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

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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.

1. 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 (CBS, 2014). A stroke is an illness with a sudden onset that affects physical, cognitive, and behavioural functioning (American Stroke Association, 2015). In the Netherlands, patients with suspected stroke are directly admitted to a 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 (Ellis-Hill and Horn, 2000). Many survivors experience depression (Wood et al., 2010), social isolation (Salter et al., 2008), and reduced well-being (Achten et al., 2012) 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 (Nanninga et al., 2014). 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 (Drummond et al., 2013; Steultjens et al., 2013). 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 (Blunt, 2005).

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 (Nanninga et al., 2014). 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.

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2. 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 (Blunt, 2005). 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 (see Chaudhury and Rowles, 2005; Peace et al., 2006; Rowles, 2000, 2008; Rowles and Bernard, 2013; Rowles and Watkins, 2003; Swenson, 1998). In line with this, it has been shown that experiences of home are an important dimension of well-being (Conradson, 2012; Wiles et al., 2012). 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 (Blunt and Dowling, 2006).

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 (Sixsmith et al., 2014. 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 (Rowles and Bernard, 2013). With respect to home as a process, we analytically distinguish three dimensions of home: the material, social, and personal (Tanner et al., 2008).

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 (Sixsmith and Sixsmith 1991). The material dimension of home links to the description of home-making as an embodied process: people experience the home through their bodies (Imrie, 2004; Moore et al., 2013; Schwanen et al., 2012a). 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 (Harrison, 2007). 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 and Simpson (2011) 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 behavioural rituals situated in places, such as getting ready for work in the morning. Such routines have been discussed by Seamon (1980) 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 (2013) re-established the importance of habit for feeling 'in place' in his study of habits that do not come forth when called upon with skilful golf players in a tournament situation. In the context of ageing, Rowles (2000) 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 neighbours (Tanner et al., 2008). 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 (Foster and Walker, 2014; McNair, 2014; RIVM, 2014). The participation society seems to tie in with Kahn and Antonucci's (1980) 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 (Antonucci et al., 2014).

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 (Tanner et al., 2008). 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 (Hopkins and Pain, 2007). 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 (Ziegler, 2012). 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.

3. Methodology[1]

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 centre 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.

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

[1] 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).