

Enriching experiences

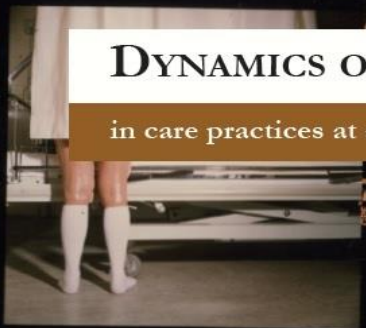
Being attentive from my perspective as a
mother and as a researcher

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DYNAMICS OF ATTENTIVENESS

in care practices at a Dutch oncology ward

Sudden regression in people with Down's Syndrome in the 18-35 age range, without complete recovery

"Getting dressed takes hours!"



"She quit speaking, and is silent for months."



"He is awake several nights in a row."



"She never became the same person again."



"He used to be a cheerful boy but now he's angry, crying and screaming for days on end."



"My daughter self-injures."



THE STUDY

STUDY POPULATION

- People with DS
- Age 18-35
- No complete recovery
- Severe functional decline
- Behavioural changes
- Dramatic impact on self and others

THE REASON

In the last five years CCE was asked to consult in 70 cases concerning people with DS in the 18-35 age range, displaying a severe functional decline and behavioural changes. Little is known about this phenomenon.

RESEARCH QUESTIONS

Is sudden regression in the 18-35 age range common in people with DS and which factors may explain this sudden regression?

METHODS AND MATERIALS

- Exploratory study
- Literature analysis
- Interviews with relatives and care professionals
- Expert interviews

RESULTS

1. Literature on existing explanations for regression in people with DS: Few articles mention sudden regression. There are several causes mentioned: katalonia, a precursor of Alzheimer and even as a new phenomenon without a name, already.

2. Broader literature on Down's Syndrome:

Literature shows studies have been done on the specific development and vulnerabilities of children with DS.

- Their whole life is governed by specific patterns and rituals.
- The way they appeal for help is unique; their needs dictate to their environment.
- To the outside world their situation appeals easier than it is in reality for their family and other people who are involved with them on a daily basis.

3. Case analysis:

Case analysis has shown that our client's development was usually quite normal until this sudden regression set in. This regression was explained by a personal life event. The impact is often much more invasive than expected and without complete recovery.

CONCLUSION

This study emphasizes the importance of a broad view in explaining sudden regression in people with Down's Syndrome in the 18-35 age range.

It describes a multitude of factors which can play a role. These can help professionals to become aware of the phenomenon and possible timely interventions.

We all are aware that the phase of life for those of 40 years and older have an increased risk of Alzheimers.

However, we should be aware that adolescence is also a susceptible phase because of all the changes that occur.

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Individuals in need of long-term care sometimes face the situation that their quality of life is in danger of becoming seriously compromised. Should they or their caregivers be no longer able to find solutions, they can apply to the CCE for 'exceptional care'. We work with independent experts in order to provide customised advice and support. In doing so, the CCE is a supplementary service to standard national healthcare services.

Being attentive

Meaning:

Both finding out *what needs to be done* and to let someone *experience that he or she matters*.

Often seen as:

depending on individual caregiver (professional or private)



Very sad news

Didn't you know?

Incredibly welcome!

Great that you stand up
for him!

Adoption?

Would I be ashamed of
him?







Thank you!

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