Rehabilitering i en livskontekst – et viktig perspektiv for sykepleien under rehabiliteringsprosessen ved nevrologiske tilstander

Marit Kirkevold
Konsekvensene av å leve med en nevrologisk sykdom på liv, helse og funksjon
Recovery and adjustment following a stroke

Ultimate goal: ‘Live a life worth living’

A gradually widening context for recovery and adjustment work

- Bodily recovery and functional improvement
- Recreating and restructuring daily life
- Biographical adjustment & transformation

Going on with life

Trajectory onset

- Initial rehabilitation
- Continued rehabilitation
- Semi-stable phase

(Kirkevold 2010)
Abstract

Telling stories is essential to the continuous process of creating meaning and to self-understanding. Persons with aphasia are vulnerable to psychosocial problems by their limited ability to talk and interact with others. This single case study illustrates how a young woman with aphasia and a trained nurse interacted to coconstruct stories within the context of a longitudinal clinical intervention aimed at promoting psychosocial well-being in the first year after a stroke. Data were collected through qualitative interviews and participant observation; they were then analyzed from a hermeneutic-phenomenological perspective. The experience of coconstructing stories made an important contribution to improving the participant’s psychological well-being. The shared construction of the participant’s story evolved as a cumulative process, and it was facilitated by the establishment of trust in the participant–nurse relationship, the systematic use of worksheets and supported conversations, and a specific focus on psychosocial topics and structural organization.
Maria’s “journey of recovery” the first 2 years following a stroke

The illustration is based on the analysis of data and was created by the authors. Maria affirmed the illustration.
Rehabilitation after spinal cord injury and the influence of the professional’s support (or lack thereof)

Sanne Angel, Marit Kirkevold and Birthe D Pedersen

Aim and objectives. To investigate how spinal cord injured patients struggle with their rehabilitation and how they feel that the professionals influence this process.

Background. Rehabilitation after a spinal cord injury is a long and arduous process during which the patient needs much support. Some patients lack adequate support from the professionals. This makes it pertinent to investigate the processes patients go through to get on with their lives and the influence professionals have.

Design. A phenomenological-hermeneutic study with a narrative approach using Ricoeur’s theory.

Method. A purposeful and consecutive sample of 12 newly injured, adult Danish-speaking patients previously living a normal life were observed 7-12 times and interviewed six or seven times over two years.

Results. The patients regained meaning and got on with life through resolute fighting for a meaningful life. We found three patterns of fight; the patients fought with themselves together with the professionals (pattern I). If consensus about the goals and pathway broke down and was not re-established, this fight could turn into a fight against the professionals (pattern II). This would, in turn, cause the patients to fight against themselves. A third pattern (III) was that the patients turned away, either going their own way or suppressing themselves by adapting to the professionals’ views. In either case, the patients would feel being left on their own.

Conclusion. When the patient and professionals agreed on the way forward, the patient experienced the professionals as supportive. However, if the patient’s goals were not consistent with the professionals’ views, the patient felt that the professionals withdrew their support.

Relevance to clinical practice. If the professional were able to maintain consensus with the patient, they contributed to the patient’s process of regaining meaning.

Key words: fight, meaning, patient participation, phenomenological-hermeneutic, rehabilitation, spinal cord injury
Three patterns of fight – trying to recover from spinal cord injury (Sanne Angel)
Living with Parkinson’s disease before and after Deep Brain Stimulation

Anita Haahr
Faserne i livet med Parkinsons sygdom

The body is acting funny
Perceiving a new life
Getting on with life
Struggling with unpredictability

Seeking help, Investigating symptoms
Learning to live with PD
Medication fails
PD is controlling life
The body is unpredictable
The everyday is unpredictable
Restrictions in life are evident
DBS is a last resort

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Tilpasningsprocessen efter DBS
Ægtefællers oplevelse af livet før og efter DBS

Solidarity – the base for joined responsibility and concern

Prior to DBS

Living in mutuality
Being available
Living the illness - knowing the partner’s body
Living actively yet restricted
Being strong for two
A space of your own

Following DBS

A sense of freedom embracing life
Life without worry
Growing mutuality
Supporting challenges and changes

The challenge of changes and constraint
Being involved and informed
Lack of mutuality
Being the promoter of change
Ulike forståelser av sykdom

- Disease
- Illness
- Sickness
## Tre viktige perspektiver på sykdom*

<table>
<thead>
<tr>
<th>Betegnelse**</th>
<th>Betydning</th>
<th>Karakterisert ved</th>
</tr>
</thead>
<tbody>
<tr>
<td>”Illness”, å være syk</td>
<td>(Negativ) subjektiv opplevelse i første person</td>
<td>Smerte/lidelse, symptomer, syndromer (samling av symptomer)</td>
</tr>
<tr>
<td>”Disease”, å ha en sykdom</td>
<td>Funn og klassifiseringer gjort av helsepersonell</td>
<td>Tegn, markører</td>
</tr>
<tr>
<td>”Sickness”, sykerolle</td>
<td>Å bli oppfattet som syk i en sosial kontekst</td>
<td>Sosial adferd</td>
</tr>
</tbody>
</table>

* Hofmann 2010, s. 120

** Begrepsene illness, disease, sickness er opprinnelig hentet fra medisinsk antropologi, bl. a. fra Arthur Kleinman
Forskjeller mellom ulike perspektiver på sykdom*

<table>
<thead>
<tr>
<th>Perspektiv</th>
<th>Å ha en sykdom (Disease)</th>
<th>Å være syk (Illness)</th>
<th>Å inneha en sykerolle (Sickness)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primæraktør</td>
<td>Profesjon</td>
<td>Personlig, eksistensielt</td>
<td>Samfunnet</td>
</tr>
<tr>
<td>Hensikt</td>
<td>Lokalisere, forklare og klassifisere fenomener for å kunne diagnostisere, behandle og lindre</td>
<td>Forklare (forstå) en ønsket situasjon for en selv</td>
<td>Gi rettigheter, frita fra plikter. Vurdere tilregnelighet</td>
</tr>
<tr>
<td>Kunnskapskilde</td>
<td>Faglig, vitenskapelig</td>
<td>Subjektivt</td>
<td>Intersubjektivt</td>
</tr>
<tr>
<td>Fenomener</td>
<td>Anatomiske, fysiologiske, biokjemiske. Molekylærbiologiske tilstander</td>
<td>Lidelse, smerte, ubehag</td>
<td>Sosial rolle, status</td>
</tr>
<tr>
<td>Fokus</td>
<td>Helbrede</td>
<td>Omsorg</td>
<td>Rettferdighet</td>
</tr>
</tbody>
</table>

*Hofmann, 2010, s. 121
Baltes’ teori om Selection, Optimization, Compensation (SOC)
Three major biocultural influence systems on life span development

(Baltes mfl. 1980)
The life-course Dynamics of Goal Pursuit and Goal Adjustment: A two-process framework

Brandstädter & Rothermund
Goal Discrepancies

ASSIMILATIVE MODE
- tenacious goal pursuit, persisting commitment
- corrective and compensatory efforts to maintain goal
- goal-focused resource mobilization

Related Cognitive Set
- convergent, goal-focused attention
- increased availability of cognitions supporting goal pursuit
- inhibition of distractive influences, enhanced top-down processing

Dysfunctional Side Effects
- escalation of commitment
- entrapment in barren projects
- exhaustion of resources

ACCOMMODATIVE MODE
- adjusting goals to constraints
- positive reappraisal of loss, benefit finding
- channeling resources to new, feasible goals

Related Cognitive Set
- defocalized attention, holistic processing
- increased availability of cognitions enhancing disengagement from blocked goals
- inhibition of top-down processes, greater sensitivity to external stimuli

Dysfunctional Side Effects
- unstable, vacillating commitment
- premature disengagement from goals
- premature compliance with constraints

Moderating personal and contextual conditions
⊕ resources of action, self-percepts of control
⊙ flexibility of goal structures
⊖ substitutability of goals
Implikasjoner for psykososial rehabilitering
• Psychosocial needs are related to:
  – Cognitive aspects of illness
  – Emotional aspects
  – Social aspects
  – Existential aspects
Psychosocial needs/problems following a severe neurological event

Suffering from severe neurological condition may lead to:

• Lack of understanding
• Stress, chaos and loss of control
• Depression and anxiety
• Social isolation and loneliness
• Difficulties managing the illness & its consequences
• Fatigue
• Inadequate coping
Psychosocial needs/problems following a severe neurological event

• Suffering from a neurological condition may lead to existential crisis
  – «losing oneself»
  – «losing one’s life»
  – «losing one’s purpose in life»
  – «loosing one’s place in society»
Rehabilitation

- A personal adaptation and coping process

- A set of measures to achieve and maintain optimal functioning in interaction with their environments.

- Originates in functional problems experienced by the users

- Must be viewed in a bio-psycho-social context.

- Enabling the individual to participate and resume former valued daily activities is an essential part of rehabilitation

(WHO 2011, Norwegian whitepaper on rehabilitation)
Nursing interventions to promote psychosocial rehabilitation
# The Therapeutic Role of Nursing in Rehabilitation

<table>
<thead>
<tr>
<th>Nursing function</th>
<th>Effect on patient (the ””why”)</th>
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</thead>
<tbody>
<tr>
<td>Conserving function</td>
<td>Maintain bodily integrity, avoid preventable complications</td>
</tr>
<tr>
<td>Consoling function</td>
<td>Consolation, reduced suffering</td>
</tr>
<tr>
<td>Interpretive function</td>
<td>Increase understanding of what has happened and the ramifications of the condition</td>
</tr>
<tr>
<td>Integrative function</td>
<td>Facilitate use new techniques and coping abilities in daily life &amp; participation in society</td>
</tr>
</tbody>
</table>

(Kirkevold 1989, 1997)
Nursing interventions focusing on psychosocial needs in patients and/or families

- Information/patient education
- Motivational interviewing
- Life review
- Management/coping support
- Social support

Recovery and adjustment following a stroke

Ultimate goal: ‘Live a life worth living’

*Stroke unit & rehabilitation context*

*Life before stroke*

*Strok*

*Trajectory onset*

*Initial rehabilitation*

*Continued rehabilitation*

*Semi-stable phase*

*Going on with life*

*A gradually widening context for recovery and adjustment work*

*Integrity promoting care*

*Bodily recovery and functional improvement*

*Recreating and restructuring daily life*

*Biographical adjustment & transformation*

(Kirkevold 2010)
Psychosocial wellbeing

Defined as:
(a) a basic mood of contentment and wellbeing and the absence of pervasive sadness or a feeling of emptiness,
(b) participation and engagement in meaningful activities beyond oneself,
(c) good social relations and a feeling of loving and being loved in mutual relations, and
(d) a self concept characterized by self acceptance, usefulness and belief in ones own abilities (S. Næss)

Theoretical structure of intervention

Acute stroke hits without warning

Struggling to understand and adapt

Sense of coherence

Psychosocial wellbeing

Patient is thrown into a situation of confusion/chaos

To
(a) Bodily changes and impairments
(b) Changes in every day life
(c) Identity threats

Life situation is:
Comprehensible, manageable & meaningful (Antonowsky)

Intervention focus

• Foster understanding and (re)creation of meaning through ‘narrative dialogues’

• Support patient’s coping efforts and development of new life skills through ‘Guided self determination’ problem solving method
«Your big trial of strength»

- Eight individual meetings over first 6 months
- Trained nurse/occupational therapist
- Patient and/or family (patient’s decision)
- Individualized intervention based on a common framework
Maria’s “journey of recovery” the first 2 years following a stroke

The illustration is based on the analysis of data and was created by the authors. Maria affirmed the illustration.
Mood in everyday-life

Emotions in everyday life are . . .
lonely and confused.

What makes me happy is . . .
when someone calls me or visits me.

What keeps me up is . . .
the belief that I will get better.

What make me angry is . . .
the ones who say, “just get out and everything will get fine.”

The most difficult now is . . .
the uncertainty about whether I can manage the things that I’m dealing with. It leads to poor sleep.

I wish to . . .
feel healthy again, go to stores and enjoy being with friends.

What makes me exhausted is . . .
thinking about everything others expect me to do.

My mood is usually . . .
good if I can use my time as I wish.
**Problem solving**

**Your reflections:**
I want to be as before!
How the future is going to be.
But understand that it is good to take one day at a time.
It's difficult.

**Your goals:**
- A normal social life
- More energy
- Be able to work
- Move to my new house

**Difficulties:**
Low energy. It's difficult
not being able to do what I want;
talk, read, write, find words,
tolerate light and sounds, see friends, listen to music,
exercise etc.

**Thoughts and feelings:**
How long do I have to live like this? Waiting all the time to get better.

I am a little angry about the situation. Others have boyfriends and children.
What about me? I can't work. Life has stopped.

**Actions:**
I try to do things that are good for me;
walk outdoors, not push myself too much (difficult),
ot think of all I could do before (very difficult).
Have to try to find myself again.
Summary

• Neurological conditions have profound impact on the lives of patients and their families

• Psychosocial needs are well documented, but inadequately addressed in neurorehabilitation

• Many psychosocial interventions have been developed, but few are documented to be effective

• We need to develop interventions based on solid empirical and theoretical knowledge of patient & family experiences, needs, and personal goals over time