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Editorial

Dutch Long-Term Care in Transition: A Guide for Other Countries



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Over the past 20 years, Dutch long-term care (LTC) has evolved and developed a strong infrastructure of academic networks of nursing homes.^{1–3} These networks are a collaboration between a University Medical Center and regional LTC organizations. The main aim of these networks is to do research, disseminate outcomes of these studies, and implement results into practice. To date, 6 networks exist that are affiliated with the medical centers of the University of Maastricht, Nijmegen, Amsterdam, Leiden, Tilburg, and Groningen. The networks collaborate in a consortium called “SANO.” The networks have a budget based on contributions (in cash) of the network partners and €870,000 in annual funding, provided by the Netherlands Organization for Health Research and Development.

Since 2019, an interesting development has started in the Netherlands to further improve the quality of life and care of residents with rare conditions or diseases in LTC. On request of the Dutch Ministry of Health, Welfare and Sports, KPMG Advisory NV issued a report (in Dutch) about so-called centers of expertise in LTC.⁴ KPMG is a global audit and advisory firm. The report was drafted by KPMG Health, the department of KPMG focusing on improving health care.

KPMG identified 7 distinct categories of LTC residents with low prevalence rates and high complexity rates for whom there is a need to improve research, implementation, collaboration, sharing of knowledge and competences, and skills of professionals working with these residents. The 7 categories refer to residents with (1) Huntington disease, (2) Korsakoff syndrome, (3) progressive multiple sclerosis, (4) prolonged disorders of consciousness, (5) adults with acquired brain injury with concomitant challenging behavior, (6) residents with mental and physical multimorbidity (referred to as “gerontopsychiatric” residents in the report), and (7) residents with dementia with (very) severe challenging behavior. KPMG advised extending the existing infrastructure with networks specifically dedicated to these categories, consisting of an academic knowledge center, 1 to 4

(national) centers of expertise, and several affiliated regional centers of expertise.

A low prevalence rate was defined as fewer than 1500 residents receiving LTC. High complexity was not specifically defined, but literature on “complex systems” lists features such as nonlinearity (a small change in a single part may lead to a huge change in other outcomes), unpredictability, blurred boundaries, adaptivity, coevaluation, and context sensitivity.⁵ Further, factors like multimorbidity, frailty, mental health impairment, resilience, and socioeconomic, cultural, environmental, and behavioral factors play a role in the concept of complexity.⁵

How to Operationally Define the Resident Categories?

Dutch LTC has a long history of grouping patient categories in separate, specialized, units.³ In order to meet the criterion of a prevalence rate of fewer than 1500 residents, the categories must be well-defined. Huntington disease, Korsakoff syndrome, and progressive multiple sclerosis are (rare) diseases with clear diagnostic criteria, and the current estimates do not exceed this limit. Prolonged disorders of consciousness encompass disorders such as unresponsive wakefulness syndrome and minimal conscious state. Unresponsive wakefulness syndrome can be diagnosed using the Coma Recovery Scale–Revised, revealing a very low prevalence of 33 residents in Dutch LTC. The prevalence of minimal conscious state is unknown, but estimates range from 100 to 150.⁶

Defining the other categories is challenging. Residents with mental and physical multimorbidity have been defined in previous Dutch research that included residents if (1) they needed both physical and psychiatric care, as shown in the medical history, and (2) the psychiatric or behavioral problems had been present for 2 years or longer without prospect of substantial recovery.⁷ Residents with dementia were excluded. In another Dutch study, these residents were called “double-care demanding” residents, in which dementia was not an exclusion criterion.⁸ The results of an unpublished Dutch Delphi study, however, agreed on excluding residents with neurocognitive disorders. By using these definitions, the group is estimated to be fewer than 1000 residents. A group of professionals is currently working on further fine-tuning the definition.

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Residents with dementia with (very) severe or even extreme challenging behavior have been described in the 7-tiered model of Brodaty et al.⁹ Tiers 6 and 7, reflecting very severe and extreme challenging behavior, have estimated prevalence rates of 1% or less.¹⁰ However, no clear operational definitions exist of these (very) severe behaviors.¹¹ Estimates based on practice result in a prevalence of fewer than 1000 residents. The group of adults with acquired brain injury and concomitant challenging behavior is a heterogeneous group with residents with traumatic brain injury, stroke, meningitis or encephalitis, brain surgery or brain tumor, hypoxia, and poisoning. The estimated prevalence rate ranges between 300 and 500. Apart from residents with prolonged disorders of consciousness or progressive multiple sclerosis, the other categories all have challenging behavior as a common feature, which contributes to the complexity of care for these residents. There are some figures on the prevalence rates of challenging behavior from Dutch studies in LTC.^{7,12–15}

The New Infrastructure

As described before, LTC organizations that offer care for these categories of residents are advised to form networks that consist of (1) an academic Knowledge Center, (2) 1 to 4 (national) centers of expertise, and (3) affiliated regional centers of expertise. The network is an association with a board. The idea is that these networks cover the entire country and provide care that also includes residents that live in LTC facilities (LTCFs) that are not part of the network and do not reside on specialized units. This refers often to 1 or 2 residents.

The 3 parts of the network have to meet general criteria, supplemented with criteria that are specific for the resident category. The Knowledge Center does research based on a research agenda and obtains funding for studies. The Knowledge Center collaborates with academia, the previously mentioned academic networks of nursing homes, but also with educational institutes such as universities for applied sciences. Patient and public involvement are very important. As a result of research, the Knowledge Center develops tools that are “ready to implement” in practice. Also, the Knowledge Center develops competency profiles and educational courses for all professionals who work with the specific resident category.

The national and regional centers of expertise provide evidence-based practice care for at least 40 (national center of expertise) or 10 (regional center of expertise) residents. The professional team is interdisciplinary, with at least an older care physician, psychologist, occupational therapist, physiotherapist, and nurse practitioner.¹⁰ The staff meets the competency profiles as developed by the Knowledge Center and participates in the educational courses. Both types of centers of expertise collaborate with partners in their region, such as general practitioners, hospitals, or mental health institutions. Resident involvement is secured and the living environment is tailored to the specific needs and preferences of the resident category.

In addition to these criteria, the national centers of expertise provide a “last-resort function.” The high complexity of some of these residents is a significant challenge for regular LTC teams, with which they sometimes cannot cope. As a result, these residents move from one facility to the next. This new infrastructure aims to “solve” this issue, with national centers of expertise having a specialized team that is available 24/7 and can reach out to the regional centers of expertise or those residents who live in LTCFs that are not part of the network. The national center of expertise is also a teaching facility and participates in research with “own” research programs and PhD students.

Auditing and Reimbursement

Dutch LTC is reimbursed by a separate health insurance as part of the Long-term Care Act. Every Dutch citizen pays taxes in case they need LTC in the future. The system of reimbursement is based on “care



Fig. 1. Geographic distribution of national (red) and regional (blue) centers of expertise.

dependency packages.” Depending on the level of impairment or whether or not the resident has a diagnosis of dementia, the reimbursement differs. One of the problems KPMG identified is that the regular budget for these highly complex residents is insufficient, and care organizations often supplement the budget with money destined for other resident categories. This situation is suboptimal for both categories. Therefore, the Dutch government decided to provide additional reimbursement for the centers of expertise and the Knowledge Center in order to facilitate and implement this transition of Dutch LTC. A system of a 4-year auditing cycle based on self-evaluation reports and onsite visits by an independent Certification Institute guarantees that the networks meet the previously mentioned criteria and receive the additional resources.

Example: Korsakoff Syndrome

Wernicke-Korsakoff syndrome (WKS) is a symptom complex in which acute Wernicke encephalopathy can proceed to chronic Korsakoff syndrome.¹⁶ WKS usually occurs in alcoholics and is caused by thiamine deficiency. A Dutch study in 9 specialized LTCFs, in which 281 residents were included, found that 96.4% showed at least 1 neuropsychiatric symptom as assessed with the Neuropsychiatric Inventory Questionnaire, and 45.8% showed 5 or more symptoms.¹² Irritability or lability (68.3%), agitation or aggression (58.7%), and disinhibition (52.7%) were most prevalent.¹² Specialized care for people with Korsakoff syndrome in the Netherlands has a long history. As early as 2007, a Knowledge Center was established that currently has 39 members. The Knowledge Center has a scientific committee that consists of 4 experts in the field, all affiliated with academia. Further, the Knowledge Center issued a research agenda and has a separate academy that offers educational courses. Despite these

achievements, there is a great need for more research, especially intervention studies, and implementation of research into practice.

Figure 1 shows the Korsakoff network with 2 national centers of expertise with respectively 152 residents (Lelie Zorggroep-Slingedael, Rotterdam) and 140 residents (Atlant, Apeldoorn), and 12 regional centers of expertise, with a range of 40 to 79 residents.

Future Directions

The process that is outlined in this editorial started in 2019. Working groups of the 7 resident categories prepared advisory reports in which they envisioned the care in the future. However, clear differences exist between the groups, with Korsakoff syndrome and adults with acquired brain injury being ahead of, for instance, the working group for dementia with (very) severe challenging behavior. To date, no formal network or Knowledge Center exists for the latter. The differences in stage of development of the working groups led the Ministry to decide to provide a funding of €500,000 to facilitate a 2-year period to transition into a phase in which the networks meet the basic criteria and can be audited and certified. For most of the working groups and affiliated LTCFs and other stakeholders, this transition is a significant challenge. Nevertheless, this new infrastructure will definitely improve the quality of care and life of these residents and will result in an enormous impulse in research, education, implementation, and skills of professional staff. In this way, the Netherlands can guide other countries toward evidence-based practice care for highly complex residents with rare conditions or diseases in LTC.

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