

## University of Groningen

### Home & place making after stroke

Nanninga, Christa

DOI:  
[10.33612/diss.149057551](https://doi.org/10.33612/diss.149057551)

**IMPORTANT NOTE:** You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

*Document Version*  
Publisher's PDF, also known as Version of record

*Publication date:*  
2021

[Link to publication in University of Groningen/UMCG research database](#)

*Citation for published version (APA):*  
Nanninga, C. (2021). *Home & place making after stroke: Exploring the gap between rehabilitation and living environment*. University of Groningen. <https://doi.org/10.33612/diss.149057551>

#### Copyright

Other than for strictly personal use, it is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), unless the work is under an open content license (like Creative Commons).

The publication may also be distributed here under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license. More information can be found on the University of Groningen website: <https://www.rug.nl/library/open-access/self-archiving-pure/taverne-amendment>.

#### Take-down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

*Downloaded from the University of Groningen/UMCG research database (Pure): <http://www.rug.nl/research/portal>. For technical reasons the number of authors shown on this cover page is limited to 10 maximum.*

# **Home & place making after stroke**

Exploring the gap between rehabilitation  
and living environment





rijksuniversiteit  
 groningen

# Home & place making after stroke

## Exploring the gap between rehabilitation and living environment

PROEFSCHRIFT

ter verkrijging van de graad van doctor aan de  
Rijksuniversiteit Groningen  
op gezag van de  
rector magnificus prof. dr. C. Wijmenga  
en volgens besluit van het College voor Promoties.

De openbare verdediging zal plaatsvinden op

woensdag 6 januari 2021 om 14.30 uur

door

**Christina Simone Nanninga**

geboren op 7 december 1975  
te Smallerland

**Promotores**

Prof. dr. K. Postema

Prof. dr. L.B. Meijering

**Copromotores**

Dr. A.T. Lettinga

Dr. M.C. Schönherr

**Beoordelingscommissie**

Prof. dr. ir. H.H. Haisma

Prof. dr. E. Buskens

Prof. dr. J.M.A. Visser-Meily

## **Paranimfen**

Inge Hovinga

Dorothee Schipper



# Contents

<b>Chapter 1</b>	General introduction	9
<b>Chapter 2</b>	Evidence and patient and caregivers' knowledge in organized stroke care: an integrated review of reviews of quantitative and qualitative research	21
<b>Chapter 3</b>	Combined Clinical and Home Rehabilitation: Case report of an integrated knowledge-to-action study in a Dutch rehabilitation stroke unit	49
<b>Chapter 4</b>	Place attachment in stroke rehabilitation: a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine	71
<b>Chapter 5</b>	Home-making after stroke. A qualitative study among Dutch stroke survivors	99
<b>Chapter 6</b>	Unpacking community mobility: a preliminary study into the embodied experiences of stroke survivors	121
<b>Chapter 7</b>	General discussion	147
	Summary	166
	Samenvatting	172
	Research Institute SHARE and previous dissertations	178
	Dankwoord	182
	Curriculum vitae	186



# **Chapter 1**

## **General introduction**

## About stroke, its consequences and the recovery process

Stroke is one of the leading causes of mortality, disability and reduced quality of life worldwide.<sup>1</sup> The global burden of stroke is high, with more than 80 million stroke survivors in 2016.<sup>2</sup> While stroke mortality has decreased, the global burden of disease of stroke remains high.<sup>2</sup> Stroke is an expensive disease from a patient, family/caregiver and societal perspective. In addition to the direct costs of hospitalization, emergency care, rehabilitation and cost of illness, indirect costs related to the loss of productivity and long-term care further increase the overall cost of stroke.<sup>3</sup> In the Netherlands, more than 320,000 persons are living with the consequences of a stroke.<sup>4</sup> The incidence is currently 2 to 3 per 1,000 people per year.<sup>5</sup> It is expected that the absolute number of strokes will increase with 54 per cent between 2015 and 2040 mainly because of the aging of the population.<sup>6</sup> This means that, also in the Netherlands, stroke-related care will increase, just because of the increasing numbers in survivors.

Stroke, or cerebrovascular accident, is a disease where the blood supply to the brain is disrupted, resulting in brain damage and loss of function.<sup>5</sup> It is most frequently caused by ischemia, whereby a clot in an artery is blocking blood supply to the brain.<sup>5</sup> It can also be caused by hemorrhage when a burst vessel causes blood to leak into the brain. The extent and location of the damage determines the severity of the stroke, which can range from minimal to catastrophic. Brain damage can also be caused by traumatic brain injury as a result of an external force. Primary focus of this thesis is on people who have experienced a stroke.

The main burden of stroke for patients themselves is as a leading cause for disability, whereby about 40 percent of stroke survivors are left with some degree of functional impairment.<sup>7</sup> The consequences of stroke are often distinguished in four types: physical, cognitive, emotional and behavioral problems.<sup>8,9</sup> Physical problems include muscle weakness, paralysis and spasticity of limbs usually affecting one side of the body. This can result in making it harder to move parts of the body or having problems with balance and struggling with everyday activities.<sup>8,10</sup> Cognitive problems encompass loss of concentration, memory and communication.<sup>8,10</sup> Emotional problems comprise feelings of anxiety, depression, anger and frustration or having difficulty controlling emotions. Behavioral problems refer to changes to personality so that to others the survivor seems like a different person.

For both stroke survivors and their families stroke is a sudden, life-changing event, and the emotional impact of stroke can be as devastating as the physical effects.<sup>10</sup> Stroke survivors grieve for the life they have lost so suddenly and unexpectedly. Their partners and families often grieve as well, as their loved one has changed after the stroke. As a result of the impairments following a stroke, survivors are often unable to carry out everyday

tasks such as ADL activities, which they used to take for granted. Many stroke survivors therefore require assistance from informal caregivers, often family members, for such activities.<sup>11</sup> In turn, this burden of care often has a negative effect on caregivers' physical and psychosocial well-being.<sup>10-12</sup>

Recovery after stroke is the focus of many studies.<sup>13</sup> From a rehabilitation point of view the recovery process of stroke survivors is typically divided into three phases: the acute phase, the rehabilitation phase and the chronic phase.<sup>14,15</sup> Typically, stroke survivors go through all three phases. In the acute phase, medical care is offered in a hospital.<sup>14</sup> The priority is to stabilize the medical condition, control life-threatening conditions, prevent another stroke and limit any stroke-related complications. In the rehabilitation phase, focus is on treatment of the physical, emotional, behavioral and cognitive consequences of the stroke by a multidisciplinary team.<sup>14</sup> Multidisciplinary team working is seen as a key contributor to delivering effective care across the pathway of stroke recovery.<sup>16</sup> The multidisciplinary team mostly consists of physiatrists, physical, occupational and speech therapists, nutritionists, psychologists, recreational therapists, social workers and nursing staff. Rehabilitation treatment aims to reduce impairments and promote activity and participation among patients.<sup>9</sup> In the chronic phase, stroke survivors have to learn to live with the residual effects of the stroke and engage in community reintegration.<sup>14</sup> Community reintegration can be defined as returning to the mainstream of family and community life, engaging in normal roles and responsibilities, and actively contributing to one's social groups and society as a whole.<sup>17</sup> A lot of stroke survivors struggle with community reintegration, because they struggle with the loss of their independence, abilities and social relations.<sup>18</sup>

## Stroke services and pathways of care in the Netherlands

In this section, the systems and pathways of care that stroke survivors typically go through in the Netherlands are described. We link these systems and pathways to the phases of recovery that were discussed above. Integrated stroke care is organized differently in each country, depending on, for example, the overarching system of healthcare, i.e. public or private, as well as more practical circumstances such as distances that need to be crossed to access services. In the Netherlands, stroke patients receive integrated care in stroke services.<sup>19</sup> A stroke service can be defined as a network of providers working together during the acute, the rehabilitation and the chronic phase of stroke patient care.<sup>20</sup> A large number of disciplines and organizations such as hospitals, nursing homes, rehabilitation centers, general practitioners and home care providers, are involved in the provision of stroke care. Stroke services aim to deliver coherent and patient centered integrated care.<sup>19</sup>

Currently, there are approximately 75 stroke services in the Netherlands.<sup>21</sup> Delivering coherent and patient centered care is done in a regional setting, where all relevant health and social care stakeholders and the local community, work together to provide multidisciplinary, coordinated care and support.<sup>19</sup> Stroke survivors follow different routes within the overall system of stroke services, because their experiences differ in terms of severity of stroke-related problems and age.<sup>14</sup> In the Netherlands, different pathways can be distinguished, such as a short hospital route to home for stroke patient with mild disability, a nursing home route for fragile elderly, and a side-inflow route for patients of which the impact of stroke was not recognized as such.<sup>14</sup> This thesis focuses on the rehabilitation route. Stroke patients take the rehabilitation pathway when they experience moderate to severe stroke-related problems.<sup>22</sup> They work on their recovery in a rehabilitation center before they are discharged home. After discharge, rehabilitation is mostly continued by means of outpatient treatment in a rehabilitation center or at home. Even though stroke services are well-organized in the Netherlands, and clear pathways of care are identified, stroke survivors and their families often experience difficulties when they try to take up their lives at home again. In spite of multidisciplinary care in the rehabilitation phase, they often struggle after being discharged, which is why these stroke survivors and their caregivers struggle to take up life again, are the focus of this thesis.<sup>18</sup>

### **Zooming into the gap between rehabilitation and living environment**

As outlined above, even though stroke services and pathways in care are well-organized, many survivors and their families experience the transfer from the clinical setting to the home setting as if they were falling in a black hole.<sup>18</sup> This phenomenon is not specific to the Netherlands, but rather it can be observed throughout the Western World. In the chronic phase, survivors and their families often face a downward spiral of physical decline, social isolation and depression.<sup>18-23</sup> This downward spiral seems to be reinforced by the realization that stroke is not a disease that can be treated with complete recovery as the result, but rather is a major life event that may result in life-long impairments.<sup>10</sup> The day-to-day struggle with stroke-related impairments typically does not arrive during rehabilitation treatment, but months later, when stroke survivors try to re-integrate in their home and community life. It is recognized, both in stroke rehabilitation practice and research, that stroke survivors get the best possible support after clinical rehabilitation to help them cope with the emotional impact of stroke-related issues on their lives.<sup>10</sup> Moreover, support is also offered in order to achieve and enhance social participation.<sup>6</sup> Even when they have had that support, why is there still a gap between rehabilitation and living environment?

In rehabilitation, three arguments prevail as to why a gap between rehabilitation and living environment persists. First, some rehabilitation researchers argue that it persists because of the differences between evidence and practice. These researchers try to tackle the gap between clinic and home by developing support for stroke survivors in terms of evidence-based practice. They argue that rehabilitation professionals insufficiently use available evidence about stroke rehabilitation in their local practices. They experience a gap between the knowledge researchers produce in terms of systematic reviews and related guidelines and the knowledge professionals apply to their local practice.<sup>24</sup> However, at the same time, rehabilitation professionals complain about the poor quality of the evidence produced by researchers in terms of relevance and fit. And researchers, in turn, point to therapists who insist on providing care in their own experience-based way.<sup>25</sup> Several implementation approaches have been developed to reduce the evidence-practice gap, such as the knowledge-to-action (KTA) approach.<sup>26</sup> In this thesis, we applied this KTA approach in a local rehabilitation setting in the Netherlands to co-create knowledge and engage local therapists in a two-way knowledge translation and multidirectional learning process.

Second, other researchers reason that there is a gap between rehabilitation and living environment, as there is not enough in-depth knowledge of how stroke survivors and their families themselves experience their lives after having survived a stroke.<sup>27,28</sup> Such researchers argue that both rehabilitation professionals and rehabilitation researchers should have a better understanding of the problems stroke survivors encounter after being discharged home.<sup>29</sup> More specifically, they argue that rehabilitation researchers should attune their research to stroke survivors' changed needs across the different phases of rehabilitation care. This implies that differences in stroke survivors' needs between the acute, rehabilitation and chronic phases should be explored in more detail. In this thesis, this challenge is taken up, by delving into the everyday experiences and needs of stroke survivors and their families in the rehabilitation and chronic phase.

Third, there are also researchers that plea for more attention for theory in order to improve clinical practice.<sup>30,31</sup> It is said that it is important to value the use of treatment theory in outcome evaluations and conduct more theory-based research.<sup>32-34</sup> This challenge is taken up, through grounding this thesis in theoretical inspiration from human geography and environmental psychology. These fields look into the bonds between people and places or environments.<sup>35-37</sup> This is useful for rehabilitation medicine, as stroke rehabilitation is situated in different places, as has been discussed above. Building on these scholars, home- and place-making can be broadly defined as the processes of attributing meaning to places, such as home, work, neighborhood, park or shopping mall. This is important for stroke rehabilitation, as stroke survivors typically have to re-define the meaning that places have for them, to accommodate their post-stroke identities.

## **Aim of this thesis**

Based on the gap and challenges identified above, the aim of this thesis is twofold: 1) to gain a better understanding of the experienced gap between the rehabilitation and living environment of stroke survivors in the Netherlands, and 2) to help improve the transfer from the clinical setting to the home setting in stroke rehabilitation with help of research knowledge.

## **Research questions are:**

1. What evidence is available for organized stroke care, and what is the relevance and fit of it, for improving the transfer from the clinical to home environment?
2. How do stroke survivors and their families experience their lives after in-patient rehabilitation, when being discharged home?
3. How can theoretical frameworks of home- and place-making contribute to a better understanding of the experienced gap between the clinical and home environment?

## Methodology

A combination of several knowledge sources and methods was used to address the research questions articulated above. First, a systematic literature study was carried out to review the available evidence on the transfer from rehabilitation to the living environment. This resulted in a review of reviews in which both quantitative and qualitative reviews were used. Also a study was done to the concepts from human geography and environmental psychology, such as home-making, place attachment and place identity.<sup>38,39</sup> Subsequently these concepts were used to develop a new framework that better understand stroke survivors' experiences and needs in different places, i.e. the rehabilitation clinic, home and community. This framework informed the qualitative methodology, which is discussed in more detail below.

Second, action research was used to co-create knowledge with stroke rehabilitation therapists, and engage them in a knowledge translation and multidirectional learning process. In this action research, an integrated knowledge-to-action (KTA) framework guided the study and involved researchers, therapists and other stakeholders. The knowledge-to-action (KTA) process proposed by Graham et al<sup>40</sup> is a framework to facilitate the development and application of research evidence into clinical practice.<sup>41</sup>

Action research is an approach that involves collaboration between different stakeholders, to contribute to knowledge building and social change. Hereby, active interaction between researchers and those researched influences the learning processes and the self-reflective capacity of both parties, which is essential for success.<sup>42</sup> Action research takes its cues from the perceptions of practitioners within particular, local practice contexts.<sup>43</sup>

Third, a qualitative methodology was used to gain insight into the experiences and perceptions of stroke survivors and their caregivers in the rehabilitation and home environment. Methods used included in-depth interviews with stroke survivors and caregivers, and focus group discussions with caregivers and rehabilitation professionals.

## Outline of the thesis

**Chapter 2** sets the scene for the rest of the thesis and explores the available evidence for organized stroke services in the whole chain of care. The Chapter includes a review of both quantitative and qualitative reviews. In so doing, this Chapter addresses the first research question posed in this thesis: What evidence is available, and what is the relevance and fit of it, for improving the transfer from the clinical to home environment? The relevance and fit of this evidence-based knowledge in relation to needs and experiences of stroke patients is articulated in reviews summarizing qualitative studies. In doing so prudent directions for research in organized stroke care were identified in order to improve discharge for stroke survivors with moderate to severe disability.

Subsequently, **Chapter 3** zooms in on a specific case where scientific evidence is translated into practice. It discusses an evidence-informed improvement process in a local rehabilitation setting in the Netherlands. An integrated knowledge-to-action (KTA) approach is used to co-create knowledge and engage local therapists in a two-way knowledge translation and multidirectional learning process. This KTA-approach draws on sociological conceptions of science that aim to integrate the scientific and stakeholder perspective in local rehabilitation research.

**Chapters 4 to 6** address the second and third research question. The second research question is: How do stroke survivors and their families experience their lives after in-patient rehabilitation, when being discharged home? And the third research question is: How can theoretical frameworks of home- and place-making contribute to a better understanding of the experienced gap between the clinical and home environment?

**Chapter 4** explores the experienced gap between the clinical and the home setting from the perspectives of stroke survivors and their families by means of semi-structured interviews. In this chapter, the aim is to gain insight into stroke survivors' needs and experiences in different environments. Therefore, their experiences are related to human geographical knowledge and focus on differences in bonding between stroke survivors and their meaningful places in both the clinical and own living environments.

**Chapter 5** examines stroke survivors' and, to a smaller extent their family caregivers' experiences of the chronic phase in more depth, by focusing on the place-making process in their own home. In so doing, we draw on theoretical frameworks from cultural geography and geographical gerontology, in which the home is conceptualized as a material as well as affective space, shaped by people's everyday practices, experiences, social relations, memories

and emotions. The analytical distinction between physical, social and personal home provides insight into what provides stability and a sense of being anchored to the home of people who have brusquely lost these anchors. In this chapter we draw on semi-structured interviews with stroke survivors, and a focus group discussion with informal caregivers.

**Chapter 6** deepens the discussion on community mobility in stroke rehabilitation, based on secondary analysis of the previously mentioned interview data by translating theoretical repertoires of mobility from the context of geography to stroke rehabilitation. We choose to define mobility as a way to connect places that are meaningful to individuals rather than as movements from A to B. This allows us to study the experiences of stroke survivors with respect to mobility as a way to connect places that are meaningful to them.

In the concluding **Chapter 7**, the findings from the **Chapters 2-6** are summarized and positioned to the literature, in order to attempt to answer the research questions that were posed in this introduction. Furthermore, the strengths and limitations of the thesis are discussed, implications for practice are addressed and future directions for research are explored.

## References

1. Wesselhoff, S., Hanke, T. A., & Evans, C. C. (2018). Community mobility after stroke: a systematic review. *Topics in stroke rehabilitation*, 25(3), 224–238.
2. GBD 2016 Stroke Collaborators (2019). Global, regional, and national burden of stroke, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet. Neurology*, 18(5), 439–458.
3. Di Carlo A. (2009). Human and economic burden of stroke. *Age and ageing*, 38(1), 4–5.
4. Hartstichting 2019. <https://www.hartstichting.nl/hart-en-vaatziekten/beroerte>.
5. NHG-standaard beroerte. Herzien op: 5 april, 2018: <https://www.nhg.org/standaarden/samenvatting/beroerte>.
6. VRA 2015. Actief naar zelfredzaamheid en eigen regie. Position Paper Revalidatiegeneeskunde. Volksgezondheid.info, 2019. <https://www.volksgezondheidenzorg.info/onderwerp/beroerte>.
7. Young, J., & Forster, A. (2007). Review of stroke rehabilitation. *BMJ (Clinical research ed.)*, 334(7584), 86–90.
8. Hersenstichting 2019. <https://www.hersenstichting.nl>.
9. Langhorne, P., Bernhardt, J., & Kwakkel, G. (2011). Stroke rehabilitation. *Lancet (London, England)*, 377(9778), 1693–1702.
10. The Stroke Association. *Feeling overwhelmed. The emotional impact of stroke*. 2013.
11. Greenwood, N., Mackenzie, A., Cloud, G. C., & Wilson, N. (2008). Informal carers of stroke survivors--factors influencing carers: a systematic review of quantitative studies. *Disability and rehabilitation*, 30(18), 1329–1349.
12. Cameron, J. I., & Gignac, M. A. (2008). "Timing It Right": a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient education and counseling*, 70(3), 305–314.
13. Cassidy, J. M., & Cramer, S. C. (2017). Spontaneous and Therapeutic-Induced Mechanisms of Functional Recovery After Stroke. *Translational stroke research*, 8(1), 33–46.
14. Stokman, M., Verhoeff, H., & Heineke, D. (2011). Navigeren naar herstel. Bouwstenen voor cliëntgerichte en samenhangende zorg ten behoeven van mensen met een hersenletsel. Den Haag: Hersenstichting.
15. Teasell, R. W., Foley, N. C., Bhogal, S. K., & Speechley, M. R. (2003). An evidence-based review of stroke rehabilitation. *Topics in stroke rehabilitation*, 10(1), 29–58.
16. Clarke, D. J., & Forster, A. (2015). Improving post-stroke recovery: the role of the multidisciplinary health care team. *Journal of multidisciplinary healthcare*, 8, 433–442.
17. Obembe, A., Mapayi, B., Johnson, O., Agunbiade, T., Emechete, A. (2013). Community reintegration in stroke survivors: Relationship with motor function and depression. *Hong Kong Physiotherapy Journal*, 31(2): 69–74.
18. Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experience of living with stroke: a qualitative meta-synthesis. *Journal of rehabilitation medicine*, 40(8), 595–602.
19. Vat, L. E., Middelkoop, I., Buijck, B. I., & Minkman, M. M. (2016). The Development of Integrated Stroke Care in the Netherlands a Benchmark Study. *International journal of integrated care*, 16(4), 12.
20. Minkman, M. M., Schouten, L. M., Huijsman, R., & van Splunteren, P. T. (2005). Integrated care for patients with a stroke in the Netherlands: results and experiences from a national Breakthrough Collaborative Improvement project. *International journal of integrated care*, 5, e14.
21. Kennisnetwerk CVA Nederland [Stroke Knowledge Network Netherlands]. Available from: <http://kennisnetwerkcva.nl> [in Dutch].
22. Stroke Unit Trialists' Collaboration (2013). Organised inpatient (stroke unit) care for stroke. *The Cochrane database of systematic reviews*, 2013(9), CD000197.
23. Murray, J., Ashworth, R., Forster, A., & Young, J. (2003). Developing a primary care-based stroke service: a review of the qualitative literature. *The British journal of general practice: the journal of the Royal College of General Practitioners*, 53(487), 137–142.

24. Tugwell, P. S., Santesso, N. A., O'Connor, A. M., Wilson, A. J., & Effective Consumer Investigative Group (2007). Knowledge translation for effective consumers. *Physical therapy*, 87(12), 1728–1738.
25. Green L. W. (2008). Making research relevant: if it is an evidence-based practice, where's the practice-based evidence?. *Family practice*, 25 Suppl 1, i20–i24.
26. Field, B., Booth, A., Illott, I., & Gerrish, K. (2014). Using the Knowledge to Action Framework in practice: a citation analysis and systematic review. *Implementation science: IS*, 9, 172.
27. Aziz, N. A., Pindus, D. M., Mullis, R., Walter, F. M., & Mant, J. (2016). Understanding stroke survivors' and informal carers' experiences of and need for primary care and community health services--a systematic review of the qualitative literature: protocol. *BMJ open*, 6(1), e009244.
28. Krishnan, S., Pappadis, M. R., Weller, S. C., Stearnes, M., Kumar, A., Ottenbacher, K. J., & Reistetter, T. A. (2017). Needs of Stroke Survivors as Perceived by Their Caregivers: A Scoping Review. *American journal of physical medicine & rehabilitation*, 96(7), 487–505.
29. Cott C. A. (2004). Client-centred rehabilitation: client perspectives. *Disability and rehabilitation*, 26(24), 1411–1422.
30. Siemonsma, P. C., Schroder, C. D., Dekker, J. H., & Lettinga, A. T. (2008). The benefits of theory for clinical practice: cognitive treatment for chronic low back pain patients as an illustrative example. *Disability and rehabilitation*, 30(17), 1309–1317.
31. van Twillert, S., Postema, K., Geertzen, J. H., Hemminga, T., & Lettinga, A. T. (2009). Improving rehabilitation treatment in a local setting: a case study of prosthetic rehabilitation. *Clinical rehabilitation*, 23(10), 938–947.
32. Lettinga, A. T., van Twillert, S., Poels, B. J., & Postema, K. (2006). Distinguishing theories of dysfunction, treatment and care. Reflections on 'describing rehabilitation interventions'. *Clinical rehabilitation*, 20(5), 369–374.
33. Whyte, J. (2006). Using treatment theories to refine the designs of brain injury rehabilitation treatment effectiveness studies. *The Journal of head trauma rehabilitation*, 21(2), 99–106.
34. van Twillert, S., Geertzen, J., Hemminga, T., Postema, K., & Lettinga, A. (2013). Reconsidering evidence-based practice in prosthetic rehabilitation: a shared enterprise. *Prosthetics and orthotics international*, 37(3), 203–211.
35. Cresswell, T. (2004). *Place: A short introduction*. Malden, MA: Blackwell Pub.
36. Manzo, L.C. (2005). For better or worse: exploring multiple dimensions of place meaning. *Journal of Environmental Psychology*, 25, 67–86.
37. Massey DB (2005). *For space*. London, UK: Sage Publications.
38. Hernández, B. & Hidalgo, M. & Salazar-Laplace, M. & Hess-Medler, S. (2007). Place Attachment and Place Identity in Natives and Non-natives. *Journal of Environmental Psychology*, 27, 310–319.
39. Lewicka, M. (2011). Place attachment: how far have we come in the last 40 years? *Journal of Environmental Psychology*, 31(3), 207–230.
40. Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: time for a map?. *The Journal of continuing education in the health professions*, 26(1), 13–24.
41. Bowen, S. J., & Graham, I. D. (2013). From knowledge translation to engaged scholarship: promoting research relevance and utilization. *Archives of physical medicine and rehabilitation*, 94(1 Suppl), S3–S8.
42. Hutter, I., Hennink, M., & Bailey, A. (2011). *Qualitative Research Methods*. UK: SAGE Publications Inc.
43. Herr, K., & Anderson, G. L. (2005). *The action research dissertation: A guide for students and faculty*. Thousand Oaks, CA: SAGE Publications, Inc.



## **Chapter 2**

# **Evidence and patient and caregivers' knowledge in organized stroke care: an integrated review of reviews of quantitative and qualitative research**

## **Abstract**

### **Background**

Despite the fast-growing amount of reviews critically appraising the diversity of stroke services, rehabilitation professionals have difficulties in interpreting the relevance and fit of the averaged body of evidence to local settings. This integrative review of reviews aims to support professionals in translating existing scientific knowledge on organized stroke care and patient needs into improved rehabilitation care in local settings.

### **Methods**

Pubmed/Medline, Cinahl and Cochrane Library were searched for reviews summarizing available evidence for stroke services. Services were classified in a matrix with four quadrants differentiating more and less-organized services and inpatient and outpatient services. Then, qualitative reviews were added and knowledge about the needs and experiences of stroke survivors and their caregivers was integrated in the evidence-informed interpretation process.

### **Findings**

For all stroke patients best evidence is available for well-organized inpatient services including acute, rehabilitation and comprehensive stroke units. Less-organized inpatient services such as mobile rehabilitation teams, mixed or general wards lack sufficient evidence. 'Early supported discharge' is the most evidence-based outpatient service for patients with mild to moderate disability in the (post-)discharge stage, whereas 'hospital at home' lacks evidence for these subgroups. Inconclusive evidence is available for home- and community outpatient services delivered in the chronic stage. The qualitative reviews demonstrated that the role of social and emotional loss, for both stroke survivors and their informal caregivers, are important issues to address, especially in the post-discharge and chronic phases of stroke rehabilitation. Furthermore, the consequence of the fragmented nature of care services is that stroke survivors and their informal carers have difficulty with finding adequate and consistent care.

### **Conclusions**

Directions to explore are combined inpatient and outpatient alternatives to improve supported discharge for stroke patients with severe disability. Based on the findings from the qualitative reviews, we conclude that patient and caregiver knowledge and perspectives need to be incorporated into the post-discharge and chronic stages of multidisciplinary rehabilitation.

## Introduction

Scientific literature on stroke care is growing faster than any professional can keep up with.<sup>1</sup> Reviews are becoming vital in keeping abreast of research findings, by summarizing large bodies of scientific knowledge on different topics of interest. Most systematic reviews on stroke rehabilitation summarize individual quantitative studies. The focus of these systematic reviews is predominantly on Randomized Controlled Trials in order to determine the effectiveness of services. Main topics in stroke rehabilitation trials are odds of death, dependency, length of hospital stay, mood and deterioration in ability.<sup>2-4</sup>

The diversity in stroke services makes the application of review findings to rehabilitation practice even more difficult.<sup>5</sup> Clinical trials have been undertaken in several countries in various settings, using diverging names to distinguish well-organized from less-organized ones. Moreover, services investigated in different trials vary in duration, control group, and target group with respect to stroke severity.<sup>6</sup> This variety in organization, setting, duration, control group, target group makes it difficult for professionals to interpret the relevance and fit of the available body of evidence for their local setting.<sup>7-10</sup> To conclude, a divide remains between available scientific knowledge and its translation into improved local stroke services.<sup>1</sup>

At the same time, the amount of qualitative reviews that synthesizes stroke survivors' and caregivers' needs, concerns, and values in the care continuum is growing. Qualitative studies concern knowledge about a wide range of issues related to stroke survivors' experiences with the organization and delivery of services, and about the impact of stroke on individuals and caregivers at home. Most reviews include either quantitative<sup>2-4</sup> or qualitative studies<sup>11-16</sup> and only a few integrate both.<sup>17</sup>

The great variety of qualitative and quantitative reviews makes the reading and interpretation of review findings for professionals a difficult and time-consuming activity. It is not surprising that they use them infrequently and prefer more user-friendly formats for accessing evidence.<sup>1</sup> For instance, stroke guidelines are developed to fulfil such a function by recommending evidence based ways of working.<sup>5,18</sup> However, these guidelines rarely incorporate knowledge from qualitative studies about the needs, concerns and values in post-stroke life and they are not focused on local settings.

The objective of this article is to support rehabilitation professionals in translating existing scientific knowledge on organized stroke care and patient needs into improved rehabilitation care in local settings. Therefore, we first arrange the various stroke services summarized in quantitative systematic reviews into a user-friendly matrix, that visualizes

available evidence for different types of rehabilitation care in the whole rehabilitation services continuum. Subsequently, stroke survivors and caregivers' experiences and concerns summarized in qualitative reviews are explored and related to the evidence-informed perspective. In so doing, we pinpoint: 1) directions in which local settings should move to improve their local services, and 2) research directions in the delivery of stroke care in the whole chain of care.

## **Methods**

Multiple databases (PubMed/MEDLINE, Cinahl and Cochrane Library) were searched for studies summarizing available evidence for stroke services in the whole chain of care. Keywords that were included in the search strategy were stroke rehabilitation, administration and organization, inpatient stroke services and outpatient stroke services. In addition, reference lists, relevant studies, grey literature were checked for additional references. Titles and abstracts of retrieved articles based on the predefined selection criteria were reviewed. Articles were included, if they were published from January 1, 2000 to September 31, 2012, were written in English, and had a focus on organization of stroke rehabilitation in primary and secondary care. This resulted in 1028 studies. In line with the objective of our study, we then excluded individual studies, limiting the results to reviews, systematic reviews and meta-analyses, which resulted in 105 reviews. Finally, the search results were narrowed by excluding reviews that specifically focused on diagnostic procedures and treatments for stroke patients. Two authors explored the scientific literature and independently extracted the data from every selected article. A total of 22 reviews, met the criteria and were included (see Table 1).<sup>2,3,19-38</sup>

Table1: Characteristics of the included quantitative reviews

Ref	Study (year)	Qua- drant	Type of review	Purpose	Outcome measures	Service	Included trials (trial setting)
2	Fearon et al. (2012)	III	Systematic review	To establish the effects and costs of ESD services compared with conventional services.	Primary outcome: death or long-term dependency. or institutionalisation.	Conventional hospital care and discharge procedures compared with alternative services which aimed to accelerate the patient's discharge from hospital in a community setting (early supported discharge).	13 (Australia, Adelaide, Norway, Thailand, Ireland, Denmark, United Kingdom, Canada, Sweden)
3	Langhorne et al. (2007)	III	Systematic review	To establish whether ESD services, in comparison with conventional hospital care and discharge arrangements, could improve patient outcomes and reduce the length of hospital stay.	Primary outcome: death or dependency. Secondary outcome: death, place of residence, activities of daily living (ADL) score, extended ADL score, subjective health status, mood or depression score, carer outcomes (mood and subjective health), plus patient and carer satisfaction. The primary resource outcome was the length of the index hospital admission, the number of re-admissions and total cost of service interventions reported in the original trials.	Early supported discharge services compared with conventional care - a single multidisciplinary ESD team coordinated hospital discharge and provided rehabilitation at home. - the ESD team coordinated discharge and provided immediate post-discharge care, but not ongoing rehabilitation. - uncoordinated community services or input from healthcare volunteers.	12 (?)

(Continuing) Table 1: Characteristics of the included quantitative reviews

Ref	Study (year)	Qua- drant	Type of review	Purpose	Outcome measures	Service	Included trials (trial setting)
19	Anderson et al. (2002)	III	Systematic review	To review the evidence of the cost effectiveness of services that accelerate hospital discharge and provide home-based rehabilitation for patients with acute stroke.	Hospital stay, death, institutionalisation, disability, and readmission rates; and resource use associated with hospital stay, rehabilitation, and community services and costs	Early hospital discharge and domiciliary rehabilitation compared with usual care.	7 (?)
20	Aziz et al. (2008)	IVb	Systematic review	To ascertain whether therapy-based rehabilitation services can influence outcome one year or more after stroke.	Primary outcomes: death or poor outcome (deterioration, dependency, institutionalisation) and performance in activities of daily living. Secondary outcome measures: case fatality (death), patient's performance in extended activities of daily living (EADL), patient's subjective health status or quality of life, patient's mood, carer's mood, re-admission to hospital and days spent in hospital at the end of scheduled follow up, and patient and carer satisfaction with services.	Community-based stroke patients, in which at least 75% were recruited one year after stroke and received a therapy-based rehabilitation intervention compared with conventional care.	5 (?)
21	Brady et al. (2005)	I, III, IV	Systematic review	To assess the evidence on the relative cost or cost-effectiveness of three rehabilitation services after stroke: stroke unit care versus care on another hospital ward, early supported discharge (ESD) services versus "usual care," and community or home-based rehabilitation versus "usual care."	Cost effectiveness	Three rehabilitation services after stroke: stroke unit care versus care on another hospital ward, early supported discharge (ESD) services versus "usual care," and community or home-based rehabilitation versus "usual care."	15 (?)

Ref	Study (year)	Quadrant	Type of review	Purpose	Outcome measures	Service	Included trials (trial setting)
22	Britton and Andersson (2000)	IV	Review	To assess whether home rehabilitation after stroke is better and/or less expensive than the more conventional alternatives, i.e., rehabilitation during inpatient care, day care, and outpatient visits--alone or in combinations appropriate to disease stage and patient needs.	?	Home rehabilitation offered within one year of stroke onset or discharge from hospital compared with rehabilitation during inpatient care, day care, and outpatient visits--alone or in combinations.	7 (?)
23	Foley al. (2007)	I	Meta-analysis	To identify and discriminate between three different forms of inpatient stroke care based on timing and duration of treatment and to compare the results of clinically important outcomes.	Mortality, combined death and dependency and length of hospital stay.	Acute stroke units, combined stroke units and rehabilitation stroke units.	14 (?)
24	Fuentes and Diez-Tejedor (2009)	I	Topical/narrative review	To review the current issues associated with the provision of SU care from an international perspective.	Death, complications, institutionalization, functional status, length of stay.	Intensive care stroke units Intermediate care stroke units Stroke teams Stroke units vs. neurology ward Stroke units vs. stroke teams	18 (?)

(Continuing) Table 1: Characteristics of the included quantitative reviews

Ref	Study (year)	Qua- drant	Type of review	Purpose	Outcome measures	Service	Included trials (trial setting)
25	Hillier and Inglis-Jassiem (2010)	IV	Systematic review	To evaluate the effectiveness of stroke rehabilitation for community-dwelling people with stroke, delivered in the home of the client compared with stroke rehabilitation delivered in an outpatient clinic or day hospital setting, on measures of activity or function as a primary outcome and on carer issues, cost and other benefits as secondary measures.	Primary outcome measures: Independence in function. Secondary outcome measures: carer satisfaction or stress, cost effectiveness or other benefits related to impairment, participation or psychological domains.	Stroke rehabilitation delivered in the home of the person with stroke (also called home rehabilitation or domiciliary services) offered within one year of stroke onset or discharge from hospital in comparison with stroke rehabilitation delivered in a centre (e.g., an outpatient clinic or day hospital). Stroke rehabilitation included single discipline or multi/interdisciplinary services provided by allied health, medical and/or nursing staff.	11 (7: United Kingdom, 1 Denmark, 1 New Zealand, 1 Sweden and 1 the USA)
26	Langhorne et al. (2000)	I	Meta-analysis	To establish the costs and effects of such services compared with conventional services.	Death, place of residence, dependency and/or an activities of daily living (ADL) score, social activity (extended ADL activity), psychosocial outcomes (mood score, quality of life score), carer outcomes (carer mood and quality of life scores), patient and carer preferences.	Services which provided support with an aim of helping prevent admission to hospital with conventional services (which could include hospital admission).	3 (United Kingdom)

Ref	Study (year)	Qua- drant	Type of review	Purpose	Outcome measures	Service	Included trials (trial setting)
27	Langhorne et al. (2005)	II	Meta-analysis	To establish the effectiveness of mobile stroke teams.	Death, dependency, the need for institutional care and measures of the process of care such as the delivery of key investigations and treatments.	Peripatetic systems of organised stroke care (stroke team care) compared with alternative hospital services.	6 (United Kingdom, South Africa, Canada, USA, Sweden)
28	Langhorne and Duncan (2001)	I	Systematic review	To evaluate the effectiveness of post-acute stroke services.	All-cause case fatality, place of residence, physical dependency (dependent in activities of daily living), activities of daily living score, and length of stay in the hospital.	Organized inpatient multidisciplinary rehabilitation commencing at least 1 week after stroke compared with alternative care.	9 (6: stroke rehabilitation units; 3 general rehabilitation wards).
29	Langhorne et al. (2002)	I	Survey/ review	To survey in a systematic way the processes of care adopted by those stroke units for which there is reasonably reliable evidence of effectiveness, and to explore the hypothesis that there may be common codes of practice which are characteristic of effective stroke unit care.	Death, dependency and the requirement for institutional care.	A comprehensive unit combining acute care and rehabilitation, rehabilitation stroke units, a stroke unit continuum with both a comprehensive unit and 'step-down' rehabilitation unit.	11 trials (?)

(Continuing) Table 1: Characteristics of the included quantitative reviews

Ref	Study (year)	Qua- drant	Type of review	Purpose	Outcome measures	Service	Included trials (trial setting)
30	Langhorne et al. (2005)	III	Meta-analysis	To assess the effects and costs of services that offer patients early discharge from hospital with rehabilitation at home (early supported discharge [ESD]).	Primary outcome: Death or dependency. Secondary outcomes: Place of residence, activities of daily living (ADL) score, extended ADL score, subjective health status, mood or depression score, outcomes for carers (mood and subjective health), and satisfaction of patients and carers. Primary resource outcome: duration of the index hospital admission. Secondary resource outcomes: the number of readmissions and the total cost of service interventions.	An Early Supported Discharge (ESD) service intervention that provided rehabilitation and support in a community setting with the aim of shortening the duration of hospital care compared with conventional care.	11 (Australia, Canada, Norway, Sweden, Thailand, UK).
31	Larsen et al. (2006)	III	Systematic review	To compare the effectiveness and efficiency of stroke units with or without the early home-supported discharge by a multidisciplinary team that plans, coordinates, and delivers care at home (EHSD).	Poor outcomes, referral to nursing home or institution, length of stay at hospital, and costs.	Early home-supported discharge by a multidisciplinary team that plans, coordinates, and delivers care at home (EHSD) was undertaken was compared with conventional rehabilitation at stroke units.	7 (?)

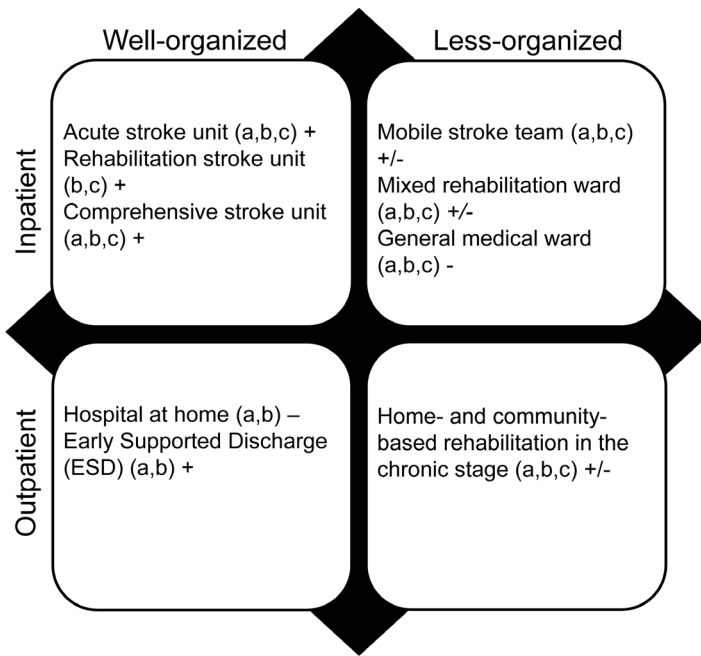
Ref	Study (year)	Qua- drant	Type of review	Purpose	Outcome measures	Service	Included trials (trial setting)
32	Outpatient Service Trialists (2003)	IVa	Systematic review	To assess the effects of therapy- based rehabilitation services targeted towards stroke patients resident in the community within one year of stroke onset/discharge from hospital following stroke.	Primary outcomes: Poor outcomes, dependency.	Therapy-based rehabilitation services targeted at stroke patients living at home compared with conventional or no care. Therapy services were those provided by physiotherapy, occupational therapy, or multidisciplinary staff working with patients primarily to improve task- orientated behavior and hence increase activity and participation.	14 (China, UK, USA, Denmark)
33	Teasell et al. (2003)	III	Review	To assess the effectiveness of early supported discharge programmes for stroke rehabilitation.	Hospital length of stay, functional outcomes, costs.	Early supported discharge (ESD) for stroke rehabilitation at home in comparison with conventional care	15 (?)
34	Rousseaux et al. (2009)	III	Review	To report on and discuss ESD's effects on various outcome parameters in stroke patients.	Death, dependency, institutionalization participation in ADL, health status, mood, satisfaction, duration of institutional stay costs.	Early supported discharge Type of care: type 1: coordination and performance by the ESD team; Type 2: coordination by the ESD team; Type 3: no involvement of the ESD team outside the hospital.	10 (Australia, Canada, Norway, Sweden, Thailand and the UK)

(Continuing) Table 1: Characteristics of the included quantitative reviews

Ref	Study (year)	Qua- drant	Type of review	Purpose	Outcome measures	Service	Included trials (trial setting)
35	Seenan, Long and Langhorne (2007)	I	Systematic review	To assess the effects of stroke unit care in routine clinical settings.	The primary outcome was death within one year. Secondary outcomes were failure to be discharged home, or failure to regain independence in daily activities.	Stroke unit care compared with absence of stroke unit care.	25 (18: Northern Europe, 3: Mediterranean countries, 1: North America, 1: Central Europe, and 1: Asia)
36	Shepperd et al. (2009)	II	Systematic review	To determine the effectiveness and cost of managing patients with early discharge hospital at home compared with in-patient hospital care.	Mortality, readmissions, general and disease-specific health status, functional status, psychological well-being, clinical complications, patient satisfaction, carer satisfaction, carer burden, staff views (including general practitioners' satisfaction), discharge destination from hospital at home, length of stay in hospital and hospital at home, and cost.	Studies comparing early discharge hospital at home with acute hospital inpatient care. Early discharge hospital at home care could be either provided in the patients' homes by a hospital outreach service, by community services or by a hospital-based stroke team or physician in conjunction with community based services.	11 (?)

Ref	Study (year)	Qua- drant	Type of review	Purpose	Outcome measures	Service	Included trials (trial setting)
37	Stroke Unit Trialists' Collaboration (2007)	I	Systematic review	To assess the effect of stroke unit care compared with alternative forms of care for patients following a stroke.	Primary outcome measures: Death, dependency and the requirement for institutional care at the end of scheduled follow up of the original trial. Secondary outcome measures patient quality of life, patient and carer satisfaction, and duration of stay in hospital or institution or both.	Dedicated ward (stroke, acute, rehabilitation, comprehensive) compared with a mobile stroke team or within a generic disability service (mixed rehabilitation ward).	31 (2: Norway, 1: Greece, 1: China, 8: UK, 1: Africa, 1: Scotland, 5: Sweden, 1: Netherlands, 3: Finnland, 2: USA, 1: France, 1: Canada, 1: Japan, 1: Italy, 1: Australia, 1: Denmark)
38	Langhorne et al. (2000)	II	Systematic review	To establish the costs and effects of services that help people avoid admission to hospital ('hospital- at-home') compared with conventional services.	Consequences of disability, death, dependency and requirement for change of residence, costs	Care of people with recent strokes at home using a community support team compared with conventional care using the usual referral process by a general practitioner or local service and which includes admission to hospital.	3 (?)

Subsequently, the available evidence was arranged in a user-friendly matrix structure. Hereby, quantitative evidence was summarized in words and visualized in a matrix. The resulting matrix consisted of four quadrants, distinguishing services in inpatient and outpatient services on the one hand and services in well- and less-organized on the other. The categorization in inpatient and outpatient and well- and less-organized services was derived from the systematic reviews. Two authors (CN, ATL) placed the services articulated in the reviews independently into the matrix structure (see Figure 1). In case of disagreements the authors discussed the matter until consensus was reached.



**Figure 1. Ordering in well-/less-organized and inpatient/outpatient services**

a = mild disability, b = moderate disability, c = severe disability;  
+ evidence, +/- inconclusive evidence, - no evidence

The format of Langhorne<sup>38</sup>, developed for ordering evidence for *inpatient* services in relation to stroke severity, was extended by including *outpatient* services into the format. Inpatient stroke services are defined as health care services provided to stroke patients who are admitted to a specific facility.<sup>37</sup> In contrast, outpatient stroke services are defined as health care services directed at patients who reside at home.<sup>32</sup> In order to distinguish between well- and less-organized services, the criteria of the Stroke Unit Trialists Collaboration for well-organized inpatient stroke services were also used for outpatient services.<sup>29</sup>

In most systematic reviews, stroke severity was articulated in terms of mild (a), moderate (b), and severe disability (c).<sup>2,32,37,38</sup> Also in line with the findings in the systematic reviews a distinction was made between a strong evidence-base (+), inconclusive evidence (+/-), and no evidence (-).<sup>2,32,37,38</sup> As a next step, qualitative systematic reviews that articulated stroke survivors and caregivers' needs and experiences in the whole care continuum were searched. To achieve this, the above-mentioned search strategy was extended with the keywords qualitative research, needs and experiences. The same in- and exclusion criteria were used. As a result, 1868 studies were found. Individual studies were excluded, thereby focusing on reviews, which resulted in 495 reviews. Search results were narrowed by excluding reviews that specifically focused on diagnostic procedures and treatments for stroke patients. Finally, 9 reviews were added to incorporate the patient and caregiver perspective in this synthesizing review (see Table 2).<sup>7,11-17,39</sup>

**Table 2** Characteristics of the included qualitative reviews

Ref	Study (year)	Stage	Type of review	Purpose	Participants	Included trials (Area)
7	Cameron et al. (2008 <sup>a</sup> )	Post-discharge and chronic stage	Topical/scoping review	To conduct a scoping review of the literature on stroke transitions to identify the current areas of research emphasis.	Stroke survivors and caregivers	75 (North America, United Kingdom, and Europe)
11	Cameron et Gignac (2008 <sup>b</sup> )	Acute, rehabilitation, post-discharge and chronic stage	Conceptual review	To discuss family caregivers of stroke survivors' changing needs for education and support across the care continuum.	Caregivers	79 (North America, the UK and Europe)
12	McKevitt et al. (2004)	Acute stage, rehabilitation stage, post-discharge and chronic stage	Systematic review	To identify the scope of published qualitative studies of stroke, consider their relevance to development and delivery of services for people with stroke, and make recommendations for future work	Stroke survivors and caregivers	95 (UK, Canada, USA, China, ?)
13	Murray et al. (2003)	Acute, rehabilitation and post-discharge stage	Systematic review	To identify the most frequently encountered longer-term problems experienced by stroke patients and their informal carers.	Stroke survivors and caregivers	23 (17: UK, 5: USA, 1: Sweden)
14	Peoples et al. (2011)	Rehabilitation stage	Systematic review	To obtain the best available knowledge on stroke survivors' experiences of rehabilitation.	Stroke survivors	12 (?)
15	Pringle et al. (2008)	Post-discharge stage	Systematic review	To identify studies that have researched stroke patients and carers experiences a few days after being discharged home.	Stroke survivors and caregivers	28

Ref	Study (year)	Stage	Type of review	Purpose	Participants	Included trials (Area)
16	Salter et al. (2008)	Post-discharge and chronic stage	Qualitative meta-synthesis	To examine the contribution of the published qualitative literature to our understanding of the experience of living with stroke.	Stroke survivors	9 (2: USA, 1: Sweden, 1: Canada, 4: UK, 1: Australia)
17	MacKenzie and Greenwood (2012)	Acute, rehabilitation, post-discharge and chronic stage	Systematic review	To identify positive experiences of caregivers, who are unpaid carers not statutory, looking after stroke survivors by systematically reviewing published quantitative and qualitative studies.	Caregivers	9
39	Greenwood and Mackenzie (2010)	Post-discharge and chronic stage	Systematic review	To summarize qualitative studies from the last decade that focus on experiences of caring for stroke survivors and to describe challenges, satisfactions and coping strategies.	Stroke survivors and caregivers	17 (9: USA, 2: UK, 2: Australia, 2: Scotland, 1: Hong Kong, 1: Thailand)

## Findings

An overview of the quantitative reviews that we analyzed is presented in Table 1. Based on these reviews, we arranged the various stroke services summarized in quantitative systematic reviews into a user-friendly matrix, that visualizes available evidence for different types of rehabilitation care in the whole rehabilitation continuum (see Figure 1). First, the findings with respect to quadrant I and quadrant II will be presented, in terms of available evidence for *inpatient* services for stroke patients with mild, moderate and severe disability. Second, the findings concerning evidence for *outpatients* services will be outlined in a similar way in quadrant III and quadrant IV (see Figure 1). Third, the knowledge assembled from the qualitative reviews will be presented and related to the knowledge collected from the quantitative reviews.

### Well- and less-organized inpatient services: quadrants I and II

The questions we addressed are: 1) "Which *inpatient* services are considered as well-organized in the reviews and which as less- organized, and for what reasons?"; 2) "What evidence is available for which service?"

#### ***Well-organized inpatient services: acute, rehabilitation and comprehensive stroke units***

Stroke units were presented as well-organized inpatient services. *Stroke units* in general are typified as well-organized *inpatient* services when they are set up in a *dedicated* ward within a *clinical* setting.<sup>29,37</sup> Well-organized implies that stroke units meet the four criteria set out in the Stroke Unit Trialists' Collaboration: 1) coordinated multidisciplinary rehabilitation; 2) staff with specialized interest in stroke and rehabilitation; 3) routine involvement of carers in the rehabilitation process; 4) regular programmes of education and training.<sup>29,37</sup> A *dedicated* ward was broadly defined, including acute, rehabilitation and comprehensive stroke units. Dedicated means a ward that exclusively manages stroke patients and not patients with other diagnoses.<sup>37</sup> *Acute stroke units* accept patients acutely but discharge early (usually within seven days). Focus of acute treatment is on preserving life and preventing complications.<sup>5,18</sup> *Rehabilitation stroke units* accept patients after a delay (usually seven days or more) at another ward or location and focus treatment on functional recovery and future independent living.<sup>5,18</sup> *Comprehensive stroke units* combine acute and rehabilitation treatment at the same ward for at least several weeks.<sup>37</sup>

### ***Less-organized inpatient services: mobile stroke teams mixed and general wards***

Mobile stroke teams, mixed and general wards<sup>27,37</sup> were typified in the systematic reviews as less-organized inpatient services, as they did not satisfy all the criteria set out by stroke unit trialists.<sup>37</sup> Mobile stroke teams offer specialized multidisciplinary stroke care (nursing staff excluded) in a variety of settings<sup>27,37</sup>, while mixed rehabilitation wards provide a generic multidisciplinary rehabilitation services (nursing staff included) for a variety of diagnosis groups including stroke patients.<sup>37</sup> So, both services are delivered in non-dedicated wards. A general ward is also described as a non-dedicated acute medical or general neurology ward, whereby care is provided without routine multidisciplinary input.<sup>37</sup>

As care is neither delivered in a dedicated ward for stroke patients nor offered by a specialized multidisciplinary team, we placed *general medical wards* at the end of the less-organized inpatient spectrum.<sup>37</sup> *Mobile stroke teams* and *mixed rehabilitation wards* were placed between well-organized services (stroke units) and less-organized services (general wards) in the spectrum, as their services are offered by a multidisciplinary team. The difference between them is, is that *mobile* stroke teams are *specialized* in stroke rehabilitation, whereas in *mixed* rehabilitation wards the multidisciplinary team is more *generalist* of character, as it treats also other diagnose groups (orthopedic and neurological) than just stroke patients. The Stroke Unit Trialists pinpointed mixed rehabilitation wards as more organized than mobile stroke teams.<sup>37</sup>

## **What evidence is available for which inpatient service?**

Reviews reported that the better services were organized, the less stroke patients suffered from disabling consequences when being discharged.<sup>24,29,37</sup> This yielded for patients with mild, moderate and severe disability.<sup>37</sup> Stroke patients receiving organized inpatient stroke unit care in dedicated wards were more likely to survive, be independent and live at home one year after stroke than patients in general medical wards or other less-organized inpatient services.<sup>23,24,28,35,37</sup> A combination of acute and early rehabilitation turned out to be one of the most important factors for effective stroke unit care.<sup>29,37</sup> Composition of disciplines and level of expertise specialization in stroke rehabilitation of multidisciplinary teams in the different services were however not reported on in the reviews.

## Well- and less-organized outpatient services: quadrants III and IV

The questions we address here are: 1) “Which *outpatient* services are considered as well- and which as less-organized in the reviews?”, and 2) “Which evidence is available for which *outpatient* service?”

### **Well-organized outpatient services: Hospital at home and Early Supported Discharge**

Two services, namely- ‘Hospital at home’ and ‘Early Supported Discharge’ (ESD)- are considered in the reviews as more organized compared with other outpatient services, because they generally meet the criteria set by Stroke Unit Trialists.<sup>37</sup> ‘Hospital at home’ is set up with the aim of avoiding hospital admission through provision of hospital care and treatment at home.<sup>26,36</sup> A mobile team of therapists, nurses and other professionals delivers (sub) acute hospital care to patients with mild to moderate stroke in the home setting in a rather organized manner.<sup>36</sup> The type of physician who was in lead (a consultant geriatrician, general practitioner or physiatrist) differed between the individual studies as well as the composition of other disciplines within the team and amount of specialized care delivered to stroke patients.<sup>26,36</sup>

ESD is an *outpatient* service that attempts to get the best out of two opposites: stroke units and hospital at home. It aims to offer patients early discharge from hospital, followed by support in their own home environment.<sup>2</sup> It seeks to reduce costs as well as the social implications of prolonged inpatient care. ESD aims to provide a seamless service spanning the transition from the clinical to the home setting. Well-organized ESD comprises a multidisciplinary team specialized in stroke rehabilitation that plans and coordinates early discharge from hospital and post-discharge care and rehabilitation at home through weekly team meetings, usually followed by a visit from the case manager of the ESD team at home.<sup>2</sup>

Coordination and delivery of ESD can be either a *community inreach* service or a *hospital outreach* service, whereby the former has a community and the latter a hospital base.<sup>2,3,30</sup> Within this scope a range of approaches can be distinguished in terms of when, where and how ESD-teams plan and coordinate discharge and hand over care to community services. The degree of involvement of specialized staff in ESD management varied in the studies from no involvement outside the stroke unit, solely post-discharge planning and coordination, to both planning, coordination and delivery of early home rehabilitation.<sup>2,3</sup>

## Less-organized outpatient services: home and community rehabilitation

*Home and community rehabilitation services* aim at continuing rehabilitation at home or in the community after discharge from an inpatient setting.<sup>32</sup> They differ from ‘Hospital at home’ and ESD in terms of time of onset of rehabilitation at home post-stroke. Hospital at home’ is delivered in the (sub)acute stage’, ESD in the early (post-)discharge stage, and home and community rehabilitation is delivered in the post-discharge and chronic stages. The focus of most home and community rehabilitation reviews was on therapy-based services offered within one year of stroke onset or discharge from hospital.<sup>22,25,32</sup> Only one review focused on community services delivered more than one year after stroke.<sup>20</sup>

The great variety of home and community services was categorized as being less-organized, because the reviews were not clear about the criteria set by the Stroke Unit Trialists.<sup>37</sup> Two reviews summarized studies comparing a mixture of home-based, outpatient clinic and day hospital services, with conventional care or no care.<sup>20,32</sup> Three reviews listed studies comparing therapy-based rehabilitation services delivered at home or in the community with hospital-based services.<sup>22,25</sup> These therapy-based outpatient services were delivered by either a multidisciplinary team or individual therapists.<sup>20,22,25,32</sup>

## What evidence is available for which outpatient service?

There is no evidence to support a radical shift from inpatient to outpatient care for acute stroke patients as aimed for in *hospital at home*.<sup>19,26,32,36</sup> Best evidence for outpatient services was available for well-coordinated ESD teams in terms of independent living and cost-effectiveness.<sup>2,3,19,21,30,31,33,34</sup> Best results were seen for stroke patients with mild to moderate disability.<sup>3</sup> However, stroke patients with severe disability were excluded in most ESD studies, as early home discharge poses logistic and human problems for this subgroup.<sup>2,5,33,34</sup> Variability across programs in terms of experimental and control groups, composition of the team, number of participants, length of follow-up, and phase of intervention complicated establishment of a clear evidence base for home- and community-based rehabilitation services.<sup>20,22,25,32</sup> It also remained unclear which service worked best for stroke patients with what severity. Evidence for the surplus value for home- and community-based alternatives is therefore inconclusive.

## Adding knowledge from patient and caregiver perspectives

The questions we address here are: 1) what knowledge can be drawn from qualitative research articulating the needs and experiences from stroke survivors and their caregivers; and 2) how does this patient and caregiver knowledge relates to the evidence-based knowledge presented in figure 1. The qualitative evidence that we found is shown in Table 2, which presents and overview of the qualitative reviews that we analyzed.

### *Acute and rehabilitation stage in the clinic*

Two of the selected reviews reported about patient experiences in the acute stage.<sup>12,13</sup> Most patients expressed high levels of satisfaction, and valued being cared about and cared for during hospital admission in the acute stage.<sup>12,13</sup> However, some patients experienced difficulties in dealing with their situation because of inflexible ward routines and lack of privacy. Furthermore, unclear goal setting and lack of carer involvement was experienced.<sup>13</sup>

Three reviews summarized the experiences and needs of patients during the rehabilitation stage.<sup>12-14</sup> Patients valued physiotherapy, because it was felt that it led directly to functional recovery. At the same time, a high overlap between occupational and physical therapy was experienced.<sup>12</sup> While appreciating a focus on functional recovery, stroke survivors also experienced an overly emphasis on physical needs. In line with this, stroke survivors expressed the need for more attention to non-physical needs, such as the social consequences of stroke, psychological support, couple counseling, and spirituality.<sup>14</sup>

Another important area in the experiences of stroke survivors concerns the relation with rehabilitation professionals, which was discussed in different ways. First, contrasting expectations of rehabilitation between patients and professionals were described. For patients, rehabilitation implied the ability to recover if they worked hard enough, resulting in a feeling of being let down when recovery did not occur. With professionals, the idea dominated that the potential to influence the illness trajectory was limited.<sup>12</sup> Patients' experiences of collaboration with staff were diverse, which reflects the dynamic nature of patient participation and professional participation.<sup>14</sup> Patients reported a need for active participation during rehabilitation treatment, but some perceived certain demands placed on them as frustrating.<sup>14</sup> Empowerment of stroke patients was thereby articulated as a matter of constantly weighing contrasting issues against each other, e.g. the right to decide versus the right not to decide.<sup>14</sup> The balance between these contrasting issues in patient-professional interaction requires further analysis and reflection, to fully accommodate the needs of stroke survivors and their informal caregivers.

### ***Post-discharge and chronic stage***

Four reviews revealed that many stroke survivors and their families perceive the post-discharge period as an exciting but difficult period.<sup>7,11,15,16</sup> They experience huge problems and disappointment when attempting to reintegrate in the community after discharge.<sup>7,15,16</sup> The impact of stroke on survivors is not only described as loss in terms of reduced functional ability and independence, but also as emotional and social loss, often articulated as a loss or change in roles, relations and identity.<sup>12,16,39</sup> These latter losses in particular are typically neglected in the quantitative systematic reviews on organized stroke care, which may in part explain the experienced gap between the clinical and home settings in the post-discharge phase.

Emotional and social loss does not only yield for individuals who have survived a stroke, but also impacts their family caregivers, in particular in the chronic phase. Caregiving to a family member can result in physical, emotional and financial problems and thus in loss and involuntary lifestyle changes. Many caregivers feel that their own needs are ignored, family relationships suffer, and become socially isolated.<sup>12</sup> Furthermore, caregivers are confronted with uncertainty with regard to the prospects of their loved ones and call for more information about long term implications of stroke, as well as about availability of, and fine-tuning with, community services.<sup>12</sup> As a result of the fragmentation of services in the community, stroke survivors and their families also experience problems in finding and accessing adequate and consistent care.<sup>7</sup> Current rehabilitation models are criticized for paying little attention to the transition from the non-disabled to the disabled-self, and the validity of this criticism manifests itself in all intensity when stroke survivors and their families try to take up their former lives again in the chronic phase of stroke rehabilitation.<sup>12</sup>

## **Discussion and conclusion**

In this article, we aimed to assist professionals in interpreting the relevance and fit of the averaged body of evidence with respect to organized stroke care to local settings. The best evidence regarding inpatient services in terms of survival and independence is available for combined acute and rehabilitation stroke unit care at dedicated wards for patients with mild, moderate and severe disability.<sup>4,37</sup> This implies that we recommend that professionals, who identify their own local service as one listed in the second quadrant (mobile rehabilitation team, mixed or general ward), move into the direction of well-organized services in the first quadrant, to improve their local setting in an evidence-informed manner. A research direction to be addressed in quadrant I is identifying the optimal and most efficient disciplinary composition of a multidisciplinary team.<sup>5,18</sup>

Despite the strong evidence-base for stroke units there is a tendency to shift from well-organized stroke units to home and community alternatives, at an earlier stage, thereby attempting to satisfy criteria set by the Stroke Unit Trialists Collaboration.<sup>37</sup> Though such ESD-services might work well for stroke patients with mild to moderate disability in research settings, they might fail when a well-organized outpatient infrastructure is lacking.<sup>5,18</sup> Professionals stimulated by the evidence in the third quadrant thus need to be cautious in applying ESD to their local settings, because it was not recommended for stroke patients with severe disability.<sup>18</sup> Another point of concern is that the material and organizational environment in home and community settings is entirely different from stroke units, and so are the needs of patients and the problems they face.<sup>7,11,12,16,39,40</sup> This might in part explain the experienced gap post-discharge between the clinical and home setting in the qualitative reviews that we studied. This shows the tension with the evidence for early supported discharge services reported in the quantitative reviews. This tension can be explained by the fact that quantitative and qualitative reviews typically have different areas of focus. Whereas quantitative reviews on ESD focus on independence and cost-effectiveness<sup>2,3,19,21,30,31,33,34</sup>, qualitative reviews emphasize emotional and social loss<sup>12,16,39</sup>.

The matrix furthermore visualizes shortage of evidence and organization of rehabilitation services in home and community settings in the fourth quadrant. The focus of quantitative research on home and community rehabilitation is still on functional recovery, independence in activities of daily living, odds of death, and cost reduction.<sup>2-4,37</sup> Quantitative research scarcely addresses other outcomes that are meaningful for stroke patients and caregivers in their own living environments, such as the role of environment, nature of community, importance of meaning and choice when thinking about life situations, and change in abilities across the life course.<sup>40</sup> This is striking, especially since current rehabilitation models emphasize the importance of involvement in a life situation. In contrast, the majority of the qualitative reviews did discuss how loss of identity, roles and relationships, decreased social interaction and increasing social isolation affect stroke survivors and their families living in the community.<sup>16</sup> In conclusion, stroke rehabilitation trials that focus on home and community services should also incorporate outcomes that are meaningful to patients and their families, and not only the assumed needs or outcomes as defined by rehabilitation professionals and researchers.<sup>40,41</sup>

To include meaningful outcomes, professionals working in home and community settings should therefore shift their focus of intervention from functional recovery and independent living in the clinic to loss of identity, roles and relationships, that were articulated in qualitative reviews.<sup>7,12,16,39</sup> Furthermore, fragmentation and poor coordination of long-term care are huge obstacles in ensuring adequate post-stroke care and rehabilitation.<sup>42</sup> Therefore outpatient stroke services in the (post-) discharge and chronic stage need to

move to an integrated care model that recognizes the wax and wanes of stroke disability over time and incorporates a self-, or, even better, a shared-management approach.<sup>43,44</sup> As stroke is not only an acute condition, but also a lifelong illness process, a comprehensive post stroke continuum of care in the chronic phase should be established to address the varied needs of stroke survivors, caregivers, and society at large.<sup>42</sup>

To conclude, the matrix provides a conceptual analytical tool to distinguish inpatient from outpatient and well-organized from less-organized services, that is easy to use for rehabilitation professionals. In the future, the dividing lines between the four quadrants of the matrix need to fade away to create a seamless transition from inpatient to outpatient services for all stroke patients in the whole chain of care. In creating this transition, attempts to organize outpatient services in the same multidisciplinary way as evidence-based inpatient services should be questioned. Indeed, qualitative research reveals that the needs of stroke survivors and their families, as well as the material and organizational environments of stroke services, are different in the (sub)acute, (post-) discharge, and chronic stage after stroke.

## List of abbreviations

ESD = Early Supported Discharge

## Competing interests

The authors declare that they have no competing interests.

## Acknowledgements

We gratefully acknowledge Stichting Beatrixoord NN for providing financial support for the present research.

## References

1. Hakim A. M. (2007). Vascular disease: the tsunami of health care. *Stroke*, 38(12), 3296–3301.
2. Fearon, P., Langhorne, P., & Early Supported Discharge Trialists (2012). Services for reducing duration of hospital care for acute stroke patients. *The Cochrane database of systematic reviews*, (9), CD000443.
3. Langhorne, P., Holmqvist, L. W., & Early Supported Discharge Trialists (2007). Early supported discharge after stroke. *Journal of rehabilitation medicine*, 39(2), 103–108.
4. Stroke Unit Trialists' Collaboration (2013). Organised inpatient (stroke unit) care for stroke. *The Cochrane database of systematic reviews*, 2013(9), CD000197.
5. The Management of Stroke Rehabilitation Working Group. (2010). *VA/DoD Clinical Practice Guideline for the Management of Stroke Rehabilitation*. Version 2.0.
6. Kalra, L., & Langhorne, P. (2007). Facilitating recovery: evidence for organized stroke care. *Journal of rehabilitation medicine*, 39(2), 97–102.
7. Cameron, J. I., Tsoi, C., & Marsella, A. (2008<sup>a</sup>). Optimizing stroke systems of care by enhancing transitions across care environments. *Stroke*, 39(9), 2637–2643.
8. Green L. W. (2008). Making research relevant: if it is an evidence-based practice, where's the practice-based evidence?. *Family practice*, 25 Suppl 1, i20–i24.
9. Green, L. W., & Glasgow, R. E. (2006). Evaluating the relevance, generalization, and applicability of research: issues in external validation and translation methodology. *Evaluation & the health professions*, 29(1), 126–153.
10. Scott, N. A., Moga, C., Barton, P., Rashid, S., Schopflocher, D., Taenzer, P., Harstall, C., & Alberta Ambassador Program Team (2007). Creating clinically relevant knowledge from systematic reviews: the challenges of knowledge translation. *Journal of evaluation in clinical practice*, 13(4), 681–688.
11. Cameron, J. I., & Gignac, M. A. (2008<sup>b</sup>). "Timing It Right": a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient education and counseling*, 70(3), 305–314.
12. McKevitt, C., Redfern, J., Mold, F., & Wolfe, C. (2004). Qualitative studies of stroke: a systematic review. *Stroke*, 35(6), 1499–1505.
13. Murray, J., Ashworth, R., Forster, A., & Young, J. (2003). Developing a primary care-based stroke service: a review of the qualitative literature. *The British journal of general practice: the journal of the Royal College of General Practitioners*, 53(487), 137–142.
14. Peoples, H., Satink, T., & Steultjens, E. (2011). Stroke survivors' experiences of rehabilitation: a systematic review of qualitative studies. *Scandinavian journal of occupational therapy*, 18(3), 163–171.
15. Pringle, J., Hendry, C., & McLafferty, E. (2008). A review of the early discharge experiences of stroke survivors and their carers. *Journal of clinical nursing*, 17(18), 2384–2397.
16. Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experience of living with stroke: a qualitative meta-synthesis. *Journal of rehabilitation medicine*, 40(8), 595–602.
17. Mackenzie, A., & Greenwood, N. (2012). Positive experiences of caregiving in stroke: a systematic review. *Disability and rehabilitation*, 34(17), 1413–1422.
18. Intercollegiate Stroke Working Party. (2008). *National clinical guideline for stroke*: 3rd edition. London: Royal College of Physicians.
19. Anderson, C., Ni Mhurchu, C., Brown, P. M., & Carter, K. (2002). Stroke rehabilitation services to accelerate hospital discharge and provide home-based care: an overview and cost analysis. *PharmacoEconomics*, 20(8), 537–552.
20. Aziz, N. A., Leonardi-Bee, J., Phillips, M., Gladman, J. R., Legg, L., & Walker, M. F. (2008). Therapy-based rehabilitation services for patients living at home more than one year after stroke. *The Cochrane database of systematic reviews*, 2008(2), CD005952.
21. Brady, B. K., McGahan, L., & Skidmore, B. (2005). Systematic review of economic evidence on stroke rehabilitation services. *International journal of technology assessment in health care*, 21(1), 15–21.

22. Britton, M., & Andersson, A. (2000). Home rehabilitation after stroke. Reviewing the scientific evidence on effects and costs. *International journal of technology assessment in health care*, 16(3), 842–848.
23. Foley, N., Salter, K., & Teasell, R. (2007). Specialized stroke services: a meta-analysis comparing three models of care. *Cerebrovascular diseases (Basel, Switzerland)*, 23(2-3), 194–202.
24. Fuentes, B., & Díez-Tejedor, E. (2009). Stroke units: many questions, some answers. *International journal of stroke: official journal of the International Stroke Society*, 4(1), 28–37.
25. Hillier, S., & Inglis-Jassiem, G. (2010). Rehabilitation for community-dwelling people with stroke: home or centre based? A systematic review. *International journal of stroke: official journal of the International Stroke Society*, 5(3), 178–186.
26. Langhorne, P., Dennis, M. S., Kalra, L., Shepperd, S., Wade, D. T., & Wolfe, C. D. (2000). Services for helping acute stroke patients avoid hospital admission. *The Cochrane database of systematic reviews*, (2), CD000444.
27. Langhorne, P., Dey, P., Woodman, M., Kalra, L., Wood-Dauphinee, S., Patel, N., & Hamrin, E. (2005). Is stroke unit care portable? A systematic review of the clinical trials. *Age and ageing*, 34(4), 324–330.
28. Langhorne, P., & Duncan, P. (2001). Does the organization of postacute stroke care really matter?. *Stroke*, 32(1), 268–274.
29. Langhorne, P., Pollock, A., & Stroke Unit Trialists' Collaboration (2002). What are the components of effective stroke unit care?. *Age and ageing*, 31(5), 365–371.
30. Langhorne, P., Taylor, G., Murray, G., Dennis, M., Anderson, C., Bautz-Holter, E., Dey, P., Indredavik, B., Mayo, N., Power, M., Rodgers, H., Ronning, O. M., Rudd, A., Suwanwela, N., Widen-Holmqvist, L., & Wolfe, C. (2005). Early supported discharge services for stroke patients: a meta-analysis of individual patients' data. *Lancet (London, England)*, 365(9458), 501–506.
31. Larsen, T., Olsen, T. S., & Sorensen, J. (2006). Early home-supported discharge of stroke patients: a health technology assessment. *International journal of technology assessment in health care*, 22(3), 313–320.
32. Outpatient Service Trialists (2003). Therapy-based rehabilitation services for stroke patients at home. *The Cochrane database of systematic reviews*, 2003(1), CD002925.
33. Teasell, R. W., Foley, N. C., Bhogal, S. K., & Speechley, M. R. (2003). Early supported discharge in stroke rehabilitation. *Topics in stroke rehabilitation*, 10(2), 19–33.
34. Rousseaux, M., Daveluy, W., & Kozłowski, R. (2009). Value and efficacy of early supported discharge from stroke units. *Annals of physical and rehabilitation medicine*, 52(3), 224–233.
35. Seenan, P., Long, M., & Langhorne, P. (2007). Stroke units in their natural habitat: systematic review of observational studies. *Stroke*, 38(6), 1886–1892.
36. Shepperd, S., Doll, H., Broad, J., Gladman, J., Iliffe, S., Langhorne, P., Richards, S., Martin, F., & Harris, R. (2009). Early discharge hospital at home. *The Cochrane database of systematic reviews*, (1), CD000356.
37. Stroke Unit Trialists' Collaboration (2007). Organised inpatient (stroke unit) care for stroke. *The Cochrane database of systematic reviews*, (4), CD000197.
38. Langhorne P. (2000). Organisation of acute stroke care. *British medical bulletin*, 56(2), 436–443.
39. Greenwood, N., & Mackenzie, A. (2010). Informal caring for stroke survivors: meta-ethnographic review of qualitative literature. *Maturitas*, 66(3), 268–276.
40. Cott, C. A., Wiles, R., & Devitt, R. (2007). Continuity, transition and participation: preparing clients for life in the community post-stroke. *Disability and rehabilitation*, 29(20-21), 1566–1574.
41. Struhkamp, R., Mol, A., Swierstra, T. (2009). Dealing with in/dependence: doctoring in physical rehabilitation practice. *Science, Technology & Human Values*, 34(1), 55–76.
42. Wissel, J., Olver, J., & Sunnerhagen, K. S. (2013). Navigating the poststroke continuum of care. *Journal of stroke and cerebrovascular diseases: the official journal of National Stroke Association*, 22(1), 1–8.
43. Jansma, F. F., Twillert, S. v., Postema, K., Sanderman, R., & Lettinga, A. T. (2010). Physical and rehabilitation medicine and self-management education: a comparative analysis of two approaches. *Journal of rehabilitation medicine*, 42(9), 808–814.
44. Jones, F., & Riazi, A. (2011). Self-efficacy and self-management after stroke: a systematic review. *Disability and rehabilitation*, 33(10), 797–810.



## Chapter 3

# **Combined Clinical and Home Rehabilitation: Case report of an integrated knowledge-to-action study in a Dutch rehabilitation stroke unit**

Christa S. Nanninga

Klaas Postema

Marleen C. Schönherr

Sacha van Twillert

Ant T. Lettinga

Physical Therapy, 2015; 95(4): 558-567.

## Abstract

### Background and Purpose

There is growing awareness that the poor uptake of evidence in health care is not a knowledge-transfer problem but rather one of knowledge production. This issue calls for re-examination of the evidence produced and assumptions that underpin existing knowledge-to-action (KTA) activities. Accordingly, it has been advocated that KTA studies should treat research knowledge and local practical knowledge with analytical impartiality. The purpose of this case report is to illustrate the complexities in an evidence-informed improvement process of organized stroke care in a local rehabilitation setting.

### Case Description

A participatory action approach was used to co-create knowledge and engage local therapists in a 2-way knowledge translation and multidirectional learning process. Evidence regarding rehabilitation stroke units was applied in a straightforward manner, as the setting met the criteria articulated in stroke unit reviews. Evidence on early supported discharge (ESD) could not be directly applied because of differences in target group and implementation environment between the local and reviewed settings. Early supported discharge was tailored to the needs of patients severely affected by stroke admitted to the local rehabilitation stroke unit by combining clinical and home rehabilitation (CCHR).

### Outcomes

Local therapists welcomed CCHR because it helped them make their task-specific training truly context-specific. Key barriers to implementation were travel time, logistical problems, partitioning walls between financing streams, and legislative procedures.

### Discussion

Improving local settings with available evidence is not a straightforward application process but rather a matter of searching, logical reasoning, and creatively working with heterogeneous knowledge sources in partnership with different stakeholders. Multiple organizational levels need to be addressed rather than focusing on therapists as sole site of change.

## Introduction

Physical therapy subscribes to the ideal of evidence-based practice, but how do we achieve that ideal? The health care sector, including physical therapy, has difficulty in applying and achieving widespread uptake of evidence in local practices.<sup>1-4</sup> Despite the ever greater technologies available for critically assembling, appraising, and synthesizing the relevant studies of interest on any given topic, therapists still experience difficulties when applying the results of systematic reviews and related guidelines to their routine daily practice.<sup>2</sup> They complain about the poor quality in terms of relevance and fit of the evidence produced by researchers. Researchers, in turn, point to therapists who insist on doing it in their own experience-based way. There is growing recognition that the research-practice gap thus experienced is really a problem of knowledge production rather than one of knowledge transfer.<sup>5-7</sup> Research goes unused because researchers fail to address the most important problems facing patients, therapists, and decision makers.<sup>8</sup>

The research-practice gap is increasingly articulated in terms of concern about the relative neglect of external validity when it comes to clinical epidemiological research. It is a *sine qua non* that researchers need to eliminate the possibility of bias in order to provide high-quality evidence. The focus of the research community is on the methodological quality of the clinical trials rather than on the usefulness of their results.<sup>1,8-11</sup> A drawback that ensues from the stringent rating of research proposals and publications in terms of the rigor of their internal validity control is the creation of a rather “sterile” evidence base.<sup>1</sup> Because clinical trials require such tight criteria when it comes to the interventions and selection of participants, they are likely to end up not having a very high external validity.<sup>1</sup> Much more space, therefore, should be devoted to issues of external validity,<sup>1,8-11</sup> engaged scholarship,<sup>5,6</sup> and the conduct of knowledge translation work in a disinterested way.<sup>12</sup>

This case report illustrates the complexities involved in an evidence-informed improvement process in a local rehabilitation stroke unit. It is an integrated knowledge-to-action (KTA) process that draws on a sociologically informed way of considering what sciences are and do.<sup>12,13</sup> In such a conception of science, research knowledge is not privileged over practical knowledge.<sup>12-14</sup> Translation is conceived in our KTA process as a 2-way knowledge exchange between knowledge producers and users.<sup>6,8,12</sup> Both forms of knowledge are thereby considered as being distinct but equally valued knowledge practices.

## Case Description and Methods

### *Target Setting*

The target setting was the stroke unit of a Dutch rehabilitation center to which patients with multifaceted problems are admitted for multidisciplinary rehabilitation after discharge from an acute stroke unit. The multidisciplinary team consists of psychiatrists, physical therapists, occupational therapists, nutritionists, speech therapists, psychologists, social workers, and nursing staff specializing in stroke rehabilitation. A medical and team manager coordinate the multidisciplinary team's work.

### *Identified Problem*

This KTA project started with a request from the head of the department to improve the local service with the best evidence available in the whole chain of care. The request stemmed from his concern that home- and community-based rehabilitation were less organized in the Netherlands compared with, for instance, Scandinavian countries. Despite (or because of) the wealth of systematic reviews and related guideline recommendations on the organization of stroke services, the local therapists experienced difficulties in critically appraising the research knowledge and guideline documents in terms of their usefulness for their local setting.<sup>15</sup> Together with the multidisciplinary team, we performed an integrated KTA project on organized stroke care by co-creating knowledge that fitted the local circumstances.

### *Methods*

A fieldwork approach including participatory action research was used to assist the local therapists in KTA activities regarding organized stroke care. In such an approach, active interaction between researchers and those researched influences the learning processes and the self-reflective capacity of both parties.<sup>16</sup> An integrated KTA framework guided the study and involved researchers, therapists, and other stakeholders in a 2-way knowledge translation and multidirectional learning process (see Table 1 for an overview of phases, stakeholders, tools, and products).<sup>17</sup> A mixture of research tools was used to bridge the research-practice gap, comprising literature study, individual and focus group interviews, a pilot study, and expert meetings. All individual and focus group interviews were digitally recorded, and files were verbatim transcribed. Data were subsequently coded and compared with regard to facilitators/barriers and advantages/disadvantages of the service to be put into action. The Atlas-ti software program (Atlas-ti GmbH, Berlin, Germany) was used for qualitative data analysis.<sup>18</sup>

**Table 1** Two-way knowledge exchange and multidirectional learning process

Phase	Stakeholders	Tools	Products
1 Specify problem	Head of department ↔ multidisciplinary team ↔ PR and SR	Local meetings, literature study (research-practice gap and organized stroke care)	Lack of local knowledge Knowledge production problem Diversity in services
2 Knowledge creation	PR (researcher ↔ content expert) ↔ SR (theoretical expert) ↔ project team	Review of reviews (organized stroke care) ordering services	User-friendly matrix
3 Tailor knowledge to address identified problem	Project team ↔ PR and SR ↔ multidisciplinary team	Project team meeting, mapping differences and similarities, information meeting (team)	Firm evidence-base local rehabilitation stroke unit Challenge to translate ESD evidence in alternatives CCHR as a possibility
4 Adapt knowledge to local context	Multidisciplinary team ↔ PR and SR ↔ multidisciplinary team	Two focus group interviews with team members, literature studies (goal setting and task- and context-specific training), feedback meeting (team)	Practical knowledge to build on Research knowledge to specify CCHR Engaged therapists
5 Access barriers to knowledge users	Project team ↔ PR and SR ↔ PTs and OTs, stroke survivors and caregivers ↔ PR and SR ↔ board of directors, health insurance experts ↔ PR and SR ↔ local care manager, multidisciplinary team	Local meetings, pilot study (4 survivors of stroke and caregivers), expert consultation, feedback meeting (team)	Specification of CCHR Barriers: travel time, logistical problems, walls between financing streams, legislative procedures → need to address multiple organization levels
6 Reshape problem	Project team ↔ PR and SR ↔ regional care managers, health insurance experts, policy makers, GP, local care manager ↔ PR and SR ↔ OT and PT primary care ↔ PR and SR ↔ multidisciplinary team	Project team meetings, regional expert meetings, qualitative study, information meeting (team)	Idea 1: “combined coaching at home and over distance” Idea 2: second KTA study with focus on multi-actor process on different organizational levels

PR = participatory researcher, SR = senior researcher, PTs = physical therapists, OTs = occupational therapists, CCHR = Combined Clinical and Home Rehabilitation, GP = general practitioner, ESD = early supported discharge, KTA = knowledge-to-action.

A project team was appointed, consisting of the head of the department, the medical manager of the stroke unit, the participatory researcher, and a senior researcher. A human movement scientist, who also worked as a physical therapist in the stroke rehabilitation team, fulfilled both the role of participatory researcher and that of content and setting expert. A philosopher of science and medicine (senior researcher), who was not involved in local practice, fulfilled the role of reflective questioner and supported the participatory

researcher in the conceptualization, analysis, triangulation, and interpretation of the data. Ongoing collaboration took place with the multidisciplinary team and their team manager in terms of consultation, information, and feedback meetings. The Board of Directors of University Medical Center Groningen and health care insurance experts were consulted to answer questions about financial, legislation, and regulatory matters.

## **Case Report**

### **Phase 1: Specify Problem**

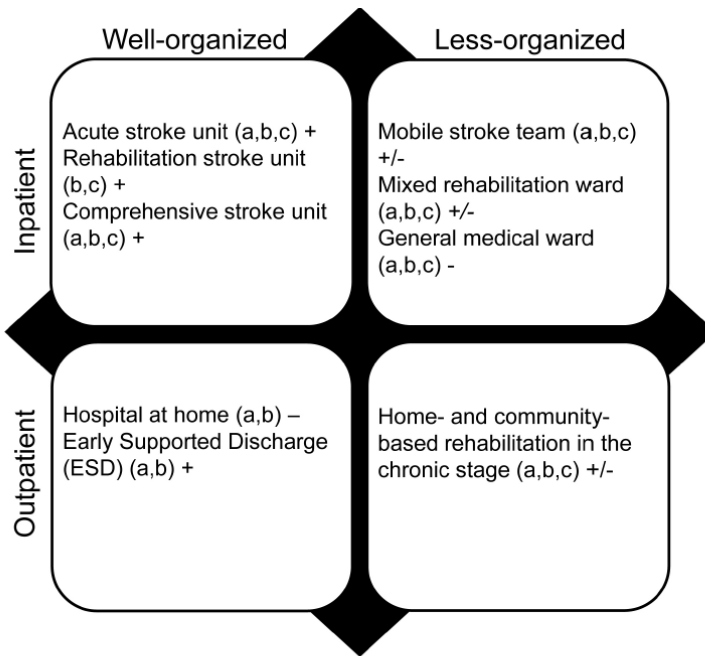
In this phase, the participatory and senior researchers specified the problem of the local team by examining literature about the research-practice gap in general, and more specifically about organized stroke care. They identified the problem not just as a lack of knowledge of local therapists but also as a knowledge production problem. The evidence for well-organized stroke care was widely acknowledged.<sup>15,19</sup> However, trials had been undertaken in several countries in various settings, using different names to distinguish well-organized from less-organized ones and selecting different target groups with respect to severity due to stroke.<sup>15</sup> This variability in naming, setting, and target population complicated the translation of the body of evidence summarized in numerous reviews into local improvements. Thus, the poor uptake of evidence on organized stroke care in local practices was attributed to the great diversity in stroke services examined in clinical trials.<sup>15,20,21</sup>

### **Phase 2: Knowledge Creation**

In this phase, the researchers searched for reviews summarizing the evidence produced in clinical trials on organized stroke care and stroke rehabilitation. Two guidelines on stroke management were used as additional knowledge sources.<sup>20,21</sup>

#### ***Review of reviews***

PubMed, CINAHL, and The Cochrane Library revealed a great variety of reviews on stroke rehabilitation and organized stroke care services. The researchers selected a total of 16 reviews between January 2003 and September 2013 that were relevant to the identified problem. These reviews had their focus on the organization of stroke rehabilitation in primary and secondary care.<sup>22–37</sup> Reviews with a focus on diagnostic procedures and rehabilitation treatments were excluded.



**Figure 1. Ordering in well-/less-organized and inpatient/outpatient services**

a = mild disability, b = moderate disability, c = severe disability;  
 + evidence, +/- inconclusive evidence, - no evidence

### ***Making research knowledge manageable***

The project team asked the researchers to make the diversity of stroke services and related evidence manageable in a user-friendly tool. Informed by distinctions made in the reviews, the researchers ordered the research knowledge in a matrix with 4 quadrants (Figure).<sup>22–38</sup> They distinguished services in well- and less-organized services and inpatient and outpatient services (see Appendix for definitions of services).<sup>22,26–31</sup> In addition, they differentiated stroke severity as mild (a), moderate (b), or severe disability (c) and evidence as firm (+), inconclusive (+/-), or no evidence (-).<sup>38</sup> In so doing, they reflected the emerging hierarchy of service organizations and target group descriptions articulated by “stroke unit trialists”.<sup>22</sup>

### **Phase 3: Tailor Knowledge to Address Identified Problem**

In this phase, the project team applied the matrix as an ordering figure to: (1) determine the nature of the local rehabilitation service, (2) explicate the available evidence for the local service, and (3) pinpoint research knowledge that could be used locally for improving home and community-based services. To address these issues, the researchers explored differences and similarities in target population, content, and implementation environment between the services reviewed and the local service under study.

### ***A rehabilitation stroke unit: a firm evidence base to start with***

The project team determined their local service as an evidence-based rehabilitation stroke unit (quadrant I), as their service met the 4 criteria set out in stroke unit reviews.<sup>22–25</sup> First, there was a multidisciplinary team that provided stroke care in a dedicated ward; second, the stroke team (including nursing staff) was specialized and trained in stroke rehabilitation; third, routine involvement of caregivers in the rehabilitation process was established in the form of partner groups; and, fourth, new insights and skills in stroke rehabilitation were taught in regular meetings and courses.<sup>22–25</sup> Furthermore, the target population of the local service were adult patients with moderate to severe disability who had been admitted to a dedicated department after care in the acute stroke unit of a hospital. The multifaceted problems meant that rehabilitation treatment could not adequately and safely be managed at home. This approach was in line with stroke guidelines recommending that all patients not suitable for transfer home after completion of acute diagnosis and treatment should be treated in a specialist rehabilitation stroke unit.<sup>20,21</sup> Research knowledge about rehabilitation stroke units thus served as a firm evidence base (level A) for the target group in the local setting.

### ***Early supported discharge (ESD): a challenge to translate the evidence***

Evidence concerning home and community rehabilitation services was inconclusive because of variability across services (quadrant IV).<sup>28–30</sup> The project team endorsed ESD as a well-organized and evidence-based cost-saving outpatient alternative to regularly supported discharge (quadrant III).<sup>31–37</sup> Early supported discharge involves a multidisciplinary team specialized in stroke rehabilitation that plans and coordinates early discharge from the hospital, post-discharge care, and rehabilitation at home through weekly team meetings, usually followed by a visit from the case manager of the ESD team.<sup>31</sup> Stroke guidelines recommend that patients should be discharged early from stroke unit care only if there is a specialist stroke rehabilitation team able to continue rehabilitation in the community from the day of transfer.<sup>20,21</sup>

The project team noted that well-organized, specialist home- and community-based stroke services were scarce in the region. Moreover, the greatest benefits from ESD are attributed to patients with mild to moderate disability in acute stroke units, whereas the target group in their local setting are patients with moderate to severe disability treated in a rehabilitation stroke unit.<sup>31–36</sup> They concluded that the original evidence on ESD did not exactly fit the circumstances of the target setting. Even so, they argued that the local rehabilitation stroke unit could well profit from the ESD recommendation to shift more—and at an earlier stage—into home-based alternatives.<sup>31–33,35,36</sup> In light of these findings, the idea of an alternative service tailored to patients with moderate and severe disability following stroke surfaced; that is, combined clinical home rehabilitation (CCHR), in which

specialist multidisciplinary treatment in the rehabilitation unit could be combined with home treatment at an early stage. The participatory researcher used the matrix to inform the multidisciplinary team about: (1) how to build on the evidence available for stroke rehabilitation units and (2) how to learn from evidence for ESD.

#### **Phase 4: Adapt Knowledge to Local Context**

In this phase, the researchers traced and articulated ways of attending to clinical and home rehabilitation of the local team. Therefore, they conducted 2 focus group discussions, each with 8 participants from different disciplines of the multidisciplinary team. The focus groups addressed the question: “How could one learn the most from the advantages or disadvantages of combined clinical and home rehabilitation.” To elaborate on the practical contextual knowledge of the team, the researchers subsequently conducted a second literature review focused on items that the participants addressed as challenging.

##### ***Practical knowledge of the team***

The participants articulated the greatest advantage of CCHR as being an easier carryover of skills learned in the clinical setting to the home setting. They discussed the carryover problem in terms of “a gap, into which patients and their families threaten to fall after discharge from the rehabilitation unit.” Patients faced the problem of being treated in an institution and then having to master an environment that differed from this institution in various ways. This problem could not be prevented by means of weekend leaves and routine involvement of partners in the rehabilitation process, or even by home visits. Therapists critically reflected on the “artificial state” of their treatments by stressing that activities training in a clinical setting was always an imperfect simulation of the natural setting at home. Therefore, they welcomed CCHR because it made training more “tailor-made” and task- and context-specific. Patient goals could be better set in collaboration with patients and significant others at home, thereby taking problems in real life as a directive for treatment. The added value of CCHR was expressed in a better transition to the home setting rather than in cost savings such as in ESD.

One disadvantage discussed by the participants was the distance that needed to be bridged in order to deliver treatment at home. Travel time made them less employable in the clinical setting, and they doubted whether health insurance companies were willing to pay for such indirect costs. Asking community therapists to deliver home treatment was not an alternative because they lacked specialist expertise in stroke rehabilitation. Fatigue of patients with stroke was a concern that also needed to be considered with respect to travel time. Also, although family members could be actively involved in CCHR, they might not always be able to free themselves from work obligations during home treatment.

**Research knowledge from the literature**

To build on the practical knowledge of the local team, the researchers conducted a literature review on task- and context-specific training and goal setting. This review confirmed and specified the practical knowledge of the team. Indeed, most patients with stroke had difficulty with generalizing what had been learned in the therapeutic setting to their own living environments.<sup>39</sup> The context in which tasks are learned, therefore, should be as personalized and home-like as possible. Task-specific training enhanced functional outcomes in stroke rehabilitation, where there is increasing evidence available for neural plastic changes.<sup>40</sup> Intensive, meaningful, repetitive task-specific and client-centered treatments that targeted the whole body were advocated in an enriched environment.<sup>40,41</sup> Goal setting in close collaboration with patients and their families was considered a key element in rehabilitation treatment.<sup>42</sup> Goals should be meaningful and challenging but achievable and should include both short-term (days/weeks) and long-term (weeks/months) targets and time-bound measurable outcomes.<sup>42</sup> Qualitative studies on the actual use of goals in rehabilitation practice revealed, however, that goals are frequently unattained, modified, or contested.<sup>43,44</sup> In rehabilitation, goals are set for the home setting that differ—in terms of spatial and social characteristics—from those in the clinical setting, where people are training for the accomplishment of goals.<sup>44</sup> The research knowledge on task- and context-specific training and goal setting supported the practical knowledge and drives of the therapists and the uptake of CCHR. The therapists explicated these findings in a feedback meeting with the team.

Table 2. Participants characteristics

	Gender	Age (years)	Stroke	Effects of stroke (MRS score)	Marital status	Clinical stay (days)	Duration of CCHR (weeks)	Amount of home treatments	Therapist involved with home treatments
1	Male	72	Hemorrhagic stroke right	Motor problems (MRS 2)	Married	65	3	6	PT and OT
2	Male	70	Hemorrhagic stroke left	Motor, cognitive and speech problems (MRS 4)	Married	88	5	10	PT and OT
3	Female	44	Ischemic stroke right	Motor problems (MRS 3)	Married	61	4	8	PT and OT
4	Male	47	Ischemic stroke left	Motor, cognitive and speech problems. (MRS 4)	Married	70	2	2	PT and OT

MRS = Modified Rankin Scale, PT = physical therapist, OT = occupational therapist

## **Phase 5: Assess Barriers to Knowledge Use**

In this phase, the project team decided in close cooperation with the team to conduct a pilot study with 4 patients with varying cognitive and motor problems poststroke (see Table 2). Physical therapists and occupational therapists were indicated as best candidates for delivery of CCHR. The participatory researcher assisted the therapists in making CCHR practical. After the pilot study, the researchers assessed facilitators and barriers in the application of CCHR by conducting semi-structured individual interviews with 9 therapists and the 4 patients and their caregivers involved in the pilot study. The head of the department and the senior researcher subsequently talked with members of the Board of Directors of University Medical Center Groningen and with regional health insurance experts about the potential of CCHR.

### ***Specification of CCHR***

Informed by ESD evidence, the participatory researcher decided in partnership with the therapists to begin with CCHR as early as possible, that is, within 4 weeks after admission to the rehabilitation stroke unit. The literature studies on task- and context-specific training and goal setting made them decide that goals needed to be set in the home setting in close collaboration with the patients and their caregivers. Whole tasks should subsequently be assessed and trained in the home setting and then problematic tasks repeatedly practiced in the clinical setting with a focus on the missing components. Subsequently, the whole tasks had to be trained in the home setting again.

### ***Experiences of therapists and patients and their caregivers***

Therapists embraced the alternative: CCHR provided a great deal of insight into the home environment, including the problems their patients had to face. Although they experienced difficulties with restructuring their existing skills, they felt they could offer their patients a more customized treatment. According to one therapist, “CCHR was a lottery ticket for a patient with severe cognitive problems.” This patient showed astonishing improvements when training took place in his own living environment. Patients were satisfied, because they were taught to use, in their own home environment, what they had learned in the clinical setting. Home treatments made family members feel more secure in assisting patients in performing daily activities in the absence of the therapist during weekend leaves.

Most of the goals that were set at home, and subsequently trained for in the clinical setting, were attained. A frequency of two 45-minute home treatment sessions a week appeared to be enough for goal setting and treatment. The total duration of CCHR ranged from 2 to 5 weeks, in which the total number of home treatments ranged from 2 to 10 sessions, depending on the complexity of problems poststroke. However, starting early (ie, within 4 weeks) became a barrier for some patients and their caregivers. For logistical reasons,

the team could not select more than 2 patients for home treatment at the same time; otherwise, too few therapists would then be available for regular treatment in the clinic. Therapists also experienced time pressure in their schedules caused by additional travel time and time to fine-tune activities. As a solution, home treatments were connected to weekend leaves.

### ***Expert consultation***

A barrier beyond the control of the therapists involved the organization and finance system of health care services in the Netherlands. The consulted board of directors and health insurance experts foresaw financial and legislative problems were it to be implemented structurally. Dutch inpatient and outpatient therapists work in separate organizational environments with different employment relationships and financing agencies. They suggested involving care financing agencies in the project because legislative procedures and partitioning walls between health-financing systems in primary and secondary care might hamper structural implementation of CCHR. This suggestion implied that the project team had to redefine the problem and integrate practical and contextual knowledge of regional managers, therapists, and financial and policy experts in the local knowledge co-creation process. Several therapists were eager to give content to the new idea.

## **Phase 6: Redefine Identified Problem**

In this phase, the researchers placed the problematic integration of primary and secondary care services in a broader perspective by organizing an expert meeting with 1 local care manager as well as 4 care managers, 1 health insurance expert, 1 general practitioner, and 2 policy makers in the region. Another expert meeting was organized with 6 physical therapists, 5 occupational therapists, and 2 speech therapists treating survivors of stroke in the region. Subsequently, the researchers conducted a qualitative study to gain knowledge of the needs of survivors of stroke and family caregivers in the clinical, post-discharge, and reintegration phases of the rehabilitation process.

### ***Expert meetings***

The region had identified active and healthy aging as a major societal challenge. All participants were supportive of a better integration between primary and secondary stroke care services. To meet the demands associated with demographic change in terms of low birthrates, increasing longevity, the related shortage of health care professionals, and increasing pressure on public budgets, the policy makers felt the need to rethink the way stroke services were organized in the regional chain of care. Delivery of stroke care with less fragmentation, close to home, and bridging distances with the help of innovative technology were shared challenges. The physical therapists, occupational therapists, and speech therapists expressed a shortage of knowledge in outpatient services concerning the treatment and multifaceted problems of survivors of stroke as a major concern. The qualitative study revealed that

survivors of stroke foregrounded functional recovery in the clinical phase, were confronted with an identity confusion and related mourning process in the post-discharge phase, and longed for recognition and a sense of belonging in the reintegration phase.<sup>45</sup>

### ***Reshape problem***

Informed by this practical, contextual, and research knowledge, the project team suggested that individual coaching of survivors of stroke and family caregivers rather than multidisciplinary treatment should be pivotal in home- and community-based rehabilitation. The project team decided to reshape the identified therapeutic problem by placing it in a regional policy and multi-stakeholder perspective and then go through the knowledge creation and action cycle again. The therapeutic question “How can therapists improve the transition from the clinical to the home setting with the available evidence on organized stroke care?” was reshaped into a decision-making question: “How do we organize rehabilitation service through to the home environment of survivors of stroke in a sustainable, efficient, and smart way, eventually with the help of e-health technology?” Combined coaching at home (face-to-face) and over distance (screen-to-screen) was articulated as an alternative that might contribute to regional challenges. How the project team addressed multiple organization levels in a second KTA study on organized stroke care and how they managed that therapists remained involved will be presented in the near future.

## **Discussion**

This case report illustrates the iterative and dynamic process of integrated KTA research aimed at translating evidence, produced in controlled research settings, to complicated implementation environments such as those seen in clinics. To bridge the research-practice gap experienced, we used a participative action approach, thereby treating research and practical contextual knowledge with analytical impartiality.<sup>5,12</sup> The lessons learned by doing are discussed below.

### ***Different Translations of Evidence to Local Setting***

By articulating similarities and differences in the target population and environments of local and research settings, we learned that evidence produced in clinical trials could help to advance local settings in different ways. Similarities indicate proof of actual practice in local settings, implying that local therapists already worked in an evidence-based manner, as was the case in the local rehabilitation stroke unit described in this case report. Differences indicate that there is a challenge to improve local reality in an evidence-informed way, as we did with evidence for ESD. This finding might imply that therapists need to deviate from original evidence produced in research settings, as was done in CCHR, in order to tailor it to the abilities of patients who are severely disabled poststroke

treated in a rehabilitation stroke unit. In most reviewed trials, severity was measured with the Barthel Index. Whether the Barthel Index is a valid instrument for objectifying the multi-faceness of problems of survivors of stroke in their own living environments might be a topic for future research.

### ***Generalizability of Case Studies***

Case studies and participatory action research do not have generalizing power, in that we can now recommend how other stroke rehabilitation services can improve their service in a well-organized and evidence-informed manner. This conclusion, however, does not mean that the findings in this KTA project only have local value. We hope to have demonstrated that detailed analysis and description of a bidirectional evidence-informed translation process in one location might have value for stakeholders working in another location. Indeed, such a specification of a local improvement process renders it possible for therapists in other settings to examine what will remain the same and what will change, when they want to improve the organization of their service in an evidence-informed manner. The user-friendly matrix that we developed as an ordering figure for navigating through the different types of services on organized stroke care including available evidence also might facilitate others in improving their local setting in an evidence-informed way.

### ***Lack of Attention to Multiple Organizational Levels***

One limitation of this case report is that we did not take broader organizational levels into account from the very beginning of our KTA process. We learned that improving rehabilitation practice with available evidence on organized stroke care is not just a matter of mobilizing its key users but also one of augmenting its material and organizational environment.<sup>7,8</sup> Partitioning walls between different financing systems along with stifling legislation and regulatory procedures were detected as main barriers for structural implementation of CCHR. Thus, multiple organizational levels need to be addressed in KTA studies rather than focusing on therapists as the sole site of change.<sup>46</sup> That is why we reshaped our identified problem and started to go through the knowledge creation funnel and action cycle again. The philosophy underlying, and methodology used, in transition management research may prove to be useful in such a multi-actor process.<sup>47</sup>

### ***Transformed Terminology and KTA Framework***

Translation was conceived in the KTA process as a 2-way knowledge exchange and multidirectional learning process for knowledge “producers” and “users”.<sup>5,6,12</sup> Conventional KTA frameworks suggest a one-way knowledge transfer by the KTA expert, as is illustrated by the arrows of the action cycle pointing in just one direction.<sup>2,5</sup> We welcome the bidirectional arrows of present frameworks that visualize the iterative, dynamic, and multidirectional learning process in KTA work more adequately.<sup>17</sup> Knowledge translation experts may have

been too focused on applied and evaluation research, which privileges scientific knowledge over local practical knowledge.<sup>12</sup> As such, they might overlook the multiplicity of KTA work, in particular the production of new knowledge, which arises from the interactions between scientific and practical contextual knowledge. This situation implies that we need to reconsider the terminology in which current KTA frameworks articulate their knowledge creation and KTA activities. Also, the contradiction between knowledge “producers” and knowledge “users” might no longer be appropriate terminology. We argue that evidence-informed improvements of local practices are achieved more easily if the terminology remains equally valued and yet is fluid enough to change shape, to make it adaptable to the requirements of the new surroundings. Improving rehabilitation practice is quite a different enterprise from proving its effectiveness.<sup>14</sup> Improving settings with the help of research findings from a rather “sterile” evidence base and translating these findings into the complex world of health care delivery is a matter of creatively working with heterogeneous information sources.<sup>3,13,14</sup> It is an iterative, cyclical, and dynamic translation and transformation process that requires practical and contextually relevant wisdom on the part of all involved, such as researchers, therapists, patients, caregivers, managers, and policy makers.

All authors provided concept/idea/project design. Ms Nanninga, Dr Postema, Ms van Twillert, and Dr Lettinga provided writing. Ms Nanninga provided data collection. Ms Nanninga, Ms van Twillert, and Dr Lettinga provided data analysis. Ms Nanninga and Dr Lettinga provided project management. Ms Nanninga provided fund procurement. Ms Nanninga and Dr Schönherr provided patients and institutional liaisons. Dr Schönherr provided facilities/equipment. Dr Schönherr, Ms van Twillert, and Dr Lettinga provided consultation (including review of manuscript before submission). The authors gratefully acknowledge Stichting Beatrixoord NN for providing financial support for the present work. Special thanks go to the patients and therapists of the multidisciplinary rehabilitation team participating in this project. Project approval was obtained from the Medical Ethical Committee of University Medical Center Groningen (UMCG).

## References

1. Green L., W. (2008). Making research relevant: if it is an evidence-based practice, where's the practice-based evidence? *Family practice*, 25 Suppl 1, i20–i24.
2. Tugwell, P. S., Santesso, N. A., O'Connor, A. M., Wilson, A. J., & Effective Consumer Investigative Group (2007). Knowledge translation for effective consumers. *Physical therapy*, 87(12), 1728–1738.
3. van Twillert, S., Postema, K., Geertzen, J. H., Hemminga, T., & Lettinga, A. T. (2009). Improving rehabilitation treatment in a local setting: a case study of prosthetic rehabilitation. *Clinical rehabilitation*, 23(10), 938–947.
4. Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: time for a map?. *The Journal of continuing education in the health professions*, 26(1), 13–24.
5. Bowen, S. J., & Graham, I. D. (2013). From knowledge translation to engaged scholarship: promoting research relevance and utilization. *Archives of physical medicine and rehabilitation*, 94(1 Suppl), S3–S8.
6. Van de Ven, A. H., & Johnson, P. E. (2006). Knowledge for theory and practice. *Academy of Management Review*, 31(4), 802–821.
7. Best, A., Terpstra, J. L., Moor, G., Riley, B., Norman, C. D., & Glasgow, R. E. (2009). Building knowledge integration systems for evidence-informed decisions. *Journal of health organization and management*, 23(6), 627–641.
8. Glasgow, R. E., Green, L. W., Klesges, L. M., Abrams, D. B., Fisher, E. B., Goldstein, M. G., Hayman, L. L., Ockene, J. K., & Orleans, C. T. (2006). External validity: we need to do more. *Annals of behavioral medicine: a publication of the Society of Behavioral Medicine*, 31(2), 105–108.
9. Green, L. W., & Glasgow, R. E. (2006). Evaluating the relevance, generalization, and applicability of research: issues in external validation and translation methodology. *Evaluation & the health professions*, 29(1), 126–153.
10. Green, L. W., Ottoson, J. M., García, C., & Hiatt, R. A. (2009). Diffusion theory and knowledge dissemination, utilization, and integration in public health. *Annual review of public health*, 30, 151–174.
11. Hay, M. C., Weisner, T. S., Subramanian, S., Duan, N., Niedzinski, E. J., & Kravitz, R. L. (2008). Harnessing experience: exploring the gap between evidence-based medicine and clinical practice. *Journal of evaluation in clinical practice*, 14(5), 707–713.
12. Kitto, S. C., Sargeant, J., Reeves, S., & Silver, I. (2012). Towards a sociology of knowledge translation: the importance of being dis-interested in knowledge translation. *Advances in health sciences education: theory and practice*, 17(2), 289–299.
13. Lettinga, A., & Mol, A. (1999). Clinical specificity and the non-generalities of science. On innovation strategies for neurological physical therapy. *Theoretical medicine and bioethics*, 20(6), 517–535.
14. Mol, A. (2006). Proving or improving: on health care research as a form of self-reflection. *Qualitative health research*, 16(3), 405–414.
15. Kalra, L., & Langhorne, P. (2007). Facilitating recovery: evidence for organized stroke care. *Journal of rehabilitation medicine*, 39(2), 97–102.
16. Hutter, I., Hennink, M., & Bailey, A. (2011). *Qualitative Research Methods*. UK: SAGE Publications Inc.
17. Straus SE, Tetroe J, Graham ID, eds. (2013). *Knowledge Translation in Health Care: Moving From Evidence to Practice*. 2nd ed. UK: Wiley- Blackwell.
18. Muhr, T. & Friese, S. (2003-4). *User's manual for ATLAS.ti 5.0*, 2nd ed. Berlin: Scientific Software Development.
19. Walker, M. F., Fisher, R. J., Korner-Bitensky, N., McCluskey, A., & Carey, L. M. (2013). From what we know to what we do: translating stroke rehabilitation research into practice. *International journal of stroke: official journal of the International Stroke Society*, 8(1), 11–17.
20. Intercollegiate Stroke Working Party. (2008). *National Clinical Guideline for Stroke*. 3rd edn. London, Royal College of Physicians.
21. Kwaliteitsinstituut voor de Gezondheidszorg CBO. (2008). *Richtlijn "Diagnostiek, Behandeling en zorg voor Patiënten met een Beroerte."* Utrecht, the Netherlands: Nederlandse Vereniging voor Neurologie.

22. Stroke Unit Trialists' Collaboration (2013). Organised inpatient (stroke unit) care for stroke. *The Cochrane database of systematic reviews*, 2013(9), CD000197.
23. Foley, N., Salter, K., & Teasell, R. (2007). Specialized stroke services: a meta-analysis comparing three models of care. *Cerebrovascular diseases (Basel, Switzerland)*, 23(2-3), 194–202.
24. Fuentes, B., & Díez-Tejedor, E. (2009). Stroke units: many questions, some answers. *International journal of stroke: official journal of the International Stroke Society*, 4(1), 28–37.
25. Seenan, P., Long, M., & Langhorne, P. (2007). Stroke units in their natural habitat: systematic review of observational studies. *Stroke*, 38(6), 1886–1892.
26. Langhorne, P., Dey, P., Woodman, M., Kalra, L., Wood-Dauphinee, S., Patel, N., & Hamrin, E. (2005). Is stroke unit care portable? A systematic review of the clinical trials. *Age and ageing*, 34(4), 324–330.
27. Shepperd, S., Doll, H., Broad, J., Gladman, J., Iliffe, S., Langhorne, P., Richards, S., Martin, F., & Harris, R. (2009). Early discharge hospital at home. *The Cochrane database of systematic reviews*, (1), CD000356.
28. Legg, L., Langhorne, P., & Outpatient Service Trialists (2004). Rehabilitation therapy services for stroke patients living at home: systematic review of randomised trials. *Lancet (London, England)*, 363(9406), 352–356.
29. Hillier, S., & Inglis-Jassiem, G. (2010). Rehabilitation for community-dwelling people with stroke: home or centre based? A systematic review. *International journal of stroke: official journal of the International Stroke Society*, 5(3), 178–186.
30. Aziz, N. A., Leonardi-Bee, J., Phillips, M., Gladman, J. R., Legg, L., & Walker, M. F. (2008). Therapy-based rehabilitation services for patients living at home more than one year after stroke. *The Cochrane database of systematic reviews*, 2008(2), CD005952.
31. Fearon, P., Langhorne, P., & Early Supported Discharge Trialists (2012). Services for reducing duration of hospital care for acute stroke patients. *The Cochrane database of systematic reviews*, (9), CD000443.
32. Langhorne, P., Holmqvist, L. W., & Early Supported Discharge Trialists (2007). Early supported discharge after stroke. *Journal of rehabilitation medicine*, 39(2), 103–108.
33. Rousseaux, M., Daveluy, W., & Kozlowski, R. (2009). Value and efficacy of early supported discharge from stroke units. *Annals of physical and rehabilitation medicine*, 52(3), 224–233.
34. Larsen, T., Olsen, T. S., & Sorensen, J. (2006). Early home-supported discharge of stroke patients: a health technology assessment. *International journal of technology assessment in health care*, 22(3), 313–320.
35. Langhorne, P., Taylor, G., Murray, G., Dennis, M., Anderson, C., Bautz-Holter, E., Dey, P., Indredavik, B., Mayo, N., Power, M., Rodgers, H., Ronning, O. M., Rudd, A., Suwanwela, N., Widen-Holmqvist, L., & Wolfe, C. (2005). Early supported discharge services for stroke patients: a meta-analysis of individual patients' data. *Lancet*, 365(9458), 501–506.
36. Teasell, R. W., Foley, N. C., Bhogal, S. K., & Speechley, M. R. (2003). Early supported discharge in stroke rehabilitation. *Topics in stroke rehabilitation*, 10(2), 19–33.
37. Brady, B. K., McGahan, L., & Skidmore, B. (2005). Systematic review of economic evidence on stroke rehabilitation services. *International journal of technology assessment in health care*, 21(1), 15–21.
38. Langhorne P. (2000). Organisation of acute stroke care. *British medical bulletin*, 56(2), 436–443.
39. Mulder, T., & Hochstenbach, J. (2001). Adaptability and flexibility of the human motor system: implications for neurological rehabilitation. *Neural plasticity*, 8(1-2), 131–140.
40. Arya, K. N., Pandian, S., Verma, R., & Garg, R. K. (2011). Movement therapy induced neural reorganization and motor recovery in stroke: a review. *Journal of bodywork and movement therapies*, 15(4), 528–537.
41. Combs, S. A., Kelly, S. P., Barton, R., Ivaska, M., & Nowak, K. (2010). Effects of an intensive, task-specific rehabilitation program for individuals with chronic stroke: a case series. *Disability and rehabilitation*, 32(8), 669–678.
42. Playford, E. D., Siegert, R., Levack, W., & Freeman, J. (2009). Areas of consensus and controversy about goal setting in rehabilitation: a conference report. *Clinical rehabilitation*, 23(4), 334–344.
43. Levack, W. M., Taylor, K., Siegert, R. J., Dean, S. G., McPherson, K. M., & Weatherall, M. (2006). Is goal planning in rehabilitation effective? A systematic review. *Clinical rehabilitation*, 20(9), 739–755.

44. Struhkamp R. (2004). Goals in their setting: a normative analysis of goal setting in physical rehabilitation. *Health care analysis: HCA: journal of health philosophy and policy*, 12(2), 131–155.
45. Nanninga, C. S., Meijering, L., Schönherr, M. C., Postema, K., & Lettinga, A. T. (2015). Place attachment in stroke rehabilitation: a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine. *Disability and rehabilitation*, 37(13), 1125–1134.
46. Chesla, C. A. (2008). Translational research: essential contributions from interpretive nursing science. *Research in nursing & health*, 31(4), 381–390.
47. Loorbach D., & Rotmans, J. (2010) The practice of transition management, examples and lessons from four distinct cases. *Futures*, 42(3), 237–246.



## Appendix.

### Glossary of Stroke Services Ordered in a Matrix

---

**Acute stroke unit**—A stroke ward or unit where a multidisciplinary team including specialist nursing staff based in a discrete ward cares exclusively for patients with stroke and the focus is on acute care. Patients are accepted acutely but are discharged early (usually within 7 days).<sup>22</sup>

**Combined clinical home rehabilitation**—A service that accelerates home rehabilitation of patients admitted to a rehabilitation stroke unit and combines this rehabilitation with treatment by a multidisciplinary team including specialist nursing staff based in a discrete ward or unit exclusively for patients with stroke (ie, as in this case report).

**Comprehensive stroke unit**—A stroke ward or unit where a multidisciplinary team including specialist nursing staff based in a discrete ward cares exclusively for patients with stroke. Patients are accepted acutely, but rehabilitation also is provided for at least several weeks if necessary.<sup>22</sup>

**Early supported discharge**—A service that coordinates transfer of care from hospital to home to create a seamless transition. Discharge of patients who are admitted to the hospital is accelerated, and stroke specialist rehabilitation is provided in the community setting.<sup>31</sup>

**General medical ward**—An acute medical or neurology ward where care is provided without routine multidisciplinary input.<sup>22</sup>

**Home- and community-based rehabilitation**—Services whereby continuing rehabilitation is offered at home or in the community after discharge from an inpatient setting with or without multidisciplinary input. Rehabilitation is offered within 1 year<sup>28,29</sup> or more than 1 year after stroke onset or discharge.<sup>30</sup>

**Hospital at home**—A service that provides active treatment by health care professionals in the patient's home for a condition that otherwise would require acute hospital inpatient care, and always for a limited time period.<sup>27</sup>

**Inpatient services**—Services targeted toward patients being admitted to an institution.<sup>22</sup>

**Mixed rehabilitation ward**—A multidisciplinary team including specialist nursing staff in a ward provides a generic rehabilitation service but not exclusively caring for patients with stroke.<sup>22</sup>

**Mobile stroke team**—A peripatetic multidisciplinary team (excluding specialist nursing staff) provides care in a variety of settings.<sup>22,26</sup>

**Organized inpatient care**—The focusing of care for patients with stroke in hospital under a multidisciplinary team that is specialized in stroke management.<sup>22</sup>

**Outpatient services**—Services targeted toward patients living at home.<sup>28</sup>

**Rehabilitation stroke unit**—A stroke ward or unit where a multidisciplinary team including specialist nursing staff based in a discrete ward cares exclusively for patients with stroke and the focus is on rehabilitation. Patients are accepted after a delay, usually of 7 days or more, and a prolonged period of rehabilitation is offered.<sup>22</sup>

**Stroke unit**—A stroke ward where a multidisciplinary team including specialist nursing staff based in a discrete ward cares exclusively for patients with stroke. Stroke units can be subdivided into acute stroke units, rehabilitation stroke units, and comprehensive stroke units.<sup>22</sup>



# Chapter 4

## **Place attachment in stroke rehabilitation: a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine**

Christa S. Nanninga  
Louise Meijering  
Marleen C. Schönherr  
Klaas Postema  
Ant T. Lettinga

Disability and Rehabilitation, 2015; 37(13): 1125-1134.

## **Abstract**

### **Purpose**

To increase understanding of stroke survivor's needs to successfully re-establish attachment to meaningful places at home and in the community.

### **Methods**

Qualitative research methodology including in-depth interviews with stroke survivors in the clinical, post-discharge and reintegration phases of the rehabilitation process.

### **Results**

Participants longed for recovery and domestic places in the clinical phase, for pre-stroke activities and roles in the post-discharge phase, and for recognition and a sense of belonging in the reintegration phase. The participants' selves had changed, while the spatial and social contexts of their homes had remained the same. Their spatial scope became smaller in both a social and a geographical sense. It was difficult to achieve a feeling of being at home in their bodies and own living environments again. The complexities that needed to be dealt with to engage with the outside world, turned participants unintentionally inwards. In particular, family members of participants with cognitive problems, longed for support and recognition in dealing with the changed personality of their spouses.

### **Conclusions**

Rehabilitation should put greater effort into supporting stroke survivors and their families in home-making and community reintegration processes, and help them to re-own and renegotiate their disabled bodies and changed identities in real life.

## **Implications for Rehabilitation**

The experienced self-body split, identity confusion and related mourning process should be foregrounded in the post-discharge phase rather than functional recovery, in order to help stroke survivors understand and come to terms with their changed bodies and selves. In the post-discharge and reintegration phases stroke survivors should be coached in rebuilding meaningful relations to their bodies, home and communities again. This home-making process should start at real-life sites where stroke survivors wish to (inter)act.

## Introduction

Most stroke survivors and their families perceive the transition from the rehabilitation clinic to home as an exciting yet difficult period.<sup>1</sup> While “going home” is seen as an important milestone in the rehabilitation process, “being home” is accompanied by the development of greater self-awareness of deficits. Stroke survivors increasingly come to realize that their pre-discharge expectations of life do not match real-life experiences. Many of them experience a downward spiral of physical decline, social isolation and depression after discharge from the rehabilitation clinic.<sup>2-4</sup>

Living with disabilities after a stroke, at home and in the community, needs to be regarded as a lifelong effort.<sup>5,6</sup> To ease this effort, rehabilitation medicine should gain more knowledge about the transition from the able to the disabled self, the role of environments in societal participation, the importance of meaning and choice when thinking about life situations, and the change in abilities across the life course of stroke survivors.<sup>7</sup> Within this context, rehabilitation medicine can learn from the bonds between people and places/environments as set out in cultural geography.<sup>8,9</sup> and environmental psychology.<sup>10</sup>

Addressing the problematic integration of stroke survivors into their own living environments is especially urgent when taking account of demographic changes and related cost-saving incentives in European countries. To relieve pressure on healthcare systems, there is a trend towards transferring multidisciplinary treatment delivered in stroke rehabilitation units to home and community alternatives at an earlier stage<sup>11,12</sup>, and encouraging self-management.<sup>13</sup> Several scholars doubt whether primary health care and rehabilitation medicine are sufficiently equipped to adequately support stroke survivors and their families in their own living environments.<sup>7,14,15</sup> Although rehabilitation emphasizes the importance of involvement in real-life situations, its primary focus is on motor learning and functional independence of the disabled body rather than on social learning and societal participation of the disabled self.<sup>7,16</sup>

In order to gain insight into stroke survivors' needs at home, we focused on the bonding between stroke survivors and their meaningful places during stroke rehabilitation. Thereby, we used the concepts place attachment and place identity that are described in cultural geography and environmental psychology.<sup>17-26</sup> Place attachment involves the interplay of affect and emotions, knowledge and beliefs, and behaviors and actions in reference to a place.<sup>26</sup> It is the product of both feeling attached to a place and the dynamic process of the appropriation of places involving both the physical and social aspects of them.<sup>22,23</sup> Place identity can be defined as the process by which people portray themselves, through interaction with specific places, in terms of belonging to that particular place.<sup>20</sup> Meaningful places thus become part of who we are and the way we understand ourselves.<sup>24</sup>

People develop attachment to places on various spatial scales that are all interrelated, such as body, home and community.<sup>22</sup> The body space has been described by Rich<sup>25</sup> as “the geography the closest in”. It is argued that bodily identities associated with disability or illness are continuously contested or renegotiated by their bearers.<sup>18,19</sup> The home space is conceptualized as a material and affective space shaped by people’s everyday practices, lived experiences, social relationships, memories and emotions.<sup>17</sup> At home, people interact daily with its physical aspects, thus creating homely routines which strengthen their attachment to the home place.<sup>22</sup> People are also emotionally tied to the broader community they live in, which typically consists of the immediate neighborhood.<sup>22</sup> Within the community, people interact with place by visiting or avoiding places, both voluntarily and involuntarily.<sup>21</sup>

The aim of our transdisciplinary encounter is to increase understanding in the support that stroke survivors and their families need to successfully renegotiate their attachment to meaningful places, first in the rehabilitation clinic and subsequently in their own living environments. By drawing contrasts between the clinical, post-discharge and reintegration phase, with an attentiveness to people–place relationships, we want to gain insight into the role of environments in taking up post-stroke life including patients’ and family caregivers’ needs and concerns.

## Methods

### *Design*

Qualitative research methodology was employed including in-depth interviews. Inspired by empirical philosophical work we used the contrast between different realities – in this study, rehabilitation phases – as a tool to articulate silent layers and issues that deserve concern and care.<sup>27–30</sup>

### *Participants*

Stroke survivors with multifaceted problems, who were receiving or had received multidisciplinary treatment in a rehabilitation stroke unit, participated in this study. The characteristics of the participants are summarized in Table 1. All interviewees participated voluntarily in the study and signed a consent form. The Medical Ethical Review Committee of the University Medical Center Groningen exempted this study from being reviewed.

### *Setting*

The stroke unit is located in a Dutch rehabilitation center that accommodates different diagnosis groups in specialized rehabilitation units. Participants were admitted for multidisciplinary treatment to the rehabilitation stroke unit after discharge from acute stroke units in hospitals in the region. All participants received multidisciplinary rehabilitation from the same team, consisting of physiatrists, physical, occupational and speech therapists, nutritionists, psychologists, social workers and nursing staff, all specialized in stroke rehabilitation. Both inpatient and outpatient rehabilitation is offered. At least once during inpatient rehabilitation, stroke survivors are being visited at home by an occupational and/or physical therapist to assess whether returning home will be possible, and what kind of adaptations are needed. Patients are prepared to go home by means of weekend leaves.

Table 1. Participant characteristics

Pseudonym	Age (years)	Stroke	Effects of stroke	Marital status/children (living at home)	Moved	Work status	Interview during clinical stay (months)	Interview after discharge (months)
John	57	Ischemic stroke left	Motor and cognitive problems	Single/2 (1)	Yes (a)	Incapacitated	-	3
Paul	50	Ischemic stroke left	Motor problems	Single/2	No	Working	-	15
Jim	66	Ischemic stroke left	Motor and behavioural problems	Married/2	No	Pensioner	-	14
Simon	41	Ischemic stroke left	Motor, behavioural, mood and swallowing problems	Single/2	Yes (a)	Incapacitated	-	48
Mary	58	Ischemic stroke right	Motor, cognitive, and mood problems	Single/-	Yes (b)	Working	-	19
Tom	60	Ischemic stroke right	Motor, cognitive and speech problems	Married/2	No	Incapacitated	-	41
Caren	60	Ischemic stroke right	Motor and cognitive problems	Single/-	No	Partly incapacitated	-	20
Sam	40	Hemorrhagic stroke right	Cognitive, mood, speech and sight problems and epilepsy	Cohabiting/1 (1)	No	Partly incapacitated, partly sickness benefit	-	20
Nina	47	Hemorrhagic stroke left	Motor, cognitive, and sight problems	Married/2 (1)	No	Incapacitated	-	15
Violet	42	Hemorrhagic stroke left	Motor and cognitive problems	Cohabiting/2 (2)	No	Incapacitated	-	11
James	58	Ischemic stroke right	Cognitive and behavioural problems.	Married/2 (2)	No	Sickness	-	3.5
Victor	71	Ischemic stroke left	Motor and speech problems	Married/2	No	Pensioner	-	16

Pseudonym	Age (years)	Stroke	Effects of stroke	Marital status/children (living at home)	Moved	Work status	Interview during clinical stay (months)	Interview after discharge (months)
Rose	53	Hemorrhagic stroke right	Motor and cognitive problems	Married/2 (2)	No	Incapacitated	-	29
Laura	49	Hemorrhagic stroke left	Motor and cognitive problems	Married/-	No	Sickness benefit	-	18
Steven	49	Ischemic stroke right	Motor and cognitive problems	Married/1 (1)	No	Sickness benefit	-	29
Ben	31	Ischemic stroke left	Motor and cognitive problems	Cohabiting/-	Yes (a)	Unemployed	-	32
Marc	68	Ischemic stroke right	Motor and speech problems	Married/2	No	Pensioner	-	67
Daniel	81	Ischemic stroke left	Motor problems	Single/2	Yes (a)	Pensioner	-	37
Joan	64	Hemorrhagic stroke left	Motor and cognitive problems	Single/-	No (c)	Incapacitated	-	67
Sarah	67	Hemorrhagic stroke right	Motor, cognitive, behavioural and speech problems	Married/2	Yes (a)	Pensioner	-	46
Bob	63	Hemorrhagic stroke right	Cognitive and behavioural problems	Married/1	No	Sickness benefit	-	31
Isa	48	Ischemic stroke right	Motor and cognitive problems	Single/-	Yes (a)	Incapacitated	-	72
Linda	72	Ischemic stroke right	Motor and behavioural problems	Single/2 (1)	No	Unemployed	-	57
Mike	69	Ischemic stroke right	Motor and behavioural problems	Married/6	No	Pensioner	-	8
Kate	61	Ischemic stroke right	Motor problems	Married/5 (1)	No	Unemployed	1.5	6
Regina	55	Ischemic stroke right	Motor and cognitive problems	Widow/2	Yes (a)	Unemployed	3	5

(Continuing) Table 1. Participant characteristics

Pseudonym	Age (years)	Stroke	Effects of stroke	Marital status/children (living at home)	Moved	Work status	Interview during clinical stay (months)	Interview after discharge (months)
Henry	69	Ischemic stroke right	Motor problems	Married/1	No	Pensioner	1	3
Ron	63	Ischemic stroke right	Motor and cognitive problems	Married/-	No	Pensioner	1	1
Molly	46	Ischemic stroke left	Motor and cognitive problems	Married/1 (1)	No	Sickness benefit	1	1
Howard	51	Ischemic stroke left	Motor, cognitive, speech and sight problems	LAT relationship/1	No	Unemployed	2	3.5
Roy	66	Ischemic stroke left	Cognitive problems	Single/-	No	Pensioner	1	4
Peter	46	Ischemic stroke left	Motor and behavioural problems	Married/2 (2)	Yes (d)	Sickness benefit	1	3
Raymond	68	Ischemic stroke right	Motor problems	Married/2	No	Pensioner	1	4

Moved: (a) ground floor apartment, (b) house in a quiet quarter of a city, (c) assisted living home, (d) terraced house in the city

### ***Data collection***

Data were collected through semi-structured in-depth interviews with 33 stroke survivors. Participants' needs, concerns and relationships with meaningful places were discussed by focusing on three phases in the rehabilitation process: (1) clinical phase, (2) post-discharge phase and (3) reintegration phase. All interviews were conducted at a location that was convenient for the participants, and in the presence of a significant other.

Twenty-four participants, who were in the post-discharge or reintegration phase and had been discharged home between 2005 and 2010, were interviewed once in 2010 or 2011. They were asked to reflect on their experiences in the rehabilitation clinic, discharge home and their current lives at home and in the community. To be able to go deeper into the complicated topic of looking forward and backward to experiences, needs and concerns, it was decided to extend the recruitment with nine participants who were in respectively the clinical and post-discharge phase at time of the interview. The nine participants were interviewed twice in the course of 2011 or 2012, once during inpatient rehabilitation in the clinic and once after being discharged home. In the first interview, they were questioned about their experiences in the clinic and their expectations about going home. In the second interview, they were asked to recount their actual discharge experiences at home and in the community.

Overall, the three interview guides covered the same questions. Learning experiences in the first set of interviews in 2010/2011 were used to refine the questions in the second and third set of interviews in 2011/2012. Therefore, inductive interferences were made to open new paths of inquiry.

### ***Data analysis***

Interviews were digitally recorded, files were transcribed verbatim and coded using Atlas-ti, a software package for qualitative data analysis. A combination of inductive and deductive coding was applied.<sup>31</sup> Inductive coding involved reading and rereading the material to identify issues raised by the participants themselves. An overarching theme emerged from the initial coding process. Subthemes were subsequently articulated by drawing contrasts between the empirical material collected in respectively the reintegration, post-discharge and clinical phases of the rehabilitation process. In other words, data analysis progressed by pinpointing differences and similarities in inductively coded needs and concerns of participants in the distinguished phases. The subthemes that emerged from the coded material in each phase were subsequently refined by deductive coding derived from literature: i.e. by focusing on the three spatial scales – body, home and community – on which meaningful relationships with places were developed. Coding and analysis were carried out by the first and second author and reflected on by the last author.

Table 2. Overview of experiences and needs of stroke survivors during the rehabilitation process

Theme	Clinical phase	Post-discharge phase	Reintegration phase
<i>Longing for Body</i>	<i>Bodily recovery and domestic places</i> An impaired and dependent body	<i>Pre-stroke activities and roles</i> A disappointing physical and mental body	<i>Recognition and new sense of belonging</i> A redefined body and related changed self
Home	Temporary belonging to an unfamiliar place (clinic) adapted to an impaired and dependent body	Permanent being at a place that looked familiar but needed to be renegotiated and adapted to a not fully recovered body	Sense of belonging at familiar but often limited home spaces with a re-owned body
	Daily routines are scheduled	Daily routines are time- and energy-consuming	Daily routines are demanding
	Family members: role of visitors	Family members: role of informal carers	Family members: altered relationships
Community	Balance between longing for home and working on recovery	Discrepancy between actual being at home and remembered feeling at home	Inconsistency between changed identities and social contexts of the home
	Indoors, rather safe and untroublesome	Outdoors, rather unsafe and troublesome	Outdoors, rather pondering, and in few cases challenging
	Surrounded by skilled professionals and aware fellow patients	Exposed to unskilled and unaware people	Build up and facilitated by significant others

## Results

The overarching theme “longing for” emerged from the empirical material, and three different sub-themes were identified by contrasting the three phases that participants went through: (1) clinical phase: longing for bodily recovery and domestic places; (2) post-discharge phase: longing for pre-stroke activities and roles; (3) reintegration phase: longing for recognition and a new sense of belonging. The three sub-themes were further articulated on the spatial scales of the body, home and community (Table 2).

### Clinical phase: longing for bodily recovery and domestic places

Attachment to the home place is abruptly disrupted in the acute stage, when stroke patients are transferred to a hospital for medical care, and after that to a rehabilitation clinic for multidisciplinary treatment.

#### Body

Having survived the stroke, most participants experienced a sudden loss of control over parts of their body. Kate, for example, initially perceived the paralyzed left side of her body as useless and unpredictable. Through practice, she could gradually move her left side again, which gave her confidence that her body would recover:

*Kate: If you can't do anything, what use is your body? . . . You can't lift your hand, you can't move your fingers. . . . I could see a hand moving, I thought good grief, that's my hand. That was scary. Your brain sends a signal to your fingers and you still can't move them. . . . Very gradually the movement came back, and you really begin to practice . . . and suddenly you think, it'll be OK again.*

Henry, who was also left hemiplegic, experienced his body as dependent on others, but expected that training would give him back his independence.

*Henry: You have the feeling that you can't do anything anymore . . . There were three other people who were allowed to walk with a rollator or go to the toilet by themselves. I always had to ring the bell . . . I used to think, I wish I'd come far enough to manage by myself again . . . They expect things to get better, with support and training here. You know you're not there yet. . . . You're away for a couple of months, but you soon catch up again once you're home.*

Most participants spoke about their disabled body as if the disability was temporary. It would take some time, but if they trained hard enough, they would go home and resume

the life they lived before the stroke. They saw the training in the clinic as a necessary step towards regaining control over their bodies, and therefore appreciated the safe environment that the clinic provided:

*Howard: It's like a paradise. . . . They're always ready to help if you have problems, they'll do anything for you . . . You get help from all sides.*

Some participants perceived the professional supervision as overprotective. They felt they had not only lost control over their body but also the power to make their own decisions. They expressed their relationship with the professionals in terms of guardianship rather than partnership:

*Raymond: They want me to use a wheelchair because there isn't supervision everywhere in the building. If I fall, they want to be nearby. They don't want to take any risks. The nurses walk around at night, there's always someone keeping an eye on you – for example, to make sure you're not lying on your affected arm.*

During inpatient rehabilitation, our participants thus perceived their bodies as useless, scary, unpredictable or dependent and longed for bodily recovery. This focus on recovery allowed them to put their longing for home on the back burner.

### **Home**

Participants described the transition from home to the hospital and rehabilitation clinic as a process of being torn away from their familiar everyday environment:

*Kate: You're perfectly alright one day, and the next you're in hospital. Two weeks after that you're in a rehabilitation center. You're just snatched away from home, with a handicap. That's just how it feels.*

Leaving home for the clinic so abruptly was nevertheless perceived as vital; they had no choice, since the necessary medical care and multidisciplinary treatment could not be provided at home. Family members visited participants, bringing personal belongings and the closeness of family life with them to the clinic, which created a feeling of being at home in the clinic:

*Regina: I've brought photos from home so that I'm surrounded by the people who are important to me . . . And I've brought my pillow from home so that I can sleep comfortably.*

Nevertheless, our participants had difficulties in adjusting to the institutional setting. Compared to life at home, they had to adhere to a relatively strict timetable in the clinic, in order to enable the professionals to work efficiently. The examples reported were getting up early, dressing and eating at a certain time, having fixed appointments for therapy and receiving visitors during predetermined time periods:

Molly: *I could always do as I pleased, but not anymore. You really have to keep to the rules here.*

Some participants, however, liked the structure of the daily routines offered by the rehabilitation team, as it stimulated them to work on recovery:

Peter: *What I mean by that is doing set things at set times. The whole day is planned out for you . . . Given my limitations and tiredness at the moment, if that wasn't the case I'd just be sitting at home.*

Participants also attempted to create private places in the public space of the rehabilitation clinic, to retreat to a place where other people would not disturb them.

Regina: *At night I have my tent. I close the curtains completely so that it's really private . . . my own space . . . I look forward to escaping, then I can just be myself again and do as I please.*

Although our participants longed for domestic and private life at home, most of them were able to find a balance between their longing for home and working on bodily recovery by creating home-like places within the rehabilitation clinic.

## **Community**

To create a sense of community, participants sought ways to interact with other people in the clinic. Participants met up with fellow patients in the dining room, corridors or waiting rooms, and chatted with each other, as neighbors might on the street or in the supermarket. Howard had chosen the couch near the coffee machine as his favorite spot.

Howard: *We meet up there in the evening, have a chat. Make a few jokes, that's the best thing. And the room, of course. Quietly watching TV on the bed in the evening. Then one person asks something, then someone else.*

In a certain way the rehabilitation clinic resembled a neighborhood in a village or town, as wards join onto corridors which lead to central halls, which in turn link departments and different therapy spaces, just like houses join onto streets leading to squares that link different areas and public spaces. Yet the clinical environment was adapted to the patients' disabilities, and the multidisciplinary team determined, in consultation with the patients, when it was safe for them to move in (or to) a particular part of the clinic, with what kind of aid. Some participants objected to the spatial restrictions, which they experienced as being imposed on them by the staff:

*Regina: When I leave the ward, I actually wander all over the building. . . . Wherever I need to be, I go everywhere . . . . "We've been looking for you". I say to them, Well, I'm in the building aren't I? . . . I don't go outside much. I don't like going out in the wheelchair at the moment, it feels too unsteady.*

Most participants told us that there was no reason to wander around or go outdoors because everything they needed was provided and available inside the clinic. They accepted and appreciated the safe and temporarily restricted environment of the clinic, for they believed it would soon be replaced by something better and permanent: independent and able body acting willingly in familiar home and community settings. That is indeed what they longed for.

### Post-discharge phase: longing for pre-stroke activities and roles

After being discharged home, most of the participants still attended the clinic for outpatient multidisciplinary treatment 2–3 times a week for a couple of months. The ties with the clinic are gradually undone in the post-discharge phase.

#### **Body**

When at home after being discharged, most of our participants felt ill-prepared for the transition from the clinic to home. Although they were happy to be home again, their body was not as fully recovered as they had hoped. Taking up their pre-stroke roles and activities was experienced as confronting.

*Kate: Then I want to do this, and do that . . . And I want to get it done the same day and I don't manage it. That really drives me mad.*

Our participants explained how they needed all their energy to perform daily activities that they used to do pre-stroke without even thinking.

Peter: *Before the stroke I didn't have to think about what I was doing, I just did it. Your routine, day-to-day things, getting up, drinking coffee, having breakfast, shaving, cleaning your teeth, having a shower. Now I really have to think about those things while I'm doing them. I need to be very aware of how I use that right arm.*

Some participants spoke about their hemiplegic body as something foreign. Kate, for example, tended to objectify her sore hemiplegic arm by speaking about it as a thing alien to her.

Kate: *It's not the fact that I can't do anything with it, but the fact that it's sore. . . . Sometimes I wake up in the middle of the night because it's so sore . . . It's just so irritating that the wretched thing won't work.*

Other participants felt frustrated because their bodily impairments were not always visible to significant others. Take Henry, who found it difficult to explain to other people how his problem of dizziness restricted his abilities.

Henry: *When people break an arm or leg, you can see that something's wrong. But you can't tell by looking at me that there's anything wrong. It's in your head, isn't it. They think you've recovered from it, but that isn't the case.*

These experiences with bodies that remained out of control, unresponsive and sore had a negative effect on the participants' state of mind and some became depressed.

Regina: *That aimless life, I couldn't cope with the idea of having to carry on with half my body paralysed. . . . I really thought, if that's how I've got to live, then I don't want to carry on.*

Only a few participants reported that getting on with life again in the post-discharge phase was as they had expected. Most participants however began to realize in this phase that the brain damage caused by the stroke had not only affected their bodies physically but had also affected them mentally, which took a great deal of their energy and drained their vitality.

## Home

In spite of their disappointing bodies, most patients enjoyed being in their own living environment again, and felt that being there would enable further bodily recovery.

Henry: *You're in your own space here, your own bed, your own things and people who live here. Then you feel at home again. And then you start to think, things are getting better, I'll soon be able to do this or that again . . .*

However, being at home also reminded them of their former healthy selves and the activities they used to do, which made them long for recovery even more strongly.

*Roy: Last summer I was repainting the house. That all had to be left. And the allotment; they've just put some potatoes in there. This year wasn't the same as normal. I'll pick up where I left off once the therapy's finished.*

Although some participants continued to believe that everything would go “back to normal” in due course, others began to realize in the post-discharge phase that their life would never be the same again, and this hit them hard.

*Regina: Now you're dependent on any form of help you can get. Before the stroke, I used to do everything myself. Then I could still use both hands. There was the housework, I had my own flat. I did the shopping myself, I did everything myself. . . . The children would call in: “Mum, my trousers need mending, can you do it for me?” If the children needed looking after, Mum did it. But that's all finished now, I can't manage it anymore.*

People who were surrounded by their family experienced fewer difficulties with life back home than single people. Nevertheless, most of our participants did not manage to feel at home in the way they had before the stroke, and experienced difficulties with taking up pre-stroke roles. Kate, for example, tried to take up her previous role of “mother-in-charge” without a second thought.

*Kate: You think, I'll just start doing that again. But you can't. You're mothered on all sides . . . You think, yes but I'm only paralysed. . . . They thought there was something wrong 'upstairs' as well, but that's still all OK. How you react yourself, but also how others react. They were so terribly careful and considerate, it was nauseating. That really took some getting used to, because before the stroke, I was the boss and that was that.*

In the clinic, stroke patients had put their fate in the hands of the professionals, thereby working on recovery in a place which was unfamiliar but adapted for their disabled body. In contrast, in the post-discharge period, they had to take up responsibility for their own life and their not yet fully recovered body, in a space that looked familiar but needed to be adapted to their disabled body, as well as engage in renegotiation with their proxies. Reshaping life at home was experienced as very difficult by most participants, and taking up a meaningful community life proved to be even harder still.

## Community

During the post-discharge phase most participants spent their days at home rather than in the wider community, because home was exhausting enough. As a result of the physical limitations, arranging activities in the outside world was indeed time-consuming, and emotional barriers or lack of energy prevented participants from taking part in community life.

*Peter: Actually only one thing has changed, and that's the fact that I'm not back at work yet. The children still have to go to school, so we go out, have coffee somewhere. But shaving, showering, you name it, the everyday things. That's all so tiring that I don't feel like doing anything else for the rest of the day. Also, limited transport or not being allowed to drive a car restricted them to indoor activities.*

In some cases, these mobility barriers could be lifted, as with Howard, who was able to extend his activities outdoors once he had his mobility scooter.

*Howard: I have my freedom back again now. I take part in fishing competitions and in the afternoon I go and visit my mates on the scooter. I feel like doing things again.*

Other participants had to get used to a new community as they were forced to move house. Most of them experienced difficulty with creating a sense of attachment to their new community. Take Regina, who, although she had several lessons on driving her mobility scooter, felt out of place in her new environment and did not dare to actually use it there.

*Regina: It's just that, I don't know this area at all. And I've never been in a shop with a mobility scooter. So you can go and sit on your mobility scooter with your crazy head, and then what?*

In the post-discharge phase, it seems that for most participants it is too premature to expect community integration and societal participation. Rather, they need all their energy to come to terms with bodily changes and to recreate a sense of belonging in their own homes. These tasks are demanding enough, and in many cases there is no “room” left for the community. The tiring bodily experiences at home appeared to be an early indicator of the difficulties people would have engaging with the wider community around them. Although our participants longed to take up pre-stroke activities and roles, they began to realize their lives would never be the same again. That troubled them.

## Reintegration phase: longing for recognition and a new sense of belonging

The ties with the clinic were severed in the chronic stage. Some participants succeeded in reintegrating into the community to a certain extent, but most experienced huge problems when they became aware that no further recovery could be expected.

### **Body**

When discussing their bodily experiences in the reintegration phase, some participants reported that their bodily recovery had not just stopped but had even declined.

*Mary: Your body's already giving you trouble. That's already hindrance, because of the cramps. But if that goes on for too long and you don't move around enough, you stiffen up even more. After a while I couldn't even reach my own feet.*

Participants sometimes did not want to venture outdoors as they felt embarrassed about the visible changes in their appearance:

*Rose: I don't like other people seeing me, so I tend not to go out. I always think I look terrible, although other people say that's not the case.*

The most distressing bodily experiences, however, were articulated in terms of bodily estrangement due to the more invisible cognitive and behavioral impairments, which made participants feel that they were no longer in charge of either their physical body or mental body. These participants had to deal with a changed self:

*Steven: I no longer feel at home in my own body. I was a bricklayer, always out working and hardly ever at home. And now it's the other way around . . . My concentration isn't as good, and I'm not physically well either . . . I have changed. Especially, with talking. And everything makes me laugh.*

Most participants had expected that their physically impaired bodies would be back to normal in the post-discharge phase, but discovered in the reintegration phase that this was not feasible. Some had accepted this and were able to re-define and re-own their changed body and related self over time. Others continued to struggle, or retreated to a few “safe” places. They all longed for recognition of the physical, cognitive or behavioral problems they had to face.

## Home

When living at home again, many participants described the clinic in retrospect as “safe, surrounded by professionals and fellow sufferers”, “conveniently arranged”, “cosy”, “a second home” and described their actual home place as “demanding”, “worrying”, “silent” and even “a black hole”. Several participants preferred to restrict their living space to a few areas inside the home, like Caren, who recreated a safer and more homely place on the smaller spatial scale of her bed.

*Caren: I go to bed as early as six in the evening, because it's safe there. That's where I feel most comfortable, I can move around in bed. Normally I just stumble around a bit the whole day.*

Participants who were dependent on professionals to help them into and out of a wheelchair found themselves restricted in privacy and domestic life, as their daily routines were determined by formal care schedules.

*Joan: I always need someone to help me get up in the morning, and to go to bed at night. If there's a film on, and someone comes in after ten o'clock, I have to go to bed. Then I miss most of the film . . . I used to go to bed around eleven thirty. Now I sometimes have to go upstairs as early as nine o'clock.*

With regard to their social place identities, several participants explained that they found it difficult to interact with significant others. Mary, for example, spoke of a “short circuit” in her head.

*Mary: I can't see the bigger picture. Everything gets too much for me. I can't keep my attention on things at all: snappy, you know, when people come up to you and you say “not now!” . . . That you can't tell by looking that there's something wrong, that you have to live a very structured life now, that people can't just call in . . . that it's all too much and you're so tired all the time. You come up against that constantly. It's so frustrating.*

Many other participants discussed their changed bodies and selves in the context of altered relationships with family members and friends, and had difficulties re-establishing their place identity. Steven, for example, seemed to have accepted that his post-stroke life was in no way comparable to his pre-stroke life, but his wife doubted this:

*Steven: It's OK, enough hobbies, such as cleaning. It's hard work though, vacuuming upstairs and downstairs. I do get tired doing that.*

*Steven's wife: It actually feels very odd that this is enough for someone who was used to working 50 or 60 hours a week.*

Many partners of stroke survivors with cognitive and behavioral problems felt alone and also experienced huge difficulties in getting on with life again. Tom's wife, for example, had to manage with a husband who had entirely changed:

*Tom's wife: He doesn't know when things need doing, and he can't think what he has to do next . . . He always needs to be directed, even the simplest things . . . He can manage fine, as long as I'm nearby. But there's no way he could manage on his own . . . You've lost each other. The person who comes home to you is someone completely different. Your whole life has been turned upside-down, that's the best way to describe it.*

In the reintegration phase, most participants struggled to give meaning to their place identities in relation to their home. Feeling at home, with other household members as well as visitors, was often described as difficult to achieve. The participants' selves had changed, while the spatial and social contexts of their homes had remained the same, which often resulted in an inconsistency between the two, and turned our participants unintentionally inwards. In particular, the family members of participants with cognitive, communication or behavioral problems longed for support and recognition in dealing with the changed personality of their spouses, and in re-defining their life and relationship.

### **Community**

Many participants found it difficult to engage in meaningful interaction in the community. They longed to create a sense of continuity between their pre- and post-stroke lives by engaging in similar activities, but this was not always possible. Some missed their pre-stroke community life deeply. Mary, for example, had dramatically rescheduled her socially active and entertaining pre-stroke life:

*Mary: I had a job and I was someone who wanted to build a career. When I got home I'd do the shopping, have a meal. Give the house a quick once-over, then go to the gym. And at the weekend I often went away with friends. I had a very busy social life. There's nothing left of that at all now. The world has become very small. Actually, I'm more or less confined to the house now.*

And, Tom, who was always on the move pre-stroke, was now dependent on his wife to go out:

*Tom: Before, I had a lot of freedom. For my work I'd run an errand here, an errand there, arrange this, arrange that. I was always there, but that's not possible now. I forget everything and I can't remember where the house is.*

Others explained how they were able to develop new community activities, often with the help of significant others. Family members or friends played a major role in involving participants in the community, and made it possible to visit meaningful places:

*Steven's partner: We've still got the caravan on Ameland. We really enjoy it. He never used to like going there, but now he thinks it's fantastic. It's ideal now, because he manages really well in the caravan and I have some time to myself, simply to finish a book or something. I really enjoy that. He can go for a walk, we have plenty of help there so everything works out well, that's really good.*

Similarly, travelling through Europe with a motor-home made the lives of Charles and his wife pleasantly challenging again. They created a new sense of liberty and belonging in the world, despite Charles' communication problems and physical limitations:

*Charles' wife: In the summer we go away with the motorhome. If it goes well we don't come back until September. We tour around Europe. Often we don't have breakfast until 11 o'clock. If the weather's too hot or too cold, we move on somewhere else. If the weather's good enough we explore the local area, go shopping. He connects up the electricity supply for the motor-home, makes sure we have enough water and that the toilet is emptied. He does all that . . . We put the mobility scooter on the back of the motor-home and I do the driving.*

The empathy, understanding and creativity of significant others enabled some of our participants to re-own their post-stroke bodies and changed selves within various home and community places, where they experienced a new sense of belonging. For many others, however, their body, home and living spaces became smaller in both a social and geographical sense. Often this was caused by misunderstanding or lack of recognition of their changed selves by significant others, such as family members, friends, colleagues and professionals, and in some cases by the participants themselves. These experiences prevented them from renewing their sense of attachment to various spatial places, and kept them longing for the unachievable.

## Discussion

In this transdisciplinary encounter, the focus on place attachment in stroke rehabilitation assisted us in gaining a better understanding of people–place relationships between the different rehabilitation phases our participants went through. To some extent the attentiveness to people–place relationships may have predisposed the nature of the data arising from the interviews. Though by inductive coding (noting unique issues raised by participants) and drawing contrasts between the different phases in the rehabilitation process, subthemes relevant for the different phases emerged rather open-minded from the empirical material. Ideally, a study has a mix of inductive and deductive codes.<sup>31</sup> This was the case in our study, as we subsequently organized the empirical material by deductive codes that came from place attachment literature; namely, the three spatial scales body, home and community.<sup>22</sup>

Our study revealed that most participants longed for physical recovery and domestic places in the clinical phase, for pre-stroke activities and roles in the post-discharge phase and for recognition and a sense of belonging in the reintegration phase. Although their sense of longing was strong in each phase, they often discovered that what they longed for was difficult if not impossible to achieve. During inpatient rehabilitation, they were supported by the multidisciplinary team in optimizing bodily recovery and independent living in safe and appropriately adapted places in the clinic. This created a sense of temporarily belonging in the clinic on the one hand, and a rather carefree and unrealistic longing to return to unchanged domestic places post-discharge, on the other. To various degrees, both the stroke survivors and the multidisciplinary team appeared to be inattentive to the complexities that need to be dealt with within the outside world after inpatient rehabilitation.

Although, we acknowledge that this lack of attentiveness to the outside world is necessary in order to focus on the best possible functional recovery and independence in the clinical phase, we argue that the complexities of life post-discharge need serious attention and definitely another focus in the reintegration phase. Our study confirmed the importance of meaning and choice in the post-discharge and reintegration phase.<sup>7</sup> Attempting to independently undertake as many activities as possible in the post-discharge and reintegration phases may overburden stroke survivors, and even eventually exhaust them such that they lose their independence altogether. Indeed, it should be acknowledged that they can choose to be dependent or independent in daily life in various ways.<sup>15</sup> On one day, they may choose to dress and wash themselves, while on another day, it may be better to ask for assistance with such self-care to be able to work or visit friends. Professionals should therefore help stroke survivors and their family caregivers in seeking to establish and secure a few forms of independence, carefully adjusted to the places they would like to be.

A limitation that needs to be addressed in future studies has to do with the exploratory and cyclic nature of our study. We discovered in the first set of interviews with participants in the reintegration phase that many of them glorified their stay in the rehabilitation centre in retrospect. To gain more in-depth information about this topic, we broadened the recruitment by also interviewing stroke survivors in the clinical and post-discharge phase. To tackle this complicated topic of looking backward and forward to needs, concerns and experiences as well as looking at the present situation, it would have been better to interview the same participants in all three rehabilitation phases.

Despite these limitations, our case study illustrates the interwoven nature of the concepts of place attachment and identity, showing how a sudden change in identity, due to the abrupt onset of a stroke, can disturb a person's attachment to place, both as an outcome and a process.<sup>26</sup> After their stroke, our participants could not identify with their own bodies, homes or communities as they had before. The physical and cognitive changes they had undergone disturbed their attachment to place, as an outcome of the stroke. At the same time, the process of reestablishing meaningful relationships with places proved to be difficult for our participants in all three phases of the rehabilitation process. They continually struggled with challenges, such as unrealistic expectations held by themselves and significant others, unexpected complexities in daily life, and different feelings of longing. These difficulties might be due to the nature of the target group that was our object of study: severely affected stroke patients with multifaceted problems, who had received multidisciplinary treatment in a rehabilitation stroke unit. However, other studies have described similar problems in a sample of stroke survivors aged between 20 and 61, who probably had less severe disabilities.<sup>32</sup>

On the smallest distinguished scale – the body – our participants struggled to (re)create a sense of familiarity with their disabled bodies, especially in the context of the unrealistic longings they kept alive. They experienced the transition from being able to disabled<sup>7</sup> as no longer feeling at home in their own bodies. This alienation has been expressed as living with an altered identity or perception of self<sup>33–35</sup>, or a self-body split.<sup>36</sup> It is this self-body split, identity confusion and the related mourning process that should be foregrounded in the post-discharge phase by the rehabilitation team, in order to help stroke survivors and their families understand and come to terms with their changed bodies and selves. This is important because many problems are not only invisible to significant others, but are also difficult for stroke survivors themselves to understand. A “coming out” process needs to be facilitated to re-experience a sense of belonging to meaningful places at home and in the community.

On the spatial scale of the home, our participants longed to return to the privacy of homely routines and close relatives while they were still in the clinic. However, being at home in the discharge phase did not spontaneously result in actually feeling at home again. As their bodies had been transformed, their former home often no longer evoked the expected feelings of comfort, privacy, intimacy, security, autonomy and safety.<sup>37</sup> Our participants discovered a discrepancy between the actual and remembered home. Private places had to be redefined and pre-stroke roles and domestic activities had to be contested and renegotiated, which was experienced as extremely fatiguing by both stroke survivors and their families. Participants experienced difficulty with redefining relationships in meaningful ways, which for some participants turned their previously comfortable and secure home into a place of loneliness, decline and despair. In a phenomenological study, similar experiences were described in terms of “struggling to re-enter the family” and “screaming for acceptance”.<sup>32</sup> Rehabilitation should therefore put much more effort into supporting stroke survivors in the home-making process and help them contest and renegotiate their disabled or ill identities in the bodily geographies of everyday life.<sup>38</sup> This could be achieved by enacting the home-making process at real-life places where stroke survivors wish to act and interact, and by assisting in adapting the physical environment as well as in taking up former roles and engaging in former or new activities. Moreover, the home-making process at real-life sites could be continued by coaching over distance with screen-to-screen applications.

Functioning on the scale of the neighborhood or the wider community was the most challenging aspect for our participants.<sup>39</sup> In the clinic, community life was mostly indoors, scheduled, and therefore manageable. Upon returning home, our participants focused on feeling at home in their own bodies and homes again. Our study indicates that stroke survivors first have to learn to assess their abilities and limitations in, and re-establish their belonging to, a rather complex indoor home world and only then can they take up the challenge of dealing with the elusive complexities of the outside world and re-establish a sense of belonging to the community. In a few successful cases, family members or friends facilitated active involvement in community life, by engaging stroke survivors in new activities and helping them to escape from the drudgery of daily life and isolation at home, for example in new travel destinations and or new places of recreation.<sup>40,41</sup> However, stroke survivors and their families could be supported and coached in this in a more structured and professional way. It is a challenge for rehabilitation centers to learn how to assist stroke survivors post-discharge in rebuilding meaningful relationships with their bodies, homes and communities.

## **Acknowledgements**

Special thanks go to the individuals who participated in this study. We also thank Linden Douma and Jelle Straatsma, Master students at the Faculty of Spatial Sciences, University of Groningen, who conducted some of the interviews.

## **Declaration of interest**

The authors report no conflicts of interest.

## References

1. Turner, B. J., Fleming, J. M., Ownsworth, T. L., & Cornwell, P. L. (2008). The transition from hospital to home for individuals with acquired brain injury: a literature review and research recommendations. *Disability and rehabilitation*, 30(16), 1153–1176.
2. McKevitt, C., Redfern, J., Mold, F., & Wolfe, C. (2004). Qualitative studies of stroke: a systematic review. *Stroke*, 35(6), 1499–1505.
3. Murray, J., Ashworth, R., Forster, A., & Young, J. (2003). Developing a primary care-based stroke service: a review of the qualitative literature. *The British journal of general practice: the journal of the Royal College of General Practitioners*, 53(487), 137–142.
4. Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experience of living with stroke: a qualitative meta-synthesis. *Journal of rehabilitation medicine*, 40(8), 595–602.
5. European Stroke Organisation (ESO) Executive Committee, & ESO Writing Committee (2008). Guidelines for management of ischaemic stroke and transient ischaemic attack 2008. *Cerebrovascular diseases (Basel, Switzerland)*, 25(5), 457–507.
6. Kwaliteitsinstituut voor de Gezondheidszorg CBO. (2008) *Richtlijn 'Diagnostiek, behandeling en zorg voor patiënten met een beroerte'*. Utrecht: Nederlandse Vereniging voor Neurologie.
7. Cott, C. A., Wiles, R., & Devitt, R. (2007). Continuity, transition and participation: preparing clients for life in the community post-stroke. *Disability and rehabilitation*, 29(20–21), 1566–1574.
8. Relph, E. (1976). *Place and placelessness*. London: Pion.
9. Tuan, Y. F. (1980). Rootedness versus sense of place. *Landscape*, 24, 3–8.
10. Proshansky, H. M., Fabian, A. K., & Kaminoff, R. (1983). Place-identity: Physical world socialization of the self. *Journal of Environmental Psychology*, 3(1), 57–83.
11. Fearon, P., Langhorne, P., & Early Supported Discharge Trialists (2012). Services for reducing duration of hospital care for acute stroke patients. *The Cochrane database of systematic reviews*, (9), CD000443.
12. Langhorne, P., Holmqvist, L. W., & Early Supported Discharge Trialists (2007). Early supported discharge after stroke. *Journal of rehabilitation medicine*, 39(2), 103–108.
13. Jones, F. (2013). Self-management: is it time for a new direction in rehabilitation and post stroke care? *Panminerva medica*, 55(1), 79–86.
14. Doig, E., Fleming, J., Kuipers, P., & Cornwell, P. L. (2010). Comparison of rehabilitation outcomes in day hospital and home settings for people with acquired brain injury - a systematic review. *Disability and rehabilitation*, 32(25), 2061–2077.
15. Struhkamp, R., Mol, A., & Swierstra, T. (2009). Dealing with in/dependence doctoring in physical rehabilitation practice. *Science, Technology and Human Values*, 34(1), 55–76.
16. Jansma, F. F., Twillert, S. v., Postema, K., Sanderma, R., & Lettinga, A., T. (2010). Physical and rehabilitation medicine and self-management education: a comparative analysis of two approaches. *Journal of rehabilitation medicine*, 42(9), 808–814.
17. Blunt, A. (2005). Cultural geography: cultural geographies of home. *Progress in Human Geography*, 29(4), 505–515.
18. Crooks, V. A., Dorn, M. L., & Wilton, R. D. (2008). Emerging scholarship in the geographies of disability. *Health & place*, 14(4), 883–888.
19. Dyck, I., Kontos, P., Angus, J., & McKeever, P. (2005). The home as a site for long-term care: meanings and management of bodies and spaces. *Health & place*, 11(2), 173–185.
20. Hernandez, B., Hidalgo, M., C., Salazar-Laplace, M. E., & Hess, S. (2007). Place attachment and place identity in natives and non-natives. *Journal of Environmental Psychology*, 27, 310–319.
21. Hidalgo, M. C., & Hernandez, B. (2001). Place attachment: conceptual and empirical questions. *Journal of Environmental Psychology*, 21(3), 273–281.
22. Lewicka, M. (2011). Place attachment: how far have we come in the last 40 years? *Journal of Environmental Psychology*, 31(3), 207–230.

23. Manzo, L. C. (2003). Beyond house and haven: toward a revisioning of emotional relationships with places. *Journal of Environmental Psychology*, 23(1), 47–61.
24. Manzo, L. C. (2005). For better or worse: exploring multiple dimensions of place meaning. *Journal of Environmental Psychology*, 25(1), 67–86.
25. Rich, A. (1984). *'Notes toward s a politics of location', blood, bread and poetry*. New York: W.W. Norton and Company.
26. Scannell, L., Gifford, R. (2010). Defining place attachment: a tripartite organizing framework. *Journal of Environmental Psychology*, 30, 1–10.
27. Lettinga, A., & Mol, A. (1999). Clinical specificity and the non-generalities of science. On innovation strategies for neurological physical therapy. *Theoretical medicine and bioethics*, 20(6), 517–535.
28. Law, J. (2009). Actor network and material semiotics. In: Turner BS, ed. *The new Blackwell companion to social theory*. Oxford: Wiley-Blackwell. 141–158.
29. Mol, A. (2008). *The logic of care: health and the problem of patient choice*. London: Routledge.
30. Mol, A. (2010). Actor-Network Theory: Sensitive terms and enduring tensions. *Kölner Zeitschrift für Soziologie und Sozialpsychologie* 50(1): 253–269.
31. Hennink, M., Hutter, I., & Bailey, A. (2011). *Qualitative research methods*. London: Sage Publications.
32. Martinsen, R., Kirkeveld, M., & Sveen, U. (2012). Younger Stroke Survivors' Experiences of Family Life in a Long-Term Perspective: A Narrative Hermeneutic Phenomenological Study. *Nursing research and practice*. 2012. 948791.
33. Kitzmüller, G., Häggström, T., & Asplund, K. (2013). Living an unfamiliar body: the significance of the long-term influence of bodily changes on the perception of self after stroke. *Medicine, health care, and philosophy*, 16(1), 19–29.
34. Kvigne, K., & Kirkeveld, M. (2003). Living with bodily strangeness: women's experiences of their changing and unpredictable body following a stroke. *Qualitative health research*, 13(9), 1291–1310.
35. Pallesen, H. (2014). Body, coping and self-identity. A qualitative 5-year follow-up study of stroke. *Disability and rehabilitation*, 36(3), 232–241.
36. Ellis-Hill, C. S., Payne, S., & Ward, C. (2000). Self-body split: issues of identity in physical recovery following a stroke. *Disability and rehabilitation*, 22(16), 725–733.
37. Mallett, S. (2004). Understanding home: a critical review of the literature. *The Sociological Review*, 52(1): 62–89.
38. Dyck, I., Kontos, P., Angus, J., & McKeever, P. (2005). The home as a site for long-term care: meanings and management of bodies and spaces. *Health & place*, 11(2), 173–185.
39. Roth, E. J., & Lovell, L. (2007). Community skill performance and its association with the ability to perform everyday tasks by stroke survivors one year following rehabilitation discharge. *Topics in stroke rehabilitation*, 14(1), 48–56.
40. Beckley M. N. (2006). Community participation following cerebrovascular accident: impact of the buffering model of social support. *The American journal of occupational therapy: official publication of the American Occupational Therapy Association*, 60(2), 129–135.
41. Anderson, S., & Whitfield, K. (2013). Social identity and stroke: 'they don't make me feel like, there's something wrong with me'. *Scandinavian journal of caring sciences*, 27(4), 820–830.



## Chapter 5

# Home-making after stroke. A qualitative study among Dutch stroke survivors

Louise Meijering  
Christa S. Nanninga  
Ant T. Lettinga

Health Place, 2016; 37: 35-42.

## Abstract

Stroke survivors may suffer from physical limitations as well as cognitive and behavioural difficulties. Many survivors work on their recovery in a rehabilitation clinic with the aim to return to their own home again. Since full recovery is often not feasible, they face the challenge of coming to terms with lasting effects of the stroke and of giving meaning to their home place again.

Based on in-depth interviews with stroke survivors, we discuss the meaning of the home with respect to changed post-stroke identities. Our findings show how, for many participants, a formerly comfortable home becomes a space of struggle. Formerly stable bodily routines become time-consuming and demanding, reciprocal relationships with significant others change, often becoming unbalanced dependence. In conclusion, each stroke survivor faces a different struggle to accommodate a changed self in a house that does not feel like home anymore. These findings imply that stroke rehabilitation services need to address the individual and everyday challenges that stroke survivors and their families face at home, to improve their sense of home and well-being.

## Keywords

stroke; home; identity; the Netherlands; qualitative methodology

## Introduction

Stroke survivors form a significant and increasing group in today's ageing society. In the Netherlands, one in twenty adults aged 50 years and over experiences a stroke and survives.<sup>1</sup> A stroke is an illness with a sudden onset that affects physical, cognitive, and behavioral functioning.<sup>2</sup> In the Netherlands, patients with suspected stroke are directly admitted to an acute stroke unit in a hospital for acute diagnosis and treatment. Survivors of stroke with moderate to severe disability, who need inpatient rehabilitation after completion of their acute treatment, then move to a stroke rehabilitation unit where they are treated by a specialist multidisciplinary team.

Although the multidisciplinary team works on optimal functional recovery in the clinical setting, most stroke survivors are confronted with changes in their body, identity and life course in the home setting.<sup>3</sup> Many survivors experience depression<sup>4</sup>, social isolation<sup>5</sup>, and reduced well-being<sup>6</sup> after returning home. Psychologists and social workers in the clinic do anticipate the mental and social impact of post-stroke impairments after discharge, however, since the primary goal of stroke survivors is to gain optimal functional recovery, they tend to postpone thinking about potential lasting disabilities.<sup>7</sup> This could be related to the conceptualization of home in rehabilitation medicine as a material, physical space, whereby home evaluations are an important step in discharge planning from inpatient to home settings.<sup>8,9</sup> During home visits, occupational therapists assess safety and recommend physical adaptations where necessary, such as installing wall-handles in the bathroom. Although such adaptations contribute to stroke survivors' independence, this neglects the idea that the home is also, and maybe first and foremost, a place that has meaning for its inhabitants, and that is part of their identities.<sup>10</sup>

In an earlier study, we looked at the meaning of place for stroke survivors, and discovered that different attachments, meanings and longings mark the stroke rehabilitation process in the whole chain of care.<sup>7</sup> In the current article, we examine stroke survivors' and, to a smaller extent their family caregivers', experiences of home in more depth. This case study will provide insight into what provides stability and a sense of being anchored to the home, through zooming in to the experiences of people who have brusquely lost these anchors.

## Theoretical framework

In cultural geography and geographical gerontology, the home is conceptualized as a material as well as affective space, shaped by people's everyday practices, experiences, social relations, memories and emotions.<sup>10</sup> Central characteristics of the home are that it is a place over which people experience control, where they perform daily routines, which they decorate with objects that are meaningful to them, where they engage with significant others, and where they remember significant past events. As a result, it becomes a place where people feel they belong, and which can be a place of refuge from the outside world.<sup>11-17</sup> In line with this, it has been shown that experiences of home are an important dimension of well-being.<sup>18,19</sup> Being such a central place, the home can thus become a positive place where people can 'be themselves', but also a place where people feel locked up against their will.<sup>20</sup>

Home places are dynamic, negotiated, contested, contextual and complex processes. What 'home' is and means changes throughout the course of one's life. In later life, for instance, the role of the home may gradually transform from a basis for out-of-home activities to being the locus for every day practices.<sup>21</sup> At the same time, the home can also function as a 'portal' for imagined transportation to other people, places and times, as artefacts kept in the home may evoke memories of these.<sup>15</sup> With respect to home as a process, we analytically distinguish three dimensions of home: the material, social, and personal.<sup>22</sup>

The material home consists of the built environment and design and layout. It refers to the space that can be measured and that gains meaning through its function, culture and history.<sup>23</sup> The material dimension of home links to the description of home-making as an embodied process: people experience the home through their bodies.<sup>24-26</sup> The body and embodiment have been prominent subjects of research in geography, especially its relationality with the outside world, in terms of both time and space.<sup>27</sup> This means that the body can never be seen 'on its own', but always in relation to its environment. For instance, a post-stroke body may perform differently in a stroke rehabilitation unit, specialized to cater for its needs, than in the stroke survivor's home. Abrahamsson & Simpson<sup>28</sup> recently advanced the literature on relationality of the body by introducing the idea of the various 'limits' a body may have. One of the limits they discussed is that of capacity, which means that the – changing – capacities a body has, affect the practices it can perform in place and time. This notion helps us to think about how embodiment is linked with experiences of home.

The outcomes of the interactions between people, their bodies and the material space of the home are the behavioral rituals situated in places, such as getting ready for work in the morning. Such routines have been discussed by Seamon<sup>29</sup> as "body and place choreographies" (p. 157). When something out of the ordinary happens, people find stability and support in

their daily routines, which shows the importance of habit and routine in establishing a sense of comfort and feeling at home. In later work, Bissell<sup>30</sup> re-established the importance of habit for feeling 'in place' in his study of habits that do not come forth when called upon with skillful golf players in a tournament situation. In the context of ageing, Rowles<sup>33</sup> argued that unanticipated changes in one's body may occur, that require changes in the home and its routines. At the same time, however, perpetuation of routines can be comforting, in spite of the fact that they become more difficult to achieve. In such cases, the crux is to achieve a mix of old and new routines, maximizing both autonomy and comfort.

The social home encompasses relationships with significant others who live in as well as visit the home. This includes close relatives such as a partner and children, but also other family members, friends, and neighbors.<sup>22</sup> Such a social network may be called upon for emotional support, but also for informal care. In many rapidly ageing (Western) countries, governments, inspired by ever-increasing healthcare expenditures, advocate a 'participation society', where significant others are to provide informal care at home, to sustain their relatives' basic well-being.<sup>31-33</sup> The participation society seems to tie in with Kahn & Antonucci's<sup>34</sup> convoy model, which is an interdisciplinary model of social relations, focusing on the idea that social relations are rooted in the life course. It argues that individuals are surrounded by supportive people, such as a partner, children, family members, friends and neighbours, over their life course. The relationships with these supportive people vary in their closeness, structure, function and quality, and are influenced by personal and situational characteristics, which change over the life course.<sup>35</sup>

Through its material space, meaningful objects, routines and social relations, the personal home gains meaning as a place of self-expression, as a secure, familiar point in a person's life.<sup>22</sup> Thus, our home forms part of our identity. Identity is defined as how we make sense of ourselves, in relation to others, in everyday and local places.<sup>36</sup> Identities are constantly re-positioned and re-produced over time and in the socio-spatial context. This pertains especially to processes such as ageing, the physical and social aspects of which require constant re-positioning of the self.<sup>37</sup> Similarly to identity, the home is also constantly re-positioned in the light of processes such as ageing. In the specific case of stroke, however, survivors abruptly face huge changes in their identity, and struggle to accommodate their changed selves in an unchanged house, which does not feel like home anymore.

## Methodology<sup>a</sup>

To study the stroke survivors' experiences of home, we adopted a qualitative research methodology and conducted 31 semi-structured in-depth interviews with adults who had survived a stroke and experienced moderate to severe post-stroke disabilities. The participants underwent multidisciplinary treatment in a stroke rehabilitation unit for at least one month, and returned home afterwards. The stroke rehabilitation unit is located in a Dutch rehabilitation center that accommodates different patient groups in specialized rehabilitation departments. All participants received rehabilitation services from a multidisciplinary team of therapists, consisting of physiatrists, physical, occupational, and speech therapists, nutritionists, psychologists, social workers, movement therapists, and nursing staff. The in-depth interviews were conducted at a location that was convenient for the participants, typically the home. In most interviews, a significant other, often a partner or a sibling, was present during the interview. The characteristics of the participants are summarized in Table 1.

---

<sup>a</sup> This study forms part of a previously published larger study. Given that a similar methodology was used, parts of this section are taken from Nanninga et al (2014).

Table 1: Study participants

Name	Age	Stroke effects	Marital status	Children (living at home)	House type	Moved	Interview round	Time since stroke onset (months) <sup>a</sup>
John	57	Physical and cognitive	Single	2 (1)	Apartment	Yes	1	10
Paul	50	Physical	Single	2	Row house	No	1	17
Jim	66	Physical and behavioural	Married	2	Row house	No	1	16
Simon	58	Physical and behavioural	Single	2	Apartment	Yes	1	60
Mary	58	Physical, cognitive and behavioural	Single	0	Row house	Yes	1	48
Tom	60	Physical and cognitive	Married	2	Detached	No	1	47
Caren	60	Physical and cognitive	Single	0	Row	No	1	25
Sam	40	Cognitive and behavioural	Cohabiting	1 (1)	Detached	No	1	23
Nina	47	Physical and cognitive	Married	2 (1)	Row	No	1	17
Violet	42	Physical and cognitive	Cohabiting	2 (2)	Row	No	1	23
James	58	Cognitive and behavioural	Married	2 (2)	Row	No	1	7
Victor	71	Physical	Married	2	Apartment	No	1	19
Rose	53	Physical and cognitive	Married	2 (2)	Row	No	1	33
Laura	49	Physical and cognitive	Married	0	Detached	No	1	21
Steven	49	Physical and cognitive	Married	1 (1)	Row	No	1	34
Ben	31	Physical and cognitive	Cohabiting	0	Apartment	Yes	1	36
Marc	68	Physical	Married	2	Row	No	1	71
Daniel	81	Physical	Single	2	Apartment	Yes	1	40
Joan	64	Physical and cognitive	Single	0	Apartment	No	1	77
Sarah	67	Physical, cognitive and behavioural	Married	2	Apartment	Yes	1	49

(Continuing) Table 1: Study participants

Name	Age	Stroke effects	Marital status	Children (living at home)	House type	Moved	Interview round	Time since stroke onset (months) <sup>a</sup>
Bob	63	Cognitive and behavioural	Married	1	Apartment	No	1	34
Isa	48	Physical and cognitive	Single	0	Apartment	Yes	1	78
Linda	72	Physical and behavioural	Single	2 (1)	Apartment	No	1	60
Mike	69	Physical and behavioural	Married	6	Row	No	1	10
Regina	64	Physical and cognitive	Widowed	2	Apartment	Yes	2	10
Kate	61	Physical	Married	5 (1)	Row	No	2	8
Henry	69	Physical	Married	1	Detached	No	2	6
Howard	51	Physical, and cognitive	LAT relationship	1	Row	No	2	6
Raymond	68	Physical	Married	2	Detached	No	2	6
Roy	66	Cognitive	Single	0	Detached	No	2	6
Peter	46	Physical and behavioural	Married	2 (2)	Row	Yes	2	6

<sup>a</sup> For the participants who were interviewed in round 2, we recorded the time post-stroke at the time of the second interview

The effects of the stroke as listed for each participant in Table 1 need some further explanation. Physical effects of the stroke typically entail a hemiplegia, which is paralysis and loss of coordination of one half of the body. Swallowing and speech problems can also be caused by loss of coordination. Cognitive impairments include loss of language, memory, attention, speed of information processing, hemispatial neglect (deficit in awareness of one side of the body and the environment), and apraxia (the inability to perform a series of activities in a sequence or handle objects). These cognitive deficits may in turn influence stroke survivors' behavioural style, in becoming either more slow and cautious, or quick and inquisitive.<sup>2</sup>

Twenty-four participants were interviewed once in 2010 or 2011, between seven months and 6.5 years after the onset of the stroke. They were asked to reflect on their current lives at home and in the community. We also recruited seven participants in 2011 and 2012. They were interviewed twice, once during in-patient rehabilitation in the clinic and once between six and eight months post-stroke. In the first interview, we discussed the participants'

expectations about going home, while in the second interview participants were asked to recount their actual post-discharge experiences at home and in the community. Overall, the interview guides covered the same questions; however, our learning experiences and inductive inferences in the first set of interviews were used to refine the questions in the second set of interviews and opened new paths of inquiry. The interviews were conducted by the second author and two research assistants. The first author was present at and observed several interviews. In the second set of interviews, the time since the onset of the stroke was, on average, much shorter than in the first round. However, we did not find a difference between the home-making experiences between the two groups of participants, neither did we find a pattern in the effect of the time since the onset of the stroke on the participants' home-making process.

To increase our understanding of the social dimension of the home, we also conducted a focus-group discussion with nine partners of stroke survivors. The focus group took place at the rehabilitation stroke unit in 2011. The nine participants, five men and four women, all had a partner who had experienced a stroke one to six years prior to the focus group. The consequences of the stroke varied from moderate to severe impairments. The age of the participants was between 45 and 70 years. Some participants were still working at the moment of the focus group, and/or caring for children living at home, whereas others were pensioned. All partners had rehabilitated at the stroke unit described above, and returned to live at home. The discussion was moderated by a research assistant. The second author was present to take notes, as well as to provide clarification and steer the discussion if necessary. Topics discussed during the focus group discussion included physical adaptations to the home as well as changes that took place with respect to social contacts.

All participants were informed about the aims of the study, signed an informed consent form, and participated voluntarily. The Medical Ethical Review Committee of the University Medical Center Groningen exempted the study from being reviewed. The in-depth interviews and focus group were digitally recorded, transcribed verbatim and coded using Atlas-ti, a software package for qualitative data analysis. In the process of data-analysis, we combined inductive and deductive coding and analysis.<sup>38</sup> First, we applied a more inductive strategy of analysis, identifying issues raised by the participants themselves which were not necessarily part of the existing theoretical framework on home. This enabled us to identify new themes and patterns. To increase the depth of our analysis of home-making we then applied a more deductive approach by using the material, social and personal dimensions of home as sensitizing concepts, which means they guided the process of data-analysis. As a result, we can build on existing theoretical concepts of home. Coding and analysis were carried out by the first and second authors. The last author reflected on the findings, by reviewing some of the transcripts, the coding and the data-analysis.

## Findings

We begin our findings by discussing the changes in identity that our participants experienced as a result of the stroke. These help to situate their routines and social relations.

### *Changed identities and paths in life*

Some of our participants managed to come to terms with the post-stroke changes in their identity. Victor, for example, who used to lead an active life, working irregular shifts and travelling a lot after his retirement, together with his wife, accepted and even appreciated that his life was now centering more around the home:

*I do enjoy spending time at home. [...] Yes, well, we are done with [travelling]. And we both feel ok with it, yes. [...] We have done a lot, travelled a lot, and I am happy we did all those things.*  
(Victor)

For Victor and his wife, spending more time at home became a next joint step in their personal life history. Although he felt impeded in his daily life because of the stroke – in not being able to use his right hand, having to walk with a walker, and tiring very quickly – the stroke happened during a phase in his life where he was already looking forward to spending more time at home. The stroke may have sped up this process, but the existing anticipation may have facilitated the ease with which Viktor came to terms with his stroke-induced disabilities. Victor's story confirms the insight that in later life, the home may gradually transform from a basis for out-of-home activities to being the locus for every day practices.<sup>17,21</sup> It also relates to the concept of biographical flow in the sense that a stroke and its consequences are seen as something that is part of later life.<sup>39,40</sup> Like Victor, around one fifth of our participants had incorporated being 'a stroke survivor' fairly smoothly into their identities. In some cases, such as Viktor's, this was related to their phase in life, post-retirement. In others, however, this was related to a lifestyle that already was not very active pre-stroke, which could be continued without much change post-stroke.

The majority of our participants, however, felt they could not incorporate their changed body into their identities, since they abruptly lost the opportunity to engage in activities that were meaningful to them pre-stroke. Their stories show how they struggled to give meaning to their lives at home, such as Simon who went through a divorce, and could not continue his work as a lecturer post-stroke. He explained how the stroke had profoundly changed his sense of home and who he was:

*[I feel I] have nothing to offer. [...] I have no work, no partner, no hobbies [...] not even a stove, and cooking used to be a hobby.... [but] because I can't eat or drink, hardly anyone drops by to visit me.*  
(Simon)

Simon did lose many roles that did define his pre-stroke life: husband, father, academic and cook. For instance, cooking and sharing food with family and friends used to be his hobby, but Simon stopped pursuing this, since he experienced swallowing problems that prevented him from eating and drinking normally. As a result, his home changed from a social place into a lonely one. This relates to Rowles'<sup>14</sup> notion of autobiographical insideness, stressing the link between past, present and future in the ties between people and places. Simon struggled to incorporate the stroke and its consequences in his personal life history. The memories about his meaningful and active pre-stroke life and the huge loss he experienced post-stroke restricted him in recreating a sense of purpose and direction in his life in general, and experiences of home in particular. His series of remembered places clashed with his present personal place. Bury<sup>41</sup> introduced the concept of 'biographical disruption' for patients with chronic illness. However, the term 'disruption' might be too weak for what Simon experienced through the acute stroke-induced illness. He told us that it was only because of his children that he chose to continue life.

The majority of our participants, both stroke survivors and their partners, struggled to give meaning to their personal homes and lives in relation to who they used and wanted to be, whereas some managed to achieve this rather smoothly, and others with a lot of support from significant others. This does underline the link between the personal home and identity, as well as the nature of identity as being fluid and constantly re-negotiated. The latter has also been argued to be the case for older adults.<sup>37</sup> In the rest of our findings, we zoom in to how stroke survivors engage in routines and social relations in the home, in the context of these 'new' identities, that are often still 'torn'.

### ***Re-negotiating routines at home***

As a result of lasting stroke-induced bodily impairments that our participants experienced, the physical and social configuration of their home became difficult to handle, understand and navigate routinely. Almost all participants told us how routine activities of daily life (ADL), such as getting up, having breakfast, and getting a shower, as well as routines in leisure activities in the home, had changed for them. These activities take so much concentration and energy, every day anew, that they can hardly be called 'routine' anymore. For those participants who 'only' experienced physical disabilities, certain behaviors did become re-embodied and taken-for-granted, over time, but at a different level of environmental participation than prior to the stroke. However, the situation was different for participants who – also – suffered from cognitive effects of the stroke. Isa, for instance, told us how taking a shower had become an activity that she needed to plan and lay out carefully. She suffered from apraxia which means she found it difficult to understand the functions of utensils as well as to plan the order of (routine) activities:

*In the morning, when taking a shower, you need much more time. But when I just put everything in the right place before I take a shower, I need only 45 minutes for it. [...] I line up what I want to wear in the order I need it, otherwise I put things on in the wrong order, and then you realize and have to start all over. [...] I don't have the overview, I know the order, but when I do not see everything I need, I tend to forget it.*

(Isa)

Isa's story shows how she had learned to accommodate the demands of her new, apraxic, body, by carefully setting out her clothes, and planning more time for taking a shower. These stories illustrate the multi-facetness of body and place choreographies of daily routines, as well as what happens when these routines are suddenly disrupted.<sup>29</sup> This confirms the importance of taken for granted bodily routines in the process of home-making, as well as the flexibility they make possible in 'non-disabled' lives. For our participants who suffered both physical and cognitive effects of the stroke, routines potentially changed even more deeply, because for them, it is difficult to combine social routines with routine activities of daily life. This did clash, for instance, with the identities of our female participants with children living at home, since they felt they could not fulfill their former roles as a mother and partner anymore:

*V: [As a] mother, [I] used to be able to do ten things at the same time, but I can't anymore. So if my son has something to tell me, I say "[Robert], please, I have to cook dinner first, and then we'll talk later". And they understand [...] They sometimes forget, they just want to share a story and I also understand that.*

*I: So it's difficult that it doesn't work.*

*V: Yes, normally I was cooking dinner, doing stuff with my son, talking with my husband, all at the same time. [...] And I just can't do that anymore.*

(Violet)

Violet's quote illustrates how the bodily effects of the stroke, played out in physical and cognitive impairments, prevented her from being the mother and partner she used to be. This was especially difficult for her, since she felt her family longs for her function again as she used to and to be their mother again. She herself had to remind them that she could not combine all these things simultaneously anymore. Because of the hemiplegic effects of the stroke as well as oversensitivity for stimuli and delayed information processing, Violet was not able to combine ADL and social routines anymore, which involved interacting in a fulfilling way with her husband and children while doing household chores. Violet's story illustrates the entwinement of bodily routines, social routines and social roles and

relations, and as such the complicated nature of the loss stroke survivors and their families have to deal with upon returning home.<sup>6,42,48</sup>

For many participants, re-establishing old new routines was mainly facilitated by physical adaptations to the house, such as a grab-bar along the stairs. Although this made walking the stairs a bit easier, it remained a challenge to go up- and downstairs. Seven of our participants did move to a new house after having a stroke. Most of them were happy that they had a new house more suited to their physical needs, such as Isa, who moved to a single-floor apartment from a row house with upstairs bedrooms:

*This is all even-floored, and the toilet and bathroom are more spacious; because when you look further down the street, [those houses] have a very small bathroom. [...] So here I have more space to manoeuvre.*

(Isa)

Besides the space, Isa also appreciated there being no stairs, no doorsteps, and less cleaning and maintenance. As a result, it was easier for her to establish new routines, that cost less energy, which enabled her to do other things, such as social activities. In all cases, moving to a new home environment, was not experienced as disrupting, but as enabling. This does contrast with findings in the literature on older adults, where moving is discussed as complex and ambivalent, in which the – feared – loss of the old home, and problems with re-negotiating a new sense of home feature prominently.<sup>5,6,42</sup>

### ***Interacting with other people at home***

Socially, the homes of our participants also often changed fundamentally. Mary, who had become much more sensitive to stimuli and suffered from fatigue, discussed how she changed the social dimension of her home to accommodate her post-stroke self. She contrasted her 'safe' home with spaces outside, which she experienced as tiring.

*Everything wears me out, but as soon as I'm [at home], it's fine. It's weird, but as soon as I go outside, everything takes so much energy. Having a normal conversation can be dead tiring [...]. It's the constant effort, so I ended up socially isolated. I want to do it, but I can't. [...] I don't invite friends, because I need to take into account my own fatigue, planning, and how I feel. Yes, there's hardly anything left. [...] I avoid busy places, yes [I go to] the places where I am comfortable, that I know well, the quiet places, but to go into town, no. I can't cope with all the stimuli. I can do the shopping mall, but I need to be really fit to manage that, so I go there on my day off, usually Wednesday afternoon.*

(Mary)

Mary, being single, had managed to recreate her home according to her post-stroke needs by not inviting friends anymore, although this resulted in her becoming socially isolated against her will. She thereby had to give up not only her home as a place for strengthening important relationships, but also part of her pre-stroke identity as a sociable person and a good friend. Mary's story thus shows that the home can become both a refuge and a place where stroke survivors feel locked up against their will at the same time. Similar tensions were reported by most of our participants. This reveals that the process of home-making of stroke survivors is often full of tensions, an insight which may deepen theoretical insights in home-making, in the rehabilitation literature in particular.<sup>4,45,46</sup> When looking at those participants who did not live alone, we observed they typically became more dependent on their partners. In some cases, such as Sarah's, this was discussed as a natural process of relating differently to each other:

*I: Did your relationship change because of the stroke?*

*P: It may have become more intense, since we need to take each other's needs into account.*

*S: We rely more on each other.*

*P: She has lost her independence, which has led to us relating differently to each other.*

*(Sarah and partner)*

Sarah and her husband told us how their relationship had improved after the stroke. Her husband had found a new experience of home and personal growth in providing informal care to his wife. However, this was a rare case, since many partners resented how their home had become a place of giving and receiving informal care. This excerpt from the focus group interview with family caregivers is illustrative in this respect:

*“M: I am still married, but I don't have a wife, in terms of continuing the relationship we used to have. That's over [She did not recognise me as her husband]. I remained 'he' for a long time, when something needed to be taken care of. I wasn't [Martin] for her. I was a stranger. And although she might have had the faintest awareness that I would be her husband, she could not express that. Really difficult [...]*

*J: Yes, you have to give up a lot. Did you get help to deal with this?*

*E: No. Although that's very important. I don't know whether you also experienced it like that, but I thought I could handle it all. [group approves]. And I collapsed after two years. I couldn't do it anymore, nobody can. I could never do things the right way.*

G: No appreciation.

E: *Indeed, and suspicion, my husband is so suspicious, he asks me why I do stuff with everything I do, he keeps making demands on me, and that wears me out. That you can't even take a breath without the other, that's very difficult.*

Several family caregivers said they felt they had to care for another child, and that their partners had become strangers for them (and the other way around). This fact made assisting with ADL and especially dealing with behavioral changes in their beloved very demanding. These caregiving experiences dramatically changed both the social home in terms of roles and relationships and the identities of family caregivers. This does confirm findings in the literature on caregiving experiences, such as by Hammarström & Torres<sup>47</sup>, Milligan<sup>48</sup>, Milligan & Wiles<sup>49</sup> and Sixsmith et al<sup>21</sup>. Although caregivers' experiences were not the focus of our study, our findings seem to capture a more negative experience of caregiving than that articulated in other studies.

In many cases, the challenge of coping with the situation was increased by the fact that other people in the social network tended to refrain from providing the much needed support and understanding. James and his partner, for instance, felt that the people in their social network let them down: at first, family, friends and colleagues would come to visit and showed empathy, but this decreased over time.

P: *I can count the people who remain, whom we can rely on, on the fingers of one hand. [...]*

J: *They figured, well he's on his feet again, he's alright. [...] They don't understand. Do you need to show the outside world all the time how you've been hit? So if you look 'normal' but have changed inside, what about that? [...] Since it does not show, it's like, oh, that's not too bad, wow, you're cycling, too?*

(James and partner)

Both James and his wife told us that their social network now encompassed only their children and a couple of close friends, and most other participants recounted similar experiences. James and his wife felt this happened because people could not understand the invisible, cognitive and emotional effects of the stroke: James' body did still look the same on the outside, but its inside had changed, and he felt that other people did not interacted properly with his, seemingly recovered, post-stroke body. Our single participants expressed similar experiences, which affected them even more, since they did not have a partner to rely upon in everyday life. Overall, the composition of our participants' social relationships, in terms of closeness, quality, function and structure, not only changed but also decreased drastically<sup>35</sup>, and against the will and control

of stroke survivors and their partners. This contradicts Rowles<sup>50</sup> work on older adults in the United States in which he discussed how older adults engage with other people, to become part of the social order of a place. Our findings confirm that support from a larger social network is important when (re)negotiating the social meaning of home.<sup>51,52</sup> Social support may prevent stroke survivors, their partners, and their children from becoming socially isolated.

## Conclusions

Our study focused on adults who survived a moderate to severe stroke and returned to home with lasting disabilities after discharge from a stroke rehabilitation unit. We found that since the bodies of stroke survivors suddenly become limited in terms of capacity, their experiences of home, over time, and in relation to both other people and the material environment are affected. Thus, we conclude that 'home' is an emergent outcome of bodily being-in-the-world, full of ambiguity and replete with tensions, rather than a pre-given. This confirms findings from the literature on home, that when the "choreography of being in place"<sup>13</sup> (59S) is disrupted there is a diminution of self and a loss of identity and relationship to place and community. Our participants had to redefine both their identities and their homes to solve the incongruences between pre- and post-stroke, and most of them struggled at this. Similarly, Price<sup>53</sup> showed that it often takes a lot of time and energy to abandon the previously anticipated life course, and to develop an alternative projected life course that is acceptable and satisfying.<sup>53</sup>

We showed that routines and social relations have the potential to provide a renewed sense of stability to home-experiences. Many participants had lost the inherent bodily awareness of the physical aspects of their home environment: those with coordination problems in the time and effort it takes to move from one place to another and conduct routine daily activities such as shaving, dressing and cooking, and those with perception problems such as apraxia and neglect in terms of literally losing their way in routine activities, in information, and at 'familiar' places. Furthermore, individuals' pre-stroke social routines were also effected, and needed to be adjusted by carefully planning or cancelling them, to recreate a sense of home. This also impacted the identities and homes of our participants' partners and sometimes children, who often became informal caregivers. This calls for more in-depth research, especially on the experiences and emotions of (informal) caregivers in the home setting.

Our findings carry several implications for stroke rehabilitation. Firstly, that it is important to develop interventions that help to strengthen the home-making process of stroke survivors and their families in all its complexity. Our study increased the understanding that modifications to the physical house are just a preliminary step in the home-making process. Re-creating built-in bodily and social routines, that create stability and control, is

necessary to re-develop a sense of home. The key question is how to shift conceptualizations and related stories of home from the context of cultural geography and geographical gerontology, including the findings of our case study, to that of rehabilitation medicine in general and neurological rehabilitation in particular, thus how to transform, to translate and to put it in action in the field of rehabilitation practice and stroke care.

Another implication for the field of rehabilitation practice, stems from the enormous diversity in the experiences of our participants, with regard to re-positioning and re-producing their homes and identities. Factors such as the precise effect of the stroke, coping strategies, gender, age, pre-stroke roles, lifestyle and personality, as well as a stroke survivor's social network and home-environment all effect both each other and the process of home-making. Therefore, we conclude that re-producing a sense of home post-stroke is a highly individualised practice. This does provide a case for providing person-centered support and care, that is tailored to the needs of individual stroke survivors and their families.<sup>54</sup>

In our study, we asked survivors and their family caregivers to talk about their experiences and feelings, for instance how stroke as an illness effected their home place. By focusing on the embodied experiences of stroke survivors we chose to take a phenomenological stance in our study, as has been done recently by others such as Antoninetti & Garrett<sup>55</sup>, Schwanen et al<sup>56</sup> and Ziegler<sup>37</sup>. However, an important area for future research entails how home-making is *done* at different places post-stroke, through methods such as (participant) observation and go-along-interviews. Such methods will foreground the practices through which materialities such as staircases, doorbells, kitchens, paralyzed limbs, food, leaflets, intake or measurement tools are handled. Inspired by material semiotics and Actor Network Theory, such materialities will then be imagined as active agents that come into being – and disappear – with the practices through which they are played out and manipulated.<sup>57-59</sup> Such an approach would contribute to current theoretical debates in material geographies and Non-Representational Theory on the one hand<sup>60,61</sup>, and to knowledge practices in the field of rehabilitation on the other.<sup>62</sup> This will further the insight that the quality of stroke rehabilitation is not only to work against loss, but also to bear it.

## Acknowledgements

We want to express our gratitude to our participants for sharing their stories with us. Also, we thank Linden Douma, Carina Koops, and Jelle Straatsma for their role in collecting the data. This study was financed by 1) the Urban and Regional Studies Institute, Population Research Centre, University of Groningen, the Netherlands and 2) the Center for Rehabilitation, University Medical Center Groningen, the Netherlands.

## References

1. CBS. (2014). Beroerte [Stroke prevalence]. *Centraal Bureau voor de Statistiek (CBS)* [Office for National Statistics], The Hague. <http://statline.cbs.nl/statweb/Statline>. Accessed 17-06-2015.
2. American Stroke Association. (2015). Effects of stroke. American Heart Association. <http://www.strokeassociation.org>. Accessed 17-06-2015.
3. Ellis-Hill, C. S., & Horn, S. (2000). Change in identity and self-concept: a new theoretical approach to recovery following a stroke. *Clinical rehabilitation*, 14(3), 279–287.
4. Wood, J. P., Connelly, D. M., & Maly, M. R. (2010). 'Getting back to real living': A qualitative study of the process of community reintegration after stroke. *Clinical rehabilitation*, 24(11), 1045–1056.
5. Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experience of living with stroke: a qualitative meta-synthesis. *Journal of rehabilitation medicine*, 40(8), 595–602.
6. Achten, D., Visser-Meily, J. M., Post, M. W., & Schepers, V. P. (2012). Life satisfaction of couples 3 years after stroke. *Disability and rehabilitation*, 34(17), 1468–1472.
7. Nanninga, C. S., Meijering, L., Schönherr, M. C., Postema, K., & Lettinga, A. T. (2015). Place attachment in stroke rehabilitation: a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine. *Disability and rehabilitation*, 37(13), 1125–1134.
8. Drummond, A. E., Whitehead, P., Fellows, K., Sprigg, N., Sampson, C. J., Edwards, C., & Lincoln, N. B. (2013). Occupational therapy predischARGE home visits for patients with a stroke (HOVIS): results of a feasibility randomized controlled trial. *Clinical rehabilitation*, 27(5), 387–397.
9. Steultjens, E.M.J., Cup, E.H.C., Zajec, J., & Van Hees, S. (2013). *Ergotherapie richtlijn CVA* [Guidelines for occupational therapy after a Cerebrovascular Accident].
10. Blunt, A. (2005). Cultural geography: cultural geographies of home. *Progress in Human Geography*, 29(4), 505–515.
11. Chaudhury, H., & Rowles, G.D. (2005). Between the shores of recollection and imagination: self, aging, and home. In: Rowles, G.D., Chaudhury, H. (Eds.). *Home and Identity in Late Life*. International Perspectives. Springer, New York, pp. 3–18.
12. Peace, S.M., Holland, C., & Kellaher, L. (2006). *Environment and Identity in Later Life*. Open University Press, Maidenhead.
13. Rowles, G.D. (2000). Habituation and being in place. *Occupational therapy journal of research*, 20(1), 52S–67S.
14. Rowles, G.D. (2008). Place in occupational science: a life course perspective on the role of environmental context in the quest for meaning. *Journal of Occupational Science*, 15, 127–135.
15. Rowles, G.D., & Bernard, M. (2013). *The meaning and significance of place in old age*. In: Rowles, G.D., Bernard, M. (Eds.), *Environmental Gerontology*. Springer, New York, pp. 3–24.
16. Rowles, G.D., & Watkins, J.F. (2003). *History, habit, heart, and hearth: on making spaces into places*. In: Warner Shaie, K., Wahl, H.W., Mollenkopf, H., Oswald, F. (Eds.), *Aging Independently. Living Arrangements and Mobility*. Springer, New York, pp. 77–96.
17. Swenson, M.M. (1998). The meaning of home to five elderly women. *Health care for women international*, 19, 381–393.
18. Conradson, D. (2012). *Wellbeing: reflections on geographical engagements*. In: Atkinson, S., Fuller, S., Painter, J. (Eds.), *Wellbeing and Place*. Ashgate, Farnham, pp. 15–34.
19. Wiles, J.L., Leibing, A., Guberman, N., Reeve, J., & Allen, R.E.S. (2012). The meaning of “ageing in place” to older people. *The Gerontologist*, 52, 357–366.
20. Blunt, A., & Dowling, R. (2006). *Home*. London: Routledge.
21. Sixsmith, J., Sixsmith, A., Fänge, A. M., Naumann, D., Kucsera, C., Tomsone, S., Haak, M., Dahlin-Ivanoff, S., & Woolrych, R. (2014). Healthy ageing and home: the perspectives of very old people in five European countries. *Social science & medicine* (1982), 106, 1–9.

22. Tanner, B., Tilse, C., & de Jonge, D. (2008). Restoring and sustaining home: the impact of home modifications on the meaning of home for older people. *Journal of Housing for the Elderly*, 22(3), 195-215.
23. Sixsmith, A.J., & Sixsmith J.A. (1991). Transitions in home experience in later life. *Journal of architectural and planning research*, 8(3), 181-191.
24. Imrie, R. (2004). Disability, embodiment and the meaning of the home. *Housing Studies*, 19, 745-764.
25. Moore, A., Carter, B., Hunt, A., & Sheikh, K. (2013). 'I am closer to this place'--space, place and notions of home in lived experiences of hospice day care. *Health & place*, 19, 151-158.
26. Schwanen, T., Hardill, I., & Lucas, S. (2012<sup>a</sup>). Spatialities of ageing: The co-construction and co-evolution of old age and space. *Geoforum*, 43(6), 1291-1295.
27. Harrison, P. (2007). 'How shall I say it?' Relating the non-relational. *Environment and Planning A*, 39(3), 590-608.
28. Abrahamsson, S., & Simpson, P. (2011). The limits of the body: boundaries, capacities, thresholds. *Social and Cultural Geography*, 12(4), 331-338.
29. Seamon, D. (1980). *Body-subject, time-space routines, and place-ballets*. In: Buttner, A., Seamon, D. (Eds.), *The Human Experience of Space and Place*. Academic Publishers, New York, pp. 146-165.
30. Bissell, D. (2013). Habit displaced: the disruption of skilful performance. *Geographical Research*, 51(2), 120-129.
31. Foster, L., & Walker, A. (2015). Active and successful aging: a European policy perspective. *The Gerontologist*, 55(1), 83-90.
32. McNair, S. (2014). *More years, better lives - a strategic research agenda on demographic change*. Joint Programming Initiative More Years, Better Lives - The Potential and Challenges of Demographic Change. Brussels.
33. RIVM. (2014). *Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid*, versie 4.17 [Exploring Future Public Health, National Public Health Compass, version 4.17]. <http://www.rivm.nl>.
34. Kahn, R.L., & Antonucci, T.C. (1980). *Convoys over the life course: attachment, roles, and social support*. In: Baltes, P.B., Brim, O. (Eds.), *Life span development and behavior*. Academic Press, New York, pp. 254-283.
35. Antonucci, T.C., Ajrouch, K.J., & Birditt, K.S. (2014). The convoy model: explaining social relations from a multidisciplinary perspective. *The Gerontologist*, 54(1), 82-92.
36. Hopkins, P., & Pain, R. (2007). Geographies of age: thinking relationally. *Area*, 39(3), 287-294.
37. Ziegler, F. (2012). "You have to engage with life, or life will go away": An intersectional life course analysis of older women's social participation in a disadvantaged urban area. *Geoforum*, 43, 1296-1305.
38. Thornberg, R. (2012). Informed grounded theory. *Scandinavian Journal of Educational Research*, 56(3), 243-259.
39. Faircloth, C.A., Boylstein, C., Rittman, M., Gubrium, J. (2005). Constructing the stroke: sudden-onset narratives of stroke survivors. *Qualitative Health Research*; 15, 928-941.
40. Faircloth, C. A., Boylstein, C., Rittman, M., Young, M. E., & Gubrium, J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of health & illness*, 26(2), 242-261.
41. Bury M. (1982). Chronic illness as biographical disruption. *Sociology of health & illness*, 4(2), 167-182.
42. Kitzmüller, G., Häggström, T., & Asplund, K. (2013). Living an unfamiliar body: the significance of the long-term influence of bodily changes on the perception of self after stroke. *Medicine, health care, and philosophy*, 16(1), 19-29.
43. Löfqvist, C., Granbom, M., Himmelsbach, I., Iwarsson, S., Oswald, F., & Haak, M. (2013). Voices on relocation and aging in place in very old age--a complex and ambivalent matter. *The Gerontologist*, 53(6), 919-927.
44. Nygren, C., & Iwarsson, S. (2009). Negotiating and effectuating relocation to sheltered housing in old age: a Swedish study over 11 years. *European journal of ageing*, 6(3), 177-189.
45. Mayo, N. E., Wood-Dauphinee, S., Côté, R., Gayton, D., Carlton, J., Buttery, J., & Tamblyn, R. (2000). There's no place like home: an evaluation of early supported discharge for stroke. *Stroke*, 31(5), 1016-1023. <https://doi.org/10.1161/01.str.31.5.1016>
46. Struhkamp, R., Mol, A., Swierstra, T. (2009). Dealing with in/dependence: doctoring in physical rehabilitation practice. *Science, Technology & Human Values*, 34(1), 55-76.

47. Hammarström, G., & Torres, S. (2010). Being, feeling and acting: a qualitative study of Swedish home-help care recipients' understandings of dependence and independence. *Journal of Aging Studies*, 24, 75-87.
48. Milligan, C. (2005). From home to 'home': situating emotions within the caregiving experience. *Environment and Planning A*, 37, 2105-2120. doi:10.1068/a37419.
49. Milligan, C., & Wiles, J. (2010). Landscapes of care. *Progress in Human Geography*, 34(6), 736-754.
50. Rowles, G.D. (1983). Place and personal identity in old age: Observations from Appalachia. *Journal of Environmental Psychology*, 3, 299-313.
51. Antonsich, M. (2010). Meanings of place and aspects of the Self: an interdisciplinary and empirical account. *GeoJournal*, 75(1), 119-132.
52. Shin, J. (2014). Making home in the age of globalization: a comparative analysis of elderly homes in the U.S. and Korea. *Journal of Environmental Psychology*, 37, 80-93.
53. Price, P., Kinghorn, J., Patrick, R., & Cardell, B. (2012). "Still there is beauty": one man's resilient adaptation to stroke. *Scandinavian journal of occupational therapy*, 19(2), 111-117.
54. Lund, A., Michelet, M., Kjekken, I., Wyller, T.B., Sween, U. (2012). Development of a person-centered lifestyle intervention for older adults following a stroke or transient ischaemic attack. *Scandinavian Journal of Occupational Therapy*, 19, 140-149.
55. Antoninetti, M., Garrett, M. (2012) Body capital and the geography of aging. *Area*, 44(3), 364-370.
56. Schwanen, T., Banister, D., Bowling, A. (2012<sup>b</sup>). Independence and mobility in later life. *Geoforum*, 43(6), 1313-1322.
57. Law, J., Mol, A. (Eds), 2002. *Complexities: social studies of knowledge practices*. Duke University Press, Durham, NC.
58. Mol, A., 2002. *The Body Multiple: Ontology in Medical Practice*. Duke University Press, Durham, NC.
59. Mol, A., 2008. *I eat an apple. On theorizing subjectivities*. *Subjectivity* 22, 28-37.
60. Cook, I., Tolia-Kelly, D.P., 2010. *Material Geographies*. In: Beaudry, M.C., Hicks, D. (Eds.), *The Oxford Handbook of Material Culture Studies*. Oxford University Press, Oxford, pp. 1-16. doi: 10.1093/oxfordhb/9780199218714.013.0003.
61. Simpson, P. (2013). Ecologies of experience: materiality, sociality, and the embodied experience of (street) performing. *Environment and Planning A*, 45, 180-196. doi:10.1068/a4566.
62. Lettinga, A., Mol, A. (1999). Clinical specificity and the non-generalities of science. On innovation strategies for neurological physical therapy. *Theoretical Medicine & Bioethics*, 20, 517-535.





# Chapter 6

## **Unpacking community mobility: a preliminary study into the embodied experiences of stroke survivors**

Christa S. Nanninga  
Louise Meijering  
Klaas Postema  
Marleen C. Schönherr  
Ant T. Lettinga

Disability and Rehabilitation, 2018; 40(17): 2015-2024.

## Abstract

### Purpose

To enrich the discussion on mobility in stroke rehabilitation by translating theoretical repertoires of mobility from the context of geography to rehabilitation.

### Method

Qualitative research methodology was applied, and included in-depth interviews with stroke survivors.

### Results

This study revealed: (a) social and material differences in clinical, private and public places; (b) ambivalences and shifting tensions in bodily, family and community life; (c) differences in access to resources to be used for mobility. Moving around safely was not a matter of being physically able to walk independently, it also involved dealing with different human actors – such as children, partners and shoppers, and non-human actors – such as doorbells and traffic rules. Stroke survivors had to balance exercise and training, family and working life, and leisure and pleasure, and to renegotiate their mobility in each context.

### Conclusions

Our study showed that mobility has many aspects that interact with each other in multiple ways for stroke survivors when they return home and thereafter. The current focus on adherence to mobility and exercise training at home needs to be critically reviewed as it does not capture the multiplicities embodied in real-life settings.

## Implications for rehabilitation

- Rehabilitation medicine needs to consider mobility as a way to connect places that are meaningful to individuals rather than as movements from A to B.
- Clinical outcome measurement tools, such as the 10-meter walk test, are inadequate for evaluating participation in the mobility domain at home or in the community.
- Mobility issues at the participation domain need to be considered in “how they hang together” rather than distinguished in different disciplinary domains.
- Rehabilitation practitioners should teach stroke survivors concrete strategies on how to creatively deal with the ambivalences and tensions around mobility in home and community life.

## Introduction

Improving mobility is a primary goal in stroke rehabilitation.<sup>1,2</sup> The International Classification of Functioning, Disability, and Health (ICF) defines mobility as “moving by changing body position or location or by transferring from one place to another, by carrying, moving or manipulating objects, by walking, running or climbing, and by using various forms of transportation”.<sup>3</sup> Beneficial effects in improving the mobility of stroke survivors have been recorded for fitness training, high-intensity therapy and repetitive task training in specialist multidisciplinary stroke units.<sup>4</sup> However, despite good mobility outcomes in stroke units, it remains a challenge to translate the improvements made in the clinic into enhanced participation in community ambulation.<sup>5,6</sup> On returning home, stroke survivors often experience loss of independence in activities of daily living and restricted community ambulation, which in turn limits their ability to engage in work, leisure and community events, often with devastating consequences for family caregivers.<sup>7,8</sup> This illustrates the importance of a more detailed study of mobility following stroke, specifically in the participation domain.<sup>9,10</sup> As individuals with chronic stroke are vulnerable to the effects of a sedentary lifestyle, adherence to fitness and exercise training after inpatient rehabilitation is strongly promoted.<sup>11–16</sup> Community ambulation interventions are also applied to prevent mobility decline in individuals with chronic stroke, consisting of walking practice in a variety of settings in the community, an indoor activity that mimics community walking (including virtual reality and mental imagery).<sup>8,17,18</sup> Current evidence shows that interventions including behaviour change techniques tend to be more effective in improving real world walking habits than exercise alone.<sup>18</sup> However, there is insufficient evidence to establish the effect of fitness or community ambulation interventions in improving the community mobility of stroke survivors in their own living environments.<sup>8,17</sup>

Mobility training is assessed and evaluated in rehabilitation medicine using validated measurement tools that range from simple scales of timed tests, the examination of gait, balance, posture and independence to portable ambulatory activity monitors and complex laboratory-bound equipment that measures physical force, movements and physiological markers (e.g., heart rate and oxygen uptake).<sup>5,15,19</sup> Self-reported measures including survey questionnaires and diary entries are also used.<sup>6,19,20</sup> According to Lord and Rochester<sup>5</sup>, this way of defining and measuring mobility in clinical and laboratory settings does not capture the full complexity of the concept and its meaning in stroke survivors’ own living environments. A better theoretical understanding of community mobility is therefore critical when designing therapeutic strategies that maximize participation and minimize disability.<sup>5,9</sup> Gardner<sup>9</sup> describes community mobility as a process that is complex, dynamic and often difficult, since it is challenged by a myriad of individual and environmental factors that change from one day to the next. Therefore, it is important to also study the knowledge

that stroke survivors develop about mobility in their daily lives, and make this practical patient knowledge transferable and useful to others, or “turn it into science” (p. 1).<sup>21</sup> In this article, we aim to enrich the discussion on mobility in stroke rehabilitation by articulating the practical knowledge of stroke survivors about their (im)mobilities, at the places where they wish to (inter)act. To achieve this aim, we draw on care research that unravels and articulates details to do with care, to strengthen care practices, and whoever is involved in them.<sup>21–23</sup> Our assumption is that the articulated practical knowledge of patients may help to improve the knowledge practices of therapists and researchers. For that purpose, we delved into the embodied mobility practices of stroke survivors in the clinic, at home and in the community, as part of a broader qualitative study on home- and place-making with stroke survivors who were discharged after inpatient rehabilitation in a Dutch rehabilitation stroke unit.<sup>7</sup> To open up new ways of understanding mobility we translated theoretical repertoires of mobility from the context of the social sciences and geography to rehabilitation. In the next section, we will take the reader on a condensed tour of the social science literature, geography in particular, on mobility.<sup>24–27</sup>

### The mobility turn in the social sciences

In the social sciences, mobility has long been understood as movements from one place to another, which is quite similar to how it is currently conceptualized in the ICF and related rehabilitation literature. In the 1990s, with the worldwide increase in mobility (globalization) and emerging virtual forms of mobility, ideas on mobility began to change; this has been labeled the “mobility turn” in the social sciences.<sup>24</sup> Sheller and Urry<sup>24</sup> described mobility as “the importance of the systematic movements of people for work and family life, for leisure and pleasure, and for politics and protest” (p. 208). This resembles the way stroke rehabilitation defines community ambulation, albeit on a smaller scale: mobility inside and outside the home “to encompass activities such as visits to the supermarket, shopping mall, and bank; social outings; vacations, and pursuit of leisure activities”.<sup>10</sup> In the social sciences, however, there is also a political dimension to mobility on a larger scale.<sup>24,26</sup> For instance, international travel is associated with both elite, high-skilled migrants and undocumented migrants, each revealing very different mobility resources. Depending on resources, such as financial means, time and abilities, different people thus have different access to mobility. Cresswell<sup>25,26</sup> divided the concept of mobility into three analytical dimensions: physical movement, representations and practices. Physical movement is about actual movement from one place to another. Representations of movement give it its shared meaning. The practice of movement encompasses mobility as experienced and embodied in everyday activities.<sup>25,26</sup> The dimension of mobility practices is particularly important in the context of our study, as it shifts the focus to everyday mobilities and to the

spatial scale of the body. The practices dimension also directs attention to the movement of people, things and ideas. Moreover, it expresses the idea that human and non-human actors may enable or hinder each other.<sup>24</sup> The concept of mobility practices therefore allows for a better understanding of mobility in terms of the specific physical and mental opportunities and human and non-human “obstacles” that both enable and disable the mobility of stroke survivors in everyday activities. This also implies that there is not one “mobility”, but rather that mobilities such as driving, virtual travel, letter writing, flying and walking need to be understood in their fluid interdependence, and as being situated in different socio-spatial contexts.<sup>24–26</sup> Further work on mobility that is relevant for stroke survivors has focused on the mobility of older adults.<sup>28,29</sup> Especially relevant there is the concept of the “mobility of the self” or the idea that mobility is also related to a general will to connect with and be part of the world.<sup>27</sup> As stroke survivors become impaired in their capacity to move, both physically and cognitively, they may also lose this ability or general will to connect with the outside world.<sup>7</sup> Our theoretical study on the “mobility turn” allowed us to study the practical knowledge of stroke survivors in home and community life through a human geographical lens. Human geography “is centrally concerned with the ways in which place, space and environment are both the condition and in part the consequence of human activities.” (p. 350).<sup>30</sup> In this context, mobility is considered as a way to connect places that are meaningful to individuals rather than as movements from A to B. Such a perspective has the potential to uncover the challenges and shifting tensions in bodily, family and community life of stroke survivors. This requires stroke survivors’ attention and tinkering upon getting back to everyday life after inpatient rehabilitation. Tinkering as well as doctoring are concepts that have been developed in ethnographic research to give words to the specificities of care and clinical practices in contrast to the linear way of working established in clinical epidemiological research.<sup>22</sup>

## Methods

### *Design*

The design of this study is interdisciplinary of character. It moves theoretical repertoires – that are developed in spatial sciences after the mobility turn – to the field of stroke rehabilitation, with the aim to articulate silent layers and issues that deserve concern and attention in rehabilitation practice and science. The concept of “embodied mobility practices” needs to be understood as being situated in different socio-spatial contexts. Moreover, it enabled us to study mobility as a set of materially heterogeneous practices through which meaningful places are connected, rather than as an individual’s ability to move from A to B. This bears a resemblance to the material semiotic work of ethnographers who aim to improve and strengthen care practices by articulating their specificities, by drawing contrasts, and giving words to events that have been previously unspoken. In so doing, they also seek to rethink and frame care and technology by analyzing them together.<sup>22,31</sup> We drew on this ethnographic approach, and directed our attention to the (im)mobilities practiced by stroke survivors in the clinic, at home and in the community, focusing on differences and similarities between places.

### *Participants*

The study participants were 33 stroke survivors with moderate to severe stroke who received or had received multidisciplinary treatment in a rehabilitation stroke unit. The characteristics of the stroke survivors are summarized in Table 1. Each participant took part voluntarily and provided informed consent. The Medical Ethical Review Committee of the University Medical Center Groningen exempted this study from the review process.

### *Setting*

All participants had been admitted to a rehabilitation stroke unit in the Netherlands after being discharged from an acute stroke unit at a hospital. So, this local service meets the four criteria set out for a rehabilitation stroke unit: (a) there was a multidisciplinary team that provides stroke care at a dedicated ward; (b) the stroke team, including nursing staff, is specialized and trained in stroke rehabilitation; (c) routine involvement of caregivers in the rehabilitation process is established in the form of partner groups; and (d) new insights and skills in stroke rehabilitation are taught in regular meetings and courses.<sup>32</sup> Inpatient and outpatient rehabilitation are offered at the rehabilitation stroke unit. Participants are prepared for their return home by means of a weekend leave. After care is provided after discharge by a nurse specialized in stroke rehabilitation for a maximum of two years with a minimum of three contact moments in the two-year period.

Table 1. Participant characteristics

No*	Pseudo-nym	Age (years)	Stroke	Effects of stroke	Mobility aid	Mobility means**	Marital status/children (living at home)	Moved ***	Work status	Time of interview after stroke (months) ****
1	John	57	Ischemic stroke left	Motor and cognitive problems	Cane	Mobility scooter	Single/2 (1)	Yes (a)	Incapacitated	5-6
2	Paul	50	Ischemic stroke left	Motor problems	None	Bike	Single/2	No	Working	16-17
3	Jim	66	Ischemic stroke left	Motor and behavioural problems	None	Electric bike, car	Married/2	No	Pensioner	16-17
4	Simon	41	Ischemic stroke left	Motor, behavioural and mood problems, swallowing problems	Walker	None	Single/2	Yes (a)	Incapacitated	49-50
5	Mary	58	Ischemic stroke right	Motor, cognitive and mood problems	None	Bike, car	Single/-	Yes (b)	Working	33-34
6	Tom	60	Ischemic stroke right	Motor, cognitive and speech problems	None	None	Married/2	No	Incapacitated	44-45
7	Caren	60	Ischemic stroke right	Motor and cognitive problems	None	Bike, taxi	Single/-	No	Partly incapacitated	22-23
8	Sam	40	Hemorrhagic stroke right	Cognitive, mood, speech and sight problems, Epilepsy	None	Bike	Cohabiting/1 (1)	No	Partly incapacitated, partly sickness benefit	22-23
9	Nina	47	Hemorrhagic stroke left	Motor, cognitive and sight problems	None	None	Married/2 (1)	No	Incapacitated	16-17

(Continuing) Table 1. Participant characteristics

No*	Pseudo-nym	Age (years)	Stroke	Effects of stroke	Mobility aid	Mobility means**	Marital status/children (living at home)	Moved ***	Work status	Time of interview after stroke (months) ****
10	Violet	42	Hemorrhagic stroke left	Motor and cognitive problems	None	Bike, car	Cohabiting/2 (2)	No	Incapacitated	13-14
11	James	58	Ischemic stroke right	Cognitive and behavioural problems	None	Bike	Married/2 (2)	No	Sickness	5-6
12	Victor	71	Ischemic stroke left	Motor and speech problems	Walker	Electric bike, taxi	Married/2	No	Pensioner	19-20
13	Rose	53	Hemorrhagic stroke right	Motor and cognitive problems	None	Bike	Married/2 (2)	No	Incapacitated	31-32
4	Laura	49	Hemorrhagic stroke left	Motor and cognitive problems	Cane	None	Married/-	No	Sickness benefit	22-23
15	Steven	49	Ischemic stroke right	Motor and cognitive problems	None	None	Married/1 (1)	No	Sickness benefit	32-33
16	Ben	31	Ischemic stroke left	Motor and cognitive problems	None	Ladies bike, car	Cohabiting/-	Yes (a)	Unemployed	31-32
17	Marc	68	Ischemic stroke right	Motor and speech problems	None	Mobility scooter, car	Married/2	No	Pensioner	70-71
18	Daniel	81	Ischemic stroke left	Motor problems	Cane or walker	Taxi	Single/2	Yes (a)	Pensioner	41-42
19	Joan	64	Hemorrhagic stroke left	Motor and cognitive problems	Cane	Mobility scooter, shared taxi	Single/-	No (c)	Incapacitated	72-73
20	Sarah	67	Hemorrhagic stroke right	Motor, cognitive, behavioural and speech problems	Cane	Mobility scooter	Married/2	Yes (a)	Pensioner	55-56
21	Bob	63	Hemorrhagic stroke right	Cognitive and behavioural problems	None	Car	Married/1	No	Sickness benefit	32-33

No*	Pseudo-nym	Age (years)	Stroke	Effects of stroke	Mobility aid	Mobility means**	Marital status/children (living at home)	Moved ***	Work status	Time of interview after stroke (months) ****
22	Isa	48	Ischemic stroke right	Motor and cognitive problems	Walker	Mobility scooter	Single/-	Yes (a)	Incapacitated	77-78
23	Linda	72	Ischemic stroke right	Motor and behavioural problems	Walker	None	Single/2 (1)	No	Unemployed	59-60
24	Mike	69	Ischemic stroke right	Motor and behavioural problems	None	Bike, shared taxi	Married/6	No	Pensioner	9-10
25*	Kate	61	Ischemic stroke right	Motor problems	1) Walker 2) None	1) None 2) Bike	Married/5 (1)	No	Unemployed	1-2 7-8
26*	Regina	55	Ischemic stroke right	Motor and cognitive problems	1) Quad cane 2) Cane	1) Wheelchair, taxi, mobility scooter 2) Shared taxi, wheelchair, work chair	Widow/2	Yes (a)	Unemployed	3-4  9-10
27*	Henry	69	Ischemic stroke right	Motor problems	1) Walker 2) None	1) Three-wheeled bike 2) Bus	Married/1	No	Pensioner	1-2  4-5
28*	Ron	63	Ischemic stroke right	Motor and cognitive problems	1) None 2) None	1) Bike 2) -	Married/-	No	Pensioner	1-2 2-3
29*	Molly	46	Ischemic stroke left	Motor and cognitive problems	1) Cane 2) Cane	1) Wheelchair 2) Wheelchair, taxi	Married/1 (1)	No	Sickness benefit	1-2 3-4
30*	Howard	51	Ischemic stroke left	Motor, cognitive, speech and sight problems	1) Walker 2) Walker	1) Mobility scooter 2) Taxi, mobility scooter	Long-distance relationship/1	No	Unemployed	2-3 6-7
31*	Roy	66	Ischemic stroke left	Cognitive problems	1) None 2) None	1) Bike 2) Bike	Single/-	No	Pensioner	1-2 5-6

(Continuing) Table 1. Participant characteristics

No*	Pseudo-nym	Age (years)	Stroke	Effects of stroke	Mobility aid	Mobility means**	Marital status/children (living at home)	Moved ***	Work status	Time of interview after stroke (months)****
32*	Peter	46	Ischemic stroke left	Motor and behavioural problems	1) Elbow crutch 2) None	1) Wheelchair 2) Bike, public transport	Married/2 (2)	Yes (d)	Sickness benefit	1-2 5-6
33*	Raymond	68	Ischemic stroke right	Motor problems	1) None 2) None	1) Wheelchair 2) -	Married/2	No	Pensioner	1-2 6-7

\* Participants 25-33 were interviewed twice, once during the clinical phase, and once during the discharge phase.  
\*\* Mobility means (participants 25-33): 1) Mobility means used in the clinical phase, 2) Mobility means used in the discharge phase.  
\*\*\* Moved: (a) to a ground-floor apartment, (b) to a house in a quiet city neighbourhood, (c) to an assisted-living home, (d) to a terraced house in a city.  
\*\*\*\* Time of interview after stroke (participants 25-33): 1) Time of first interview (conducted in the clinical phase between 1-4 month post-stroke); 2) Time of second interview (conducted in the discharge phase between 2.5 and 10 month post-stroke).

### ***Data collection***

This article presents findings from an in-depth study that was part of a larger qualitative research project on home- and place-making by stroke survivors with moderate to severe disability.<sup>7</sup> For the larger study, we conducted semi-structured interviews with stroke survivors about their needs, concerns and expectations during the rehabilitation, post-discharge, and reintegration phases in the rehabilitation process. Since participants frequently raised the issue of mobility, we decided to gain a deeper understanding of their mobility practices by performing a second qualitative analysis of the empirical material. Inspired by literature we extracted all texts on mobility from the transcripts, by focusing on mobility practices in clinical, family, work, and leisure life, as well as on the political dimension of mobility.

Semi-structured interviews with stroke survivors were carried out in the larger study by the first author (a movement scientist and physiotherapist) and two students from human geography. The interviews lasted between 45 minutes to 1.5 hours. All interviews were conducted at a location that was convenient for the participants, and a significant other was often present. A sample of twenty-four participants were interviewed once, in the reintegration phase between 6 months and 6.5 years, after the onset of the stroke. A sample of nine participants were interviewed twice. First, they were interviewed in the clinical phase during inpatient rehabilitation (between 1 and 4 months post-stroke). The second interview was conducted in the discharge phase, after being discharged from the rehabilitation stroke unit (between 2.5 and 10 months post-stroke). Overall, the interview guides covered the same questions. Participants were asked to reflect on their needs, concerns, expectations, and relations with meaningful places in the clinic and their pre-stroke and post-stroke current lives at home and in the community. In the second interview session, they were also asked to recount their actual discharge experiences in an attempt to deal with the complicated issue of looking forward and backward to needs, concerns, and expectations. The interviews were digitally recorded and transcribed verbatim.

### ***Data analysis***

We applied our theoretical understanding of mobility as discussed in the section above, and focused our analysis on how stroke survivors embody and handle their (im)mobilities in everyday life.<sup>25,26</sup> The notion of embodied mobility as situated in different socio-spatial contexts directed our attention to human and non-human actors that enabled or disabled stroke survivors' mobilities at and between places. Our approach to the data-analysis was both deductive (secondary analysis) and inductive (primary analysis larger study)<sup>33</sup>, which enhanced the depth of our analysis.<sup>34</sup>

Coding and analysis were carried out separately by the first (physiotherapist and movement scientist) and second author (human geographer) with help of Atlas-ti, a software package for qualitative data analysis.<sup>35</sup> The emerging results were discussed with and reflected on by the last author (philosopher of science and medicine and physiotherapist). In case of disagreements, the authors discussed these matters until consensus was reached, often resulting in a specification of the analyses. Thus, inter-coder reliability was enhanced. Our interdisciplinary analytical work helped to articulate the specificities of the mobility practices of stroke survivors by unraveling and articulating them from more than one theoretical position. Thus, our focus was on theoretical triangulation rather than methodological triangulation.<sup>36</sup>

## Findings

### *Context in mobility practices*

In this study, we focused on three contexts in which mobility practices are played out: the rehabilitation center, home and community.<sup>24–26</sup> We found that our participants' mobilities are enabled or disabled in everyday activities, both by physically and cognitive opportunities, and by human and non-human obstacles. During inpatient rehabilitation, most participants learned to move around fairly safely and independently in the clinic. When back home again, however, many reported having difficulties with this aspect in their own house. They said that the physical environment in the clinic was adapted to their needs, unlike the impediments at home. Staircases were a frequently cited example. John, for instance, explained that mobility training in the clinic had not really prepared him for the stairs he had to climb at home.

*John: For example, we had practised on the stairs, but the stairs at Beatrixoord were very different from at home. They're not the same at all. It might have been easier if someone had come with me to practise at home, for safety reasons to see how it all went. Then you'd know what to do. Now I had to work it all out by myself, which I found very difficult in the beginning. It was also hard for my sons because they also didn't know what to do.*

At home, John felt that he had to work out for himself how to go up and down stairs. Especially troubling was the fact that the stairs at the clinic were straight, whereas those at home turned a 90° corner. This meant that some steps were narrower on one side and difficult to negotiate, and John was afraid of falling when going downstairs. Home modifications, such as installing grab handles in this case, only solved part of the problem, since John still had to take the stairs. It was not only the physical environment (stairs, corner) that differed between home and the clinic, however. The social environment was also different. At the clinic, therapists taught John how to manage the stairs and they were always close at hand,

whereas his sons were not always at home, and when there, did not know how to help their father take the stairs. Because of the uncertainties John experienced, he decided to move to a single-storey apartment. Like John, many of our participants had difficulty applying the skills learned in a therapeutic environment to their own living environments. Mike developed various strategies for taking the stairs:

*Mike: It takes so long because I have to take the stairs slowly and then there's no problem. And going down again, from upstairs to downstairs, on a good day I can walk down as well as anyone. But if I hear the doorbell and I have to go down quickly, I go down backwards, to be on the safe side.*

Mike was able to adjust his pace and the way he tackled the stairs, depending on the situation, which shows considerable flexibility. It was not just the staircase, however; all his pre-stroke routines took a lot of time and energy. He therefore chose to move to a house with a downstairs bedroom so that he could free up time for more pleasant things than going up and down stairs. When going outdoors, our participants faced more and different obstacles than inside the home. Typically, these obstacles were caused by their hemiplegic body. There were also cognitive problems when dealing with busy situations. Rose told us how the physical environment outdoors did not accommodate her hemiplegic body:

*Rose: I just don't feel confident when I walk. The paving stones are hopeless, you soon discover that if you can't walk properly, all paved paths are crooked. That means that I go out less often than I could.*

Because footpaths differed from the even paths at the rehabilitation clinic, Rose went outdoors less often than she would have liked after returning home. Ben explained that although he did go out, he sometimes struggled if something unexpected happened, such as having to go to the second floor of a shop without a lift.

*Ben: Well, in shops with a lift, I take the lift. Because people are used to walking on the right-hand side of the stairs. I can use my right hand, but it drags a lot. So I really have to try and get my arm up onto the railing and raise my leg as well, which is very difficult. I should really walk on the left if I take the stairs.*

Ben, who suffered from a right-sided hemiplegia, took the left side of the stairs because that gave him more support for his body. However, that meant having to move against the traffic flow, as people in the Netherlands keep to the right. Therefore, although most shop staircases are wide and therefore resemble staircases in rehabilitation clinics, they are not used solely by rehabilitation professionals and peers, but by people who are unaware of the

special needs of hemiplegics. Similarly, other participants' stories show that post-stroke bodies are often not acknowledged and accommodated in public spaces, in both social and physical respects. Sarah, for instance, would avoid crowded places or ask her husband to accompany her.

*Sarah: Then I go out onto the street with my husband because I've fallen over a few times.... Busy places and such, people push against you and don't watch where they're going. I tend to avoid it, escalators and that sort of thing ... In my case, my husband also needs to feel like going out with me.*

Because Sarah was afraid of falling in public, she became dependent on her husband's support. The above stories demonstrate the challenges involved in moving around in the outdoor physical and social environment. Many of our participants avoided public places, or when they had to go out, they planned carefully how, when and with whom they would go. We found that it is more difficult for stroke survivors to achieve satisfactory ambulation in public than in private spaces, and more difficult in private than in clinical spaces. This indicates that stroke survivors should not just comply with lessons that professionals set out for them in the clinic. Rather they should be supported in coordinating, transforming, dismissing, and attuning the taught lessons to ever changing socio-spatial contexts outside the clinic.

### ***Ambivalences in mobility practices***

Mobility is important for balancing work, family life, in leisure and pleasure.<sup>20</sup> We describe the ambivalences that our participants experienced in their attempts to be mobile at home and in the community in their post-stroke lives. John, for instance, told us how he juggled to maintain his mobility after his discharge from the clinic:

*John: I've actually gone backwards because I move a lot less now, only when I have to. The therapy (at Beatrixoord) was like a big stick to keep me moving. I only go outside occasionally now. ...I can't get to the shops because I would have to walk and it's too far, it's 500 metres I think. I'm still getting a mobility scooter and a serving trolley, I've applied for them. But it'll take ages before I get them..... Everything depends on my son, who still lives at home. I don't get any household help, because he still lives at home and he also has to do the grocery shopping. That's really difficult because he's away from home for 12 hours and has to do it all in the evening.*

There are several ambivalences in John's story. First, he wanted to go outdoors in order to maintain his walking ability, but when outdoors he was unable to participate in valued activities, such as walking to the shop. This clashed with his wish to engage in useful

activities and to give his son some relief from the triple burden of work, household and care activities. John did get a mobility scooter in the end, which enabled him to engage in activities such as grocery shopping, thereby improving his family and community life. At the same time, however, his frequent use of the mobility scooter meant that he walked even less, which led to a further deterioration in his physical condition. The major ambivalence that is played out in John's case is how family and societal roles were served by a mobility scooter, which at the same time worked against his physical fitness, a clinically significant factor. Similar ambivalences surfaced in the stories of other participants. As well as physical impairments, our participants also talked about cognitive impairments that limited their community mobility. Mary, for instance, had become hypersensitive to stimuli after her stroke. Mary was single and had a busy working and social life pre-stroke. However, cognitive impairments and fatigue meant that she could not continue all these activities. Mary chose to continue to work, but that meant she had to quit activities such as regular visits to friends and going to the fitness center. She also had to plan almost all her activities in advance, such as shopping.

*Mary: When I go shopping I always prepare a shopping list the day before. I know exactly where everything is in the shop. So I write my list based on the route I take through the shop. ... And so I arrive, grab a trolley, go into the shop and don't even have to think about it. I grab what's on the list, pay and leave. I never think "Oh, that's on special" or "hey, what's that?" No, that's what I need, I grab it and in it goes. Then I'm happy to be able to go home, ha ha.*

For Mary, shopping had become a planned, controlled trip. She could no longer take the time to compare different products and get the best deals available, as that took too much of her energy. As well as working and grocery shopping, Mary continued cycling as a leisure activity, although it had become demanding for her post-stroke. She had to think consciously about every push on the pedals to prevent herself from falling. Despite this, she developed strategies that enabled her to enjoy cycling again:

*Mary: I don't take the time to look around and think, hey this is lovely ... No, you think gosh I'm tired or I have to sit for a bit. ... Then I find a bench and I go and sit down. .... I always have a book with me or a puzzle book you know, or a bottle of water, I always carry all those things with me. ... It keeps me happy for a whole afternoon.*

Cycling used to be a leisure activity in which Mary could enjoy both the physical activity and the scenery along the way. Poststroke, however, she had to plan it in advance, including creating opportunities for rest, during which she could look at the scenery. The ambivalence in Mary's story comes from the time and effort she now needed for work, shopping and cycling. As a result, she had very little time and energy to engage in other activities that

were valuable to her, such as meeting friends, going to the fitness center and shopping for pleasure. The quotes from Mary and the other participants show how stroke survivors have to be creative in dealing with the ambivalences and tensions they face in regaining mobility in home and community life. It is this process of endless tinkering, weighing, adjusting, and coordinating mobility practices in each situation anew, that needs to be acknowledged by the rehabilitation team.<sup>22</sup> Indeed, at home everything hangs together, whereas different aspects of post-stroke life are allocated to different team members in the clinic pre-discharge. After discharge, stroke survivors and their families need to figure out how to set priorities in their mobility practices, to achieve satisfactory bodily, family, working, and community lives, to let go of particular pre-stroke pleasures, and to reformulate goals every day and everywhere, every time and again.

### ***The politics of mobility practices***

Our third findings-section outlines the inequalities in access to resources, such as personal abilities, a social network and money, between the participants. This underlines the political dimension of mobility.<sup>24,26</sup> Participants experienced differences in accessing health care in general, and obtaining mobility aids in particular. Their stories revealed that it is in fact difficult to arrange mobility aids such as grab bars along the stairs, braces, walkers, wheelchairs, mobility scooters and taxi transport. Many participants felt that they had to work out by themselves what aids they needed, and how to get them. Take, for example, the story of Tom's partner, who explained how they discovered that the mobility aids recommended by professionals at the rehabilitation center – in their case a mobility scooter and wheelchair for community ambulation – did not work well for them at home, and how they struggled to get the right aids.

*Tom's partner: So, you're discharged home, and you're asked what would you need at home, what kind of aids, what kind of support, but at that moment, you have no idea yet. Only when you're at home does it become clear what you need, or what's missing, only then is it possible to say. [...] So we needed to change stuff. We got the mobility scooter, we got the wheelchair. But then I asked for a disability parking permit. "Well," she said, "we don't need to apply for that, you'll never get it, it's very difficult". But now, it's what we enjoy most. I put a lot of effort into getting the permit, because you're not allowed to park anywhere these days, and he couldn't walk that far, so I didn't go anywhere. [...] So we gave back the wheelchair and bought a smaller mobility scooter.*

Although Tom did not use his large mobility scooter for months, they had to pay for it every month. And the wheelchair did not work out in practice because Tom's wife, who was much lighter than Tom, had to push it. She would quickly become exhausted, especially on difficult surfaces. Both Tom and his wife found the small mobility scooter and the

parking permit ideal for their community mobility. However, many of our participants did not have the capabilities or support of family members to select and negotiate the aids and facilities that are available from municipalities but are difficult to acquire, such as a disability parking permit. Their mobility at home and in the community remained limited. In particular, the fragmented organization of health care and related provisions was seen as an almost insurmountable obstacle to extending their mobility range and with that, their social participation. Steven's partner explained how she felt burdened by this fragmentation as an informal carer:

*Steven's partner: You just have to apply for everything yourself, all that paperwork, it's enough to drive you crazy. Those appointments, you have to make the time for it all. He has to go in a wheelchair, in a shared taxi, he needs to have grab bars, he needs such and such. And every appointment is something different. So a grab bar is something different from a modification for the shower, which is different again from another appointment with the council and the share taxi that you need. And that's different again from having the back of the house modified. Yes, you can't keep dividing yourself up and working thirty hours and everything ...And another year has just flown by.*

The fragmentation Steven's partner told us about is caused at least in part by the fact that in the Dutch health care system, different organizations are responsible for different aids and facilities, and there is a lot of administration involved. Stroke survivors and their families have to make separate appointments and arrangements for mobility aids, home adaptations and transport provision. Stroke survivors and caregivers explained that schemes are often not clear and differ from one municipality to the next. This seems to give stroke survivors and their spouses unequal access to resources, which also indirectly restricts their community mobility. As a result, some participants were unable to arrange the mobility aids and facilities they needed in their own living environment, or it took a long time to do so. For example, not all our participants had the resources to get their driving license back or the financial resources to maintain a car. Take Isa, for example, whose social life was hugely affected:

*Isa: You do lose quite a few friends because you can't do everything independently any more. I always used to drive myself – I went everywhere. I couldn't do that now. And now I'm allowed to drive again, but I can't afford a car anymore because I've been incapacitated.*

Although Isa eventually regained her driving license, she could no longer afford a car. The stroke had left her unable to work, which limited her financial resources. Like Isa, many of our working- age participants became unfit for work post-stroke, and received a sickness benefit that was less than the income they had earned when working. This illustrates that

participants with better financial resources and pre-stroke working conditions appear to be less home-bound. This section has shown that the political aspect of mobility, in terms of having unequal access to resources, influences the number of outings and activities of stroke survivors and their families. Moreover, the bureaucratic logic survivors and their families are facing post-discharge, complicates the tinkering process that has been articulated in the previous two sections. Such findings would have been easily overlooked when framing mobility as a movement from A to B, or in effectiveness research that isolates a few variables to be able to account them.

## Discussion

Inspired by the mobility turn in the social sciences<sup>24–27</sup>, we analyzed post-stroke mobility as embodied by survivors and their families in real-life practice. In our in-depth study, we conceptualized mobility as a set of materially heterogeneous practices rather than as an individual's ability to move from A to B. This revealed our participants' mobility in its full complexity. The first complexity that emerged was that stroke survivors' mobility differs from one context to the next. Our participants' stories showed that moving around in public and private spaces safely, easily and independently involves more than simply being physically able to walk without the help of others and assistive devices in an otherwise rather empty space with an even floor, such as the rehabilitation clinic gym. Instead, it involves dealing with different human actors (such as children, partners, and passengers in public space) and non-human actors (such as staircase winders, bars, doorbells and traffic rules), which interact differently in a range of contexts. The problems survivors face in the private context of home may eventually be manageable because the home environment is relatively easy to control, through creative strategies, practical home adaptations and the family adjusting to the stroke survivors' physical and cognitive impairments. Public space, however, is much more difficult to control as it involves greater complexity. It is extremely difficult for stroke survivors to navigate through public spaces in both a physical and social sense.<sup>9</sup> People in public spaces are barely aware of the problems stroke survivors face and therefore do not take them into account, unlike in clinical and private spaces. Because moving around in different contexts involves dealing with different interacting human and non-human actors, stroke survivors have to learn and negotiate their mobility anew in each context. This is extremely fatiguing and may play a part in fatigue as a unique post-stroke condition rather than add to tiredness as an ordinary life event.<sup>37,38</sup>

The second complexity that emerged was that the mobility of stroke survivors is full of ambivalences and shifting tensions. They have to do a lot of tinkering to balance exercise and training, family and working life, and leisure and pleasure.<sup>22</sup> To improve social

participation in the mobility domain we need to regard stroke survivors as people who are both attached and detached, independent and dependent, moving on their own and being moved by others.<sup>39</sup> Our study demonstrates that stroke survivors find their way between these opposing states by making small alterations and adjustments to their socio-spatial environments where they want or need to be, such as taking the stairs at the shopping mall against the flow of the crowd in the absence of a lift, relying on a mobility scooter to provide some relief for family caregivers, making an efficient shopping list as a guide for the route taken through the supermarket in order to save time and energy, and planning a cycling trip that incorporates rest stops at benches along the way. This corresponds to the core category of “striving to manage an everyday life of uncertainty” in Carlsson et al.’s study.<sup>40</sup>

The third complexity is that mobility is impacted by the different resources that stroke survivors have in terms of income, pre-stroke working conditions, health literacy skills and social support. The bureaucratic logic and fragmentation of the Dutch health care system in general, and the different municipal arrangements in particular, can mean a never-ending story of applying for mobility aids and driving licenses, transport compensations, house modifications and so on. Stroke survivors with cognitive impairments have difficulty dealing with these complex administrative matters, which means that their partners or other family members have to do it all, which in turn places a heavy burden on them. As a result, both stroke survivors and their partners are at risk of becoming socially isolated or burnt out.<sup>40-43</sup> We therefore argue that this burden should not be placed on the shoulders of stroke survivors and their spouses alone, with individuals expected to take more responsibility for their own health. Instead, it should be seen as a collective task, as shared work to reduce the burden for stroke survivors and their family caregivers.<sup>44-46</sup> The political dimension of access to healthcare in general has also been described as highly dynamic, multi-dimensional and contingent character in minority group research.<sup>47</sup> In their critical interpretive study of the literature Dixon-Woods and associates<sup>47</sup> describe transport as a key practical resource that impacts on the ability to seek care for the socio-economically disadvantaged. Also, financial costs and lack of awareness of certain services act as a barrier to attending “optional” services related to health promotion and health prevention.<sup>47</sup>

As in all research, there are several limitations to our study. One limitation is that we conducted a secondary analysis of empirical material that had been collected for a different purpose originally.<sup>7</sup> Therefore, saturation - in the sense that researcher reaches a point in the analysis that sampling of more data will not lead to more information related to the research questions, is a matter of concern. However, the value of saturation, beyond grounded theory, is under debate<sup>48</sup>, and may not apply to our study, since the aim of our study was not to develop theory that is grounded in data systematically gathered and analyzed. Rather, we

aimed to extract practical, sometimes silenced, knowledge of stroke survivors that may be useful for peers, practitioners, and researchers.<sup>21</sup> Our interdisciplinary analytical approach did have an added value with respect to that aim. Indeed, triangulation is not just about methodological validation, but also about theoretical triangulation aimed at deepening and explaining more fully the richness and complexity of human behavior from more than one theoretical perspective, in this case stroke patients' (im)mobilities from the perspectives of rehabilitation medicine, human geography, and philosophy of science and medicine.<sup>36</sup> A second limitation is that we did not observe our participants' mobility practices, but took the stories about their (im)mobilities in everyday life as object of analysis. To enhance methodological triangulation, we recommend conducting "go-along" interviews<sup>48,49</sup> with stroke survivors in future research. These will facilitate observation of mobility practices with reflective questioning.<sup>50</sup> The advantage of go-along interviews as a research method is that it may help to turn the articulated patient knowledge into ethnographic science.<sup>21</sup> In this emerging field of research, knowledge is not about facts and truths, but a tool in improving rehabilitation care.<sup>22</sup> As such it shifts focus away from proving to improving care practices, and makes it transferable and useful for others.<sup>21,51</sup>

In spite of our study's limitations, the complexities we uncovered suggest that there needs to be a critical review of the current focus by rehabilitation practitioners and researchers on adherence to mobility and exercise training at home.<sup>12-14,16</sup> These scholars seem to implicitly assume that an effective exercise program at a fitness center or at home is the best way to sustain or improve mobility after inpatient rehabilitation. Rimmer et al.<sup>12</sup>, for example, identified five common barriers to exercise adherence: the cost of the program, not knowing about a fitness center in the vicinity, no way of getting to the fitness center, and no knowledge of how and where to exercise. Similarly, van de Port et al.<sup>11</sup> suggest in their prognostic study that intensive physical training aimed at improving the walking competence of chronic stroke patients, combined with pharmacological treatment, will increase mobility and reduce the risk factors of fatigue and depression. Contrary to these studies, our findings indicate that sustaining or improving physical activity and related ambulation in home and community settings can only be explored in these varied settings themselves, and should not be controlled or introduced from the outside in a general way or in accordance with general physiological and pharmacological principles. Rather, in rehabilitation medicine, community participation, ambulation and mobility should be seen as a personal goal, and dealt with in the context of the complexities inherent in home, working and community life in private and public spaces outside the clinic.

Our findings thus underline that outcome measurements developed for the clinic such as the 10-meter walk test, independence and fatigue scales<sup>52-55</sup> may be inadequate for evaluating participation in the mobility domain.<sup>5</sup> Such measurements do not capture the multiplicities inherent in real-life settings and therefore say little about how mobility or home and community

ambulation occurs outside the clinic. That is why it would be useful for future research to objectify individual stroke survivors' favorite places in the community in terms of how often they go there and whether or not they extend their mobility range, during their life course or after an intervention. This could be achieved through GPS technology, which has been used in other fields of health research.<sup>56</sup> The complexities in mobility practices that we uncovered in this article call for the support of professionals who are aware of the many aspects of community mobility after a stroke and the multiple ways these interact with each other when survivors return home and thereafter. This is important because in clinical terms different aspects of mobility and alternative forms of transport tend to be viewed as separate disciplinary domains, rather than as fluid and interconnected. For example, the rehabilitation unit under study assigned gait and bike training, including adaptations, to the domain of physiotherapists, home adaptations, wheelchair and mobility scooter provisions and related administrative matters to the domain of occupational therapists, and spouse problems and administrative matters to that of social workers. Therefore, we are currently working on an intervention in which a multi-problem coach has a key-role in helping stroke survivors and family caregivers to take up their lives again in their everyday environment. The idea of the multi-problem coach has been conceptualized in co-creation with researchers, rehabilitation practitioners and stroke survivors, including family caregivers. The theoretical foundations of the intervention can be traced to concepts of home-making, place attachment and place identity that have been developed in human geography and environmental psychology<sup>7</sup>, as well as on knowledge from migrant, transport and science studies.<sup>24,26,31,39</sup> By combining coaching at home (face-to-face contact) and over distance (screen-to-screen application), and by developing an assessment tool that focuses on the altered (place) identity of stroke survivors, we aim to support the home-making process and mobility of stroke survivors in places they wish or need to be. In this way, we hope to help bring about change in the way that care for community-dwelling stroke survivors and their spouses is thought about, implemented and organized, and thereby to narrow the gap between clinical and home settings. We hope that others will join us.

## Acknowledgements

Special thanks go to the individuals who took part in this study. We would also like to thank Linden Douma and Jelle Straatsma, Master's students at the Faculty of Spatial Sciences, University of Groningen for their contribution to this study.

## Disclosure statement

The authors report no conflicts of interest.

## References

1. Craig, L. E., Wu, O., Bernhardt, J., & Langhorne, P. (2011). Predictors of poststroke mobility: systematic review. *International journal of stroke: official journal of the International Stroke Society*, 6(4), 321–327.
2. Intercollegiate Stroke Working Party. (2012). *National Clinical Guideline for Stroke*. 4th ed. London: Royal College of Physicians.
3. World Health Organization. (2001). *International Classification of Functioning, Disability and Health (ICF)*. Geneva: World Health Organization.
4. Langhorne, P., Bernhardt, J., & Kwakkel, G. (2011). Stroke rehabilitation. *Lancet (London, England)*, 377(9778), 1693–1702.
5. Lord, S. E., & Rochester, L. (2005). Measurement of community ambulation after stroke: current status and future developments. *Stroke*, 36(7), 1457–1461.
6. Robinson, C. A., Matsuda, P. N., Ciol, M. A., & Shumway-Cook, A. (2013). Participation in community walking following stroke: the influence of self-perceived environmental barriers. *Physical therapy*, 93(5), 620–627.
7. Nanninga, C. S., Meijering, L., Schönherr, M. C., Postema, K., & Lettinga, A. T. (2015). Place attachment in stroke rehabilitation: a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine. *Disability and rehabilitation*, 37(13), 1125–1134.
8. Logan, P. A., Armstrong, S., Avery, T. J., Barer, D., Barton, G. R., Darby, J., Gladman, J. R., Horne, J., Leach, S., Lincoln, N. B., Mehta, S., Newell, O., O'Neil, K., Sach, T. H., Walker, M. F., Williams, H. C., Woodhouse, L. J., & Leighton, M. P. (2014). Rehabilitation aimed at improving outdoor mobility for people after stroke: a multicentre randomised controlled study (the Getting out of the House Study). *Health technology assessment (Winchester, England)*, 18(29), vii–113.
9. Gardner P. (2014). The role of social engagement and identity in community mobility among older adults aging in place. *Disability and rehabilitation*, 36(15), 1249–1257.
10. Lord, S. E., McPherson, K., McNaughton, H. K., Rochester, L., & Weatherall, M. (2004). Community ambulation after stroke: how important and obtainable is it and what measures appear predictive?. *Archives of physical medicine and rehabilitation*, 85(2), 234–239.
11. van de Port, I. G., Kwakkel, G., van Wijk, I., & Lindeman, E. (2006). Susceptibility to deterioration of mobility long-term after stroke: a prospective cohort study. *Stroke*, 37(1), 167–171.
12. Rimmer, J. H., Wang, E., & Smith, D. (2008). Barriers associated with exercise and community access for individuals with stroke. *Journal of rehabilitation research and development*, 45(2), 315–322.
13. Simpson, L. A., Eng, J. J., & Tawashy, A. E. (2011). Exercise perceptions among people with stroke: Barriers and facilitators to participation. *International journal of therapy and rehabilitation*, 18(9), 520–530.
14. Gordon, N. F., Gulanick, M., Costa, F., Fletcher, G., Franklin, B. A., Roth, E. J., & Shephard, T. (2004). Physical activity and exercise recommendations for stroke survivors: An American Heart Association scientific statement from the Council on Clinical Cardiology, Subcommittee on Exercise, Cardiac Rehabilitation, and Prevention; the Council on Cardiovascular Nursing; the Council on Nutrition, Physical Activity, and Metabolism; and the Stroke Council. *Stroke*, 35(5), 1230–1240.
15. Yong V. Mobility limitations. (2010). In: JH Stone, M Blouin, editors. *International Encyclopedia of Rehabilitation*. New York (USA): the Center for International Rehabilitation Research Information and Exchange (CIRRIE). Available from: <http://cirrie.buffalo.edu/encyclopedia/en/article/259/>.
16. Pollock, A., Baer, G., Campbell, P., Choo, P. L., Forster, A., Morris, J., Pomeroy, V. M., & Langhorne, P. (2014). Physical rehabilitation approaches for the recovery of function and mobility following stroke. *The Cochrane database of systematic reviews*, 2014(4), CD001920.
17. Barclay, R. E., Stevenson, T. J., Poluha, W., Ripat, J., Nett, C., & Sriksavan, C. S. (2015). Interventions for improving community ambulation in individuals with stroke. *The Cochrane database of systematic reviews*, 2015(3), CD010200.

18. Stretton, C. M., Mudge, S., Kayes, N. M., & McPherson, K. M. (2017). Interventions to improve real-world walking after stroke: a systematic review and meta-analysis. *Clinical rehabilitation*, 31(3), 310–318.
19. Robinson, C. A., Shumway-Cook, A., Ciol, M. A., & Kartin, D. (2011). Participation in community walking following stroke: subjective versus objective measures and the impact of personal factors. *Physical therapy*, 91(12), 1865–1876.
20. Elbers, R. G., Rietberg, M. B., van Wegen, E. E., Verhoef, J., Kramer, S. F., Terwee, C. B., & Kwakkel, G. (2012). Self-report fatigue questionnaires in multiple sclerosis, Parkinson's disease and stroke: a systematic review of measurement properties. *Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation*, 21(6), 925–944.
21. Pols, J. (2014). Knowing patients: turning patient knowledge into science. *Science, Technology & Human Value*, 39(1): 73–97.
22. Mol, A., Moser, I., & Pols J, editors. (2010). Care in practice: on tinkering in clinics, homes and farms. Bielefeld: Verlag.
23. Mol, A. The logic of care. (2008). Health and the problem of patient choice. London: Routledge.
24. Sheller, M., & Urry, J. (2006). The new mobilities paradigm. *Environment and Planning A*, 38(2), 207–226.
25. Cresswell, T. (2011). Mobilities I: catching up. *Progress in Human Geography*, 35(4), 550–558.
26. Cresswell, T. (2012). Mobilities II: still. *Progress in Human Geography*, 36(5), 645–653.
27. Ziegler, F., & Schwanen, T. (2011). 'I like to go out to be energised by different people': an exploratory analysis of mobility and well-being in later life. *Ageing and Society*, 31(5): 758–781.
28. Schwanen, T., & Ziegler, F. (2011). Wellbeing, independence and mobility: an introduction. *Ageing and Society*, 31(5): 719–733.
29. Schwanen, T., Hardill, I., & Lucas, S. (2012). Spatialities of ageing: the co-construction and co-evolution of old age and space. *Geoforum*, 43(6): 1291–1295.
30. Gregory, D., Johnston, R., Pratt, G., Watts, M., & Whatmore, S. (2009). *The dictionary of human geography*. 5th ed. Oxford: Wiley-Blackwell.
31. Struhkamp, R., Mol, A., & Swierstra, T. (2009). Dealing with in/dependence: doctoring in physical rehabilitation practice. *Science, Technology & Human Values*, 34(1), 55–76.
32. Stroke Unit Trialists' Collaboration (2013). Organised inpatient (stroke unit) care for stroke. *The Cochrane database of systematic reviews*, 2013(9), CD000197.
33. Hennink, M. M., Hutter, I., & Bailey, A. (2011). *Qualitative research methods*. London: SAGE. Thornberg R. Informed grounded theory. *Scandinavian Journal of Educational Research* 2012; 56: 243–259.
34. Thornberg R. Informed grounded theory. *Scandinavian Journal of Educational Research*, 2012; 56: 243–259.
35. Muhr, T. (2004) User's Manual for ATLAS.ti 5.0. Berlin: ATLAS.ti Scientific Software Development GmbH.
36. Walsh K. (2013). When I say ... triangulation. *Medical education*, 47(9), 866.
37. Kirkevold, M., Christensen, D., Andersen, G., Johansen, S. P., & Harder, I. (2012). Fatigue after stroke: manifestations and strategies. *Disability and rehabilitation*, 34(8), 665–670.
38. Flinn, N. A., & Stube, J. E. (2010). Post-stroke fatigue: qualitative study of three focus groups. *Occupational therapy international*, 17(2), 81–91.
39. Winance, M. (2010). Care and disability. Practices of experimenting, tinkering with, and arranging people and technical aids. In: Care in practice: on tinkering in clinics, homes and farms. Bielefeld: Verlag; p. 93–117.
40. Carlsson, G. E., Möller, A., & Blomstrand, C. (2009). Managing an everyday life of uncertainty--a qualitative study of coping in persons with mild stroke. *Disability and rehabilitation*, 31(10), 773–782.
41. Haley, W. E., Roth, D. L., Kissela, B., Perkins, M., & Howard, G. (2011). Quality of life after stroke: a prospective longitudinal study. *Quality of life research: an international journal of quality of life aspects of treatment, care and rehabilitation*, 20(6), 799–806.
42. Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experience of living with stroke: a qualitative meta-synthesis. *Journal of rehabilitation medicine*, 40(8), 595–602.

43. Andrew, N. E., Kilkenny, M. F., Naylor, R., Purvis, T., & Cadilhac, D. A. (2015). The relationship between caregiver impacts and the unmet needs of survivors of stroke. *Patient preference and adherence*, 9, 1065–1073.
44. Greenwood, N., & Mackenzie, A. (2010). Informal caring for stroke survivors: meta-ethnographic review of qualitative literature. *Maturitas*, 66(3), 268–276.
45. Gallacher, K., Morrison, D., Jani, B., Macdonald, S., May, C. R., Montori, V. M., Erwin, P. J., Batty, G. D., Eton, D. T., Langhorne, P., & Mair, F. S. (2013). Uncovering treatment burden as a key concept for stroke care: a systematic review of qualitative research. *PLoS medicine*, 10(6), e1001473.
46. van Heugten, C., Visser-Meily, A., Post, M., & Lindeman, E. (2006). Care for carers of stroke patients: evidence-based clinical practice guidelines. *Journal of rehabilitation medicine*, 38(3), 153–158.
47. Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., Hsu, R., Katbamna, S., Olsen, R., Smith, L., Riley, R., & Sutton, A. J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC medical research methodology*, 6, 35.
48. O'Reilly, M., & Parker, N. (2013). "Unsatisfactory saturation": a critical exploration of the notion of saturated sample sizes in qualitative research. *Qualitative Research*, 13, 190–197.
49. Carpiano, R. M. (2009). Come take a walk with me: the 'go-along' interview as a novel method for studying the implications of place for health and well-being. *Health Place* 15(1), 263–272.
50. Lager, D., Hoven, B. V., Huigen, P.P.P. (2015). Understanding older adults' social capital in place: obstacles to and opportunities for social contacts in the neighbourhood. *Geoforum*, 59, 87–97.
51. Evans J, Jones P. (2011). The walking interview: methodology, mobility and place. *Applied Geography*, 31(2), 849–858.
52. Mol A. (2006). Proving or improving: on health care research as a form of self-reflection. *Qualitative health research*, 16(3), 405–414.
53. Chitralakshimi K., Balasubramanian, C. K., Clark, D. J., & Fox, E. J. (2014). Walking adaptability after a stroke and its assessment in clinical settings. *Stroke research and treatment*, 2014, 591013.
54. Rand, D., Eng, J. J., Tang, P. F., Jeng, J. S., & Hung, C. (2009). How active are people with stroke?: use of accelerometers to assess physical activity. *Stroke*, 40(1), 163–168.
55. Eng, J. J., Chu, K. S., Dawson, A. S., Kim, C. M., & Hepburn, K. E. (2002). Functional walk tests in individuals with stroke: relation to perceived exertion and myocardial exertion. *Stroke*, 33(3), 756–761.
56. Hirsch, J. A., Winters, M., Clarke, P., & McKay, H. (2014). Generating GPS activity spaces that shed light upon the mobility habits of older adults: a descriptive analysis. *International journal of health geographics*, 13, 51.





# **Chapter 7**

## **General discussion**

In rehabilitation medicine in general, and in stroke rehabilitation in particular, there is growing concern about the poor carry-over of learned skills in a clinical environment to the home environment. Working as a physical therapist in a multidisciplinary rehabilitation team, I became more and more aware of the fact that the skills we taught stroke survivors in the clinical setting were barely preserved in the home setting. As a human movement scientist, I posed myself the questions ‘Whether there was evidence for my professional experience, or not?’ and if so, ‘How to reduce this gap between the rehabilitation and home environment with help of clinical research?’ My growing concern about this carry-over problem became the object of study in this PhD-thesis.

The aim of this thesis was twofold: 1) to gain a better understanding of the experienced gap between the rehabilitation and living environment of stroke survivors in the Netherlands, and 2) to help improve the transfer from the clinical setting to the home setting in stroke rehabilitation with help of research knowledge.

Researchers have explained the persistence of the gap between clinic and home using three different arguments. Some rehabilitation researchers argue that the gap between clinic and home persists because of the differences between evidence and practice. They blame rehabilitation professionals for insufficiently using available evidence about stroke rehabilitation in their local practices.<sup>1</sup> They try to tackle the gap between clinic and home by developing support for stroke survivors in terms of evidence-based practice (EBP). Other researchers contend that it is not so much the lack of interest of professionals in the available evidence, but the relevance and fit of that evidence for local practices.<sup>1-3</sup> In line with this, researchers argue that there is not enough in-depth knowledge of how stroke survivors and their families themselves experience their lives after having survived a stroke.<sup>4,5</sup> More in-depth knowledge of these experiences could help rehabilitation researchers and rehabilitation professionals to attune their research and practice to stroke survivors’ changed needs across the different phases of rehabilitation care.<sup>6</sup> Finally, there are researchers who point to a lack of theory in (stroke) rehabilitation research.<sup>7-10</sup> They argue that theory can be used to get a better understanding of the problems researchers and practitioners face in (stroke) rehabilitation care.

This thesis contributes to knowledge that strengthens and improves ways of working in rehabilitation care till into the own living environment of stroke survivors, while building on the three arguments outlined above. It connects results of evidence-based rehabilitation research with participatory research into the lived experiences of stroke survivors in different environments, and enriches rehabilitation theory and practice with human geographical theory about home-making, place identity and mobility.

The main research questions of this thesis were:

1. What evidence is available for organized stroke care, and what is the relevance and fit of it, for improving the transfer from the clinical to home environment?
2. How do stroke survivors and their families experience their lives after in-patient rehabilitation, when being discharged home?
3. How can theoretical frameworks of home- and place-making contribute to a better understanding of the experienced gap between the clinical and home environment?

## **The relevance and fit of produced evidence for improving stroke rehabilitation**

The first research question that we posed was: *What evidence is available for organized stroke care, and what is the relevance and fit of it, for improving the transfer from the clinical to home environment?*

There is growing awareness among stakeholders in health care, that evidence-based practice (EBP) as sole basis for good care has its downside. The standardized and measurable knowledge in which evidence-based practice is grounded, does insufficiently take account of the context in which it is produced.<sup>3,9,11,12</sup> The line of reasoning goes as follows. Because of the stringent rating of individual studies in terms of their methodological quality and rigor of internal validity control, EBP creates a rather sterile evidence-base for practice. The Randomized Controlled Trial (RCT) serves as the cornerstone for proof. Because RCTs require such tight criteria when it comes to interventions, outcome measures and selection of participants, they are likely to end up not having a very high external validity. In other words, high-quality evidence that has been collected within the context of RCTs is not necessarily applicable outside the context of the study in the 'real' world. This really is a dilemma for evidence-based medicine.

### ***Seeing the wood for the trees***

But there are other downsides that need to be taken into account. Take the example of organized stroke care, which is one of the topics in this PhD-thesis. The huge amount and variety of individual trials produced on organized stroke care made it very difficult to determine relevance and fit of the evidence for the local rehabilitation center I used to work as a physical therapist. The literature search we conducted with one of my supervisors in 2010 provided us with 1,028 individual studies and 21 systematic reviews (between

2003 and 2013) on different topics with respect to stroke rehabilitation and organized stroke care. After 2013 a few more reviews were conducted on the same topics.<sup>13,14</sup> It was a challenge to order the topics in our user-friendly matrix (Chapter 2). The diversity in stroke services that has been investigated and critically appraised in systematic reviews, made it even more difficult to determine the relevance and fit for our local practice. Reason for this was that the individual studies summarized in the reviews had been undertaken in several countries in various settings, using diverging names to distinguish and compare stroke services in different trials, and including different patients in terms of severity of consequences of stroke. It was hard for us researchers to see the wood for the trees. Our struggle makes it clear that it would be difficult if not impossible for practitioners to judge these topics on the relevance and fit of their local practices.

### ***Working from within local practice***

In our attempt to improve the transfer from the clinical to the home setting with help of available evidence in our local practice, we first had to determine the nature of our stroke rehabilitation service. Our local service fulfilled the criteria of a rehabilitation stroke unit, for which there was a firm evidence-base. Subsequently, we had to search for evidence-based services that might help to improve the transfer of taught skills in this evidence-based clinical setting to the home setting. For that purpose, we pinpointed differences and similarities in target population, content and context between the services researched and reviewed and our local service in need of improvement. Solely Early Supported Discharge (ESD) ended up as a well-organized, evidence-based, cost saving outpatient alternative for improving the home-clinic gap.<sup>13,15,16</sup> Unfortunately, there was no ESD-evidence available for patients with severe disability, which was for the most part the target population of our rehabilitation stroke unit. So, despite the huge amount of clinical trials conducted in these 10 years, and also until recently, on the effectiveness of the variety of stroke services, there was hardly any knowledge generated that might help us to reduce the carry-over problem.<sup>13,14,17-19</sup> Also the variety in target population, comparison groups and implementation contexts raised questions about quality of the accumulated evidence in the systematic reviews under scrutiny.

### ***Experience-based knowledge ignored***

There is another problem with the systematic reviews summarizing the results of randomized controls on organized stroke care. Due to the concept of the (quantitative) systematic reviews, they do not include experienced-based knowledge of patients and professionals that is articulated in qualitative research and summarized in qualitative reviews.<sup>20,21</sup> This not only sustains the path once taken by evidence-based rehabilitation medicine, it also undercuts the practical relevance of the produced evidence. Integrating quantitative and qualitative research findings, as we did in our literature study about

organized stroke care (Chapter 2), revealed that there was a mismatch between the measured outcomes in effectiveness research of outpatient rehabilitation services, and the needs and lived experiences of stroke survivors in their own living environments. Thus, although outcome measures - such as odds of death, a 10-meter walking test, functional ability and independence scales - can be critical in clinical studies, they are missing the point when it concerns needs of stroke survivors upon returning home and facing loss or change in roles, relations and identity (Chapter 6). Indeed, established clinical outcome measures in EBP that are suitable for measuring the effectiveness of stroke rehabilitation services in the clinic are of little relevance when judging the evidence of rehabilitation services upon returning home.<sup>6</sup> To conclude, the way outcomes are determined and measured in clinical and laboratory settings, does not capture the complexity of problems that stroke survivors' face in their own living environments.<sup>13</sup>

### ***Hierarchical problem dismissed***

There is also a hierarchical problem in conventional EBP-research, namely that evidence-based research knowledge is privileged over practical and contextual knowledge. EBP advocates a one-way knowledge transfer to practice by critically assembling, appraising and synthesizing relevant RCT's on a given topic in systematic reviews, and then translating the resulting evidence in clinical guidelines. Such a one-directional, evidence-transfer process has been characterized by scholars as a pipeline, that leaks relevant knowledge in each step of the process of guideline production.<sup>2,22</sup> A one-way evidence-transfer to practice thus results in successive constrictions of the flow of knowledge at the end of the pipeline. For instance, publication priorities and peer review are constricting the knowledge flow by 'leaking' knowledge of submitted articles that were not accepted because of sample size, power and design issues. Another large leak in the pipeline is during the research synthesis itself, when reviewers are weeding out studies that do not meet randomized controlled trial standards. This implies that a large body of potentially useful information for practitioners is lost in final guidelines.<sup>22</sup>

### ***Two-way knowledge translation process***

In established EBP-research experience-based knowledge is thus underrepresented. This is why more and more scholars consider the poor uptake of evidence in local practices more as a knowledge *production* problem of researchers than as a resistance or acceptance problem of practitioners.<sup>3,9,23</sup> They plea for a two-way knowledge exchange and multi-directional learning process between producers and users of 'evidence'. In our integrated Knowledge-to-Action study (Chapter 3), we challenged practitioners to deviate from the original evidence regarding ESD, in order to tailor it in an evidence-*informed* way to the abilities of severely affected stroke patients treated in a Dutch rehabilitation stroke unit. They experimented in practice with Combined Clinical Home Rehabilitation, as it

made the training of stroke survivors with moderate to severe disability more tailor-made and task- and context-specific. Costs of travel time and other time-consuming contextual barriers made researchers and researched decide to experiment with Combined Coaching at Home and over Distance. The idea was that a combination of face-to-face and screen-to-screen contact enabled the local rehabilitation team to organize rehabilitation through to the home environment in a more sustainable, smart and efficient way. This idea is further explored in our local practice in the so-called Rehab-4-Life project, a participative action research focused on a further multi-level learning and change process regarding the carry-over problem in stroke rehabilitation. My role in the action research was to deliver research knowledge about the lived experiences of stroke survivors in the whole chain of care. For that purpose, I interviewed and followed stroke patients with moderate to severe disability, who had been admitted to our local rehabilitation setting in the chain of care.

### ***Analytical impartiality in action research***

These downsides of traditional conceptualizations and implementations of EBP as a linear one-way application process, made us decide to explore another genre of applied research in stroke rehabilitation care: one that focuses on improving stroke care services from 'within' rather than (dis)proving their effectiveness from an outside point of view.<sup>9,24</sup> In our two-way knowledge exchange and multidirectional KTA-study (Chapter 3) we demonstrated that such evidence-informed improvements of local practices are achieved more easily if research knowledge, professional knowledge and contextual knowledge are equally valued in applied research. Furthermore, it is important that research knowledge is fluid enough to change shape, to make it adaptable to the requirements of the new local surroundings. This analytical impartiality asks for knowledge that is generated in qualitative studies, in this thesis on the lived experiences of stroke survivors and their families (Chapters 4, 5, 6). I discuss the value of this form of experience-informed knowledge for improving the transfer - or better the translation process - between the clinical and home environment in the next section.

## The meaning of lived experiences of stroke survivors in different environments

The second research question of this thesis was: *How do stroke survivors and their families experience their lives after in-patient rehabilitation, when being discharged home?*

To gain more in-depth knowledge of how stroke survivors and their families experience their lives after having survived a stroke, we conducted qualitative research into the lived experiences of a specific group of stroke survivors. We focused on the target group in the local rehabilitation stroke unit I used to work as a physical therapist and PhD-student, treating stroke survivors with moderate to severe disabilities after acute medical treatment in a hospital. This is a target group that is typically treated at rehabilitation stroke units in the Netherlands.

### ***Review of qualitative reviews***

Our review of 9 qualitative reviews (Chapter 2) confirmed my own experience as physical therapist, that most stroke survivors and their families, including those with mild to moderate severity, perceive the transfer from the clinic to home as a difficult period.<sup>25-28</sup> When they are at home, stroke survivors increasingly come to realize that their pre-discharge expectations of life do not match their real-life experiences. They typically experience huge problems and disappointment when attempting to reintegrate in their homes and community again.<sup>26-28</sup> In addition to loss in terms of reduced functional ability and independence, the reviewers focused attention to emotional and social loss, often articulated as a loss or change in roles, relations and identity.<sup>28-30</sup> They argue that living with disabilities after a stroke at home and in the community needs to be regarded as a lifelong effort. Rehabilitation medicine should therefore gain more knowledge about the transition from the able to the disabled self, the role of environments in societal participation, the importance of meaning and choice when thinking about life situations, and the change in abilities across the life course of stroke survivors.<sup>6</sup> So, the experienced gap between the clinical and home environment is not just a matter of preserving the taught skills in the clinic at home, as we thought when I started my research. It is also matter of acknowledging that for personal recovery at home and in the community, stroke patients need other skills than those taught in the clinic.

### ***Qualitative studies in this thesis***

To gain more in-depth understanding of lived experiences of stroke survivors with moderate to severe disability - as they move across different care environments - we explored differences in stroke survivors' needs between the clinical, post-discharge and re-integration phases in organized stroke care through in-depth interviews (Chapter 4). Our qualitative study into the differences between rehabilitation phases revealed that stroke survivors had different

expectations and longings in each phase. They longed for recovery and domestic places in the clinical phase, for pre-stroke activities and roles in the post-discharge phase, and for recognition and a sense of belonging in the reintegration phase. The two themes that got special attention in our qualitative research were the home and mobility (in Chapter 5 and 6), as stroke survivors experienced a discrepancy between their actual being at home and remembered feeling at home, and a loss in mobility in all its complexity.

### ***Clinical phase***

Stroke survivors perceived their bodies in the *clinical phase*, thus after the acute phase in the hospital, as useless, unpredictable and dependent. During multidisciplinary rehabilitation treatment in the clinical phase their focus was therefore predominantly on functional recovery of their body. They accepted and even liked the fixed structure of the daily routines of the treatments offered by the different members of the rehabilitation team, as it stimulated them to work hard on recovery of all post-stroke impairments. The restricted, structured and safe environment of the clinic was appreciated, because it was adapted to their disabled body and there were always professionals available for support. For instance, physical therapist assisted stroke survivors in relearning functional skills such as bed mobility, transfers, walking, taking stairs and cycling. Occupational therapists supported them to retrain self-care skills (e.g. bathing and dressing) and other daily living skills (such as preparing meals and gardening), including the appropriate use of adaptive equipment (such as a wheelchair or adapted eating tools).

As a consequence, stroke survivors were confronted less with their disabled bodies and were positive about returning home, despite careful preparation and pre-discharge counseling of the multidisciplinary team. This focus on maximal recovery in the clinical phase allowed them to put their longing for home on the back burner. This longing for functional recovery in the clinical phase thus created a sense of temporarily belonging in the rehabilitation clinic on the one hand, and a rather carefree and unrealistic expectation of going back to normal in their own home environment, on the other hand. The overwhelming character of post-stroke disabilities, perhaps in combination with one vital expectation - that everything will become all-right if they are working hard on recovery - may explain the experienced gap in the post-discharge period.

### ***Post-discharge phase***

In the *post-discharge phase*, indeed, most stroke survivors wished to take up pre-stroke activities and roles again as usual. However, in this phase most of them slowly began to realize that full bodily recovery was not achievable. The brain damage caused by the stroke had not only affected their body physically but also cognitively, which took a great deal of their energy and drained their vitality. They *were* at home again, but typically did not *feel* at home

again. In part, this resulted from the fact that their physical recovery was not as complete as they had expected in the clinical phase. However, invisible cognitive impairments – such as hypersensitivity for stimuli and difficulties in concentration, planning, and multitasking) - more than visible physical ones, made formerly stable social routines, roles and relations time-consuming and extremely demanding. Taking up their pre-stroke roles and activities, such as being a partner and mother, and combining cooking and having kitchen table talks with the children or partner, were really difficult to manage and therefore extremely fatiguing. Key to these experiences was the fact that participants returned to a home that looked familiar, but was not adapted, physically or socially to their physically and cognitively disabled body. Each participant faced a different struggle to accommodate a changed self in a house that did not feel like home anymore.

In most clinical trials, the severity of stroke is defined as the amount of independence on physical help of others and aids. However, as I briefly explained above, our qualitative studies revealed that cognitive impairments are far more disabling in stroke survivors' own living environments than physical ones. Cognitive impairments such as fatigue and sensitivity to stimuli, were experienced as the most significant barriers in engaging with the home environment, as they are difficult to understand for both stroke survivors themselves and their significant others. This seems to result from the fact that cognitive impairments are invisible and therefore less easy to observe and accommodate. As a result, for many participants in the study, a formerly comfortable home became a place of struggle. Stroke survivors needed all their energy to recreate a sense of belonging in their own homes. A focus group study revealed that family caregivers also experienced problems in redefining their relationship because of identity and personality changes of their beloved. Thus, overall, reshaping life at home was experienced as very difficult by most participants with severe cognitive and physical impairments. However, taking up a meaningful community life in the reintegration phase proved to be even harder still.

### ***Re-integration phase***

In the *reintegration phase*, stroke survivors longed for recognition and a sense of belonging in the wider community. They began to realize that their lives would never be the same again. That troubled them and their families. The tiring lived experiences and changed self at home appeared to be an early indicator of the difficulties people would have engaging with the wider community. Some stroke survivors succeeded in reintegrating into the community to a certain extent. The empathy, understanding and creativity of significant others enabled them to re-own their post-stroke bodies and changed selves within working and community life. But most experienced huge problems when they became aware that no further recovery could be expected or their functioning even declined. Often this was caused by misunderstanding or lack of recognition of the changed self by family members,

friends, colleagues and professionals. Functioning in the neighborhood or the wider community appeared to be the most challenging due to its complexities and ever-present external stimuli. For instance, a task like doing grocery shopping became very demanding and time-consuming and therefore took a lot of energy. Also, activities such as meeting family and friends at a café or birthday party typically became challenging because of the many stimuli. As a result, our participants felt very limited in undertaking such activities, and felt increasingly isolated at home. On top of that they had to manage and balance their mobility in the different domains of exercise and training, family and working life, and leisure and pleasure. In each of these activities and contexts, they had to renegotiate their mobility and changed body or self anew, which was also very challenging (Chapter 6).

As a physical therapist, I acknowledge that the focus on treating physical and cognitive impairments and relearning daily skills in the clinic is of utmost importance in order to realize the best possible functional recovery and independence at home after discharge. However, what I learned in this PhD-study is that the complexities of life post-stroke needs serious attention and definitely another focus at home and in the community. Our qualitative studies confirmed the importance of decision making and choice of stroke survivors in both the post-discharge and reintegration phase that had been raised in earlier research.<sup>6</sup> Attempting to independently undertake as many ADL and social activities as possible in the post-discharge and reintegration phases may overburden stroke survivors, and even exhaust them such that they lose their independence altogether. Indeed, they can choose to be independent in various ways.<sup>24</sup> At one day they may choose to wash and dress themselves without assistance, while on another day, they may ask for support in such daily activities as that saves energy for other activities such as working or visiting friends. I suggest that this is not only of value for stroke survivors with severe disability, but also for survivors who experience mild severity valued in terms of physical independence of others, but often experience quite severe cognitive disabilities in their own living environment.

## The value of human geographical theory for rehabilitation research and practice

The third research question we addressed in this thesis was: *How can theoretical frameworks of home- & place-making contribute to a better understanding of the experienced gap between the clinical and home environment?* Theory development in rehabilitation science is seen as relevant, but is often overlooked. An a-theoretical attitude may hamper therapists in making informed choices in their clinical work. It also impedes researchers in the development of research questions that focus on problems relevant to clinical practice.<sup>7,9,10,31-34</sup> Because of the multidisciplinary character of rehabilitation treatment and the variety in target population, theories come from many biomedical and psychosocial disciplines, such as biomechanical, neurophysiological, motor learning and behavioral disciplines.

During the research for this thesis I came in contact, and got inspired by, a rather unknown research area to rehabilitation science, namely the *spatial sciences*. These contacts resulted in an interdisciplinary collaboration between rehabilitation and human geographic researchers in our local rehabilitation center. Human geography is the academic discipline that is concerned with the interactions between people and places. In geography, space is defined as abstract and without meaning; for instance a location in terms of latitude and longitude. Place, in contrast, is space that has meaning; for instance people's home- or workplace. The ideas around place have their origin in the humanistic geography of the 1970s, where scholars such as Relph and Tuan deepened understanding of the relation between people and places.<sup>35,36</sup> Using theory and concepts from human geography did result in new types of insights for rehabilitation science.

### ***Physical, social and personal dimensions of places***

First of all, the experienced gap between the clinical and home environment was made understandable by distinguishing a physical, social and personal dimension in these places.<sup>37</sup> In my qualitative studies, I found differences between these three dimensions with regard to the clinical setting and the home environment.

The physical dimension of the clinic is a completely adapted environment, where stroke survivors can move around safely with their impaired bodies. For instance, floors are even, doors are widened and often automatic, there are grab handles in the bathroom and staircases are broad and straight. In contrast, at home stroke survivors have to deal with a physical environment that is much less adapted to the needs of their disabled bodies: there may be a winded staircase which makes the second floor out of bounds, or garden sheds and basements are not accessible anymore. In other words, the physical dimension of the home is not as accommodating as it is in the clinical setting.

Moreover, there is a physical difference between the home and clinic with respect stimuli such as sound and light. The training, cooking, dinner, leisure and sleeping places are most of the time quite spaces and separated from each other in the clinic, in comparison with home and community places where there are more often than not a cacophony of background noises such as the noise of kitchen machines or central heating and flash of light of television or play stations. What makes these background stimuli so exhausting for stroke survivors in their own living environment, is that they come to the fore in all places where they wish to (inter)act in their lives.

The social dimension of place is about routines, roles and relations. In the clinic, there are arranged routines, for instance, a structured timetable is offered and it is clear at what time stroke survivors have to train, eat or can expect visitors. However, at home no structure is offered and survivors have to structure the day themselves. There are basic daily living routines that often take up a significant amount of time and energy post-stroke. What is new for rehabilitation practice, is the importance of *social* routines in daily life, such as the kitchen table talk during cooking, going to the market on Saturday with your partner and chatting with friends in a tea-garden. Such *social* routines make people *feel* at home at places that are meaningful for them, and that need to be re-owned after discharge from the rehabilitation clinic.

Besides social routines, also the social roles and relations differ between the clinical setting and home. In the clinic, stroke survivors have to fulfill the role of patient: they train and rest, and receive visitors. Their social relations typically consisted of interacting with fellow sufferers and practitioners. Family and friends only came to visit them at fixed times. At home, first, the social roles and routines are different from in the clinic. Moreover, they have to take up a variety of roles and besides that of patient, such as that of partner, mother, friend and sometimes employee. Second, they have to change social roles and routines compared to how they had filled them pre-stroke. This includes, for instance, how to interact with the family members at home, and when and how to receive visitors. Often, this had a significant impact on the social life of our participants.

The personal dimension of place also changes for stroke survivors, due to the abrupt onset of a stroke a sudden change in identity occurs. This means that stroke survivors often had to start living with a new image of themselves, who they are, and what they would like to do and be in life. They had to build the restrictions, and sometimes opportunities, that their brain injury brought along, into a new identity. Such a new identity also typically implies a new and different engagement with places they like to be. So, the physical, social and personal dimensions of the places differed strikingly between the clinical and home setting, which needs to be taken into account in improving the clinic home transfer.

### ***Understanding life as situated in a network of meaningful places***

Second, during this research project, we realized that the process of re-owning your body requires a different theory than the process of re-owning your life. In the clinic, where the focus is on bodily recovery and functional independence, the process of re-owning the body in physical and cognitive sense is central. However, at home and in the community, where the focus shifts to personal recovery and identity change, the process of re-owning one's life is more about re-defining social routines, roles and relations at places that are important to stroke survivors. This way of understanding lives of stroke-survivors within a network of places that were, are and may become meaningful to them, is important for stroke rehabilitation, as stroke survivors typically have to re-define the meaning that places have for them, to accommodate their post-stroke identities. To achieve this shift in focus, theory and concepts with origins in human geography were suitable. We used concepts of place attachment, place identity, sense of place, and mobility.

Home- and place-making can be broadly defined as the processes of attributing meaning to places, such as home, work, neighborhood, park or shopping mall. Place attachment involves the interplay of affect and emotions, knowledge and beliefs, and behaviors and actions in reference to a place.<sup>38</sup> Place identity refers to the process by which people portray themselves, through interaction with specific places, in terms of belonging to that particular place.<sup>39</sup> In human geography a sense of self, (who you are) is inextricable bound to a sense of place (where you are).<sup>40</sup> We learned that it is important for stroke rehabilitation practice to link past (pre-stroke), current (post-stroke) and future selves (beyond the stroke) of stroke survivors to the places they like(d) and wish to interact.

Meaningful places thus become part of who we are and the way we understand ourselves, for stroke survivors on a large scale clinic, home and community and on a smaller scale a variety of domestic, education, work, and leisure places. We learned that as the spatial scale level increases, the complexity of problems that are experienced by stroke survivors also increases. The reason for this is that with an increase in spatial scale, places become larger and less easy to 'control'. Since many stroke survivors are not able to deal with the complexities of life in the community, they become home-bound.

### ***Understanding mobility as a way to connect places***

Third, the spatial sciences also provided rehabilitation research and practice with a fruitful, alternative concept of mobility.<sup>41-43</sup> Instead of considering mobility as movements from A to B - such as in the rehabilitation clinic (from bed to the chair or from the gym to the end of the corridor) - they have come to see mobility as a way to connect places that are meaningful in peoples' lives. Building on this, we wanted to make such a network of connected places visible for stroke survivors and their families, and help them to reflect on the places that

were meaningful for them before, after and beyond the stroke. To achieve this, we developed place mapping as a mapping tool for rehabilitation coaches in the action research 'Coaching in Home- & Place-making'.<sup>44</sup> Place mapping is used in human geography as a participatory, qualitative visualization technique, that gives a schematic representation of the places important for a person, and of the connections between these places.<sup>44</sup> In conclusion, looking at the experiences of stroke survivors at home through the lens of spatial and human geographical concepts enabled a shift in focus towards the network of important places where their life takes place – away from a body with lost functions.

### ***Value for human geography***

Although rehabilitation did gain from using theory and concepts from human geography, human geography has certainly also been enriched by rehabilitation science. First, human geography has traditionally had a strong focus on the white, male, able-bodied perspective. Our research has contributed to a strengthening of the representation of a more vulnerable group and showed the specificities of home and place-making for stroke survivors. Specifically, the focus on the past, present and future self in relation to place is novel in human geography. Second, human geography is often inspired by theoretically informed problems and questions articulated in research literature. Taking a problem from practice as a starting point for research has helped to shift a focus from theory to valorization, and in that sense for human geography to become more applied.

## Lessons learnt and recommendations for practice

At the start of this PhD project, we thought that the gap between the clinical setting and home could be reduced by means of applying evidence summarized in reviews into practice. I learned that in order to be able to improve local care practices, besides evidence-based knowledge, other knowledge sources are to be incorporated in the improvement process, like practical and contextual knowledge from professionals and experience-based knowledge from stroke survivors and caregivers. This implies that research aimed at improving rehabilitation practice should be more open, iterative, cyclic and multi-actor of character than the linear and one-directional evidence-based practice research that has been established in rehabilitation practice to prove its effectiveness.

An important practical insight that resulted from our study is what you learn in one place has to be adapted to every social-spatial context anew. Hence, the gap between different places, such as at the scale of clinic and home, is not a transfer problem, but a translation problem. This implies that my concern in the beginning of this PhD research – namely, that the skills we taught stroke survivors in the clinical setting were barely preserved in the home setting - needs to be revisited. Instead of trying to make stroke survivors comply with the lessons learnt in the clinic, rehabilitation therapists should try to help them to *translate* these lessons to the different places where their clients wish to re-integrate. In order to be successful at this, this has to be done place by place and not in all places at once.

Doing this PhD research has changed my practice as a physiotherapist, now in a nursing home. I put more emphasis on identity confusion and the related mourning process that inevitably emerges when survivors try to feel at home again at favorite pre-stroke places. Take the example of a 74-year-old woman with stroke-related impairments, resulting in physical, cognitive, emotional and behavioral problems. She had been discharged home from the rehabilitation stroke unit in the nursing home, where I work as a physiotherapist.

*Before the onset of the stroke, she could walk and cycle for many hours, which she enjoyed very much. However, due to the stroke-related impairments, she could only walk with a walker for 20 minutes outdoor and was not able to cycle anymore. Because moving outdoors had become tiring and she was ashamed of her walker, she became more housebound. To help her see this, I literally drew out places that were (pre-stroke) and are (post-stroke) important to her. In so doing, the drawings made clear to her and her husband that their world had become very small. The place map showed, for instance, that they did not visit their favorite pre-stroke holiday place anymore. It was a place where they grew up and where their son, some other family members and friends were living. They used to enjoy making long walks in the hilly area and combined this with family and friends visits. They had been there once since the stroke, but it turned out to be a disaster as they tried to do it the same way as they were used to do it before the stroke. She got exhausted and had no energy left for the planned social visits. When they were back home, she had to recover for two weeks.*

*In my discussions with the client and her husband, I put more emphasis on the identity confusion and mourning process that inevitably emerged when she tried to feel at home again at her favorite holiday place. It took some months to go through this mourning process, and to accept her changed body. Six months later, they went back to their holiday place and made it a success, by planning shorter walks, using the walker, alternated by taking breaks and visiting family and friends. So, they learned how to organize their holiday place differently, but in an enjoyable way. I also explored with them how to translate the success experiences at the holiday place to other places on the map where they wished to go again.*

Based on my research and experience as a professional, we therefore suggest that a rehabilitation team should also try to reduce the complexities they bring into the vulnerable lives of stroke survivors. By dedicating different activities, such as walking activities, basis daily activities, leisure activities and social activities to different members of the multidisciplinary team, stroke rehabilitation tends to increase the complexities in the daily lives of stroke survivors upon returning home. In outpatient rehabilitation, we therefore urge rehabilitation professionals to focus their support on the home-making at places where survivors wish to interact, rather than at preserving taught functional skills in the clinic into the home setting. This does not mean that inpatient rehabilitation should move away from multidisciplinary treatment focused on functional recovery and independence. Our research confirmed that this focus is needed and wished in the clinic. However, rehabilitation can improve the transfer from the clinical to the home setting by understanding the living environments of stroke survivors in terms of real-life places that are meaningful to them.

Building on this, we also recommend to organize outpatient services in a different way. The complexities stroke survivors and their families have to cope with in their own living environments call for the support of professionals who are aware of the many aspects of home- and place-making after returning home. In outpatient rehabilitation services we recommend to have one central professional, who acts as a multi-problem coach, and assists stroke survivors post-discharge in rebuilding meaningful and interconnected relationships with their bodies, homes and communities again. Here, the focus should be on places and people that are important for stroke survivors themselves. This too will contribute to reduce the experienced fragmentation and complexities in outpatient rehabilitation.

However, these recommendations do not suit the ambition of our participation society, whereby short and intensive inpatient rehabilitation treatment and early discharge with self-management and support from the informal network are the rule. It can be doubted whether rehabilitation medicine, primary health care, and the social domain in the Netherlands are equipped to adequately support stroke survivors and their families in their own living environments, let alone at an earlier stage in rehabilitation treatment. My thesis provides input that helps to organize stroke care from the clinical setting through to

the home environment in a more comprehensive way, and perhaps therewith also in a more efficient way. To achieve this, after care should be replaced with care as a precaution. With these lessons learnt, we hope to have provided the foundation on which the bridge from the clinical environment to the home environment can be built.

## References

1. Green L. W. (2008). Making research relevant: if it is an evidence-based practice, where's the practice-based evidence?. *Family practice*, 25 Suppl 1, i20–i24.
2. Atkins, L., Kelly, M. P., Littleford, C., Leng, G., & Michie, S. (2017). Reversing the pipeline? Implementing public health evidence-based guidance in english local government. *Implementation science: IS*, 12(1), 63.
3. Bowen, S. J., & Graham, I. D. (2013). From knowledge translation to engaged scholarship: promoting research relevance and utilization. *Archives of physical medicine and rehabilitation*, 94(1 Suppl), S3–S8. <https://doi.org/10.1016/j.apmr.2012.04.037>
4. Aziz, N. A., Pindus, D. M., Mullis, R., Walter, F. M., & Mant, J. (2016). Understanding stroke survivors' and informal carers' experiences of and need for primary care and community health services--a systematic review of the qualitative literature: protocol. *BMJ open*, 6(1), e009244.
5. Krishnan, S., Pappadis, M. R., Weller, S. C., Stearnes, M., Kumar, A., Ottenbacher, K. J., & Reistetter, T. A. (2017). Needs of Stroke Survivors as Perceived by Their Caregivers: A Scoping Review. *American journal of physical medicine & rehabilitation*, 96(7), 487–505.
6. Cott, C. A., Wiles, R., & Devitt, R. (2007). Continuity, transition and participation: preparing clients for life in the community post-stroke. *Disability and rehabilitation*, 29(20–21), 1566–1574.
7. Lettinga, A. T., van Twillert, S., Poels, B. J., & Postema, K. (2006). Distinguishing theories of dysfunction, treatment and care. Reflections on 'describing rehabilitation interventions'. *Clinical rehabilitation*, 20(5), 369–374.
8. Siemonsma, P. C., Schroder, C. D., Dekker, J. H., & Lettinga, A. T. (2008). The benefits of theory for clinical practice: cognitive treatment for chronic low back pain patients as an illustrative example. *Disability and rehabilitation*, 30(17), 1309–1317.
9. van Twillert, S., Postema, K., Geertzen, J. H., Hemminga, T., & Lettinga, A. T. (2009). Improving rehabilitation treatment in a local setting: a case study of prosthetic rehabilitation. *Clinical rehabilitation*, 23(10), 938–947.
10. Whyte, J. (2006). Using treatment theories to refine the designs of brain injury rehabilitation treatment effectiveness studies. *Journal of Head Trauma Rehabilitation*, 21(2), 99–106.
11. Glasgow, R. E., Green, L. W., Klesges, L. M., Abrams, D. B., Fisher, E. B., Goldstein, M. G., Hayman, L. L., Ockene, J. K., & Orleans, C. T. (2006). External validity: we need to do more. *Annals of behavioral medicine : a publication of the Society of Behavioral Medicine*, 31(2), 105–108.
12. RVS. (2017). Zonder context geen bewijs. Over de illusie van evidence-based practice in de zorg. Den Haag: Raad voor Volksgezondheid en Samenleving.
13. Langhorne, P., Baylan, S., & Early Supported Discharge Trialists (2017). Early supported discharge services for people with acute stroke. *The Cochrane database of systematic reviews*, 7(7), CD000443.
14. Meyer, M. J., Teasell, R., Thind, A., Koval, J., & Speechley, M. (2016). A Synthesis of Peer-Reviewed Literature on Team-Coordinated and Delivered Early Supported Discharge After Stroke. *The Canadian journal of neurological sciences. Le journal canadien des sciences neurologiques*, 43(3), 353–359.
15. Fearon, P., Langhorne, P., & Early Supported Discharge Trialists (2012). Services for reducing duration of hospital care for acute stroke patients. *The Cochrane database of systematic reviews*, (9), CD000443.
16. Rousseaux, M., Daveluy, W., & Kozlowski, R. (2009). Value and efficacy of early supported discharge from stroke units. *Annals of physical and rehabilitation medicine*, 52(3), 224–233.
17. Bråndal, A., Eriksson, M., Glader, E. L., & Wester, P. (2019). Effect of early supported discharge after stroke on patient reported outcome based on the Swedish Riksstroke registry. *BMC neurology*, 19(1), 40. <https://doi.org/10.1186/s12883-019-1268-8>
18. Olson, D. M., & Juengst, S. B. (2019). The Hospital to Home Transition Following Acute Stroke. *The Nursing clinics of North America*, 54(3), 385–397.
19. Osborne, C. L., & Neville, M. (2019). Understanding the Experience of Early Supported Discharge from the Perspective of Patients with Stroke and Their Carers and Health Care Providers: A Qualitative Review. *The Nursing clinics of North America*, 54(3), 367–384.

20. McKevitt, C., Redfern, J., Mold, F., & Wolfe, C. (2004). Qualitative studies of stroke: a systematic review. *Stroke*, 35(6), 1499–1505.
21. Peoples, H., Satink, T., & Steultjens, E. (2011). Stroke survivors' experiences of rehabilitation: a systematic review of qualitative studies. *Scandinavian journal of occupational therapy*, 18(3), 163–171.
22. Green L. W. (2014). Closing the chasm between research and practice: evidence of and for change. *Health promotion journal of Australia: official journal of Australian Association of Health Promotion Professionals*, 25(1), 25–29.
23. Bowen, S., & Graham, I. D. (2015). Backwards design or looking sideways? knowledge translation in the real world Comment on "A call for a backward design to knowledge translation". *International journal of health policy and management*, 4(8), 545–547.
24. Mol A. (2006). Proving or improving: on health care research as a form of self-reflection. *Qualitative health research*, 16(3), 405–414.
25. Cameron, J. I., & Gignac, M. A. (2008). "Timing It Right": a conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient education and counseling*, 70(3), 305–314.
26. Cameron, J. I., Tsoi, C., & Marsella, A. (2008). Optimizing stroke systems of care by enhancing transitions across care environments. *Stroke*, 39(9), 2637–2643.
27. Pringle, J., Hendry, C., & McLafferty, E. (2008). A review of the early discharge experiences of stroke survivors and their carers. *Journal of clinical nursing*, 17(18), 2384–2397.
28. Salter, K., Hellings, C., Foley, N., & Teasell, R. (2008). The experience of living with stroke: a qualitative meta-synthesis. *Journal of rehabilitation medicine*, 40(8), 595–602.
29. Greenwood, N., & Mackenzie, A. (2010). Informal caring for stroke survivors: meta-ethnographic review of qualitative literature. *Maturitas*, 66(3), 268–276.
30. McKevitt, C., Redfern, J., Mold, F., & Wolfe, C. (2004). Qualitative studies of stroke: a systematic review. *Stroke*, 35(6), 1499–1505.
31. Hart, T., Dijkers, M. P., Whyte, J., Turkstra, L. S., Zanca, J. M., Packel, A., Van Stan, J. H., Ferraro, M., & Chen, C. (2019). A Theory-Driven System for the Specification of Rehabilitation Treatments. *Archives of physical medicine and rehabilitation*, 100(1), 172–180.
32. Kusec, A., Velikonja, D., DeMatteo, C., & Harris, J. E. (2019). Motivation in rehabilitation and acquired brain injury: can theory help us understand it?. *Disability and rehabilitation*, 41(19), 2343–2349.
33. Siemonsma, P. C., Schröder, C. D., Roorda, L. D., & Lettinga, A. T. (2010). Benefits of treatment theory in the design of explanatory trials: cognitive treatment of illness perception in chronic low back pain rehabilitation as an illustrative example. *Journal of rehabilitation medicine*, 42(2), 111–116.
34. Solvang, P. K., Hanisch, H., & Reinhardt, J. D. (2017). The rehabilitation research matrix: producing knowledge at micro, meso, and macro levels. *Disability and rehabilitation*, 39(19), 1983–1989.
35. Cresswell, T. (2004). *Place. A short introduction*, Oxford: Blackwell.
36. Massey, D. B. (2005). *For space*. London, UK: Sage Publications.
37. Tanner, B., Tilse, C., & DeJonge, D. (2008). Restoring and sustaining home: the impact of home modifications on the meaning of home for older people. *Journal of Housing for the Elderly*, 22(3), 195–215.
38. Scannell L & Gifford R. (2010). Defining place attachment: a tripartite organizing framework. *Journal of Environmental Psychology*, 30(1), 1–10.
39. Hernandez, B., Hidalgo, M.C., Salazar-Laplace, M.E., & Hess, S. (2007). Place attachment and place identity in natives and non-natives. *Journal of Environmental Psychology*, 27, 310–319.
40. Kyle, G., Mowen, A., Tarrant, M. (2004). Linking place preferences with place meaning: an examination of the relationship between place motivation and place attachment. *Journal of Environmental Psychology*, 24, 439–454.
41. Cresswell, T. (2011). Mobilities I: catching up. *Progress in Human Geography*, 35(4), 550–558.
42. Cresswell, T. (2012). Mobilities II: still. *Prog Hum Geogr*, 36(5), 645–653.
43. Sheller, M., & Urry, J. (2006). The new mobilities paradigm. *Environment and Planning A*, 38(2), 207–226.
44. Meijering, L., Theunissen, N., & Lettinga, A. T. (2019). Re-engaging with places: Understanding bio-geographical disruption and flow in adult brain injury survivors. *Social science & medicine (1982)*, 231, 22–30.

## Summary

Most stroke survivors and their families perceive the transfer from the rehabilitation clinic to home as an exciting yet difficult period. While going home is seen as an important milestone in the rehabilitation process, being home is accompanied with growing awareness of the impact of lasting disabilities on their lives. Rehabilitation professionals and researchers have noted that the functional skills taught in the rehabilitation clinic are barely preserved in the home environment. Upon returning home, many stroke survivors experience their attempts to take up life again as if they are falling into a black hole. They fall into a downward spiral of vitality loss, social isolation and grieve.

This thesis addresses the problematic integration of stroke survivors' skills learned in a rehabilitation environment to their own living environments. The aim of this thesis is 1) to gain a better understanding of the experienced gap between the rehabilitation and living environment of stroke survivors in the Netherlands, and 2) to help improve the transfer from the clinical setting to the home setting in stroke rehabilitation with help of research knowledge. The primary focus is on stroke survivors with moderate to severe disability in the Netherlands, who followed the rehabilitation route home after acute treatment of the stroke in a hospital.

To address these aims, I explored and integrated several knowledge sources, such as available evidence-based knowledge about organized stroke care, knowledge about lived experiences of stroke survivors and their families, and theoretical knowledge about home-making, place attachment and place identity developed in human geography and environmental psychology. This resulted in a better understanding of the gap between the clinical and home environment and in important implications and recommendations for rehabilitation practitioners and researchers.

**Chapter 1** forms the introduction to this thesis. It discusses the impact of stroke on both the society and for stroke survivors themselves and their families. It outlines the specific research questions of the thesis:

1. What evidence is available for organized stroke care, and what is the relevance and fit of it, for improving the transfer from the clinical to home environment?
2. How do stroke survivors and their families themselves experience their lives after in-patient rehabilitation, when being discharged home?
3. How can theoretical frameworks of home- and place-making contribute to a better understanding of the experienced gap between the clinical and home environment?

Moreover, it places the research questions into debates surrounding evidence-based practice, patient perspectives, and theory development in rehabilitation science.

**Chapter 2**, ‘Evidence, patient and caregivers’ knowledge in organized stroke care: an integrated review of reviews of quantitative and qualitative research’, provides the basis for the rest of this thesis. It consists of an integrative review of quantitative reviews on organized stroke care, and qualitative reviews on lived experiences of stroke survivors and their family caregivers. In so doing, it addresses the first and second research question of this thesis. The Chapter first explored the available quantitative evidence for organized stroke services in the whole chain of care and translates it in a user-friendly matrix for rehabilitation professionals. Best evidence was found for well-organized inpatient stroke units. Inconclusive evidence was available for home- and community outpatient services delivered in the chronic stage. There was also evidence for ‘Early Supported Discharge’ (ESD) services, but just for stroke survivors with mild to moderate stroke severity. This implies that the evidence on ESD is not directly applicable to the target population of this thesis: stroke survivors with moderate to severe disability. Moreover, the knowledge on stroke survivors’ needs and experiences summarized in qualitative reviews revealed that there was a poor fit between the outcomes measured in the post-discharge and chronic phase, and the problems experienced in these phases by stroke survivors and their families. This might partly explain the poor transfer from the clinical to the home environment. These insights resulted in the subsequent studies carried out in this thesis: 1) an evidence-informed Knowledge-to-Action study aimed at improving supported discharge for stroke patients with moderate to severe disability (**Chapter 3**), and 2) a theory-informed in-depth study of the differences in needs and lived experiences of stroke survivors between the rehabilitation, post-discharge and chronic phase (**Chapter 4**).

**Chapter 3**, ‘Combined Clinical and Home Rehabilitation: Case Report of an Integrated Knowledge-to-Action Study in a Dutch Rehabilitation Stroke Unit’, zooms in on a specific case where scientific evidence is translated into practice. It discusses an evidence-informed improvement process in a local rehabilitation setting in the Netherlands aimed at tailoring the Early Supported Discharge service to the needs of patients severely affected by stroke, resulting in Combined Clinical and Home Rehabilitation (CCHR) in an early stage. An integrated knowledge-to-action (KTA) approach was used to co-create knowledge and engage local therapists in a two-way knowledge translation and multidirectional learning process. This KTA-approach draws on sociological conceptions of science that aim to integrate scientific and stakeholder perspectives in local rehabilitation research. Local therapists welcomed CCHR because it helped them make their task-specific training context-specific. But there were barriers to structural implementation such as travel time, logistical problems, partitioning walls between financing streams,

## Summary

and legislative procedures. It was concluded that improving local settings with available evidence is not a straightforward application process, but rather a matter of searching, reasoning and working creatively with heterogeneous knowledge sources in partnership with different stakeholders. Informed by practical, contextual, and research knowledge, it was suggested that individual coaching of survivors of stroke and family caregivers rather than multidisciplinary treatment should be pivotal in home- and community-based rehabilitation. Combined coaching at home (face-to-face) and over distance (screen-to-screen) was proposed as an alternative that could contribute to regional challenges.

In **Chapter 4**, 'Place attachment in stroke rehabilitation: a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine', the experienced gap between clinical and home setting is further explored by taking the bonds between stroke survivors and meaningful places as object of study. Aim of this cross-disciplinary encounter between rehabilitation medicine, human geography and environmental psychology was to increase understanding of the support that stroke survivors and their families need to successfully renegotiate their attachment to meaningful places, first in the rehabilitation clinic and subsequently at home and in the community. Through conducting semi-structured in-depth interviews with stroke survivors and their family caregivers with regard to the clinical, post-discharge and re-integration phases while considering people-place-relationships, this chapter connects research questions two and three. This study revealed that stroke survivors develop a different sense of longing in each phase. They longed for physical recovery and domestic places in the clinical phase, for pre-stroke activities and roles in the post-discharge phase and for recognition and a sense of belonging in the reintegration phase. Stroke survivors' selves had changed, while the spatial and social contexts of their homes and other places in their living environments had remained the same. To improve the transfer from the clinical to the home setting it was recommended that: 1) the experienced self-body split, identity confusion and related mourning process rather than functional recovery should be foregrounded in the post-discharge process; 2) in the post-discharge and reintegration phases stroke survivors should be coached to help them rebuilding meaningful relationships with their bodies, homes and communities; and 3) this so-called home-making process should start at real-life sites where stroke survivors wish to (inter) act. This called for more in-depth knowledge about the meaning of home with respect to post-stroke-identities, which is the topic of **Chapter 5**.

**Chapter 5**, 'Home-making after stroke. A qualitative study among Dutch stroke survivors', discusses the home-making process of stroke survivors and, to a smaller extent that of their family caregivers, in more detail. With help of a cultural and gerontological geographical lens, the home was conceptualized as a material and affective space, shaped

by people's everyday practices, experiences, social relations, memories and emotions. Aim was to provide insight into what provides stability and a sense of being anchored to home, through zooming in to the experiences of stroke survivors who have brusquely lost these anchors. Individual interviews with stroke survivors with moderate to severe disability and a focus interview with informal caregivers formed the research material for this study. This study showed that formerly stable bodily routines became time consuming and demanding. It also demonstrated that pre-stroke social routines, roles and relationships needed to be adjusted, to recreate a sense of home. This instability in routines did not only impact the identities of stroke survivors themselves, but also those of their partners and children. Each stroke survivor faced a different struggle to accommodate their changed selves in an unchanged house, which did not feel like home anymore. The findings implied that stroke rehabilitation has to develop interventions that help to strengthen the home-making process in all its complexity. In addition to modifications to the physical house, it is important to assist stroke survivors and their families in re-creating social routines, roles and relations, and thus with re-positioning their pre-stroke identities and homes. Indeed, such routines and relations appear to have the potential to provide a renewed sense of stability at home. This led to a further exploration of the connection between home and outside world through the concept of mobility in **Chapter 6**.

In **Chapter 6**, 'Unpacking community mobility: a preliminary study into the embodied experiences of stroke survivors', places the topic of mobility in rehabilitation research and practice in a social-spatial light. Inspired by the 'mobility turn' in social sciences mobility was conceptualized as a set of heterogeneous material practices rather than an individuals' ability to move from A to B. Aim of this chapter is to enrich the discussion on mobility in stroke rehabilitation by articulating the practical knowledge of stroke survivors about their (im)mobilities at the places where they wish to (inter)act. A secondary analysis of the previously mentioned interview data was carried out. This study revealed the complexities of stroke survivors' mobility in three different ways. The first complexity that emerged was that stroke survivors' mobility differs from one context to the other. Because moving around in different private and public spaces involves dealing with different human actors (such as children, partners, passengers) and non-human actors (such as staircase winders, bars, door bells and traffic rules), stroke survivors have to learn and negotiate their mobility anew in each context. The second complexity was that stroke survivors' mobility appeared to be full of ambivalences and tensions. They had to balance exercise and training, family and working life, and leisure and pleasure, by making small alternations to their social-spatial environments, such as taking stairs against the crowd in the absence of a lift, relying on a mobility scooter to provide relief for family caregivers, and taking an efficient shopping list as route through the super market to save time and energy. The third complexity was that mobility is impacted by different resources in terms

## Summary

of income, pre-stroke working conditions and social support. The bureaucratic logic and fragmentation of the health care system meant a never-ending story of applying for mobility aids, driving licenses, transport compensations, and so on. To be able to deal with these complexities, it was recommended that rehabilitation medicine needs to consider community mobility as a way to connect places that are meaningful to individuals rather than as movement from A to B. This implied that mobility issues in the participation domain need to be considered in “how they hang together” rather than distinguished in different disciplinary domains. For that reason, clinical outcome measurements, such as a 10-meter walk test, appeared to be inadequate for evaluating mobility at home and in the community. It was concluded that the current focus on adherence to mobility and exercise training at home needs to be critically reviewed, as it does not capture the multiplicities of mobility embodied in real-life settings.

In the concluding **Chapter 7**, the findings from the **Chapters 2-6** are summarized and positioned to the literature. This thesis shows that in order to be able to improve local care practices, besides evidence-based research knowledge, other knowledge sources are to be incorporated in the improvement process, like practical and contextual knowledge from professionals and experience-based knowledge from stroke survivors and caregivers. This implies that research aimed at improving rehabilitation practice should be more open, iterative, cyclic and multi-actor of character than the linear and one-directional evidence-based practice research that has been established in rehabilitation practice to prove its effectiveness. The qualitative studies showed that the complexities of life post-stroke need serious attention and definitely another focus at home and in the community. The differences, between the physical, social and personal dimensions of the places in the clinical and home setting, need to be taken into account in improving the clinic home transfer. The process of re-owning your body requires a different theory than the process of re-owning your life. Looking at the experiences of stroke survivors at home through the lens of spatial and human geographical concepts enabled a shift in focus towards the network of important places where their life takes place, away from a body with lost functions.

An important practical insight that resulted from our study is what you learn in one place has to be adapted to every social-spatial context anew. Hence, the gap between the clinic and home, is not a transfer problem, but a translation problem. Instead of trying to make stroke survivors comply with the lessons learnt in the clinic, rehabilitation therapists should try to help them to translate these lessons to the different places where their clients wish to interact and re-integrate. In order to be successful at this, this has to be done place by place and not in all places at once. Rehabilitation can improve the transfer from the clinical to the home setting by understanding the living environments of stroke survivors in terms of a network of real-life places that are meaningful to them.

This thesis provides input that helps to organize stroke care from the clinical setting through to the home environment in a more comprehensive and efficient way. The complexities stroke survivors and their families have to cope with in their own living environments call for the support of professionals who are aware of the many aspects of home- and place-making after returning home. In outpatient rehabilitation services it is recommended to have one central professional, who acts as a multi-problem coach, and assists stroke survivors post-discharge in rebuilding meaningful and interconnected relationships with their bodies, homes and communities again. Here, the focus should be on places and people that are important for stroke survivors themselves. This too will contribute to reduce the experienced fragmentation and complexities in outpatient rehabilitation. To achieve this, after care should be replaced with care as a precaution.

## Samenvatting

Na een beroerte of cerebrovasculair accident (CVA) ervaren de meeste mensen en hun familie de overgang van de revalidatiekliniek naar huis als een spannende, maar vooral ook moeilijke periode. 'Naar huis gaan' is een belangrijke mijlpaal in het revalidatieproces, maar 'thuis zijn' gaat vaak gepaard met een groeiend bewustzijn van de invloed van blijvende beperkingen op hun leven. Ook revalidatieprofessionals en onderzoekers geven in dit verband aan dat de functionele vaardigheden die in de revalidatiekliniek worden aangeleerd, moeilijk in de eigen leefomgeving beklijven. Bij thuiskomst ervaren veel CVA-getroffenen, in hun pogingen om hun leven weer op te pakken, dat ze in een zwart gat vallen. Ze komen in een neerwaartse spiraal van vitaliteitsverlies, sociaal isolement en gevoelens van verlies terecht.

Dit proefschrift behandelt de problematische integratie van geleerde vaardigheden in de kliniek naar de thuisomgeving van CVA-getroffenen. Het doel van dit proefschrift is tweeledig: 1) een beter inzicht krijgen in de ervaren kloof tussen de revalidatieomgeving en de eigen leefomgeving van CVA-getroffenen in Nederland, en 2) de overdracht van het geleerde in de revalidatieomgeving naar de eigen leefomgeving van getroffen en met behulp van wetenschappelijke kennis verbeteren. De primaire focus ligt op CVA-getroffenen met matige tot ernstige beperkingen die na een periode van multidisciplinaire behandeling in een revalidatie instelling weer naar huis gaan.

Om bovengenoemde doelen te bereiken hebben we verschillende kennisbronnen verkend en geïntegreerd, zoals 'evidence-based' kennis over georganiseerde CVA-zorg, ervaringskennis van CVA-getroffenen en hun families. Daarnaast hebben we gebruik gemaakt van theoretische kennis over 'home-making', 'place attachment' en 'place identity', zoals ontwikkeld in de sociale geografie en omgevingspsychologie. Dit heeft geleid tot beter inzicht en begrip van de kloof tussen klinische en thuisomgeving en tot belangrijke implicaties en aanbevelingen voor revalidatieprofessionals en revalidatieonderzoekers.

**Hoofdstuk 1** vormt de inleiding van dit proefschrift. Het bespreekt de impact van cerebrovasculaire aandoeningen op de samenleving in het algemeen, en op CVA-getroffenen en hun families in het bijzonder. Dit hoofdstuk beschrijft ook de specifieke onderzoeksvragen van het proefschrift:

1. Welk bewijs is beschikbaar voor de verschillende vormen van georganiseerde CVA-zorg en wat is de relevantie en geschiktheid ervan voor het verbeteren van de overdracht van het geleerde in de revalidatiekliniek naar de eigen leefomgeving?

2. Hoe ervaren CVA-getroffenen en hun naasten hun leven na ontslag uit een revalidatiecentrum?

3. Hoe kunnen theoretische kaders van 'home-making' en 'place-making' bijdragen aan een beter inzicht in de ervaren kloof tussen de klinische en thuisomgeving?

Met deze onderzoeksvragen levert dit proefschrift ook een bijdrage aan discussies die gaan over de waarde van 'evidence-based practice', van het patiënten perspectief en van theorie ontwikkeling in de revalidatiewetenschappen.

**Hoofdstuk 2** 'Evidence and patient and caregivers' knowledge in organized stroke care: an integrated review of reviews of quantitative and qualitative research', bestaat uit een review, waarin 'evidence-based kennis' over georganiseerde CVA zorg uit kwantitatieve reviews, en ervaringskennis van CVA-getroffenen en hun mantelzorgers samengevat in kwalitatieve reviews, inhoudelijk met elkaar in verband worden gebracht. Dit hoofdstuk, dat de basis vormt voor de andere hoofdstukken in dit proefschrift, verbindt hiermee de eerste en tweede onderzoeksvraag. Het hoofdstuk maakt eerst inzichtelijk wat er aan 'objectief' bewijs beschikbaar is voor georganiseerde revalidatiezorg in de hele CVA-keten en vertaalt deze kennis vervolgens in een gebruiksvriendelijke matrix voor revalidatieprofessionals. Het beste bewijs werd gevonden voor goed georganiseerde multidisciplinaire 'stroke units', zowel in de acute als revalidatiefase. Er bleek geen overtuigend bewijs beschikbaar voor poliklinische en thuis revalidatie in de chronische fase. Wel bleek er bewijskracht te zijn voor 'Early Supported Discharge' (ESD), dus voor vervroegd ondersteund ontslag, maar dan alleen voor CVA-getroffenen die met milde tot matige beperkingen klinisch waren opgenomen. Omdat dit promotieonderzoek zich richt op CVA-getroffenen met matige en ernstige beperkingen die worden behandeld in revalidatiecentra, bleek het bewijs voor ESD niet direct toepasbaar op de doelgroep van dit proefschrift. Ook bleek uit de kwalitatieve reviews dat uitkomstmaten die centraal stonden in de kwantitatieve reviews niet goed aansloten bij de ervaren problemen van CVA-getroffenen en hun families in de thuisomgeving, dus na ontslag uit de kliniek. Dit verschil in gemeten uitkomsten en ervaren problemen en behoeften kan de problematische overgang van de klinische omgeving naar de thuisomgeving voor een deel verklaren.

Deze nieuwe inzichten hebben geresulteerd in twee vervolgonderzoeken voor dit proefschrift: 1) een wetenschappelijk onderbouwde 'Knowledge-to-Action'-studie gericht op het verbeteren van ondersteund ontslag bij CVA-getroffenen met matige tot ernstige beperkingen (**hoofdstuk 3**), en 2) een kwalitatief onderzoek naar verschillen in behoeften en ervaringen van CVA-getroffenen tussen de revalidatiefase, de ontslagfase en de chronische fase (**hoofdstuk 4**).

**Hoofdstuk 3**, 'Combined Clinical Home Rehabilitation CCHR): case report of an integrated Knowledge-to-Action Study in a Dutch rehabilitation stroke unit', zoomt in op een specifieke revalidatiesetting waar wetenschappelijk bewijs wordt vertaald naar de praktijk. Het bespreekt een empirisch onderbouwd verbeteringsproces in een lokale revalidatiesetting in Nederland, gericht op het afstemmen van 'evidence-based' kennis over 'Early Supported Discharge' op de behoeften van ernstig beperkte CVA-getroffenen. Dit resulteerde in een praktijkexperiment met 'Gecombineerde Klinische Thuisrevalidatie' in een vroeg stadium van klinische revalidatie. Een geïntegreerde 'Knowledge-to-Action' (KTA) benadering werd gebruikt om lokale therapeuten te betrekken bij de vertaling en uitwisseling van kennis in een gezamenlijk leer- en verbeterproces. Deze KTA-benadering gebruikt wetenschappelijke inzichten uit de sociologie om perspectieven van onderzoekers en belanghebbenden in de praktijk te integreren in lokaal revalidatieonderzoek. De therapeuten die participeerden in het actieonderzoek verwelkomden het gecombineerd oefenen in de klinische en thuisomgeving, omdat het hen hielp hun taak-specifieke training daadwerkelijk context-specifiek te maken. Maar praktische en organisatorische obstakels, zoals kostbare reistijd, logistieke zaken, schotten tussen financieringsstromen en wet- en regelgevingsprocedures, zaten structurele implementatie in de weg. Geconcludeerd werd dat 'evidence-based-practice' niet als een rechtstreeks toepassingsproces van wetenschappelijk bewijs naar lokale praktijken gezien moet worden. In plaats daarvan is het meer een kwestie van zoeken, redeneren en creatief werken met heterogene kennisbronnen in partnerschap met verschillende belanghebbenden. Door de praktische, contextuele en onderzoekskennis op elkaar te betrekken ontstond het inzicht dat het individueel coachen van CVA-getroffenen en hun naasten in de thuisomgeving, en dus niet multidisciplinaire revalidatiebehandeling, van cruciaal belang is voor re-integratie in de maatschappij. Gecombineerde coaching aan huis (face-to-face) en over afstand (screen-to-screen) werd als nieuwe oplossingsrichting aangedragen om de praktische problemen uit de weg te ruimen en waar mogelijk ook de meer hardnekkige organisatorische uitdagingen aan te gaan.

In **hoofdstuk 4**, 'Place attachment in stroke rehabilitation: a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine', wordt de ervaren kloof tussen de klinische en de thuissituatie verder onderzocht door de ervaringen van CVA-getroffenen en hun naasten in een sociaal-ruimtelijk perspectief te plaatsen. Het doel van de interdisciplinaire samenwerking tussen revalidatie en ruimtelijke wetenschappen was te onderzoeken wat CVA-getroffenen en hun families nodig hebben om opnieuw en met succes verbondenheid te voelen met betekenisvolle plekken, eerst in de revalidatiekliniek en vervolgens thuis en in de samenleving. Door middel van semi-gestructureerde interviews met CVA-getroffenen en hun mantelzorgers over hun ervaringen, behoeften en verlangens in de revalidatiefase, ontslagfase en chronische fase, verbindt dit hoofdstuk onderzoeksvraag twee en drie. Dit kwalitatieve onderzoek toonde aan dat CVA-getroffenen in elke fase van

herstel andere verlangens ontwikkelden. Ze verlangden naar fysiek herstel en huiselijke plekken in de klinische fase, naar activiteiten en rollen vóór de beroerte in de fase na ontslag, en naar herkenning en een gevoel van verbondenheid in de chronische fase. Het eigen 'ik' van CVA-getroffenen was veranderd, terwijl de ruimtelijke en sociale context van hun huizen en andere plekken in hun leefomgeving hetzelfde was gebleven. Om de overgang van de revalidatieomgeving naar de eigen leefomgeving te verbeteren, werd aanbevolen dat: 1) na de ontslagfase niet functioneel herstel maar de ervaren 'lichaam-zelf split', de identiteitsverwarring en het gerelateerde rouwproces op de voorgrond zouden moeten komen te staan; 2) in de ontslagfase en re-integratiefase zouden CVA-getroffenen en hun naasten gecoacht moeten worden om hen te helpen hun lichaam weer eigen te maken en van hun huis en andere betekenisvolle plekken in hun leven weer een thuis te maken; en 3) dit zogenoemde 'home-making' proces zou moeten beginnen op echte plekken die er CVA-getroffenen toe doen. Dit vereiste meer diepgaande kennis over de betekenis van thuis met betrekking tot identiteit na een CVA, wat het onderwerp is van **hoofdstuk 5**.

**Hoofdstuk 5**, 'Home-making after stroke. A qualitative study among Dutch stroke survivors', gaat verder in op het 'home-making' proces van CVA-getroffenen en hun mantelzorgers. (T)huis wordt in dit hoofdstuk door een sociale en gerontologische geografische lens bekeken en beschouwd als een materiële en affectieve ruimte, gevormd door de dagelijkse praktijk, ervaringen, sociale relaties, herinneringen en emoties van mensen. Het doel van deze sociaal geografische studie was om inzicht te geven in wat stabiliteit en een gevoel van verankering aan huis biedt, door in te zoomen op de ervaringen van mensen die deze ankers abrupt hebben verloren, zoals in dit promotieonderzoek CVA-getroffenen. Individuele interviews met CVA-getroffenen met matige tot ernstige beperkingen en een focusgroep interview met mantelzorgers vormden het onderzoeksmateriaal voor dit onderzoek. Dit onderzoek toonde aan hoe lichamelijke routines, die voorheen stabiel waren, tijdrovend en veeleisend werden. Het toonde ook aan dat de sociale routines, rollen en relaties van voor het CVA moesten worden aangepast om een thuisgevoel te creëren. Deze instabiliteit in routines had niet alleen invloed op de identiteit van CVA-getroffenen zelf, maar ook op die van hun naasten. Iedere deelnemer streed zijn of haar eigen strijd om hun veranderde 'ik' aan te passen aan een huis dat hetzelfde was gebleven, en niet meer als thuis voelde. Deze bevindingen impliceren dat de neurorevalidatie een aanpak zou moeten ontwikkelen die het home-making proces in al zijn complexiteit helpt versterken. Naast fysieke aanpassingen aan het huis, is het belangrijk om CVA-getroffenen en hun naasten te helpen bij het opnieuw inhoud geven aan sociale routines, rollen en relaties op plekken die voor hen belangrijk zijn, en dus bij het herpositioneren van hun identiteit en thuisgevoel vóór de beroerte. Dergelijke routines en relaties lijken inderdaad het potentieel te hebben om thuis een hernieuwd gevoel van stabiliteit te geven. Dit heeft geleid tot een verdere verkenning van de verbondenheid tussen thuis en de buitenwereld door middel van het concept mobiliteit in **hoofdstuk 6**.

In **hoofdstuk 6**, 'Unpacking community mobility: a preliminary study into the embodied experiences of stroke survivors', wordt het thema mobiliteit in het onderzoek en de praktijk van de revalidatiegeneeskunde in een sociaal-ruimtelijk licht geplaatst. Geïnspireerd door de 'mobility turn' in de sociale wetenschappen wordt mobiliteit in dit hoofdstuk geconceptualiseerd als een set van heterogene materiële praktijken, in plaats van het vermogen van een individu om van A naar B te verplaatsen. Het doel van dit hoofdstuk is om de discussie over mobiliteit in de neurorevalidatie te verrijken door ervaringskennis van CVA-getroffenen over hun (in)mobiliteit te openbaren aan de hand van plekken waar ze graag willen (inter)acteren. Het betreft een secundaire analyse van interviewgegevens die voor hoofdstuk 4 en 5 zijn verzameld. Deze studie laat de complexiteit van het thema mobiliteit van CVA-getroffenen op drie verschillende manieren zien. De eerste complexiteit die naar voren kwam was dat de mobiliteit van getroffenen verschilt tussen de ene context en de andere. Omdat het bewegen in verschillende private en publieke ruimtes te maken heeft met het omgaan met verschillende menselijke actoren (zoals kinderen, partners, voorbijgangers) en niet-menselijke actoren (zoals smalle treden, leuningen, deurbellen en verkeersregels), moeten getroffenen leren om in iedere context opnieuw hun mobiliteit af te stemmen op de omgeving waarin ze verkeren. De tweede complexiteit was dat de mobiliteit van CVA-getroffenen vol ambivalenties en spanningen zit. Ze moesten oefening en training, gezin en werk, en vrije tijd en plezier met elkaar in evenwicht brengen, door het maken van kleine wijzigingen in hun sociaal-ruimtelijke omgeving, zoals het nemen van trappen tegen de menigte in als er geen lift aanwezig was, aanschaffen van een scootmobiel om hun mantelzorgers te ontzien en het gebruik maken van een efficiënte boodschappenlijst als route door de supermarkt om tijd en energie te besparen. De derde complexiteit was dat mobiliteit wordt beïnvloed door verschillende omstandigheden in termen van inkomen, arbeidscondities vóór de beroerte en beschikbare sociale ondersteuning. De bureaucratische logica en versnippering van het gezondheidszorgsysteem leidde tot eindeloze onderhandelingen met instanties over het aanvragen van mobiliteitshulpmiddelen, rijbewijzen, transportvergoedingen, enzovoort. Om beter met deze complexiteit om te kunnen gaan, zou de revalidatiegeneeskunde er goed aan doen mobiliteit in de thuisomgeving te beschouwen als een manier om plekken te verbinden die betekenisvol voor individuen zijn, in plaats van het vooral te zien als een verplaatsing van A naar B. Dit impliceert dat het nodig is om mobiliteitskwesties in het participatiedomein te bezien in "hoe ze samenhangen", in plaats van ze te onderscheiden in taakgebieden van verschillende revalidatiedisciplines. Dit maakt ook dat klinische uitkomstmaten, zoals de 10-meter looptest, niet geschikt zijn om de mobiliteit in de thuisomgeving te evalueren. Ook studies die op basis van dit soort uitkomstmaten voor behoud van resultaat fitness training thuis aanbevelen, zouden in dit licht kritisch moet worden herzien, aangezien dit soort maten niet de complexiteit van mobiliteit meewegen, waar CVA-getroffenen in hun dagelijkse leven wel voortdurend mee worden geconfronteerd.

In het afsluitende **hoofdstuk 7** worden de bevindingen uit de **hoofdstukken 2-6** samengevat en afgezet tegen de literatuur. Dit proefschrift laat zien dat om lokale revalidatiesettings te kunnen verbeteren, naast ‘evidence-based’ kennis, andere kennisbronnen moeten worden meegenomen in het verbeterproces, zoals praktische kennis van revalidatieprofessionals, contextuele kennis van organisaties en ervaringskennis van CVA-getroffenen en hun naasten. Dit houdt in dat onderzoek dat gericht is op verbetering van de revalidatiepraktijk een meer open, iteratief, cyclisch, meerlagig en multi-actor karakter moet hebben, vergeleken met de meer gestandaardiseerde, lineaire en rechtstreekse aanpak van evidence-based praktijkonderzoek dat in de revalidatiegeneeskunde wordt uitgevoerd om de effectiviteit van interventies te bewijzen. Uit de kwalitatieve studies blijkt dat de complexiteit van het leven na een CVA serieuze aandacht nodig heeft en zeker een andere focus dan in de revalidatiekliniek nodig is. Het proces om je lichaam weer eigen te maken vereist een andere theorie dan het proces om je leven opnieuw eigen te maken. Door de ervaringen van CVA-getroffenen in de thuisomgeving te bekijken door een sociaal-ruimtelijke lens, kon de focus verschuiven van een lichaam met verloren gegane functies naar een netwerk van persoonlijk belangrijke woon-, werk- en vrijetijdsplekken.

Een belangrijk praktisch inzicht uit ons onderzoek is dat wat je op één plek leert, op elke andere plek weer opnieuw moet worden afgestemd op de sociaal-ruimtelijke context van die specifieke plek. Daarom moet de kloof tussen de kliniek en thuis niet gezien worden als een overdrachtsprobleem, maar als een vertaalprobleem. In plaats van te proberen CVA-getroffenen therapietrouw bij te brengen, doen revalidatieprofessionals er beter aan hen te helpen de geleerde lessen in de kliniek te verplaatsen en te vertalen naar de plekken waar ze graag weer willen interacteren en re-integreren. Om hierin succesvol te zijn, moet dit plek voor plek gebeuren en niet op alle plekken tegelijk. De revalidatiegeneeskunde kan de overgang van de klinische omgeving naar de thuisomgeving voor CVA-getroffenen dus verbeteren door hun levens te begrijpen in termen van een netwerk van plekken dat voor, na en voorbij hun hersenletsel betekenisvol was, is of kan zijn.

Dit proefschrift levert input die helpt om de neurorevalidatie-zorg op een meer samenhangende en efficiënte manier te organiseren. De complexiteit waarmee CVA-getroffenen en hun families in de eigen leefomgeving te maken krijgen, vraagt om ondersteuning van professionals die zich bewust zijn van de vele aspecten van ‘home- en place making’ die in dit proefschrift naar voren zijn gekomen. Aanbevolen wordt om in de poliklinische en thuisrevalidatie één centrale professional aan te stellen, die optreedt als een multi-actor coach en CVA-getroffenen helpt bij het opnieuw opbouwen van betekenisvolle en onderling verbonden relaties met hun lichaam, huis en leefomgeving. Hier moet de focus komen te liggen op plekken en mensen die voor getroffen zelf belangrijk zijn. Dit kan bijdragen aan het verminderen van de ervaren versnippering en complexiteit in de eerste lijn. Om dit te bereiken zou nazorg vervangen moeten worden door voorzorg.

## Research Institute (SHARE) and previous dissertations

This thesis is published within the **Research Institute SHARE** (Science in Healthy Ageing and healthcaRE) of the University Medical Center Groningen / University of Groningen. Further information regarding the institute and its research can be obtained from our internet site: <http://www.share.umcg.nl/>

More recent theses can be found in the list below.

(supervisors are between brackets)

### 2020

#### **Jong LA de**

Health economics of direct oral anticoagulants in the Netherlands

*(prof MJ Postma, dr M van Hulst)*

#### **Diemen MCJM van**

Self-management, self-efficacy, and secondary health conditions in people with spinal cord

*(prof MWM Post, prof JHB Geertzen, dr I van Nes)*

#### **Jacobs MS**

Anticoagulation in atrial fibrillation; consideration for treatment and health economic aspects

*(prof MJ Postma, dr M van Hulst, dr RG Tieleman)*

#### **Baars ECT**

Trans-tibial prosthesis fitting and prosthesis satisfaction

*(prof JHB Geertzen, prof PU Dijkstra)*

#### **Slagt-Tichelman E**

Mother-to-infant bonding: determinants and impact in child development; challenges for maternal health care

*(prof MY Berger, prof FG Schellevis, dr H Burger)*

**Steenbergen HA**

Healthy lifestyle of people with intellectual disabilities; implementation and maintenance of lifestyle approaches within healthcare organizations

*(prof CP van der Schans, dr A Waninge, dr J de Jong)*

**Politiek K**

The challenge of hand eczema; pathogenesis, treatment, and burden of disease

*(dr MLA Schuttelaar, prof PJ Coenraads)*

**Akhbari Ziegler S**

Implementation of COPCA; a family centred early intervention programme in infant physiotherapy

*(prof M Hadders-Algra, prof M Wirz, dr T Hielkema)*

**Brouwer SI**

Motor milestones, physical activity, overweight and cardiometabolic risk; from birth to adolescence

*(prof RP Stolk, dr E Corpeleijn)*

**Lu C (Congchao)**

Physical activity and health in Dutch and Chinese children

*(prof E Corpeleijn, prof R Stolk)*

**Oosterwijk A**

From range of motion to function; loss of joint flexibility after burns: when is it a problem?

*(prof CP van der Schans, dr LJ Mouton, dr MK Nieuwenhuis)*

**Veen MM van**

Facial palsy; treatment, quality of life, and assessment

*(prof PMN Werker, prof PU Dijkstra)*

**Mooij R**

Improving quality of maternal and perinatal care in rural Tanzania

*(prof J Stekelenburg, dr J van Dillen)*

**Bunt S**

Frailty among older adults; exploring the social dimension

*(prof CP van der Schans; prof BJM Steverink; dr JSM Hobbelen)*

**Mousavi SH**

A step forward in running-related injuries

(*prof J Zwerver, prof RL Diercks, dr JM Hijmans*)

09.09.2020 PHR

**Lip SV**

The effects of preeclampsia on the maternal cardiovascular system; gene expression and its (epigenetic) regulation in experimental preeclamptic cardiovascular tissues and cells

(*prof T Plösch, dr MM Faas, prof SA Scherjon*)

**Renting N**

Clinical workplace learning today; how competency frameworks inform clinical workplace learning (and how they do not)

(*prof ROB Gans, prof ADC Jaarsma, prof JCC Borlefs*)

**Rietkerk W**

Tailoring care for older adults; understanding older adults goals and preferences

(*prof SU Zuidema, prof JPJ Slaets, prof DL Gerritsen*)

**Aalst RTA van**

An economic assessment of high-dose influenza vaccine

(*prof MJ Postma, prof JC Wilschut*)

For earlier theses visit our website



## Dankwoord

Na vele jaren sluit ik hierbij een mooie periode af. Een periode die startte toen ik nog in Groningen woonde en het moment dat ik besloot om mijn werk als fysiotherapeut te combineren met onderzoek. In 2008 ben ik gestart met een promotietraject wat uiteindelijk heeft geleid tot dit proefschrift. Dit proefschrift is er gekomen door veel mensen die mij hebben begeleid en gesteund en een aantal wil ik hierbij persoonlijk bedanken.

Allereerst wil ik alle CVA-patiënten en hun families bedanken die hebben meegewerkt aan dit onderzoek. Zonder jullie input was dit proefschrift er niet geweest. Bedankt voor het delen van jullie ervaringen, wensen en behoeften en voor jullie openheid en eerlijkheid. Ik was best aangeslagen en ook teleurgesteld tijdens het afnemen van de interviews toen ik beseftte dat zoveel mensen na een CVA in een zwart gat belanden na thuiskomst. Ik hoop dat dit proefschrift een bijdrage levert aan het verbeteren van de overgang van de revalidatiekliniek naar de eigen leefomgeving en dat dit verbeterproces door mag blijven gaan.

In het bijzonder wil ik mijn promotieteam bedanken, mijn beide promotoren Klaas Postema en Louise Meijering en mijn copromotoren Ant Lettinga en Marleen Schönherr. Ik wil jullie bedanken voor de prettige samenwerking, voor de altijd kritische en opbouwende commentaren die ik kreeg op mijn stukken en voor het sparren tijdens de besprekingen. Ik ben jullie heel veel dank verschuldigd en vooral voor het geduld dat jullie hebben gehad, waardoor ik de ruimte kreeg om naast mijn promotietraject ook helemaal te kunnen genieten van mijn gezin. Daarbij hebben jullie altijd laten weten vertrouwen te hebben in het afronden van mijn promotietraject. Ook toen ik verhuisde naar Gorinchem en de communicatie meer op afstand moest plaatsvinden.

Beste Klaas, ondanks dat je al met pensioen bent en ik je laatste promovendus bent, heb je altijd voor me klaar gestaan. Je hebt me veel vrijheid gegeven voor de invulling van het onderzoek. Het week af van de gebaande paden, maar jij hebt altijd open gestaan voor vernieuwing van de revalidatie en hebt mij de ruimte gegeven om te experimenteren. Bedankt voor je brede blik en voor je vertrouwen. Jij zorgde er altijd voor dat, tijdens het schrijven van een artikel of tijdens overlegmomenten, de rode draad duidelijk bleef en zorgde altijd voor waardevol en kritisch commentaar.

Beste Louise, jij hebt ervoor gezorgd dat mijn proefschrift verder vorm en inhoud heeft gekregen door de vernieuwende ruimtelijke concepten. Door met een andere bril (een sociaal geografische bril) naar de data te kijken heeft geleid tot nieuwe inzichten voor de revalidatie van CVA patiënten. Ik heb veel van je geleerd en je hebt me laten inzien hoe ontzettend waardevol een samenwerking buiten je eigen kaders kan zijn. Bedankt voor je snelle en nauwgezette reflectie en je schrijfkunst.

Beste Ant, dubbel dank voor jouw begeleiding en voor de mooie samenwerking. Zonder jou was het proefschrift er niet geweest. Jouw enthousiasme, energie, gedrevenheid en kritische blik op mijn stukken hebben dit proefschrift gevormd. Ik heb zoveel van je geleerd op het gebied van kwalitatief onderzoek en het doen van interdisciplinair onderzoek. Ik kon altijd bij je terecht. Bedankt voor het schrijven, analyseren, sparren en filosoferen over wat er nodig zou zijn om de revalidatie voor CVA patiënten te veranderen.

Beste Marleen, jij ook heel erg bedankt voor je begeleiding, inzet, vertrouwen en mogelijkheid om het onderzoek uit te voeren op de afdeling neurorevalidatie. Het is niet altijd makkelijk geweest, omdat we nieuwe paden gingen bewandelen, maar je gaf me wel de ruimte om te experimenteren.

De leden van de leescommissie, prof. dr. E Buskens, prof. dr. JMA Visser-Meily en prof. dr. ir. HH Haisma, wil ik bedanken voor het lezen en beoordelen van dit proefschrift.

Daarnaast wil ik ook Linden Douma en Jelle Straatsma bedanken, destijds studenten sociale geografie, die een deel van de interviews hebben afgenomen.

Dat een proefschrift alleen tot stand kan komen met behulp van anderen blijkt wel uit het feit dat de pilotstudy heeft plaatsgevonden op de afdeling neurorevalidatie van het centrum voor revalidatie UMCG locatie Beatrixoord in Haren. Betty Feringa, bedankt voor je vertrouwen in het onderzoek en je medewerking zodat het kon plaatsvinden op de afdeling. Daarnaast wil ik alle inmiddels oud-collega's bedanken van de neurorevalidatie afdeling. De pilotstudy, waaraan jullie hebben meegewerkt vormt de basis van dit proefschrift, mijn dank daarvoor. En natuurlijk in het bijzonder mijn collega's van de fysiotherapie, wat was het fijn om met jullie samen te werken en bedankt voor jullie input en steun. En in het bijzonder Froukje, Anneke L. en Anna, ook al is onze afstand onderling toegenomen, onze vriendschap blijft.

Ik heb veel plezier beleefd aan het doen van onderzoek, maar alle dingen die ik nog meer ondernam, waaronder basketbal, hebben gezorgd voor een prettige afleiding waar ik veel energie uit haalde om weer met frisse energie door te gaan met het onderzoek.

Ik wil graag ook alle oud-collega's van OKER bedanken, dat helaas niet meer bestaat. Het was fijn om met jullie allemaal op dezelfde gang te zitten en onze passie voor onderzoek en innovatie te delen. Jullie stonden altijd voor me klaar. Feyuna, we waren kamergenoten en ik wil je bedanken voor alle waardevolle gesprekken en je vriendschap. Sacha, bedankt voor het meeschrijven aan een artikel, de gezellige gesprekken en de fijne samenwerking. Ilse, bedankt voor je steun, je gezelligheid en je analytische blik. Anja, wat heb ik veel geleerd

## Dankwoord

van je organisatie talent op het gebied van de digitalisering van Rehab-4-life. Ria, bedankt voor de gezellige gesprekken, voor het uitwerken van de interviews en alle ondersteuning. Verder wil ik Judith en Carina bedanken voor de gezellige gesprekken en voor de waardevolle input die jullie hebben gegeven. En dan wil ik daarnaast nog alle anderen met wie ik door de jaren heen op de afdeling heb gewerkt bedanken voor de fijne samenwerking en de inspirerende wetenschappelijke discussies.

Ik wil al mijn huidige collega's van Zonnehuisgroep Vlaardingen bedanken. Bedankt voor jullie steun, belangstelling, collegialiteit en gezelligheid. Het was fijn om het onderzoek te combineren met het werken als fysiotherapeut met CVA-patiënten. Het is heerlijk om in zo'n leuk team te werken. En het is fijn dat ik mijn functie als fysiotherapeut kan combineren met het werken als linking pin voor het UNC-ZH, waarbij ik wetenschap en praktijk met elkaar probeer te verbinden.

Verder wil ik al mijn vrienden bedanken voor jullie steun, interesse en vriendschap. In het bijzonder wil ik mijn (schoon)familie noemen. Mama, Inge, Jan Pieter, Dorothee, Bert, Loes, Marcel en alle neven en nichten. Jullie zijn heel belangrijk voor mij en hebben ook gezorgd voor gezellige afleiding. Ik heb straks nog meer tijd voor jullie! Inge en Dorothee, jullie zijn mijn paranimfen, ik had me geen betere kunnen wensen!

En dan wil ik eindigen met het bedanken van Paul, Mark, Zoey, Steven, Melissa, Laura, Tessa en Julia. Jullie betekenen alles voor mij. Paul, tijdens dit promotietraject kwam je in mijn leven. Ik heb altijd gezegd dat ik nooit weg zou gaan uit Groningen, maar toen ik jou leerde kennen was het meteen duidelijk dat ik zou verhuizen naar Gorinchem, dus dat moet wel echte liefde zijn. Bedankt voor je liefde, steun, vertrouwen en de ruimte die je me altijd hebt gegeven om tot diep in de nacht weer eens aan een artikel te werken. Mark, Steven en Laura, jullie zijn een prachtig kado dat ik erbij heb gekregen toen ik jullie vader leerde kennen. En met de komst van Tessa en Julia is ons gezin compleet! Ik ben zo blij dat jullie allemaal in mijn leven zijn gekomen. Zonder jullie was dit niet gelukt!



## Curriculum Vitae

Christa Nanninga is op 7 december 1975 geboren te Drachten. In 1995 behaalde zij haar VWO diploma aan het Wessel Gansfort college in Groningen. In 1999 studeerde zij af aan de Rijksuniversiteit Groningen. Vervolgens startte zij met de studie fysiotherapie aan de Hanzehogeschool Groningen, die ze in 2001 afrondde. Na haar studie ging zij als fysiotherapeut aan het werk bij zowel het Heymanscentrum in Groningen als het Centrum voor Revalidatie, locatie Beatrigoord, van het Universitair Medisch Centrum Groningen. Op beide plekken heeft zij veel ervaring opgedaan met het begeleiden van patiënten na een CVA. Tijdens haar werk als fysiotherapeut deed zij onderzoek om de transitie van de klinische setting naar huis, voor mensen na een CVA, makkelijker te maken. Dit resulteerde in het promotieonderzoek 'Home and place making after stroke: Exploring the gap between rehabilitation and living environment', waar zij in 2008 mee begon. Dit onderzoek werd uitgevoerd bij de afdeling neurorevalidatie in Beatrigoord in samenwerking met Onderzoeksbureau OKER van het UMCG Centrum voor Revalidatie. Zij beschreef de wensen en behoeften van mensen die, nadat ze een CVA hadden doorgemaakt, een revalidatietraject hadden gevolgd in Beatrigoord en met ontslag naar huis waren gegaan om thuis hun leven weer op te pakken. Daarnaast onderzocht ze ook mogelijke oplossingsrichtingen. De resultaten van dit onderzoek staan beschreven in dit proefschrift.

Sinds 2010 heeft zij parttime aan haar promotieonderzoek gewerkt. Christa is verhuisd naar Gorinchem en is daar gaan samenwonen met Paul, die al drie kinderen had uit een eerder huwelijk, Mark, Steven en Laura. Samen hebben zij twee dochters gekregen, Tessa en Julia. Sinds 2014 werkt zij als fysiotherapeut bij Zonnehuisgroep Vlaarding en op de afdeling neurorevalidatie, zowel in de kliniek als in de polikliniek. Daarnaast is zij werkzaam als linking pin bij het Universitair Netwerk voor de Care sector Zuid-Holland (UNC-ZH), waar ze de verbinding legt tussen wetenschap en praktijk.

