Embodyed experiences of stroke in rural areas
A qualitative study of therapeutic landscape experiences in the North of the Netherlands

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Outline

› About stroke and place
› Therapeutic landscape experiences
› Methodology
› The study area
› Results
› Discussion
Is it a stroke? Check these signs FAST!

Massachusetts Department of Public Health
Living with stroke

› Hospital - rehabilitation clinic – outpatient treatment – GP (Dutch context)

› Longing for full recovery (Cott et al, 2007)
› But having to live with a changed body, a changed self and a changed life (Ellis-Hill et al, 2000)
› Result: depression, low quality of life (Wood et al, 2010; Achten et al, 2012)
Stroke and place

▶ What happens at home? (And, how to improve this?!)

▶ Qualitative study
▶ 34 in-depth interviews
  ▪ 25 at home
  ▪ 9 both in the clinic and at home
  ▪ Partner present
▶ FGD with informal carers
Longing for different places

› Rehabilitation phase: longing for physical recovery and domestic places;
› Post-discharge phase: longing for pre-stroke roles, relationships and activities
› Re-integration phase: longing for recognition and a new sense of belonging

› Body – home - community

(Nanninga, Meijering et al, 2014)
Home after stroke

- Changed bodily routines
- Changed social interactions
- Changed identities and paths in life

(Meijering et al, submitted)
Stroke, embodiment and the rural
Therapeutic landscape

> “how the healing process works itself out in places” (Gesler, 1992: 743)

> So far, focus on:

  - Special healing places instead of everyday geographies (Wakefield & McMullan, 2005)
  - Young people (Milligan & Bingley 2007); older adults (Milligan et al, 2004); terminally ill (Moore et al, 2013); ...

Therapeutic landscape experiences

› Relational analysis
› Self-landscape *encounter*, rather than the landscape itself
› Differences in individual experiences

(Conradson, 2005)
Place and health

➢ Ecology of place (Thrifting, 1999)
   ▪ Dynamics of association between different entities (human, non-human, material)
   ▪ Emotional dimension

➢ Relational dynamics between place and health
   ▪ Focus on well-being
   ▪ Embodied encounters and later interpretation
   ▪ Situate in (social) context
     (Conradson, 2005)
Post-stroke bodies

› Also drawing on ANT

› Body as affective vehicle, through which we sense place and movement (Hannam et al. 2006)

› Body is a form of lived experience, actively engaged with a world of socio-cultural and physical objects

› We do not only have and are our bodies, but also do our bodies (Mol 2002; Struhkamp et al. 2009; Mol & Law 2004)

› Opening up silent layers, drawing contrasts
Biographical disruption

Bury (1984)
Methodology

- Part of a larger qualitative study with stroke survivors
- 16 semi-structured in-depth interviews
  - 11 at home in 2010/11;
  - 5 in clinic and at home 2011/12;
  - Significant other present
- Rural areas, North of the Netherlands
- Themes: changes in self, important places, social relations; pre-post stroke
- Currently: analysis in Atlas.ti
## Participant characteristics

<table>
<thead>
<tr>
<th>No</th>
<th>Name</th>
<th>Age</th>
<th>Stroke effects</th>
<th>Marital status</th>
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Results (preliminary)

› Around the house
  • Doing the garden
› The local rural community
  • Material objects as obstacles
  • Doing social relations
› Beyond the local community
  › Re-shaping spaces of leisure
  › Doing the health system
Around the house
Doing the garden

“H: I do mow the lawn. We have a sizeable piece of grassland, with these precise little corners that you have to do. The first time I did it [after the stroke], I did it in three turns. [...] It’s still tiring, but I can do it now. And when I know, I’m going to mow the lawn, I don’t do [another excercise]. But it’s like, I walk in the garden, and I see all the stuff I’d like to do, but I can’t get around to doing it yet. [...] It’s my balance, when weeding, you have to get down and up again, it’s tiring. P: It’s heavy work, gardening.” (Henry and partner)
Doing the garden

“... the garden, they planted some potatoes in it, whereas [I grew] vegetables in it before. It’s all different, this year is different from how it is normally. And it’s all going to be back to normal once I finish the therapies.” (Roy)
The local rural community
Material objects as obstacles

> “You’re never going to be as secure as you were [before the stroke]. I do cycle well, but I have to go through a tunnel at first, and it’s very difficult for me to get up [the slope]. So, this hinders me.” (Victor)

> “R: I don’t trust myself in [busy traffic]. Not anymore. [...] When I want to go to the hairdresser, in the village, I have to face it as I have to go along the [main road]. And it’s pretty busy with traffic. [...] When I have to cross the street, I get off my bike. Then I think, ‘oh I look like an old lady’, but I get off and look behind me first, since I cannot look and cross at the same time.
I: What happens then?
R: I just don’t feel confident [...] I’m like, ‘did I see that correctly?’ I really need to take time to check whether it’s safe to cross the street” (Rose)
Doing social relations

L: [When going for a walk,] there are a couple of places, where I have to check, I have to wave. And, well I walk up to [partner’s workplace] and I check whether he’s there and I wave at him. Yes, that’s nice, but that’s not just going for a walk, there’s [a social purpose]. (Laura and partner)

P: And the fun thing is, [when I go shopping,] I tell him, just come along, because we’ll run into acquaintances, and we’ll have a chat. There’s the social element, and that’s important, very important (Henry’s partner)
Doing social relations

“R: I don’t like to just walk around here without an aim, then I think ‘oh they’ll see me again’, no I don’t like that at all.

I: Do you mind, that other people see you?
R: Yes.
I: Does it make you go out less?
R: Yes, I think so.
I: And how do you think other people see you?
R: Well, I always think I look like a cripple. But other people tell me it’s ok.
I: I can see it’s troubling you.
R: Yes” (Rose)
Doing social relations

“So, when you’re arm or leg is broken, you can see, oh that guy is disabled. But you can’t see I’m disabled, and people think, well he can do this and he can do that. They tend to think you’re back to your old self, whereas that’s not true. I’m in my sixth month, you cannot see it on the outside, but still, it’s in my head. But I have the impression that people see it differently.” (Henry)
Beyond the local community
Re-shaping spaces of leisure

> “P: Friends of us live in [nearby village] and they have a camper van. They [came] to pick us up, first thing in the morning, with the camper van. They said, we’ll take you to [the sea side] and we had some lunch there. And then they picked a quiet spot, and they told my husband, now you take a nap, and we’ll keep quiet. And those are people, they are true friend, they try to think of something that is fun in spite of everything.” (Henry’s partner)
Re-shaping spaces of leisure

P: We were always outdoors when we were free.
L: Canoeing. [...] 
P: She says she can’t use the paddle anymore. And I tell her, what’s the big deal.
L: I don’t want to do it, and that’s the end of it.
P: That’s nonsense.
I: But you tried. How did that go?
L: Well getting in went well, considering I expected I’d fall into the water. Maybe after next year [...] 
I: So, you don’t enjoy the canoeing when you can’t peddle?
L: No, because I wouldn’t do my job properly.
P: I don’t mind, as far as I’m concerned you could just sit and relax, read a book or something.” (Laura and partner)
Doing the health care system

> Only when you’re at home, it becomes clear what you need, or what you miss, only then it’s possible to indicate that. [...] So we needed to change stuff. We got the mobility scooter, we got the wheelchair. But then I asked for a parking card for people with a disability [and] now, it’s what we enjoy most. I put a lot of effort into getting the card, because you’re not allowed to park anywhere these days, and he could not walk that far, so I did not get anywhere. [...] So we gave back the wheelchair, and bought a smaller mobility scooter.

I: And you use that whenever you go somewhere by car?
T: Yes, it’s ideal.
Doing the health care system

> P: He used to have a huge mobility scooter, we sometimes did not use it for four months at a time, and paid for it every month, what’s the use. And the wheelchair, it did seem like a good idea, but you see, when I have to push my husband, also on the difficult surfaces, I used to be exhausted. And with this [mobility scooter] he can do it himself. Much easier [and] it’s the same with the parking card, it’s ideal.” (Tom and partner)
Discussion

› Limitations: adopting more interactive methods, such as walk-along-interviews could yield more insights

› Link to idea of ‘enabling places’: social, material and affective resources in recovery (from mental illness; Duff, 2012)

› Re-embodiment of stroke survivors needs to be considered a life-long project

› The rural plays different roles in this: therapeutic but also ‘unhealthy’
What’s next?

› Rehabilitation coach in home setting
  • Intervention
  • Evaluation

› Mobility of stroke survivors
  • GPS/ diaries / in-depth interviews/ walk-along interviews
  • Monitor mobility
  • Develop intervention
Thank you for your attention

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