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To cite this article: Ton Satink, Staffan Josephsson, Jana Zajec, Edith H. C. Cup, Bert J. M. de Swart & Maria W. G. Nijhuis-van der Sanden (2016): Negotiating role management through everyday activities: narratives in action of two stroke survivors and their spouses, *Disability and Rehabilitation*, DOI: [10.3109/09638288.2015.1129442](https://doi.org/10.3109/09638288.2015.1129442)

To link to this article: <http://dx.doi.org/10.3109/09638288.2015.1129442>



Published online: 08 Feb 2016.



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RESEARCH PAPER

Negotiating role management through everyday activities: narratives in action of two stroke survivors and their spouses

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ABSTRACT

Purpose To manage social roles is a challenging part of self-management post-stroke. This study explored how stroke survivors act as role managers with their spouses in the context of everyday activities. **Method** Two stroke survivors with a first time stroke living at home with a spouse were included. Data were generated through participant observations at their own environment at 3, 6, 9, 15 and 21 months post-discharge. The narrative analysis focused on the actions of participants. **Results** Daily activities can be understood as an arena where role management and a meaningful life is negotiated and co-constructed with others. Everyday activities gave stroke survivors and their spouses insight into stroke survivors' capacities in daily situations. This was sometimes empowering, and other times conflicting when a spouse had negative perceptions of the abilities of the stroke survivors. **Conclusion** The findings add to the current understanding of self-management and role management with regard to how these are situated in everyday activities. Daily activities can help both spouses to reflect and understand about self-management, role management and comanagement in daily life. Moreover, observing stroke survivors in everyday situations provides professionals with concrete pictures of stroke survivors' performance and self-management in interaction with their spouses.

ARTICLE HISTORY

Received 16 March 2015
Revised 1 December 2015
Accepted 4 December 2015
Published online 4 February 2016

KEYWORDS

Everyday activities; role management; narrative; self-management; stroke

► IMPLICATIONS FOR REHABILITATION

- Self-management is a dynamic process in which individuals actively manage a chronic condition and finally live a meaningful life with a long-term chronic condition; self-management can be divided into medical, role, and emotional management; comanagement is when individuals activate resources and use the capacities of other persons to manage a situation together.
- Self-management is situated in everyday activities. Everyday activities give stroke survivors and their partners impressions about stroke survivors' self-management abilities post-stroke in an everyday context.
- Everyday activities give stroke survivors and their partners an arena where role management and a meaningful life are negotiated and coconstructed through doing.
- Observing stroke survivors in everyday situations provides professionals a concrete picture of stroke survivors' self-management and comanagement with their partners than can be obtained from an informal interview.

Introduction

Most people manage themselves by routine, fulfil their roles in the community and try to find meaning in life.[1,2] Like with other acute health events and chronic

illnesses, a stroke leads to drastic changes for a person in terms of biographical disruptions of a desired, meaningful life, particularly in terms of roles, responsibilities, sense of self and identities.[3–9] A stroke often affects

the fabric of predictable everyday life,[10] and self-management post-stroke is not as it was before the stroke.[11] Depending on personal and environmental factors and the severity and the phase after a stroke, patients may experience disabilities in physical, cognitive, social and emotional functioning.[7,12–17] Together with their spouses, they have to deal with these changes and find a new balance in their everyday lives.[18,19]

Interventions supporting self-management have been recommended as methods to support stroke survivors in adjusting and coping with the consequences of the stroke.[20] To date, different stroke self-management programmes have been designed and researched.[21,22] Self-management can be defined as “an individual’s ability, in conjunction with family, community and healthcare professionals, to successfully manage the symptoms, treatment, physical, psychosocial, cultural and spiritual consequences and inherent lifestyle changes required for living with a long-term chronic disease”.[23] Self-management has the following three interacting domains: medical management, role management and emotional management.[24] However, in the literature, there is not much of a differentiation made among medical management, role management or emotional management. Alternatively, Schulman-Green et al. [25] have identified three processes of self-management in chronic illness: focusing on illness needs, activating resources and living with chronic illness.

The post-stroke process has been described as a transformation and adaptation for stroke survivors and their spouses in their daily activities, their relationship and changes and limitations in other social roles. Stroke survivors are often not able to perform daily activities or fulfil social roles the way they were used to do pre-stroke. Furthermore, spouses are mostly confronted with a new role of caregiver besides their role as partner. This causes feelings of uncertainty and changes in self and roles, as well as physical, emotional and informational needs.[5–9,18,19,26–31] With regard to self-management, stroke victims have described self-management as a complex, long-term learning process and expressed that self-management is influenced by their relatives.[11] However, there is a need for further research on how stroke survivors self-manage and act in their roles in the context of their everyday life activities.

Activities of everyday life are important for persons. It characterizes who they are, how they daily use of time and energy, such as cooking a meal, shopping, dressing, a phone call to arrange services or driving a car.[1] Role management refers to the way people regain, adapt or maintain roles within their lives.[24,32] In order to understand how people act to manage themselves and

their roles in everyday life, agency is a useful concept to study. The concept of human agency is about a person’s ability to act in different situations.[33,34] It can be seen as a means for and as a result of participation in everyday activities.[1,35–37] Agency is situated in daily activities and can be related to the way persons manage to negotiate challenges and find solutions in everyday life.[38] Agency is described as temporal, multifold and coconstructed.[37,39–41] Temporality can be related to an ongoing development of agency of a person in a changing life line; some persons post-stroke might experience differences in their agency when they compare themselves to their former capacities, their pre-stroke selves, lives and roles.[8] Agency is multifold, as it not only relates to acting, but also to identity. It is the aspect of the performance of everyday activities, the doing that helps people to make meaning of their lives and shape their identities.[35] Although agency initially refers to human acts done intentionally,[42] it is also about getting others to act. So agency is constantly coconstructed with others and negotiated in the everyday activities and environments, particularly the social ones.[39,40] However, although an agentic perspective on role management can offer a deeper understanding of the how and why questions regarding self-management post-stroke, such agentic perspective on role management post-stroke is largely absent from existing research.

Within this study, we have used a narrative theory to conceptualize everyday activities and role management. Ricoeur [43,44] has described how narratives can be observed when people “act”. In an “enacted narrative”, people can act out their narratives by performing everyday activities. Ricoeur [44] proposes that the actual doing in daily life produces images that people might connect to past experiences or to future events. For example, when a stroke survivor is making the first steps with the therapist; these first steps can be linked with images about possible scenarios as “when I am able to make these steps, I might be able to walk stairs and go home”. By doing this, people try to interpret their experiences by creating meaning in form of possible storylines or scenarios. Furthermore, when people act, they try out possible interpretations of their acts and their situations. This testing of possible interpretations is part of peoples’ ongoing negotiating of meaning.[43–45] By their engagement in different situations, people play (and test) with possible scenarios in different situations; they receive responses from spouses, family or friends and develop further understanding of their own situations. In relation to daily activities and role management, people develop interpretations of possible ways (scenarios) how they can manage their roles in the

context of everyday life. The plots people develop through this process serves as a possible meaning that captures how certain processes of life have been and how life might develop; it supports in a further understanding of their own daily life.[45]

From a narrative perspective, the process of role management post-stroke can be viewed as a personal and contextual narrative with plots, events, daily activities, roles and turning points. Consequently, everyday activities can be viewed as narratives-in action or enacted narratives [46] where the role manager acts.[46,47] For persons who are living with a spouse, role management is embedded and constructed primarily with their spouses. However, although several qualitative studies [29,48–50] have documented the ongoing post-stroke recoveries with their transformations and adaptations, less work has been done on the exploration of the way role management is enacted in everyday activities by stroke survivors and their spouses and how this evolves over time. Therefore, the aim of this study was to explore how post-stroke persons act as role managers along with their spouses in the context of their everyday activities over time.

Methods

This study was informed by a narrative theory, which has been described as a useful perspective for studying human action, experiences and meaning over time.[44–47,51] We were drawing upon “narrative-in-action” as a theoretical resource, as we were interested in how meaning was negotiated and developed in everyday actions.[46] In doing so, we altered from viewing narratives as verbalized, storied text about people’s experiences in daily life [46,52] and focused on observation of participants’ narratives as embedded in action.[46] This “narrative-in action” approach is a useful way to study how meaning is created during acting in everyday activities.[46] Based on the

reasoning that narratives and experiences are socially constructed, this study followed a socioconstructivist epistemology.[47,51]

Participants and context

Two participants were drawn from a larger longitudinal study where participants have been included after experiencing a first-time stroke, living at home at least three months after discharge, living with a spouse, and having a score lower than 8 on the Hospital Anxiety and Depression Scale (HADS).[53,54] With the requirement of a HADS score below 8, we wanted to exclude participants with a post-stroke depression, as we wanted to focus on the self-management of stroke survivors with mainly physical stroke consequences. The two participants were also selected as we also wanted to include one male and one female participant. Moreover, both participants showed in the first encounter that they could provide us with rich information. Furthermore, both the participants and their spouses, agreed to welcome the researcher several times for the participant observations. Ethical approval for the research project was given by a Regional Committee on Research involving Human Subjects (ref no. 2011–542) and followed ethical principles in accordance with Dutch research ethics regulations.

The participants in this study were 67-year-old Betsy (pseudonym) and 68-year-old Martin (pseudonym); their spouses were Jan and Annie (pseudonyms), respectively. Basic descriptions of the participants are given in Table 1.

Data generation

The first author and main researcher (TS) generated the data through participant observations in everyday activities initiated by the participants.[55] Repeated participant observations, five times with each participant over 21 months post-discharge, made it possible to be a part of the participants’ enacted narratives in their

Table 1. Demographic data of the participants.

Participant and living conditions post-discharge	Marital status, children, daily activities pre-stroke	Stroke and consequences
Betsy, 67 years old, living with Jan in a six-floor apartment	Divorced, now cohabiting; three grown children. Worked in a patisserie, voluntary language teacher of asylum-seeking family, played saxophone in a music band, played badminton, made post cards, and was involved in physiofitness.	Stroke left; mild sensomotoric problems, right side; mild memory problems; mild problems in orientation in time and place; lowered ability to maintain attention and to concentrate; mild hemi-inattention, for left side. Independent self-care. Independent walking inside the house and outside with rollator.
Martin, 68 years old, living with Annie in a four-floor apartment.	Married; two grown children. Retired, but still working as an ambulance nurse and community nurse.	Stroke right; hemi paresis, left side; spastic left arm; self-care with help; walking maximum 20 meters with walking aid; using wheelchair inside and outside the house, as well as a mobility scooter outside.

ongoing everyday lives. Most encounters lasted from two to four hours and took place at the participants' homes or if appropriate in the surrounding areas. Encounters were planned approximately around 3, 6, 9, 15 and 21 months post-discharge.

Two weeks before each encounter, participants were phoned to make appointments and to explain the purpose of the home visit. TS joined the participants while they performed everyday activities, such as grocery shopping, visiting the physiotherapist, having coffee with spouses or taking a walk. Sometimes the participants' spouses were engaged in the activities. The researcher had "informal" talks with the participants (and the spouse if present) about what was going on at that time and sometimes how this could be interpreted and helped with small steps of activities if needed, which supported the process of building rapport.[55] After each encounter, TS made field notes about the actions of the participants in everyday situations, followed by reflections.[46,55,56] Reflections were about remarkable, unexpected or specific situations and actions in general, and in relation to role management in particular.

Data analysis

The narrative analysis was an interpretative, inductive and iterative process of moving between the data from observation and informal talking and followed the principles of the hermeneutic circle, meaning that the analytical interpretation involved a constant back and forth movement between the data from each encounter

and the emerging analytical results from the period as a whole.[45,46,55,57] Moreover, existing theory was brought into the interpretative process, characterizing the hermeneutical interpretation (Figure 1).[57]

First, the field notes and reflections of encounters with Betsy and Martin were read and discussed separately among TS and the second and third authors (SJ and JZ, respectively). Significant events and actions were identified through close readings of the field notes and reflections, and preliminary plots were identified. Plots are context bound, depending on the situation (e.g., the consequences of the stroke, relatives, other people, time and the environment) and give possible meanings to a life post-stroke. Links between different events and actions of the participants, the interactions with their spouses, and the possible meanings of these events and actions were investigated. In this process of emplotment,[44,45] further interpretations about actions of participants with regard to role management were processed into possible story lines and plots by TS, SJ and JZ.

After the step of emplotment, following the encounters with each participant and their spouses, theories and literature about self- and role management, agency and meaning making in daily activities were brought into the interpretation and refinement of possible storylines and plots. Together with the process of emplotment, hermeneutical interpretation took place after every encounter with each separate participant (Figure 1).[57]

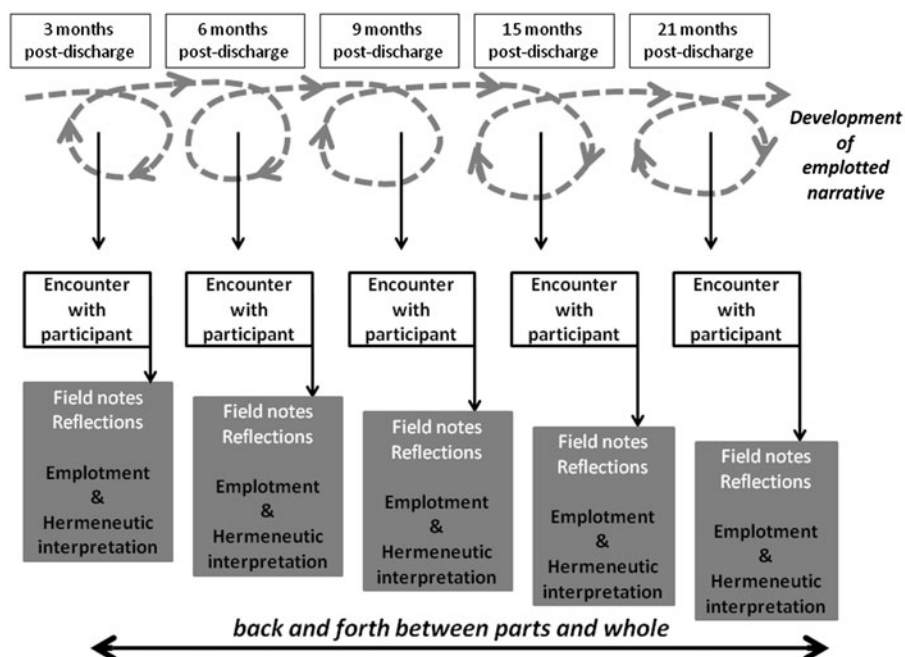


Figure 1. Process of data generation and analysis.

The generated data and possible storylines and plots were re-interpreted several times while moving back and forth between the field notes, reflections and the literature. This process stopped when possible storylines and plots were developed for each separate participant.

The analysis resulted in a storied outcome where empirical data and theoretical perspectives are presented together in order to enhance transparency. The two narratives presented below must be viewed as coconstructions of the participant, the spouse and the researcher,[46,47,57] and are the authors' interpretations of these co-constructions.

Results and discussion

Betsy: "I need him, but without him I could do more"

Betsy, 67 years old, and cohabiting with her spouse Jan, expressed that she had mixed feelings about the way Jan supported her after her stroke. During various encounters with Betsy, she repeatedly expressed to the researcher that she needed her spouse, that she was glad for his support in different situations and how he organized the household in general. However, she also said that he was too careful with her and in some ways even limited her. Two situations will be further described with possible explanations.

"I need him, but he always cooks the same!"

During the first encounter, Betsy was sitting with Jan at the dinner table preparing a shopping list. She had planned to go to the supermarket and the researcher (TS) was scheduled to join her. She stood up and put her coat on, and put her bag, wallet and keys in her walker, then she walked with the researcher to the supermarket around the corner. Outdoors Betsy said, "You know, I welcome his help, but he can only cook three meals. It is often the same". Betsy expressed to the researcher that she had always been the one who did the cooking and that she really wanted to cook again. Once in the supermarket, Betsy collected all groceries from the shopping list. She could find everything, looked at the prices and decided what to buy. She also took a few other vegetables and mentioned that she always had done so: "I often take extra vegetables. It means that you can choose, and create different meals every day. A little wok is always delicious". When Betsy came back from the supermarket, she gave the bag to her partner. After Jan responded surprised that she had bought too many vegetables, she said, "But I can help you with cooking! Maybe we can use the wok".

One possible interpretation is that Betsy explored new possibilities and tried to negotiate with her spouse about the possibility of cooking together. Based on the past, where she was always the one who cooked, and based on positive experiences in other activities she had done recently, she might have created a future storyline where she saw herself cooking again. Knowing that past and future influences present actions,[43,47] she might have bought extra vegetables to explore and negotiate the possibility of doing something she did before the stroke: cooking a meal.

Almost two years post-stroke, Betsy was not cooking anymore and rarely went to the supermarket. During the last visit, she told the researcher that Jan was often not amused when she came home with more groceries than he had written on the shopping list. At the time of the visit, Jan was doing most of the shopping. In contrast, Jan said the new situation had been overwhelming for him and that he had lost his "pal" at home. He expressed how difficult it was to cope with the changes at home, and he did not exactly know where to start to solve the challenges in the household himself. On one hand, he was devoted to assist Betsy in everyday activities, but on the other hand, he explained, he could often do these activities easier and quicker himself. Jan perceived this as the best way to manage himself: "I also have to take care of my own time. Activities like grocery shopping, cooking, or household activities I can do much faster than her. Beside these activities, I also have other things to do". Jan said they had stopped talking about it with each other and that they both tried the best they could in their new situations.

From the perspective of comanagement and role management,[11,58] one possible interpretation of the situations described previously is that each person tried to manage the situation in her or his own way, but both were taking care of their own daily business without a dialogue with each other. Both persons might have had different understandings and expectations of their everyday activities and roles, but there was no dialogue about their perceptions of the changed situation and roles post-stroke. A dialogue between Betsy and Jan about the meaning of activities and finding a new balance in role management could have been a way to negotiate capabilities and expectations about future roles and the best ways to perform activities. Moreover, a dialogue could have helped them to tune in to each other instead of maintaining the current gap between them, and it could support both persons in doing the everyday activities they really wanted.[59,60]

Concerning the cooking, Jan argued that it was best for both that he prepared everything, and that, at the

end, Betsy could sit in the kitchen and check the potatoes and vegetables when they were boiling. Jan explained his internal conflict: he wanted to help Betsy, but he also wanted to prevent any mistakes she might make, as he experienced sadness when Betsy struggled in activities. Jan said, "I sometimes have to leave the kitchen because I cannot stay close to Betsy and face her struggles during household activities". To prevent that Betsy would struggle during household activities, he took over everything. If he felt too frustrated or sad, he sometimes left the kitchen and asked Betsy to do some easy activities herself. However, the activities that Betsy was asked to do had no meaning for her. She explained, "Jan proposed that if he first prepares everything and puts it on the gas, I could sit in the kitchen beside the gas cooker and control the potatoes when they were boiling. But well, I can better read a newspaper. I stopped cooking". The consequence was that Betsy was not engaged in cooking anymore. The steps of the cooking that she was allowed to do were too simple and meaningless for her. Furthermore, it also resulted in a situation where Jan wished to see a "happy Betsy" who could do simple activities without mistakes, while Betsy said she was actually less happy because of his way of supporting her. She said she had accepted her mistakes while doing everyday activities. She just wanted to cook. Jan argued that he was critical regarding the way Betsy performed activities. He said he thought that the best way to help her was to give feedback about the failures and to structure or take over the activities when she was trying out everyday activities.

The stories and actions of both Betsy and Jan can be interpreted in different ways. Based on Vik et al. [37] and Kessler, Dubouloz, Urbanowski and Egan,[61] who described the importance of developing a sense of agency and building competences in participation in meaningful occupation in the years following stroke, one possible interpretation is that a vicious cycle started. We imagined how Jan, Betsy's spouse, did not stimulate her to perform different activities or to relearn by doing. As a result, her sense of agency decreased. If we link this to the process of role management, Betsy is an active agent in the beginning of the post-stroke process where she did the shopping and cooking. Initially, she negotiated with Jan to do more everyday activities step by step. However, during the last encounters, Betsy was a more passive agent who was not creating new situations or activities. She rarely participated in meaningful activities like cooking. Consequently, she was not able to redevelop her competences in cooking in order to regain this important role.

"I need him, but without him I could do more."

Almost a year after the stroke, Betsy said that she'd had a very good day when Jan was away for a full day with friends. She said, "We had made a list with different household activities that I could do. I was really happy at the end of the day. I had done all the household activities by myself, in my own way and own pace." When Jan had returned home, she had shown him what she had achieved at home. Betsy later told the researcher how she wanted to share her success of completing the household activities by herself and had hoped that she could do this again, but Jan had responded stoically to her achievement.

Ricoeur [43,44] described that, when performing everyday activities, people interpret their experiences and produce images that are connected to past or future events. By doing this, people create possible storylines or scenarios that are used in their negotiations about future situations. Related to this, role management and Betsy's different actions as her own agent can then be seen as a negotiation between Betsy and Jan about future activities and each other's roles. Moreover, role management was also Betsy's internal dialogue about her future scenario, her "self", and her identity and about the roles she had and which roles she was able to regain.[35,62,63] In this case, she might have interpreted her recent experiences as not only being able to do the household activities, but also as a possibility to negotiate with her spouse about doing more activities in the future.[43,44]

Betsy was also engaged in activities outside her home in the community. She repeatedly talked about her visits to an African family to coach them in the Dutch language and culture and her time at the local activity centre where she helped to serve lunch once each week. She explained, "The people at the activity centre take the time for me. I know that it costs them time, but they tell me when things are not going as it should go. I know that I'm not so quick. I can only serve two meals per time with my walker, but that is okay for them". Betsy said that she really liked to go there, that she had accepted that she made little mistakes, but she could let it go. Helping other people in the activity centre was more important for her.

In general, we have interpreted how cooking and household activities, even when these went differently before the stroke, were possibilities for Betsy to reconnect to her important pre-stroke roles. Betsy had accepted that trial and error were part of the process of self-management. For her, the experience of mastery in activities was more linked to the meaning of an activity and the satisfaction of the "self" [64] (chapter 6).

Cooking and household chores were her pre-stroke roles, and starting to do them again was a way to regain these roles as well as a sense of self and identity.[2,35,63] Betsy's self-management was embedded in the management of the "self", roles and identity, which we have interpreted as role management.[11,24]

Martin: "I can still orchestrate my life."

Orchestrating the people around him to reconnect to roles

Martin was sitting in his wheelchair during the first encounter. He told the researcher that even after his retirement he had been working as an ambulance nurse and community nurse. He shared pictures of the time he had worked as an instructor in the army before the stroke and showed how he still could track the ambulances on his computer when they had to go to an accident. Martin talked mainly about work-related issues and not about his stroke. His wife said during the first encounter that work was "his everything". When the researcher asked Martin 21 months later about the biggest changes post-stroke, he responded immediately, "Not being able to work again. That is the biggest change!" However, in the various encounters, Martin often told how he had visited some people in the flat he knew from the time he worked as a community nurse. He said, "Of course, I was not visiting them as a nurse, but I can still have a talk with them". He had also become a member of the residents' association and had recently organized an event for the residents of the flat where his old ambulance mates had given a presentation about first aid for elderly.

One possible interpretation of Martin's story is that he tried to reconnect through these activities with his pre-stroke role as nurse.[8,65] Although he was not a professional nurse, being with others and talking and giving advice to others was still meaningful for him. Martin tried to reconnect with this through new activities in and around his building in order to reconstruct his sense of self and continuity of his roles.[65] When he performed these activities, he might have created possible future storylines; [43,47] these storylines could have helped him in the negotiation with and reinvention of his social self, his roles and his identity.[62,63]

During the third encounter, Martin wanted to go to the park to take the dog out for a walk. His wife, Annie, helped him with his jacket and put the dog on a leash. Once in the garage of the flat, Martin made the transfer from his wheelchair to the mobility scooter, and Annie connected the dog leash to the mobility scooter. Martin and the researcher went to the park and a

conversation began about the possibilities for him to go out independently. Martin said he had to get used to the fact that his wife had to help him with dressing and washing, but that it felt normal now. Later on, in the conversation, he expressed that he needed her and that she was really important for him because Annie's help made it possible for him to go out to see his friends or visit people in the flat. For Annie, it was normal to do this. She said, "In the period that I was ill, he helped me so much. It is normal to do this for him now". She also said Martin had not changed after the stroke: "He is still orchestrating the people around him. He has people for all kinds of activities and knows how he can approach them". An example was given in another encounter where Martin told how he had asked a friend for help because he wanted to create a flower box on the balcony. Martin had phoned his friend, and his friend bought pots, sand and flowers for the flower box. Martin showed the researcher his balcony and how he could water the little plants. He said, "You know, I cannot sit the whole day inside my house. I want to go out or sit on the balcony".

From an agentic perspective, we have interpreted Martin in these situations as an active agent. He was the one who had the lead, but was able to ask other persons for assistance when he needed it. He used the capacity of others in order to control and manage the situation with others, which can be viewed as proxy-agency.[33,42] Role management for Martin was to organize people around him to help him and fulfil his role. Role management was situated and coconstructed by Martin through everyday activities, which is referred to in other studies as comanagement.[11,58] Moreover, role management for Martin meant considering different scenarios with regard to future roles and possible adjustments he had to make.

Another situation where Martin organized services in order to be able to go out and fulfil his social roles was when he made a phone call with someone from the municipality during the first encounter. Martin explained on the phone that his current mobility scooter was not good enough to drive into the hilly area of the city where he lived and that he could not go out with his dog or meet other people. He expressed to the researcher that arranging things like phoning people from official bodies and arranging services for himself was not difficult for him. His wife said later, "That is typically Martin. He knows how to do this. He has always done this!"

One possible interpretation is that Martin was an active agent and a good medical manager, as he arranged the care and resources in order to deal with the consequences of the stroke.[8,32] We have

interpreted this as an action of a role manager, meaning that Martin managed his surrounding situations in order to be able to perform his social roles.[8,32] Having a better mobility scooter would mean that he could go out with his dog and play his desired role in his social network. We saw a person who was able to negotiate with people to create situations as he wanted them to be. Moreover, Martin's wife trusted him and gave him space to explore possibilities. Although Martin was dependent on his wife and other persons, he was in charge. He was orchestrating the people around him in order to reconnect to and fulfil the roles as he wanted to fulfil the roles.

"There is still a life with only one hand."

In various encounters, Martin often reflected on everyday activities. He tested future possibilities with his wife and the researcher. One example is how Martin talked about his physiotherapist. He often said that she was a good professional who challenged him, knew how to handle him and trusted him. On a certain moment, almost one year after the stroke, Martin talked about the moment he had walked a few metres with the physiotherapist. He explained how good it felt to take the first steps, and how it gave him hope about his possibilities for the future. He said, "Well you know, if I can walk again, I might also be able to drive a car again, go to the shop myself, or visit people outside my own village".

One possible interpretation here is that the experiences he had and the meaning he gave to the first steps with his physiotherapist were much more than a step with a walking aid. From a narrative perspective, where the past and present can shape future storylines,[43,47] Martin could have created different scenarios around the possibilities of walking again or even driving a car. Through Martin's positive experiences of relative mastery while walking,[64] he gained access to the world of "as if",[43] which enabled him to continue stories such as walking and driving a car. Driving a car would not just be "driving a car", it would open up new possibilities and allow him to regain old roles.

A similar interpretation can be made about the following situation: Martin, who had just gotten his driver's license back, had just bought an adapted car, and he and Annie had been driving in the city. When the researcher had coffee with the two of them, Annie said, "He drives safer than me!" A bit later, Martin started to joke about travelling by car to a fisher's village the next weekend. He referred to the delicious fish they had always bought there in the past. Suddenly, he said, "And if we go to the fishers village, we might also go to [our son] Jeroen".

His wife laughed and said, "Well, if you have something on your mind, it will happen".

One possible interpretation of this situation is that the positive experience of driving the car in the city had opened up the idea of going to a fisher's village and buying some fish. It was something they had done in the past, and the idea and possibility had come alive again. Martin said that he always got his first ideas when he was doing activities. We interpreted that, through the experience of relative mastery in everyday activities, Martin created images of future activities and ways to fulfil roles.[43,44,64] He tested the possibilities of future activity and negotiated with his wife. Through the activities, either by doing or by talking about them, Martin tested new scenarios. He talked about his dreams and considered possibilities of how to manage, continue and reconnect to old roles. We interpreted Martin as an agent who had sufficient confidence to take action, to negotiate with others and to manage his old and new roles. Although he had limitations, he was an agent with the ability to create meaning in life post-stroke. As he said, "there is also a life with only one hand".

Methodological considerations

Our method to generate knowledge challenged the trustworthiness of the study by its interpretative mode, so we tried to enhance the trustworthiness using several strategies. The dialogues with the participants were not recorded, but extended field notes were written by the researcher. During data generation and interpretation, TS had ongoing conversations with SJ and JZ to reflect on the empirical data, as well as on the emerging plots and hermeneutical interpretation of the data. Furthermore, procedures for data generation and the interpretation and emplotment of the storied outcomes were considered in regular team meetings with the other authors in order to establish trustworthiness.[57]

The adoption of a socioconstructivist epistemology and a narrative approach for this study meant that the empirical data of this study should be viewed as a coconstruction between the participants and TS, who is an occupational therapist, experienced in supporting persons in their daily activities after they had suffered from strokes. To enhance trustworthiness, situations and preliminary findings were discussed during encounters with the participants. Nevertheless, the storied outcomes of this study are the researchers' constructions and the researchers' interpretations.[47,51]

The longitudinal aspect with various moments of data generation and the use of theory during the interpretation of the empirical data enhanced the credibility of this study. Moreover, the rich descriptions of the

research situation and its dynamics, along with the outlined theoretical resources, provide information for the readers to judge the plausibility of the storied outcome.[66,67]

Conclusion and implications

This study demonstrates how role management is embedded in everyday activities of stroke survivors and their spouses. Performing daily activities gives stroke survivors an experience of relative mastery with regard to their abilities, which can give them different scenarios and understandings of future possibilities.[68,69] Performing daily activities and experiencing relative mastery can facilitate stroke survivors' internal dialogues as role managers with regard to questions like, "Will I be able to manage this activity myself?" or "Will I be able to fulfil this role again?" Considering the possibilities of reconnections with meaningful past roles helps the stroke survivor as role manager.[35,43,44,62,63] Furthermore, to experience the ability of doing the activities they want, to reconnect to their pre-stroke roles and to ask support from others when needed will also influence the sense of agency of stroke survivors.[37,61,68] Besides, stroke survivors' doing gives spouses an impression about their partner's abilities post-stroke in an everyday context. Moreover, stroke survivors' activities can generate and support the dialogue between them and their spouses about each others' scenarios and future images about their roles and possibilities in comanagement. This can help spouses to adjust their future expectations and understanding with regard to the self-management of the persons post-stroke in everyday life.[43,44,64]

This study adds to the current understanding of self-management how it is situated in everyday activities through role management. Self-management is easily perceived as an individual responsibility with a focus on medical management. However, role management cannot be ignored. Role management is the revisioning and management of an acceptable meaningful future life through everyday activities and roles.[24,32] Consequently, daily activities can be understood as an arena where role management is negotiated, created and coconstructed with others. Sometimes this is conflicting, like with Betsy and Jan, and other times it is self-empowering like with Martin and his wife.

This study also informs healthcare professionals about the value of the performance of daily activities for stroke survivors in their own contexts. Therefore, we advise healthcare professionals to give stroke survivors the opportunities to perform everyday activities in their

own environments as a tool in self-management programmes. Doing daily activities gives stroke survivors' experiences of relative mastery of the activities when performing these activities, which can facilitate the internal dialogue of stroke survivors with regard to their capacities as role managers. Moreover, observing stroke survivors in everyday situations provides a richer picture of the way they act and react as agents and how they manage themselves in interactions with their partners instead of an interview only. Knowledge about their process of self-management, as well as knowledge about the "battle and alliance" between stroke survivors and their spouses,[59] can be used to offer support in terms of a realistic and meaningful balance in their everyday activities.[60] Professional support in performing daily activities, and subsequently, the dialogue between both spouses about the meaning of roles and activities, as well as the balance between taking over, or enhancing participating in activities, might support them in finding a meaningful balance in daily activities. Moreover, this can prevent spouses or other family members from becoming the second patient in the family.[70]

Concerning future research, the approach of narrative in action is a useful framework for unravelling the complex processes of self-management and specifically role management in interaction with the environment. An observation of a narrative in action generates richer empirical data in relation to role and self-management in daily life.

Finally, we encourage healthcare professionals to deliver stroke self-management interventions not only to assist stroke survivors in managing their health conditions and healthcare services, but also to support stroke survivors and their spouses in their role management. Stroke self-management programs can assist stroke survivors and their spouses with exploring different scenarios in order to find meaningful post-stroke lives and to become a couple that can put their life back together.

Acknowledgements

We are grateful to the people who allowed us to participate in their everyday activities post-stroke and to share their post-stroke experiences for this study.

Disclosure statement

The authors report no declarations of interest.

Funding information

This study was supported by a PhD grant from the HAN University of Applied Sciences, Nijmegen, the Netherlands.

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