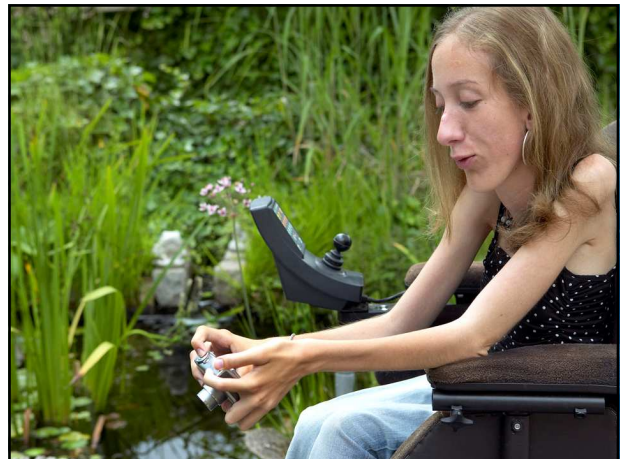


# A normal life with an unhealthy body

## self-identity in adolescents growing up with chronic disorders

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## Op Eigen Benen

Jongeren met chronische aandoeningen:  
 wat willen en kunnen zij in de zorg?

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[www.opeigenbenen.NU](http://www.opeigenbenen.NU)

**Aim:** to map preferences and competencies for self-care in order to improve preparation of adolescents with chronic disorders for transition to adulthood & to adult services

**Methods:** mixed methods design (qualitative research)

- in-depth interviews,
- Q-methodology,
- observations,
- focus group discussions

## interview study

- random sample of 31 adolescents with various congenital and acquired disorders from the total population of Erasmus MC–Sophia (12-19 years) without mental retardation
- semi-structured interviews using a topic-list (duration min. of 1 hour), digitally recorded
- qualitative analysis of all interview texts using the computer program

## characteristics of participants

**Age and sex**

Sex	12-15 yr	16-19 yr
Boys	~0.25	~0.15
Girls	~0.25	~0.15

**Duration of illness / disability**

Duration	12-15 yr	16-19 yr
since birth, >10 yrs	~55%	~15%
between 5 - 10 yrs	~15%	~45%
< 5 yrs	~0%	~40%

**Frequency of visits to hospital**

Frequency	12-15 yr	16-19 yr
1-2 times / yr	~35%	~15%
3-4 times / yr	~40%	~15%
> 4 times / yr	~15%	~10%
irregular	~10%	~55%



## a normal life

- the most common description of adolescents' lives is that they have "a normal life"
- they even deny the existence of differences with healthy peers



*"My life is normal, just like other kids. The only difference is that I have to inject insulin" (Cecilia, 14 yrs, diabetes)*

*"There are no differences. Only, they can walk and I can't" (Mustafa, 14 yrs, muscular dystrophy)*



## disclosure and view of future

- disclosure of health status is sometimes sensitive topic
- only minority of adolescents seeks active contact with fellow patients
- most hold optimistic views about their futures, but some prefer not to think about it - even deny their shortened life-expectancy



*"I know my illness is life-long, but this plays no important part with regard to my future" (Anton, 18 yrs, lung disease)*

*"I feel good as I am, so I don't want to think about death. I will not die prematurely!" (Katja, 14 yrs, NMD)*



## why normalization?

- coping strategy to deal with the 'abnormal', the fact of having a chronic health problem
- fear of being 'set apart' and excluded from peers and their activities
- denial OR a positive adaptation to difficult circumstances?



*"I do not really want to think about my RA. I'd prefer not to have it, so I don't give it too much attention" (Jolanda, 12 yrs, RA)*

*"I try not to think about it, not because it scares me, but because it's there". (Arjo, 17 yrs, immune disorder)*

## conclusion

- having a normal life is a strong motivator for the adolescent with chronic disorder
- any treatment which disrupts 'normalcy' is likely to be unpopular and will not be adhered to
- be open in discussing consequences for everyday life of treatment and seek for acceptable and feasible solutions with adolescent
- **quality of life is more important for patient than strict adherence to treatment!**



*"There's no one who's always compliant with their treatment. You wouldn't have a life then. I refuse to let CF take over" (Daphne, 19 yrs, CF)*

# thank you!

