while embedding families as partners enhances the relevance and acceptability of services.

Recent evaluations of the Dutch approach show that these networks have made substantial progress in building a knowledge infrastructure and developing practice-oriented tools. Strengthening long-term strategic planning, improving coordination between networks, and enhancing the accessibility of outputs are key priorities for further development.

Although rooted in the Dutch context, the core principles—centralizing expertise, coordinating care, and connecting knowledge development, dissemination, and practice—offer a transferable framework for improving continuity, quality, and sustainability in LTC for complex neurological conditions.

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During the preparation of this work, the authors used a language editing tool in order to improve grammar and clarity. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content of the published article.

Disclosure

The authors declare that there are no conflicts of interest related to this work.

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