

# Global meaning in people with stroke: Content and changes

Health Psychology Open  
July-December 2016: 1–9  
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sagepub.com/journalsPermissions.nav  
DOI: 10.1177/2055102916681759  
hpo.sagepub.com



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## Abstract

After a traumatic event like a stroke, people need to find meaning and control again. This study enhances knowledge on one of the driving principles behind meaning-making processes: global meaning. Global meaning refers to individuals' general orienting systems, comprising fundamental beliefs and life goals. Little is known about global meaning in people with stroke and whether global meaning changes after stroke. In this qualitative study, five aspects of global meaning were found: core values, relationships, worldview, identity and inner posture. Continuity in all aspects was reported, but worldview, identity and inner posture were also subjected to change.

## Keywords

adaptation, beliefs, global meaning, qualitative methods, stroke, values

## Introduction

Living with a stroke has a strong impact on people's lives. It can result in different combinations of physical, cognitive, emotional and behavioural problems, which have implications for all areas of life including practical, social and vocational aspects (Davis et al., 2013; Hole et al., 2014; Rochette et al., 2007). Among the most reported effects are the experience of identity changes and social isolation (Anderson and Whitfield, 2013; Haslam et al., 2008; Hole et al., 2014; Mukherjee et al., 2006). After a traumatic life event such as stroke, people need to find meaning and control again (Kessler et al., 2009; Park, 2010; Thompson, 1991). Finding meaning is positively associated with adaptation (King et al., 2002; Thompson, 1991) and quality of life or well-being in people with stroke (Davis et al., 2013).

The term 'global meaning' was first used by Park and Folkman in their meaning-making model (Park and Folkman, 1997). Global meaning refers to individuals' general orienting systems, comprising fundamental beliefs and life goals. Global meaning provides individuals with cognitive frameworks to interpret their experiences and to motivate them in their actions. Global meaning is to be seen as the more fundamental level of meaning and has to be differentiated from

meaning making. Meaning making refers to psychological processes of finding meaning in the context of a particular situation, for example, a stressful life event like a stroke (Park, 2010). The concept of global meaning has been described in several terms in various disciplines (Frankl, 1992; Janoff-Bulman, 1992; Koltko-Rivera, 2004; Littooij et al., 2015; Mooren, 1998; Park, 2010, 2013; Rokeach, 1979). Although different terms are used, there is clearly congruence among these authors on the concept of a basic set of beliefs and goals that guide the way in which people give meaning to their lives (i.e. 'global meaning').

This study is part of a larger project regarding global meaning in the context of traumatic life events such as spinal cord injury or a stroke. After spinal cord injury or stroke, people need to regain strength and learn to live with

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the consequences of their injury. Global meaning has been hypothesized to guide the process of adaptation to a traumatic event (Pargament, 1997; Park, 2010, 2013). Prior to this study, we studied global meaning in people with spinal cord injury (Littooij et al., 2015) and the perceived influence on processes and outcomes of rehabilitation (Littooij et al., 2016). In that study, we found five aspects of global meaning, namely, core values, relationships, worldview, identity and inner posture. *Core values* are fundamental beliefs about what is right and worthwhile. They give direction to thoughts and behaviour. *Relationships* refer to a connection between a person and others, for example, children, a spouse, a therapist or even a pet. Meaningful relationships and the experience of being connected are life goals. *Worldview* is a more or less coherent set of beliefs about life, death, and suffering that structure people's ideas on how life events are related. *Identity* refers to fundamental beliefs about one's deepest self. Expressing one's identity provides people with a sense of belonging, at the same time underlining their uniqueness and self-worth. *Inner posture* helps people to bear what cannot be changed, which is an important goal in life. Inner posture includes an element of acknowledgement and an element of action. It involves acknowledging the facts of life and relating to them. Four of these five aspects (core values, relationships, worldview and identity) are found in literature on stressful life events (Anderson and Whitfield, 2013; Koltko-Rivera, 2004; Ownsworth, 2014; Rokeach, 1979). The term *inner posture* was coined by us in this research project in order to indicate a dimension not found in previous research.

Besides that, we studied whether people with spinal cord injury experienced change in their global meaning. Overall, respondents reported little change in the content of global meaning after spinal cord injury. However, specific aspects of global meaning were foregrounded (Littooij et al., 2015).

In this study, we focus on global meaning in people with stroke. Psychological research on stroke does address meaning, but not global meaning. It addresses giving or finding meaning either as a coping mechanism (King et al., 2002; Rochette et al., 2006; Thompson, 1991) or as an engagement in meaningful activities (Davis et al., 2013; Kessler et al., 2009; Rochette et al., 2007). Park (2010) has reviewed the literature regarding meaning and its effect on adjustment to stressful life events (Park, 2010, 2013). She notes that global meaning tends to be stable after a stressful life event (Park, 2010), a tendency we also found in our study on global meaning in people with spinal cord injury (Littooij et al., 2015). However, given the cognitive consequences of a stroke, the question arises how these consequences may affect the stability of global meaning after stroke. Only one of the studies, Park (2010), reviewed regards stroke (Gangstad et al., 2009), and that study focuses on cognitive processing and post-traumatic growth after stroke and not on global meaning. To the best of our knowledge, an extensive exploration of global meaning

(i.e. fundamental beliefs and life goals), and its stability, in people with stroke is not available. Therefore, the purpose of this study was twofold: (1) to explore global meaning in people with stroke and (2) to explore whether or not global meaning changes after stroke.

## Methods

### Design

Semi-structured interviews were conducted with people with stroke by the first author (E.L.), who is an experienced spiritual counsellor. Interviews were held between 4 and 26 months after admission to the rehabilitation centre. A letter was sent to potential participants to which they could respond by returning a consent form. Besides that, people who spontaneously applied for participation in the study, because they heard about it from other participants, were also included if they met the inclusion criteria. In the invitation letter, supplementary counselling was offered if participants wanted to further reflect on the subjects raised in the interview. One participant made use of this option. The study was approved by the accredited Medical Research Ethics Committee Slotervaart Hospital and Reade (METC-study no. P1153).

### Recruitment

Participants were recruited from clients with a first stroke, who received outpatient treatment at Reade, centre for rehabilitation and rheumatology. Participants were purposefully selected to include both men and women and people with a more optimistic and a more pessimistic attitude, according to the physician assistant in attendance. Inclusion criteria were as follows: being in outpatient rehabilitation, adapting to living in the community with a stroke and being able to engage in a conversation. Clients with severe communication problems were excluded. Approximately half of the respondents were familiar with the two spiritual counsellors in the rehabilitation centre, of which E.L. is one. Her colleague did not take part in the study. The relationships between researcher and participants varied from an intensive counselling relationship, via knowing that spiritual counselling was available, to not knowing her at all.

### Data collection

The main method of data collection consisted of semi-structured interviews with 16 participants which, with permission of the participants, resulted in 16 audio recordings. The majority of interviews took place at the participants' homes. On average, interviews lasted 69 minutes. They were conducted between October 2013 and July 2014. The interviewer wrote down in field notes the observations she made before, during and after the interview, giving details

that could not always be heard on tape, such as the radio playing religious songs, the occasional presence of a partner or friend and nonverbal aspects of the communication.

Interviews were loosely structured using a topic list based on literature concerning global meaning (Frankl, 1992; Janoff-Bulman, 1992; Koltko-Rivera, 2004; Mooren, 1997; Rokeach, 1979) (see Appendix 1). The subjects on the topic list revolved around change and continuity, a person's values, self-image, worldview, life goals and ideas on suffering. Starting with an open question: 'What has happened?' subsequent questions were as follows: 'What has changed?' and 'What has not changed?' With the topic list in mind as a guideline, the interviewer followed the natural flow of the conversation. By summarizing and rephrasing what she heard, the researcher constantly tested her assumptions during the interview, getting to the deeper layers of global meaning. By asking the same question in different words, she tested whether the respondent was expressing his worldview, for example.

### Data analysis

In order to analyse the data, verbatim transcripts were made of the recorded interviews, which were then analysed by two researchers using the method of grounded theory (Strauss and Corbin, 1998). Data were entered into a software programme for qualitative data analysis and research, Atlas.ti (version 7.1.6). The analysis was based on the transcribed interview recordings, using the interviewer's impressions, reported in field notes, as background material. The actual recording was readily available through Atlas.ti and was used for listening to the tone of statements and remarks. Although previous research on people with spinal cord injury had already shaped ideas about global meaning (Littooi et al., 2015), the researchers who analysed the interviews were especially focused on the possibility that the interviews with people with stroke might provide different outcomes. They regularly discussed their findings with the other researchers, in order to stay as open-minded as possible. In grounded theory, a theory is developed during the process of interviewing and analysing, constantly testing assumptions and gradually adapting ideas. Therefore, in order to be as open as possible, the researchers started the analysis by 'open coding' the transcripts of the interviews, while keeping close to the text, to allow for the possibility that different aspects of global meaning might be found in people with stroke, as compared to people with spinal cord injury. The codes were grouped into concepts, and these concepts were gathered into larger categories, which the researchers assumed to be the aspects of global meaning. When eight interviews had been conducted, transcribed and analysed in this way, an overview was made of the aspects of global meaning found in each interview. On the basis of these overviews and categories,

the next interviews were analysed searching for these and different aspects of global meaning, continuity and change.

## Results

Out of 27 invitation letters and 4 spontaneous applications, 16 people reacted positively: 11 of them were male and 5 were female. Their age ranged from 42 to 77 years (see Table 1). One respondent was living in a nursing home and the other 15 in the community. For various reasons, 3 of the interviews took place at the rehabilitation centre and the other 13 at the respondents' homes. After 12 interviews, the researchers felt that saturation was reached, which was confirmed by the fact that the last four interviews produced no new information.

### Aspects of global meaning

Five aspects of global meaning emerged from the analysis of the interviews: core values, relationships, worldview, identity and inner posture. Although distinguished for reasons of clear presentation, in practice, the different aspects of global meaning were often interwoven. All aspects of global meaning were found in all respondents; however, respondents were not equally aware of their global meaning. Besides that, they differed in their ability to reflect on their global meaning.

### Core values

Based on the narratives of the participants and literature on global meaning (Rokeach, 1979), we define core values as fundamental beliefs about what is right and worthwhile and life goals worthy to be pursued. Core values are self-evident, and guide behaviour and in this sense they are prescriptive. One respondent referred to core values such as faithfulness and being trustworthy in the following quote:

Participating in volunteer work is not without obligations. (...) It is important that there is continuity and that people can trust that I will be there completely. (...) I always try to fulfil my promises. (Man, 66 years)

Another respondent expressed the core value of wanting to contribute something when he indicated why he took part in the interview:

if I can contribute to increasing knowledge, and developing insight ..., I am a big supporter of that. (Man, 50 years)

Someone else addressed core values such as respect and taking care of people while discussing his job as a security guard in a hotel and his relationships with his mother, his friends and his mentally deficient aunt:

**Table 1.** Participant characteristics.

Characteristics	Mean (range)
Average age (years)	59.25 (42–77)
Time post-injury (months)	13.31 (4–26)
	<i>n</i>
<b>Sex</b>	
Male	11
Female	5
<b>Country of birth</b>	
The Netherlands	13
Suriname	2
Curacao	1
<b>Social status</b>	
Single	6
Single with children	1
Married/living together with children	1
Married/living together without children	7
Living apart together	1
<b>Education</b>	
Lower general professional training	4
High school	3
Community college	2
Undergraduate school	2
Graduate school	5
<b>Religious background</b>	
Christian	4
Atheist	2
Humanist	1
None	9

If a junky tried to come into the hotel, I thought he was human, just like me and I treated him as a human being. And they appreciated that. They listened to me and they respected me. (...) Of course, own safety first, but I always had a clean lobby, because I treated those people as human beings. (...) I think, if a family member gets ill, and you don't take care of them, you just don't have a soul. (...) I am always prepared to help people, I just do. (Man, 49 years)

### Relationships

Relationships are clearly important in the lives of people with stroke. When asked what makes life worthwhile, participants often answered in terms of relationships with significant others. Meaningful relationships and the experience of being connected are life goals. One respondent described himself as a loner, a *bon vivant*, but when the interviewer asked him what was truly meaningful in his life, what made him really happy, his answer was:

When I see my foster son, that is when I am really happy. (Man, 67 years)

Other respondents gave comparable answers, when asked what they lived for:

I want to be there for my son, my grandson and my family. Mostly for my grandson and my son. (Woman, 57 years)

Interviewer: what gives meaning to your life now?

Respondent: my wife and children ..., (emotionally) yes. (Man, 67 years)

### Worldview

Based on the narratives of the respondents and literature on global meaning (Koltko-Rivera, 2004), worldview can be defined as fundamental beliefs about life, death and suffering. When respondents looked for explanations for the events that happened in life, their worldview would give structure to their ideas on how these were related. This helped them to find meaning. Their worldview provided an answer to the question why things happen. Worldview became pre-eminently clear when people expressed their view on suffering and their reaction to stressful life events. For one respondent, life was an assignment. He saw his suffering as something he deserved. This guided his reaction to what happened and helped him to find the motivation to go on. Because he thought he 'had it coming', he also felt he had to move on and still make the best of it, however difficult this might be:

Life is an assignment. An order to make the best of it. (...) And suffering, I am afraid that I had it coming. The way I was living ..., that I deserved this. (Man, 50 years)

The answers to the question why things happened differed. However, if they satisfied the person involved, they were worldviews that gave structure and therefore meaning. This 77-year-old woman, for example, said she looked at the world in a contemporary way, which worked well for her:

Well, I sometimes think that we are driven by a big computer or something, you know. That I think of something and it happens, and I think: 'wow, that is remarkable, well, I guess it ended up in the computer'. (...) I mean, some people call it God, but well, I think in more contemporary metaphors. (Woman, 77 years)

### Identity

After stroke, respondents often showed differences in behaviour and capabilities, which raised questions regarding their identity. Identity refers to fundamental beliefs about one's deepest self. In the narratives of the respondents, identity comprised two aspects that supplemented each other. On the one hand, respondents distinguished themselves from others. Expressing their identity was a way of underlining their uniqueness, an expression of self-worth, which gave meaning to their lives. On the other hand, participants described their identity in stressing their

being part of specific groups. This provided a sense of belonging, which also gave meaning. Both aspects of identity are shown in the following quote, in which the respondent pointed out characteristics that were unique for her, distinguishing her from other people, but also partly connecting her to others with the same background:

I was always very active. (...) I travelled a lot, I was a belly-dancer for my hobby. (...) being a dancer, that was my identity, that and being a physician. (...) I am an independent woman, from a socialist, big-city environment, who is relatively well educated. I am a Chinese-Indonesian, and very Dutch, which I noticed during my travels. (Woman, 44 years)

The importance of belonging to a group as part of a person's identity is illustrated in the following quote. This respondent grew up in a working-class family. He never felt completely that he belonged there because he felt he had greater intellectual skills and ambition than was to be expected in his social class. He went to university to study psychology but he never really felt he belonged there either:

I am an optimistic person, there is enormous strength in me. (...) I am a fighter; I want to go on. (...) I am glad that my intellectual possibilities have not changed. (...) I come from a working-class family. In my time at university, I was often argumentative. I always felt: I don't belong to this group, but neither to the other. (Man, 66 years)

Another respondent described himself as direct and helpful. The fact that his friends appreciated him for that gave his life meaning:

I'm just someone that is direct, either you like me or you don't. And ... I don't care if you like me or not. I am willing to help people, and I do if I can. I hear from my friends and acquaintances that, whenever I am there, that they feel happy, because I am quick at making contact and jokes and stuff. (Man, 49 years)

### *Inner posture*

When confronted with painful events in their lives, respondents tended to encourage themselves or to calm themselves with prayer or meditation or they reminded themselves of what they had learned earlier in life. This helped them to bear what could not be changed. But also when confronted with good things in life, they showed a tendency to react in a characteristic way. Inner posture includes an element of acknowledgement and an element of choice and action. It involves acknowledging facts of life and choosing how to relate to them. Respondents did so in different ways. One respondent, for example, showed an inner posture of looking at the positive side of things by reminding himself of the good things that were left and comparing himself to others who were worse off:

I look at others and think that I must not whine, it could have been worse. (...) I miss doing things I used to do, but then I think 'count your blessings'. (Man, 65 years)

Another respondent showed an inner posture of taking things lightly and enjoying the small things in life. This could be seen during the entire interview; it was shown in the tone of his voice as well as in his choice of words. His stroke affected his sight, and he was temporarily living in a nursing home while his wife was still living in the house they used to share:

I can easily adjust to the circumstances. That is something I always was able to. (...) Of course I sometimes think: 'gosh, I haven't improved, have I', but most of the time that blows over. I enjoy the small things, trying to read a book, trying to look at the television, messing around the house a little. (...) Or when my wife comes and says: 'let's take a stroll'. Then I am really contented, I must say. (Man, 68 years)

### *Continuity and change in global meaning*

Respondents reported both continuity and change in global meaning. This respondent's core value of contributing to society did not change:

I think it is very important that one ... despite my handicap that I contribute something to society. I still feel that way and I made a deal with the school where I had a volunteer job: as soon as I can, I'll be back. (Woman, 46 years)

This also holds for this respondent's relationships and identity:

(own name) is still (own name). He can't do as much as he used to. But I do my best. (...) I still help my mother, and my aunt, who is mentally deficient. I always looked after people. Still do. (Man, 49 years)

The same applies to this respondent's worldview:

My faith hasn't changed since my stroke. I still like to pray. (...) We have always been religious people, so I just don't ask why. (Woman, 57 years)

Or this respondent's inner posture:

I live by what comes my way. Essentially I live my life like I did before. I don't live more profoundly nor more superficially. (Man, 68 years)

Continuity in global meaning was reported by all respondents; however, respondents also reported change with regard to worldview (two respondents), inner posture (one respondent) and identity (seven respondents).

This is shown in the following quote of a respondent regarding her worldview. Before and shortly after her

stroke, she thought illness was a punishment of God. After realizing that the consequences of her stroke would not go away and that she needed to find a way to live with them, she was not that sure anymore:

At first I thought 'I am being punished'. I am a roman catholic, so I thought, 'God is punishing me'. ... But now I don't know. Maybe it is fate. ... Things just happen, illness just happens. And this doesn't go away. (Woman, 46 years)

At the same time, this woman showed an inner posture that had not changed:

Don't resign yourself to fate. Just don't give up. Believe in yourself. That is what I always tell my children. Believe in yourself. You may believe in God, we do believe in God, but first you have to believe in yourself. (Woman, 46 years)

In seven respondents, changed behaviour or diminished skills raised questions regarding their identity. One respondent questioned whether she was still the same person now that she was not able to help other people anymore, since this used to be an important part of her identity:

Yes, I think I have changed, I don't know. (...) I was always the one to help other people, always being there for others. But now I can't do it myself. (...) I don't know ... who am I? I am also more emotional than I used to be. (Woman, 57 years)

## Discussion and conclusion

### *Global meaning in people with stroke*

The first purpose of this study was to explore global meaning in people with stroke. We identified five aspects of global meaning in people with stroke: core values, relationships, worldview, identity and inner posture. These are the same aspects we found in our study on global meaning in people with spinal cord injury (Littooij et al., 2015). The operationalizations of the aspects developed and slightly changed, as compared to the previous study, which is exactly what grounded theory is supposed to be: an emerging theory that changes and develops during the research process (Strauss and Corbin, 1998). The main change was that core values appeared to be not only fundamental beliefs but also life goals, worthy to be pursued. Besides, we changed the description of worldview from 'Worldview is a more or less coherent set of global beliefs ...' into 'Worldview refers to fundamental beliefs ...'. Describing inner posture, instead of merely referring to 'the facts', we expanded that to 'the facts of life'. Finally, we refined the descriptions of all five aspects in changing global beliefs and global goals into fundamental beliefs and life goals. (Table 2)

Two of these aspects, namely, *core values* and *worldview*, have been described in the broad area of stressful life

events, but not specifically stroke (Janoff-Bulman, 1992; Koltko-Rivera, 2004; Mooren, 1998; Park, 2010; Rokeach, 1979; Tedeschi and Calhoun, 1995).

In psychological literature on living with stroke, *relationships* and *identity* have been found to be of central importance (Anderson and Whitfield, 2013; Ellis-Hill et al., 2000; Ellis-Hill and Horn, 2000; Haslam et al., 2008; Hole et al., 2014; Kruithof et al., 2013; Ownsworth, 2014). Studies on relationships focus on the role relationships play in adaptation to stroke. These studies focus on meaning-making processes, rather than global meaning. Our focus was not on the psychological processes of meaning making, but on the more fundamental level of global meaning. Global meaning is hypothesized to play a role in meaning-making processes (Park, 2010, 2013). Therefore, our finding that relationships are an aspect of global meaning corresponds with the abovementioned studies. If global meaning guides meaning making, it is to be expected that relationships, as an aspect of global meaning, play a role in processes of adaptation to stroke. Studies on identity focus mainly on change in identity after stroke, which we will address later. Most researchers distinguish at least self-identity and social identity, which is in line with our findings that respondents described themselves as unique and as part of larger groups at the same time.

The term *inner posture* has not been found in previous research (Littooij et al., 2015). However, using a different terminology, the *concept* of inner posture is found in the fields of philosophy and psychotherapy: the stoics refer to inner posture as 'attitude' (Epictetus, 2004), while Frankl describes the attitude a person can choose in the face of unavoidable suffering (Frankl, 1992). Inner posture can be seen as related to coping. However, coping strategies are applied in a specific situation (Lazarus and Folkman, 1984), while inner posture refers to the way people deal with life events in general. Inner posture, being part of global meaning, may drive coping processes, which are part of situational meaning.

Both Park (2010, 2013) and Frankl (1992) are important sources for research on meaning. However, Park does not refer to Frankl in her meaning-making model, which has been critiqued by Marks (2016). More research on global meaning, specifically attitude and inner posture, and their relationship to meaning-making processes is recommended.

### *Continuity and change in global meaning in people with stroke*

The second purpose of our study was to explore whether global meaning changes after stroke. In this study, both continuity and change in global meaning were found. All respondents reported continuity in global meaning. Some of them, however, also reported change. Several respondents reported changes in their relationships. The life goal

**Table 2.** Aspects of global meaning.

Core values	Relationships	Worldview	Identity	Inner posture
Core values are fundamental beliefs about what is right and worthwhile, and life goals worthy to be pursued. They give direction to thoughts and behaviour	Relationships refer to a connection between a person and others. Meaningful relationships and the experience of being connected are life goals	Worldview refers to fundamental beliefs about life, death and suffering that structure people's ideas on how life events are related	Identity refers to fundamental beliefs about one's deepest self. Expressing one's identity provides people with a sense of belonging, at the same time underlining their uniqueness and self-worth	Inner posture helps people to bear what cannot be changed. It includes an element of acknowledgement and an element of choice and action. It involves acknowledging the facts of life and choosing how to relate to them

of maintaining meaningful relationships, however, did not change. Only the content and the character of relationships changed. So, in these instances, global meaning did not change.

Continuity and change were found not to be mutually exclusive, but appeared to co-exist. In one interview, for example, the respondent's wife reported continuity as well as change with regard to her husband's identity. She distinguished between her husband's changed behaviour and her husband 'himself', the latter referring to his character, his self-identity. This seems to indicate a *need for* continuity, which is also mentioned in research on identity and brain injury (Gendreau and De La Sablonniere, 2014). In comparison, the above-mentioned quote of the 57-year-old woman, who was not able to help other people anymore, seems to indicate that she experienced her identity as changed because of her changed capabilities. In psychological research on identity in relation to stroke, identity change is an important issue (Ellis-Hill et al., 2000; Ellis-Hill and Horn, 2000; Hole et al., 2014). In different studies, different aspects of identity are found to change or stay the same, depending on the definition of identity and the research methods or the questionnaires used (Lennon et al., 2014; Ownsworth, 2014). Ownsworth (2014) states that change can occur as a result of a neurological disorder, a (stressful) life event or more gradually as a result of psychotherapy or self-relevant situational feedback. She states that a person can experience change and continuity at the same time, which is in line with what our respondents reported.

The change in global meaning found in people with stroke contrasts with the results of our study on global meaning in people with spinal cord injury, in which no prominent changes were found (Littooi et al., 2015). This may be a result of the fact that after stroke, it takes a longer time to reach an end-state, compared to spinal cord injury. Or it may be related to the fact that the consequences of spinal cord injury are mostly physical, whereas stroke has mental and behavioural consequences as well. This is in line with the results of a study on spiritual issues associated with traumatic onset disability, in which changes were found in people with brain injury but not in people with

spinal cord injury (McColl et al., 2000). According to McColl, people with brain injury report significantly more changes in identity and relationships compared to people with spinal cord injury (McColl et al., 2000). The change found in people with stroke may be related to cognitive and behavioural changes as a result of stroke (Lennon et al., 2014; McColl et al., 2000).

### *Methodological considerations*

In this study, the five aspects of global meaning that were found in people with stroke were the same aspects that were found in people with spinal cord injury. This may have been a result of the questions that were asked by the interviewer, because the topic list was initially developed in interviews with people with spinal cord injury. However, both researchers who analysed the interviews were cautious to keep an open mind to other possible aspects of global meaning. Nevertheless, they both independently found the same five aspects.

The time span of 4–26 months after admission to the rehabilitation centre is a rather long one. Therefore, it is to be expected that respondents were in different phases of adaptation to living with a stroke. Nevertheless, all respondents were in outpatient rehabilitation and in a process of adapting to a new situation: living with the consequences of a stroke. We did not study in exactly what phase of adaptation respondents were; however, they did report about all five aspects of global meaning. Hence, it is not likely that the phase of adaptation was of influence on the content of global meaning. However, some respondents reported change in, for example, their identity or worldview. So, in their experience, the expression of different aspects did change. Since we did not study the different phases of adaptation, it is possible that the reported changes are connected to the phase of adaptation. Therefore, more research is recommended to study the relation between phase of adaptation and perceived change in global meaning.

Besides, the interviews were all conducted in the first period after a first stroke, which may account for the fact that many questions were still open, and continuity and

change were found to be co-existing. After stroke, it takes a long time to reach a stable final situation. Longitudinal studies are recommended to explore whether global meaning changes after a longer period of living with stroke.

Since the interviews took place after stroke, they reflect the view of the respondents in retrospect. As a result, we cannot be sure whether the reported change or continuity was, at least partly, a result of retrospective bias or was affected by memory problems or lack of insight relating to stroke. This problem could be addressed by interviewing relatives of the respondents, which may be an interesting field of future research. However, our results show how respondents reflected on their current and former global meaning. Since global meaning is hypothesized to guide meaning-making processes, it may not be very relevant whether global meaning *actually* changes. If in the experience of the person with stroke it does, this needs to be addressed. Perceived changes in global meaning tend to create distress, which initiates meaning-making processes (Park, 2010, 2013; Park and Folkman, 1997).

In the interviews with respondents with whom the first author had a close counselling relationship, she was extra careful in following the topic list during the interview. She was aware of the fact that the interviews needed to be understandable for other researchers as well and she checked regularly with the person who transcribed the interviews whether she thought the researcher was taking things for granted. The fact that a relationship already existed may have resulted in faster arriving on the level of global meaning. However, this does not mean that in the other interviews, the level of global meaning was not reached, since the interviewer is an experienced spiritual counsellor, who is used to establishing a relationship and helping people to reach deep levels of introspection, whether they already know her or not.

In some interviews, a spouse or another family member was present. This can be seen as both limitation and strength. On the one hand, the respondent may not have told everything because he wanted to protect his family from certain ideas. On the other hand, the spouse or family member sometimes stimulated the respondent by reminding him of earlier actions or statements he himself did not think of telling or by complementing the story of the respondent with her own view on the situation.

## Conclusion

In this study, five aspects of global meaning in people with stroke were found: core values, relationships, worldview, identity and inner posture. These are the same aspects found in research on global meaning in people with spinal cord injury (Littooi et al., 2015). More research is needed to explore global meaning in different groups of people or in the general population to explore whether these aspects are specific for people with, for example, neurological

disorders, or whether they are related to stressful life events in general, or if they are universal.

People with stroke reported continuity as well as change in their global meaning. Continuity and change were found to co-exist rather than being mutually exclusive. Sometimes, continuity and change were found in different aspects of global meaning, one aspect changing and the other not. But especially in identity, continuity and change appeared to be present at the same time. Future research is recommended to explore continuity and change in global meaning over a longer period of time.

## Acknowledgements

The authors thank Suzan Doodeman for her contribution in processing the interviews in Atlas.ti and co-analyzing the interviews, and Leo Brederveld for his helpful remarks on a previous version of this paper. The study would have not been possible without the cooperation of Reade and of course the respondents, who generously welcomed us into their houses and lives.

## Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

## Funding

This study was financed by het Revalidatiefonds and it won the DNS Fellowship 2012.

## References

- Anderson S and 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.
- Davis CG, Egan M, Dubouloz CJ, et al. (2013) Adaptation following stroke: A personal projects analysis. *Rehabilitation Psychology* 58(3): 287–298.
- Ellis-Hill CS and Horn S (2000) Change in identity and self-concept: A new theoretical approach to recovery following a stroke. *Clinical Rehabilitation* 14(3): 279–287.
- Ellis-Hill CS, Payne S and Ward C (2000) Self-body split: Issues of identity in physical recovery following a stroke. *Disability and Rehabilitation* 22(16): 725–733.
- Epictetus (2004) *Enchirion*. In: Negri P and Crawford T (eds) *Epictetus' Enchirion*. Mineola, NY: Dover Publications.
- Frankl VE (1992) *Man's Search for Meaning: An Introduction to Logotherapy*. Boston, MA: Beacon Press.
- Gangstad B, Norman P and Barton J (2009) Cognitive processing and posttraumatic growth after stroke. *Rehabilitation Psychology* 54(1): 69–75.
- Gendreau A and De La Sablonniere R (2014) The cognitive process of identity reconstruction after the onset of a neurological disability. *Disability and Rehabilitation* 36(19): 1608–1617.
- Haslam C, Holme A, Haslam SA, et al. (2008) Maintaining group memberships: Social identity continuity predicts well-being after stroke. *Neuropsychological Rehabilitation* 18(5–6): 671–691.



- Hole E, Stubbs B, Roskell C, et al. (2014) The patient's experience of the psychosocial process that influences identity following stroke rehabilitation: A metaethnography. *The Scientific World Journal*. Available at: <https://www.hindawi.com/journals/tswj/2014/349151/>
- Janoff-Bulman R (1992) *Shattered Assumptions: Towards a New Psychology of Trauma*. New York: The Free Press.
- Kessler D, Dubouloz CJ, Urbanowski R, et al. (2009) Meaning perspective transformation following stroke: The process of change. *Disability and Rehabilitation* 31(13): 1056–1065.
- King RB, Shade-Zeldow Y, Carlson CE, et al. (2002) Adaptation to stroke: A longitudinal study of depressive symptoms, physical health, and coping process. *Topics in Stroke Rehabilitation* 9(1): 46–66.
- Koltko-Rivera ME (2004) The psychology of worldviews. *Review of General Psychology* 8(1): 3–58.
- Kruihof WJ, Van Mierlo ML, Visser-Meily JM, et al. (2013) Associations between social support and stroke survivors' health-related quality of life – A systematic review. *Patient Education and Counseling* 93(2): 169–176.
- Lazarus RS and Folkman S (1984) *Stress, Appraisal and Coping*. New York: Springer Publishing Company.
- Lennon A, Bramham J, Carroll A, et al. (2014) A qualitative exploration of how individuals reconstruct their sense of self following acquired brain injury in comparison with spinal cord injury. *Brain Injury* 28(1): 27–37.
- Littooij EC, Leget CJW, Stolwijk-Swüste JM, et al. (2016) The importance of 'global meaning' for people rehabilitating from spinal cord injury. *Spinal Cord*. Epub ahead of print 19 April. DOI: 10.1038/sc.2016.48.
- Littooij EC, Widdershoven GAM, Stolwijk-Swüste JM, et al. (2015) Global meaning in people with spinal cord injury: Content and changes. *Journal of Spinal Cord Medicine* 39(2): 197–205.
- McColl MA, Bickenbach J, Johnston J, et al. (2000) Spiritual issues associated with traumatic-onset disability. *Disability and Rehabilitation* 22(12): 555–564.
- Marks DF (2016) Dyshomeostasis, obesity, addiction and chronic stress. *Health Psychology Open* 3: 1–20.
- Mooren JH (1997) Zingeving en cognitieve regulatie. Een conceptueel model ten behoeve van onderzoek naar zingeving en levensbeschouwing. In: Janssen J, Van Uden R and Van De Ven H (eds) *Schering en inslag*. Nijmegen: KSGV, pp. 193–206.
- Mooren JH (1998) Trauma, coping and meaning of life. *Praktische Humanistiek* 7(3): 21–29.
- Mukherjee D, Levin RL and Heller W (2006) The cognitive, emotional, and social sequelae of stroke: Psychological and ethical concerns in post-stroke adaptation. *Topics in Stroke Rehabilitation* 13(4): 26–35.
- Owensworth T (2014) *Self-identity after Brain Injury*. London; New York: Psychology Press.
- Pargament KI (1997) *The Psychology of Religion and Coping: Theory, Research, Practice*. New York: The Guilford Press.
- Park CL (2010) Making sense of the meaning literature: An integrative review of meaning making and its effects on adjustment to stressful life events. *Psychological Bulletin* 136(2): 257–301.
- Park CL (2013) The meaning making model: A framework for understanding meaning, spirituality, and stress-related growth in health psychology. *European Health Psychologist* 15(2): 40–47.
- Park CL and Folkman S (1997) Meaning in the context of stress and coping. *Review of General Psychology* 1(2): 115–144.
- Rochette A, Bravo G, Desrosiers J, et al. (2007) Adaptation process, participation and depression over six months in first-stroke individuals and spouses. *Clinical Rehabilitation* 21(6): 554–562.
- Rochette A, Tribble DS, Desrosiers J, et al. (2006) Adaptation and coping following a first stroke: A qualitative analysis of a phenomenological orientation. *International Journal of Rehabilitation Research* 29(3): 247–249.
- Rokeach M (1979) *Understanding Human Values*. New York: The Free Press.
- Strauss A and Corbin J (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. London: SAGE.
- Tedeschi RG and Calhoun LG (1995) *Trauma & Transformation: Growing in the Aftermath of Suffering*. London: SAGE.
- Thompson SC (1991) The search for meaning following a stroke. *Basic and Applied Social Psychology* 12(1): 81–96.

## Appendix I

### Topic list global meaning

1. Could you tell me what happened to you?
2. What has changed?
3. What has remained the same?
4. Do you think your stroke has a meaning or a purpose?
5. Do you think life in general has a meaning or a purpose?
6. What is really important to you in life?
7. When do you get annoyed?
8. What do you hope others will say or think about you?
9. If I ask you: 'Who are you?' what would be your answer?  
(Please finish the sentence: I am ... someone who ...)
10. Could you share some of your thoughts about death with me?
11. How do you manage to live with your stroke?
12. Has what we have discussed so far affected your rehabilitation? In what way?
13. Is there anything else you would like to say, in reaction to the interview so far?
14. How did you experience this interview?