

Disability, identity and life change

A qualitative five-year follow-up study of stroke

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Objective

The purpose of this paper is to shed light on how stroke survivors experience their disability, how they see themselves and how they manage a changed life.

Methods

Qualitative interviews were conducted with ten men and five women, aged 42 to 84, who had suffered first-time stroke five years earlier. The interviews took place in the participants' homes. The interviews and analyses were inspired by phenomenological philosophy.

Table 1 Sample characteristics

Criteria	
Age:	
> 65	7
65- 85	8
Gender:	
Male	10
Female	5
Living situation:	
Alone	5
With partner or family	10
Self-reported mRs:	
Level 1 (<i>Able to carry out all usual activities, despite some symptoms</i>)	4
Level 2 (<i>Slight disability, able to look after own affairs without assistance, but unable to carry out all previous activities</i>)	3
Level 3 (<i>Moderate disability</i>)	5
Level 4 (<i>Moderately severe disability</i>)	3

Results

Though these stroke individuals had achieved greater acceptance of the situation the stroke had created for them compared with immediately after the end of the rehabilitation programme, all respondents described how they still were confronted with individual consequences of their stroke. New illnesses and additions to the stroke had occurred, and disability alongside changes of identity and life patterns seemed to constitute a continuous process that never truly stabilises.

They coped with this continuous process in at least two different ways: resignation versus personal growth.

Conclusion

Stroke has submitted the stroke individuals to considerable difficulties as regards disability, identity and everyday life, which demand a continuous process of change that can drain their energy. The study also shows that adopting an optimistic approach to life can lead to continued learning about abilities and limitations, to the development of new skills and to the fashioning of a new identity.

This study suggests that stroke survivors should be offered individualised rehabilitation programmes that include aspects of how to cope an altered life.

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Figure 1: Themes in the analytical process – Body experiences and coping

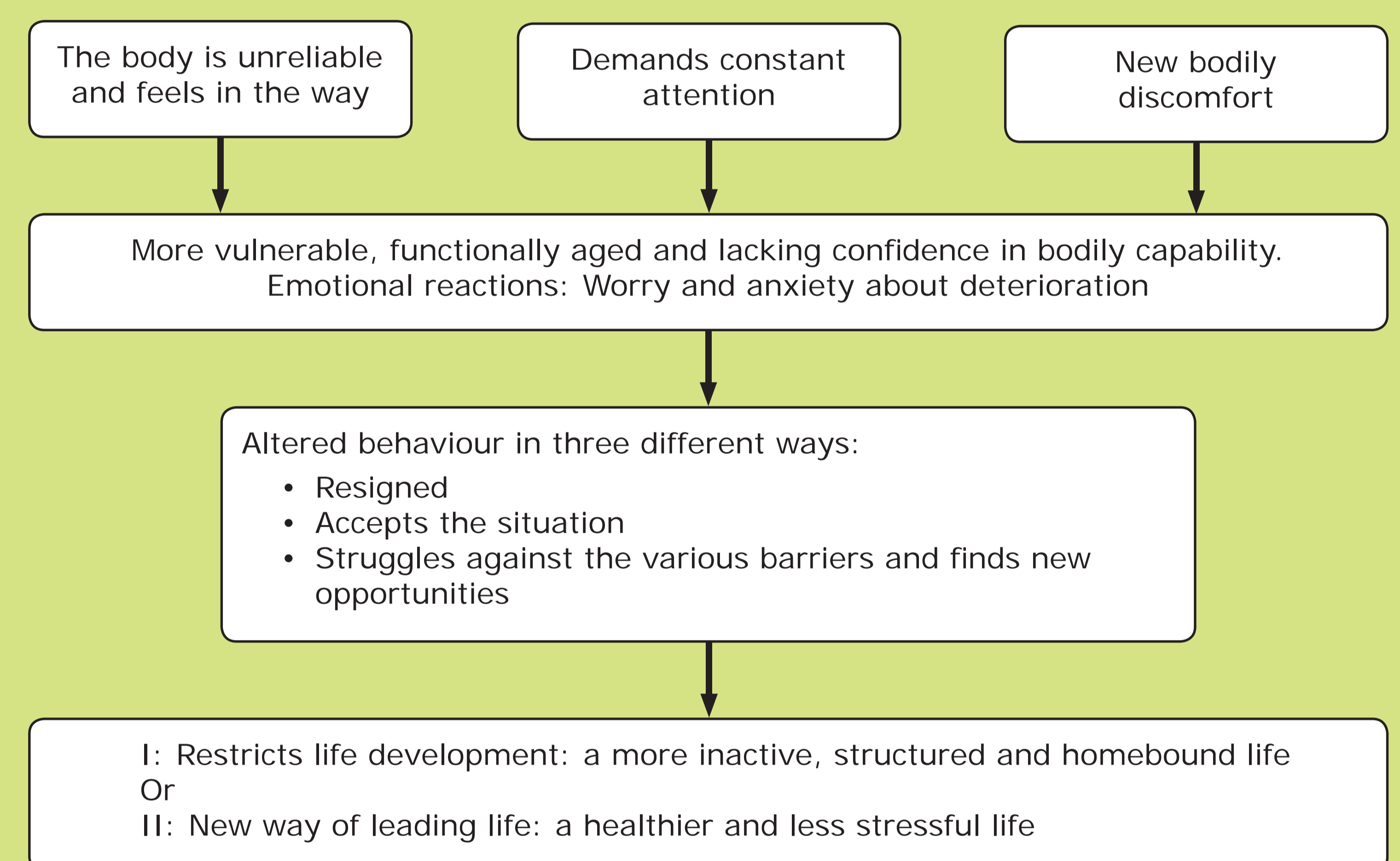


Figure 2. Themes in the analytical process – Disability and identity

The stroke survivors' view of themselves in relation to stroke:

- Not as being ill, but as someone who has got certain handicaps
- Not different from others, but recognising that they have to relate differently to existence
- The same person they have always been, but also aware that they have been hit by an event whose consequences they will always have to live with
- The majority see themselves as having fewer opportunities now than before the stroke, and this is a theme that often surfaces in their everyday lives

Their experiences in relation to others

- Reciprocity in near relations are dislocated in relation to practical tasks, intimacy with partner and relations to children and close family
- Several are deeply dependent on help from their partner
- Most find that they have fewer social and work-place contacts than formerly, which is seen as being inevitable but also as a major loss

Others look at them in a different way and have changed behaviour

- Several find that acquaintances and former friends avoid them in everyday situations such as shopping and at local events
- Fewer spontaneous offers and invitations

- Autonomy is a theme that comes up and that threatens self-perception as well as the moods of close family.
- Management and performance of everyday tasks in the home and at work reinforce identity. When opportunities for continuing with these tasks disappears, i.e. with early retirement or with the introduction of home help, stroke survivor feels frustrated and worthless.
- Other people's perception of them and having fewer social contacts are circumstances that have negative emotional effects on most and give them a sense of isolation.