

**De Hoogstraat**  
Revalidatie

**Trajectories in quality of life:  
How to connect to people in the different  
trajectories?**

# Content

- What is quality of life?
- Umbrella study and trajectories in quality of life?
- Which factors influence quality of life in persons with SCI?
- Psychosocial rehabilitation in persons with SCI
- Discussion: How can patient organisations and rehabilitation centers work together?

## Definition of quality of life

- According to Shalock (2000) there are more than 100 different definitions of QoL.
- According to van Heck (2006) there are as many definitions of QoL as there are scientists in the field of QoL.

# How do you define quality of life?

- MD's, PT's, OT's in the UK (N=1572)
  - Happiness 72.2%
  - Social 25.8%
  - Physical 25.2%
  - Mental 17.8%
  - Independence 13.0%
  - Subjective 12.3%
  - Economic 6.6%
  - Good health 5.3%
  - Indefinable 2.0%
  - Other 1.6%

(McKevitt, Redfern, et al. Clin Rehabil 2003)

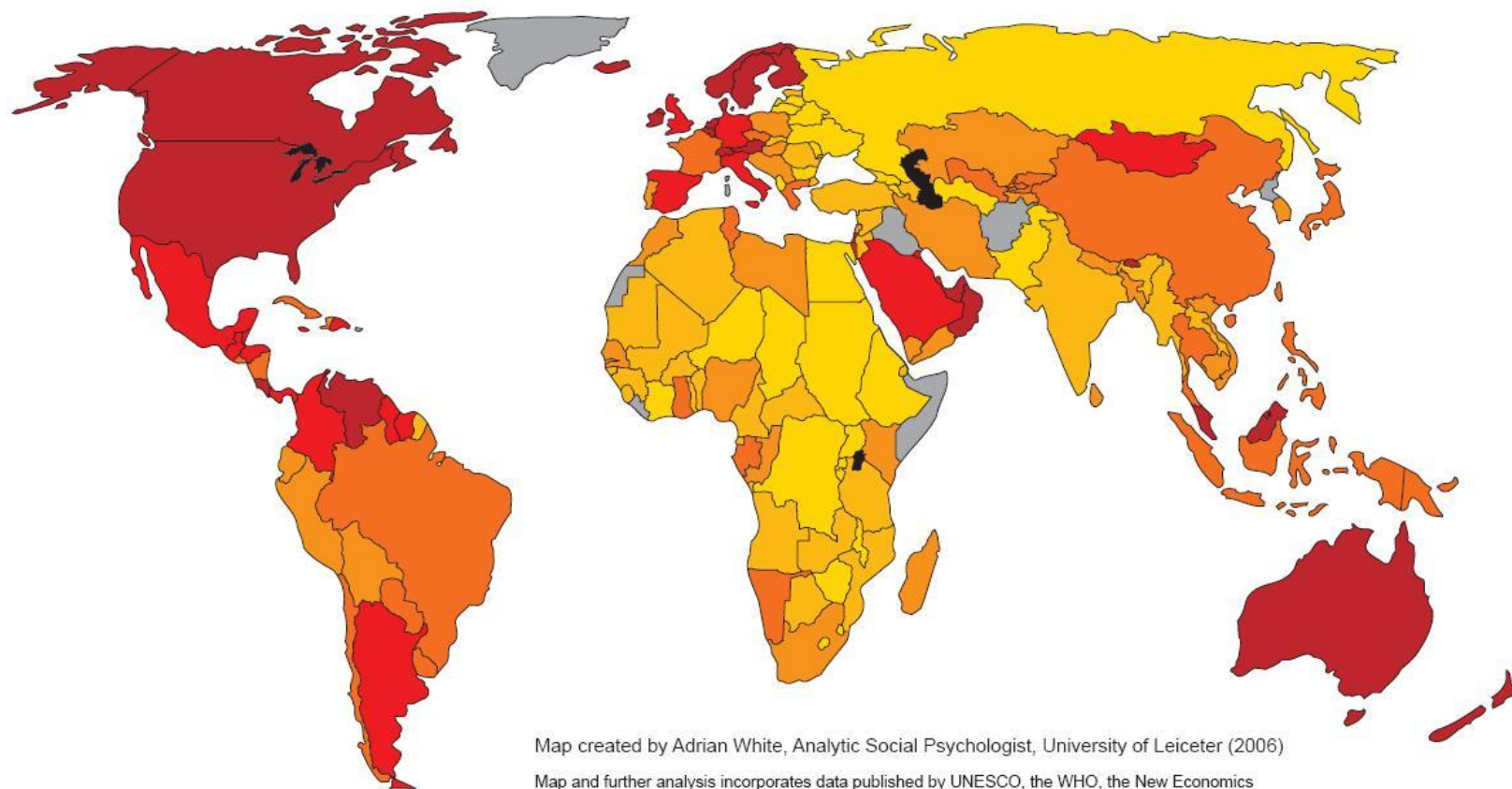
## WHO defines quality of life as:

Individuals perception of their position in life **in the context of the culture and value systems** in which they live and in relation to their goals, expectations, standards and concerns



# World happiness

A Global Projection of Subjective Well-being:  
The First Published Map of World Happiness



Map created by Adrian White, Analytic Social Psychologist, University of Leicester (2006)

Map and further analysis incorporates data published by UNESCO, the WHO, the New Economics Foundation, the Veenhoven Database, the Latinbarometer, the Afrobarometer, the CIA, and the UN Human Development Report.



Happy ----- Average ----- Unhappy

# Which factors influence QOL?

- Climate
- Safety
- Education
- Civil status
- Personality
- Social network
- **Health (health facilities)**
- **Surroundings (accessibility)**
- **Infrastructure**

## Discussion

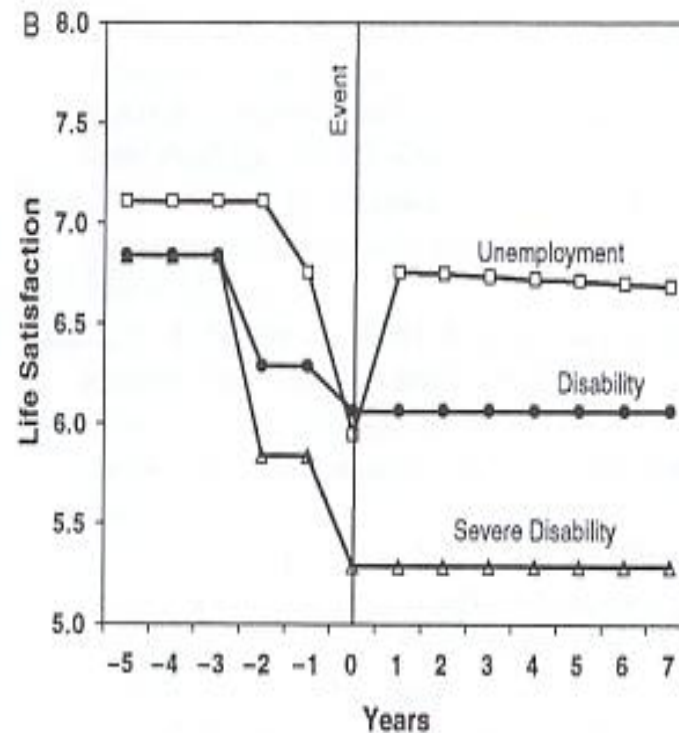
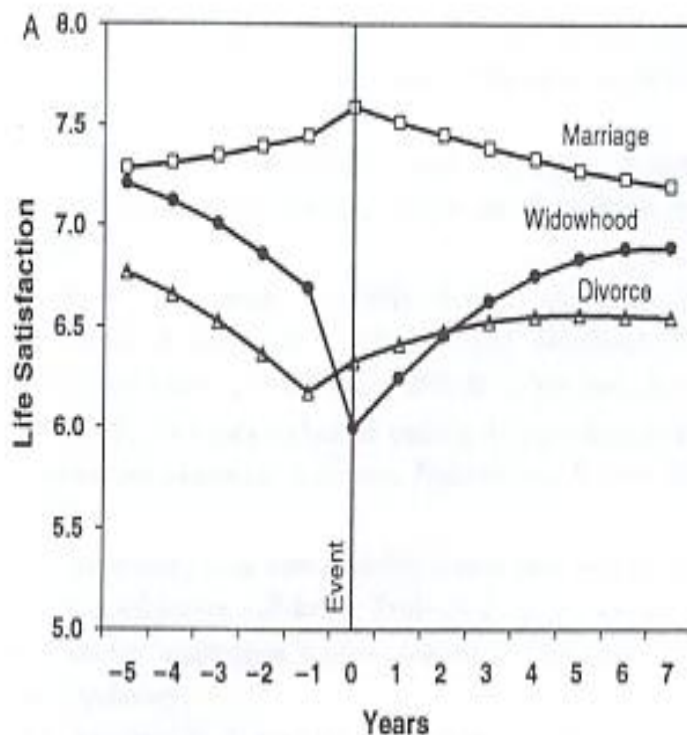
Exchange between countries: How is quality of life for persons with SCI in ....?

- Which environmental factors play a role?
- Which health care factors play a role?
- Are there any other factors which play a role?





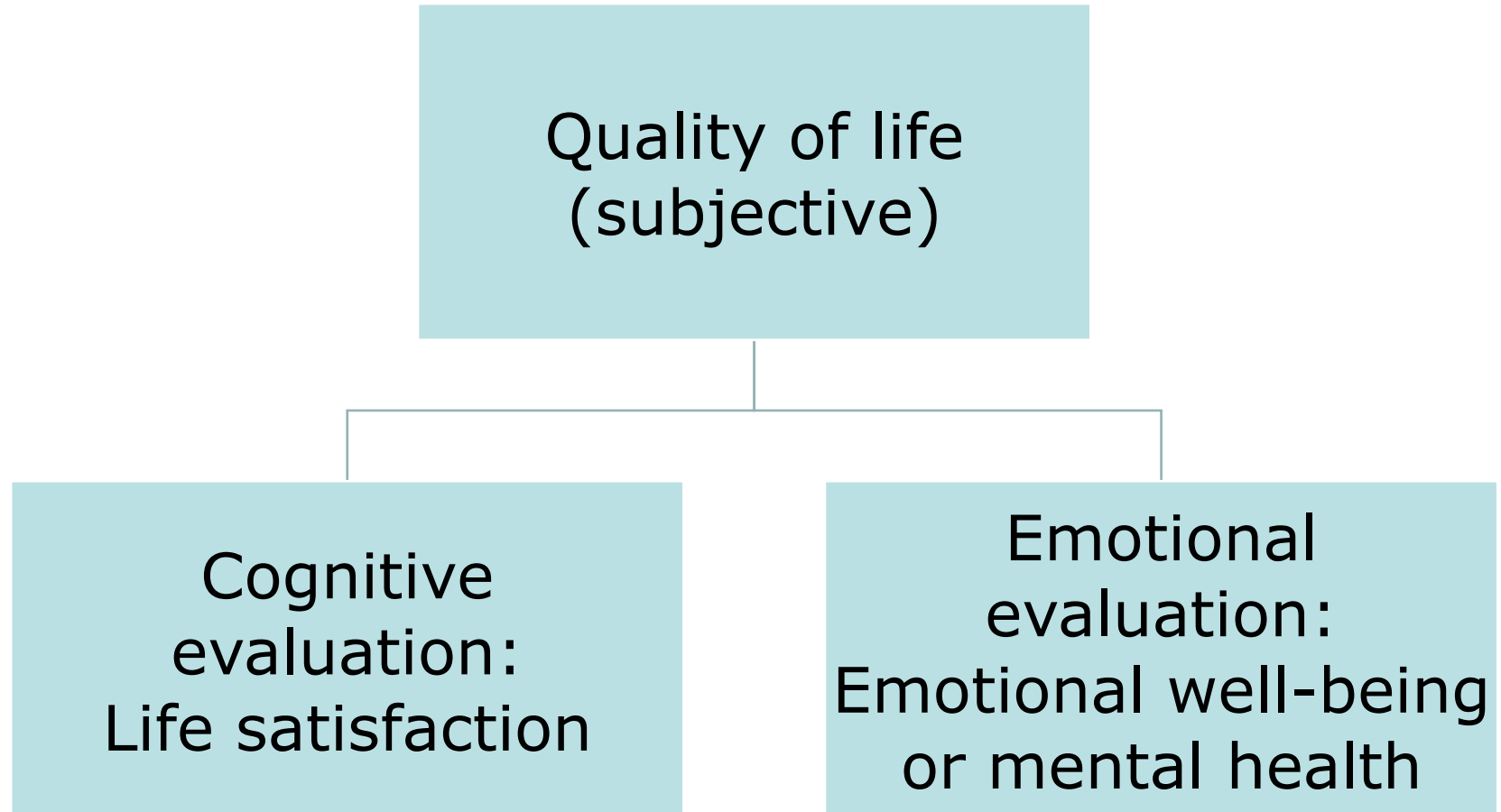
# Life satisfaction and life events



- Lucas RE. Long-term disability is associated with lasting changes in subjective well-being: evidence from two nationally representative longitudinal studies. *J Pers Soc Psychol* 2007;92:717-730.



## But what is quality of life?



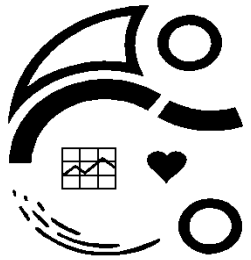
# Spinal cord injury and Quality of Life

**“It is so difficult to accept this terrible life”**




**“I found out that also with my SCI I can be succesful, independent, handsome, cheerful, and happy”**





# Cohort study



Beatrixoord 

heliomare 

Reade   
revalidatie | reumatologie

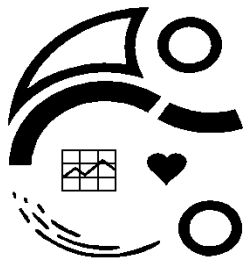
Het Roessingh   
centrum voor revalidatie

Revalidatiecentrum  
**De Hoogstraat**

Rijndam  revalidatiecentrum

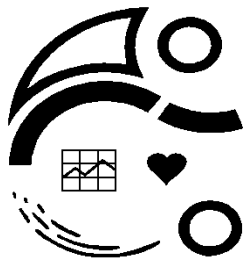
Sint Maartenskliniek   
NIJMEGEN

adelante   
haal het beste uit jezelf



## Measurement occasions

| <b>Measurement</b> | <b>N</b> | <b>When?</b>                   |
|--------------------|----------|--------------------------------|
| T1                 | 225      | Start of active rehabilitation |
| T2                 | 155      | 3 months after start           |
| T3                 | 198      | Discharge from rehabilitation  |
| T4                 | 156      | 1 year after discharge         |
| T5                 | 99       | 2 years after discharge        |
| T6                 | 146      | 5 years after discharge        |



## Research questions

- What is **the course of** life satisfaction of persons with SCI during and after initial rehabilitation up to five years after discharge?
- What is **the influence of** demographics, SCI characteristics, physical factors, and psychosocial factors on life satisfaction of persons with SCI during and after initial rehabilitation?

# Course of life satisfaction after spinal cord injury

- 1. What is your quality of life at the moment?  
(1= very unsatisfying, 6= very satisfying)*
  - 2. Is your quality of life at the moment worse, equal or better than before the SCI?  
(1= much worse, 7= much better)*
- Sum score of both questions (range 2-13)

# Course of life satisfaction after spinal cord injury

What do you expect?

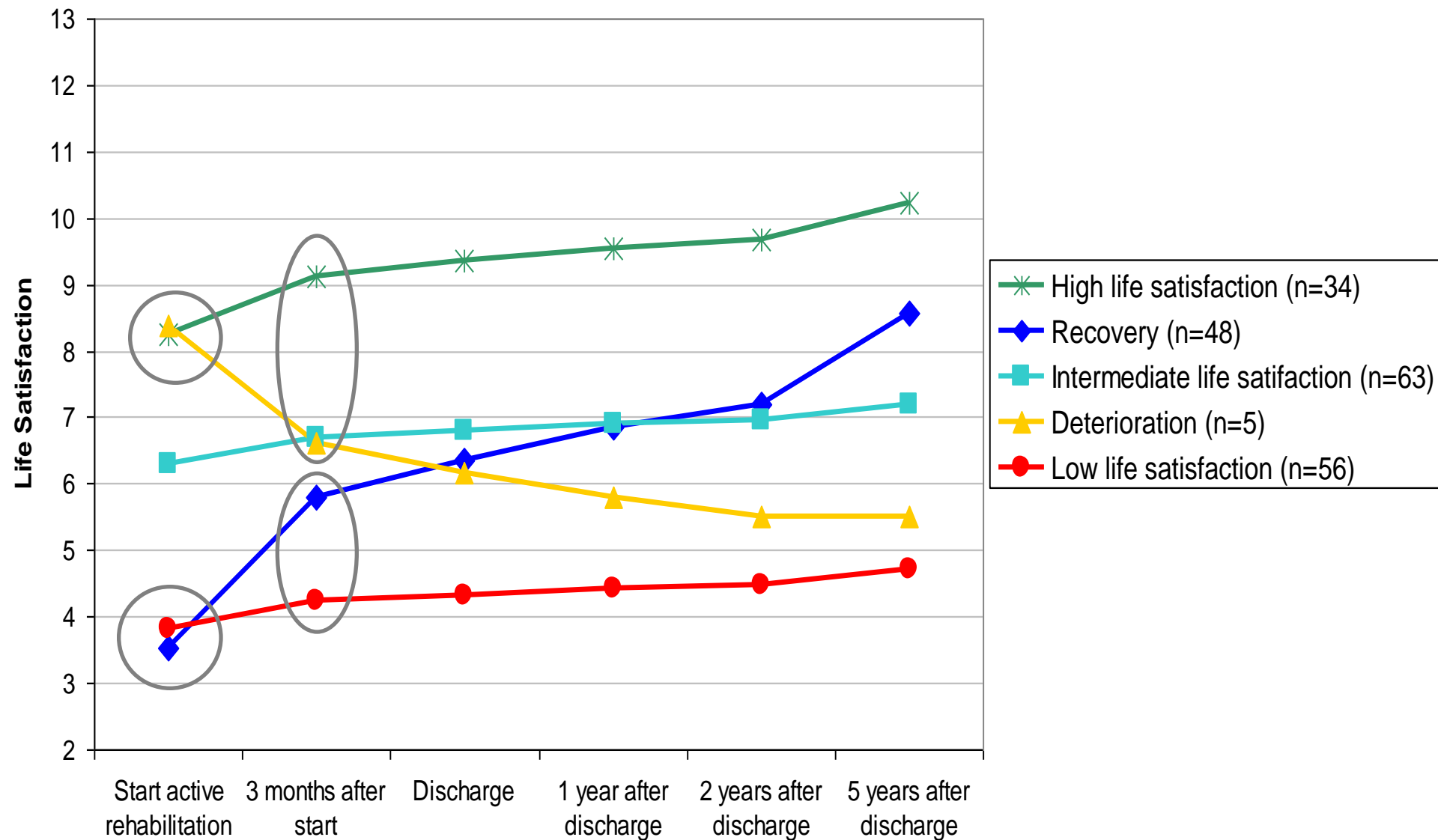


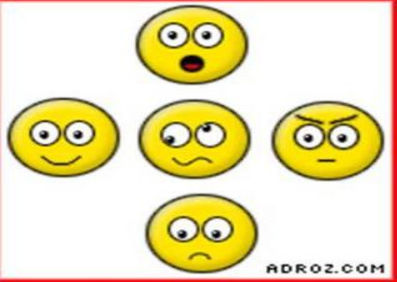
# Methods

## *Latent Class Growth Mixture Model*

Based on regression- and structural equation models.

# Five life satisfaction trajectories

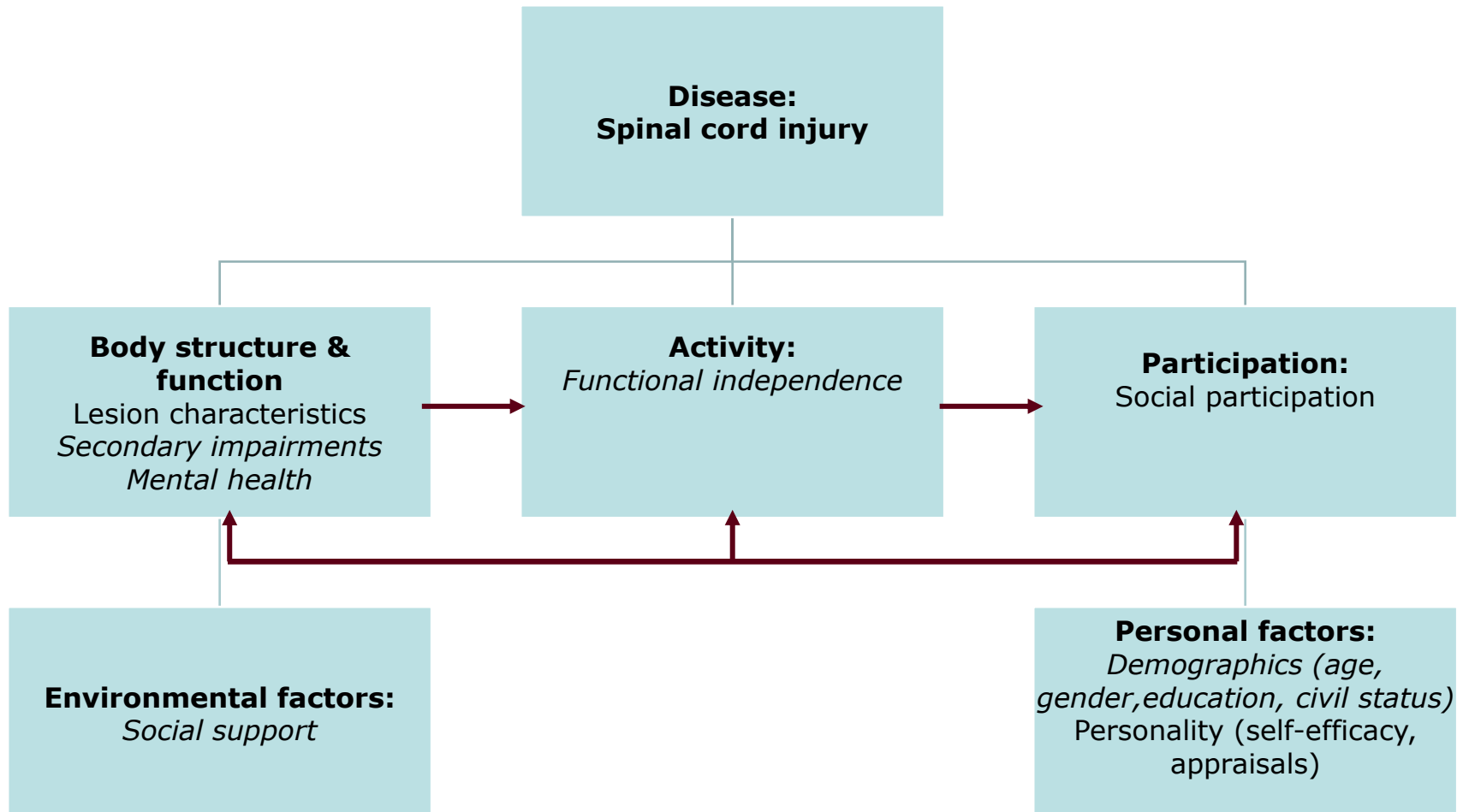




## Main findings

- Five different life satisfaction trajectories
- Two risk groups: low life satisfaction, deteriorating
- Monitoring during rehabilitation can help to identify persons at risk for poor long-term adjustment

# Determinants of quality of life: ICF model





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# Determinants

- Functional impairment
- Pain and secondary complications
- Social support (emotional support, practical support and esteem support)
- Personality: self-efficacy, appraisals (helplessness, acceptance)

# Clinical implications

- **Maximize** functional independence
- **Minimize** secondary impairments and pain
- **Psychological screening** at the start of active rehabilitation and 3 months after: Identify persons at risk
- **Develop psychosocial interventions** in persons with SCI

# **The Dutch SCI rehabilitation: psychosocial**






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## Three phases

- Hospital phase
- Rehabilitation phase
- Chronic phase



Beatrixoord 

**heliomare**

**Reade**  
revalidatie | reumatologie

**Het Roessingh**  
centrum voor revalidatie

Revalidatiecentrum  
**De Hoogstraat**

  
**Rijndam** revalidatiecentrum

  
**Sint Maartenskliniek**  
NIJMEGEN

  
**adelante**  
haal het beste uit jezelf

## NVDG

The [Dutch-Flemish Society of Paraplegia](#) exists since 1993 as a society of co-workers from the specialized units for SCI rehabilitation. Goal is to stimulate:

- The collaboration between persons working in the rehabilitation of SCI;
- The exchange of ideas and experience between these persons (national and international);
- Research within the field of SCI rehabilitation.

# Patient organisation

- Dwarslaesie Organisatie Nederland

[www.dwarslaesie.nl](http://www.dwarslaesie.nl)

# Psychosocial rehabilitation: Who?

## Standard disciplines:

- Intake psychologist
- Intake social worker

## Standard or optional:

- Intake peer counselor
- Intake nurse specialised in sexuality
- Intake creative therapist
- Intake sport therapist
- Intake humanistic worker

## Consultation:

- Psychiatrist
- Sexuologist

# Psychosocial screening

- Adjustment: depression, anxiety, post-traumatic stress
- Personality: strengths and weaknesses
- Coping and appraisals
- Cognition: planning and organisation
- Social network

## Outcome:

**Inclusion in one of three psychosocial profiles: Resilient, recovery, low life satisfaction**

## Treatment: Resilient group

- Education about SCI and about adjustment
- Main focus is on physical rehabilitation

## Treatment: Recovery group

- Education about SCI and adjustment
- Physical and psychosocial rehabilitation
- Psychosocial treatment involves:
  - EMDR (trauma)
  - Graded activity (depression)
  - Graded exposure (anxiety)
  - Acceptance and commitment therapy
  - Psychomotor therapy (body image)
  - System therapy (partner, children)

## Treatment: Low life satisfaction group

- Education about SCI and adjustment
- Main focus is on psychosocial rehabilitation:

**Team counseling:** how to collaborate together?

Focus on **self-management:** what is possible and what is not possible?

**Arrange support in society:** family doctor, home care, peer support, keep a link with the rehabilitation center → transmural nurse



# Power study



Decreased  
length inpatient  
care

High level of  
burden carers

Felt gap after  
discharge clinic

# Aims POWER



Decreased  
length inpatient  
care

High level of  
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Felt gap after  
discharge clinic

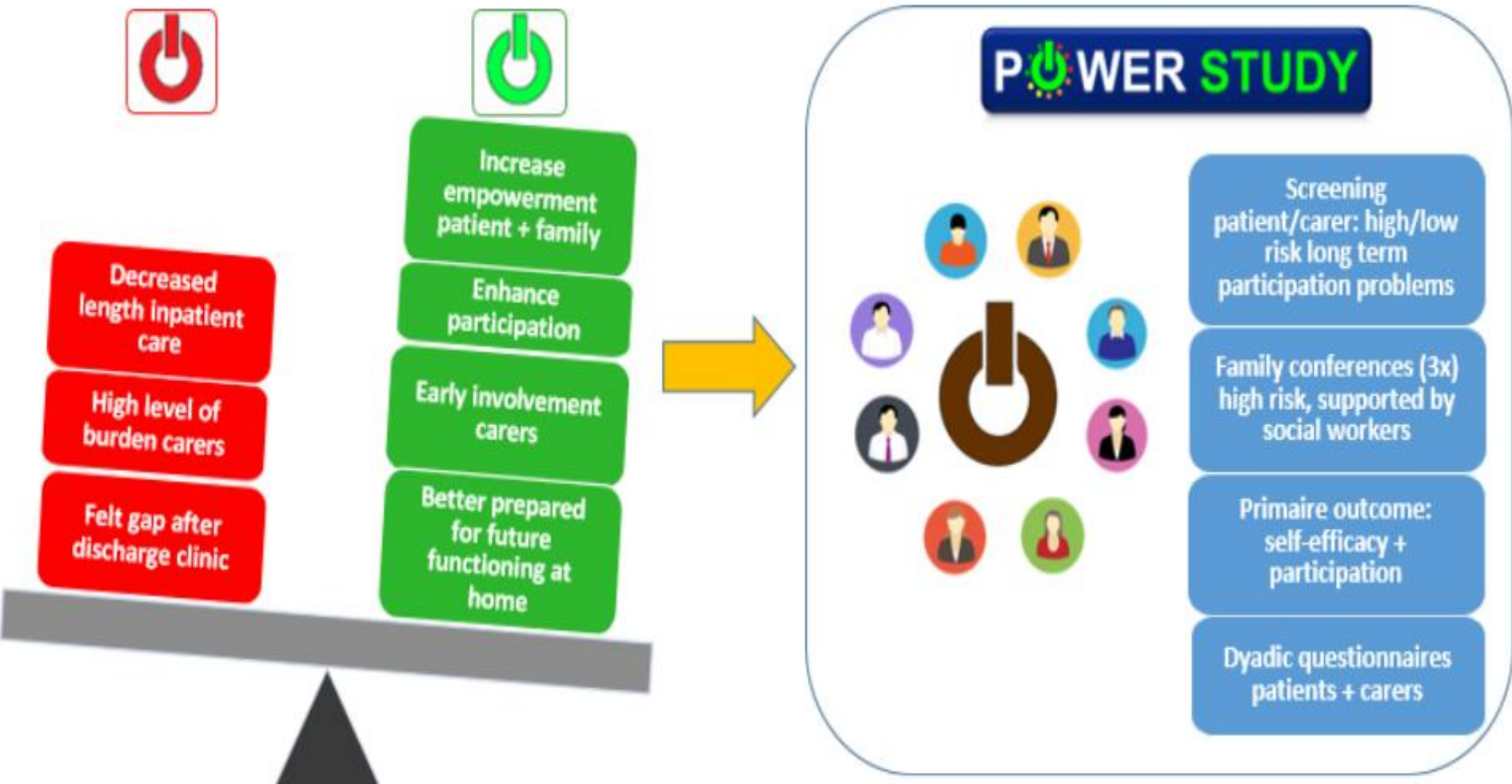
Increase  
empowerment  
patient + family

Enhance  
participation

Early involvement  
carers

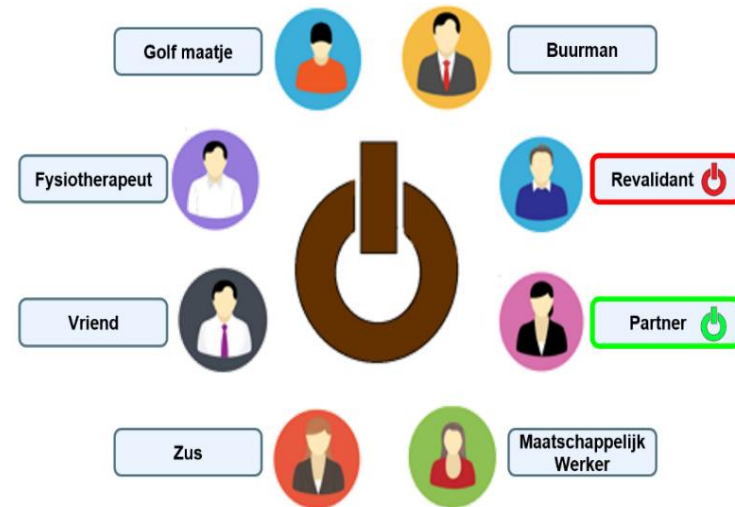
Better prepared  
for future  
functioning at  
home





# Intervention Family Group Conference

|               | When                       |
|---------------|----------------------------|
| <b>Start</b>  | End of inpatient rehab.    |
| <b>Future</b> | 1,5 months after discharge |
| <b>End</b>    | 3 months after discharge   |



- 3 meetings led by a social worker
- Involving social network members (neighbours, family, friends) and professionals
- Together make concrete participation goals and an action plan

## Further research in the Netherlands

- Peer support: How is it organised in every SCI rehabilitation center in the Netherlands and what works best?
- Partners for partners organised by the patient organisation



## Discussion

- How can patient organisations and rehabilitation centers work together?
- How do patient organisations try to reach persons with SCI?



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# Case description: resilient



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# Case description: recovery



# Case description: low life satisfaction



## ESCIF

- “to live a more independent and full life and participate as any other citizen”
- “to develop your own life project based on your needs and objectives”
- “take charge of your own life instead of having others doing it”

## ESCIF: services regarding QOL

- Sports and leisure time activities
- Information
- Legislation and policy lobbying
- Advocacy
- Individual counselling
- Advice and information on health issues
- Peer support
- Accessible accommodations and transportation
- Vocational training
- Skills for independent living
- Courses, Camps, Seminars, support service

**ESCIF:** self-motivation, self-determination, empowerment, coaching and/or peer-support

- Social and vocational rehabilitation
- Personal assistance
- Person centered goal setting
- Self-help groups
- Self-advocacy courses.

# What can patient organisations do?

- Make contact during clinical rehabilitation. Lower the threshold by giving education (technical aids, healthy lifestyle), organising activities, facilitating peer support.
- Organise social activities during the weekends in inpatient rehabilitation, such as sport games, going to a theatre/restaurant.
- There is a need for role models. Share your story, also with professionals: videos, presentations, books
- Set up a peer support system for persons in the recovery trajectory and low life satisfaction trajectory and discuss with the person with SCI and the rehabilitation team what the focus should be of everyone who is involved (see Power study).

# ESCIF SIP QOL

## List of facilitators and barriers

|  |  |   |
|--|--|---|
| Acceptance from the public               | Consumer organisations to enforce the rights and interests of people living with SCI | Peers to exchange experiences   |
| Accessibility                            | Consumer organisations to help people to get back to life                            | Professional and leisure time activities                                |
| Access to information                    | Knowledge about SCI to avoid complications   | Technical aids – advice and help with the choice, finances, maintenance |
| Adequate medical care and rehabilitation | Legal support  |   |