

Like everybody else

A phenomenological analysis of adult life with spinal muscular atrophy type 2

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Background

Today children and adults with spinal muscular atrophy type 2 (SMA2) are offered treatment of their respiratory problems and more and more experience adulthood. We still, however, have very little knowledge about life as an adult with SMA2.

Aim

- The purpose of this study was to examine how adults with SMA2
 - see and understand their own lives
 - perceive what is important for how their lives have been shaped

Conclusion

- In spite of their comprehensive physical disability, the participants perceived themselves as people like everybody else.
- They are motivated to start an education but they neither expect to nor do they complete an education.
- Having a job was one of the things that mattered most to the participants.
- Their parents or society never expected them to complete an education.
- Relationships was the other thing that mattered most to the participants. Many of them lived in a stable relationship with a non-disabled partner.
- Personal assistants, technical aids and ventilators were considered quite natural in their everyday lives.



Materials and methods

- Six people >18 years of age with SMA2 were selected with respect to maximal variation. One participant was <20, two between 20 and 40, three >40.
- Semi-structured, qualitative interviews of 1½-3 hours duration based on an interview guide were performed.
- A phenomenological analysis of 160 pages of transcribed text was broken down into four main steps as described by Giorgi.

Theory

Theories of social interaction and the perspective of everyday life were applied:

- Schutz' notion about the life-world and common sense.
- Goffman's frame analysis and his notion about stigma and social interaction.
- ICF's understanding of the state of health.

Results

The frame 'like everybody else'

The recurring theme in all interviews was 'like everybody else'. 'Like everybody else' worked as a frame set by all the study subjects for the interview as well as for their lives.

I'm just trying to do the same as everybody else.

To feel that you're living a normal life like everybody else.

Well, I would like to live a life as normal as possible, won't I.

Physical function

- Half of them were unable to move their hands from the joystick without help.
- Almost all of them were using respiratory aids.

View on own body:

- They accepted their body as it was and were content with it.
- 'Bad diseases' and disabilities were something other people had or something they were at risk of getting.

If I'm suddenly in an accident that gives me a disability.

It's somebody else who is disabled.

Hand and respiratory function

- Loss or fear of loss of hand and respiratory function was described emotionally.
- They found that using non-invasive assisted ventilation (Bi-PAP) was a natural and minor part of their everyday lives but they feared having to use invasive assisted ventilation (ventilator).
- They experienced using invasive assisted ventilation as a relief and as an essential improvement of their physical function and everyday life.
- To live with a ventilator was considered natural, unimportant and unproblematic.

After I had my tracheostomy, I began to eat a lot more, I mean REAL food, and I was able to sit up as well.

It was just difficult to breathe.

I don't think I would be happy to find out that I needed a ventilator.

I was tracheostomized, and that meant that I was first and foremost able to breathe and that my pneumonia stopped.

Identity

- They identified themselves as being like everybody else and expected equal treatment and equal rights.
- They did not see their disability as being central for understanding or describing their lives.

I wasn't raised like a disabled person.

I don't see the disability as a positive or negative thing. It's like having brown eyes or blond hair.

I think they think I'm like everyone else.

Other people's view on self

- They had experienced being met with prejudice, superiority and a lack of confidence in their ability to work and participate actively in society.
- 'Like everybody else' was only a frame used by people close to them and people who knew them.

Nobody expects you to be someone who participates actively in society or has a job.

'To do something' and 'to participate'

Education:

- Having completed elementary school, they were motivated to move on 'like other young people' and get an education.
- The key element in getting an education was 'to participate' and 'to do something'.
- Most of them did not expect to complete their education and did not think that their parents had expected it either.
- The participants did not have any incentive to complete their education and they never made it to graduation.

I was looking forward to start on something I really wanted to do.

What was important was that I participated.

I had studied from I was six till I was 27, and then I thought, heck no, I don't want to study anymore.

No, my family didn't have any expectations.

To have a job:

- Most of them were in flexible jobs or did volunteer work.
- 'To do something' was the desire to show that you were good at something and to live 'like everybody else'.

I think it's great to be together with the people I work with.

I get my money, whether I work or not.

To have a job meant that you were part of a team.

Work was the normal thing to do and I wanted to show that I could easily do that.

Leisure time:

- 'To do something', 'to spend time with other people' and 'to live like other people' were the three recurring themes in relation to leisure time.
- Without a personal assistant the opportunities 'to do something' and 'to participate' were limited.
- The opportunities 'to do something' and 'to participate' in something were limited during the day if they did not have a job.

I was home alone for many hours and all I did was read magazines.

For many years, I actually didn't have the opportunity to get out.

I can't do anything, so I might as well do something I'm good at.

Help and personal assistants

- To ask for help or to receive help had always been a natural part of their lives.
- It felt natural that the people surrounding them were always ready to 'lend a hand' and it was difficult for them if those people refused to help.
- Not having sufficient help was described as dependence, powerlessness and lack of self-determination and participation.
- PA made it possible for them to stay within the 'like everybody else' frame.
- They all had a PA under a personal assistant scheme, most of them around the clock.

That he's annoyed by having to cut my meat at dinner.

It's often just some of my friends who want to help me.

Relationships and family

- Most of them were or had been involved with somebody or in a steady relationship.
- Several of them had been in a long relationship with a non-disabled person.
- When they had decided to live out the dream of having a child they did not fear SMA2, they feared all the other bad diseases.

I've always dreamed about having children and a family.

I was at home being a wife and a housewife, taking care of all the practical matters.

We have been married since 1967.

The PA scheme is the foundation of my life. Without it I can't do anything.

Discussion

- The fear of having a ventilator is, paradoxically, not derived from self-experience with a Bi-PAP or knowledge about other people on a ventilator. Instead it could be interpreted as a myth.
- Strangers saw them as disabled and tended to add a social and mental dimension to their physical disability.
- In spite of other people's view on them, they defined themselves as a person like everybody else whose identity was composed of the same elements as everybody else.
- Their ability to work was not dependent on their hand function.
- To have a job was a key issue regardless of the type of work and in contrast the fact that almost all of them had been granted disability pension when they turned 18 and that they were paid for their work accordingly.
- It indicated that being granted disability pension was important for the young people's way through the educational system.

Young people with SMA 2 in the educational system

