Global meaning in people with spinal cord injury or stroke

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How did it start?

- Cancer research: change of values
- Clinical experience as a health care chaplain
- Continuity and discontinuity

✓ “People see me differently, but I am still the same person”
✓ “If I can’t be the old me, I will have to become the new me”
✓ “I am used to doing things. Now that my body doesn’t work the way it used to, who am I now?”

What am I looking for? Values, meaning in life, spirituality?
Meaning of life?

I WANT TO KNOW THE MEANING OF LIFE

HAVE YOU TRIED GOOGLING IT?
Meaning model (Mooren 1998)

Cognitive (self-)regulation factors

Meaning making processes
- Contingency
- Goals
- Values
- Self-image
- Manageability

Experience of meaning
- Comprehensibility
- Commitment
- Peace of mind
- Self-worth
- Competence

Meaning framework
- Worldview
- Life perspective
- Ethics
- Concept of man
- Soteriology

Elements of the life-stance
Meaning making model (Park 2013)
Purpose

(i) to explore global meaning in people with SCI or stroke

(ii) to explore whether global meaning changed after SCI or stroke

(iii) to explore the influence of global meaning on processes and outcomes of rehabilitation after SCI or stroke
Methods

Qualitative research:
- grounded theory
- semi-structured interviews
- points of interest: aspects from the Mooren-model

Respondents, criteria:
- SCI or first stroke 6 – 24 months ago
- Permanent limitations
- 18 years or older
- Speaking Dutch

- Exclusion criteria: severe cognitive problems, afasia
1. Could you tell me what happened to you?
2. What has changed?
3. What has remained the same?
4. Do you think your SCI/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 SCI/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?
Results (i) aspects of global meaning

SCI: out of 29 invitations, interviews with 9 men, 7 women
Stroke: out of 31 invitations, interviews with 11 men, 5 women

Five aspects of global meaning in people with SCI or stroke:

Core values
Relationships
Worldview
Identity
Inner posture
Core values are fundamental beliefs about what is right and life goals worthy to pursue. They give direction to thoughts and behavior.

“I have always felt that it is important to contribute to society. If my participation in this study can help others, why not.”  
(man, 50)
Relationships refer to a connection between a person and others. Meaningful relationships and the experience of being connected are life goals.

“Interviewer: what gives meaning to your life now? 
Respondent: my wife and children…, (emotionally) yes.” (man, 67)
Worldview is a more or less coherent set of fundamental beliefs about life, death, and suffering, that structure people’s ideas on how life events are related.

“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)
Identity

Identity refers to fundamental beliefs about one’s deepest self and one’s place in the world. It provides a sense of belonging, which gives meaning to people’s lives. At the same time it is a way of underlining their uniqueness, an expression of self-worth.

“Yes, I do want to know the cause [of the SCI], I do. That is who I am. (...) I am someone, who, when I want to know something, wants to know everything. Also what is at the bottom, under the bottom, preferably. Someone else may think ‘what do I care, it is written,’ but I go beyond what is written.” (woman, 68)
Inner posture refers to global beliefs about how to deal with life events. It helps people to bear what cannot be changed. Inner posture includes an element of acknowledgement and an element of choice and action. It involves acknowledging the facts of life and relating to them.

“[People ask:] doesn’t it gnaw at you? I say: no. No. I don’t let it gnaw at me. (...) I see rehabilitation as my work now. Three days a week I go and practice. You go to your work. I go and work on my physical health.” (man, 42)
Results (ii) continuity or change in global meaning

SCI: global meaning hardly changes after SCI. People become more aware of aspects of their global meaning.

Stroke: continuity in all aspects of global meaning, and change in worldview, identity and inner posture after stroke.
Results (iii) influence on rehabilitation

<table>
<thead>
<tr>
<th>SCI</th>
<th>Stroke</th>
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<tbody>
<tr>
<td>(all aspects of global meaning)</td>
<td>(relationships, identity, inner posture – core values and worldview far less)</td>
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**Processes**

- 1. Motivation  
- 2. Regulation of emotion  
- 3. Making decisions  
- 1. Motivation  
- 2. Handling stress and emotions

**Outcomes**

- 1. Physical functioning  
- 2. Emotional functioning  
- 3. Social functioning and participation  
- 4. Subjective sense of meaning  
- 1. Physical functioning  
- 2. Acceptance
Influence of global meaning on rehabilitation processes

Relationships / core values -> Motivation
“Life has a meaning, yes. In relation to other people, my wife for example. (...) I believe I still have value for other people. If you don’t, you can just as well end it right away. (...) That has given me motivation during my rehabilitation. I want to be able to really contribute something again.” (man, 59)

Worldview -> Motivation
“What shall I say, it is fate. Everybody gets his fate. You cannot get around that. (...) I can’t practice. I just can’t.” (man, 67)

Worldview / inner posture -> Regulation of emotion
“When we are sad, when things are heavy, my wife and I cry together, but then I say: ‘stop, I have to go on’. And then I go on again. You just have to go on. (...) Everything goes on. Back to the source. And then it starts again. (...) One would be stupid to not go on, wouldn’t one? Of course you go on, you just do.” (man, 74)
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Influence of global meaning on outcomes of rehabilitation

Relationships -> Physical functioning

“Most important in my life are my children. My family. They are number 1. That includes the father of my children. He has his own house, I have mine, but he still stands by me. Yes, being a mother for my children is my primary goal in life. (...) I used to make breakfast and lunch for my daughters, that was my passion, being their mother. That is what I wanted to be able to do again. And that is what I achieved. I wanted to make that sandwich, for them to take and eat and think ‘my handicapped mother made that for me.’” (woman, 48)

Inner posture -> Acceptance

“Before my stroke I was already interested in mindfulness, trying to practice acceptance and inner peace. (...) I try to inform myself as good as possible, read books about all kinds of subjects. Yes, that played a big role. I could feel my breath, my body, acceptance, all those things. I could feel the resistance flow away. Now that I am in more pain, this is more difficult, but I still try.” (Man, 50)


In conclusion

Global meaning
Fundamental beliefs and life goals concerning core values, relationships, worldview, identity and inner posture

Meaning making
Psychological, situational processes

Processes and outcomes of rehabilitation
Conceptualization of global meaning

Park: global goals and beliefs and a subjective sense of meaning

Us: fundamental beliefs and life goals concerning core values, relationships, worldview, identity and inner posture

Different angles - terminology:
meaning (in life), spirituality, religion, existential meaning?

Different angles - content:
Multi-faceted concepts, various definitions
Purpose, goals, relationships, values, hope, compassion, etc.

More angles?

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Thank you!