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A NORMAL LIFE WITH AN UNHEALTHY BODY: SELF-IDENTITY IN ADOLESCENTS GROWING UP WITH CHRONIC ILLNESS

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Introduction

Chronic illness is often described in terms of biographic disruption. But for those growing up with congenital disorders, an unhealthy body is the norm. An important developmental task in adolescence is the formation of self-identity. How does a chronic disorder influence the development of self-identity in adolescents?

Aim and material

Aim was to investigate attitudes and preferences of adolescents living with chronic disorders. A qualitative study was conducted using semi-structured interviews focusing on daily life issues. The sample was 31 adolescents (12-19 years) with various chronic disorders, randomly selected from the patient database of Erasmus MC–Sophia. Data analysis was performed by using a qualitative analysis computer program ATLAS-Ti.

Results

For most adolescents with chronic disorders, living with illness is ‘normal’. By comparing themselves with healthy peers, they recurrently stress their own normality. They strongly agree with the statement *“I am like everyone else, my illness is something extra”*. Therefore, disclosure of health problems remains a sensitive issue and contact with fellow patients is not often sought. Most hold optimistic views about their futures, only a minority tells problematic accounts of the acceptance of their dysfunctional bodies.

Conclusions

Normalization of an unhealthy childhood seems an important strategy in identity forming in adolescents. It may be interpreted as denial, but adolescents consider denial as *‘dangerous’* and *‘stupid’*. We view normalization as a strategy to accept reality, while preventing illness to dominate their life: *“I try not to think about it, not because it scares me, but because it’s there”*.

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SLIDE 2 background

As a result of improved pediatric care, 90% of all children in Western countries with a chronic illness of physical disability now survive into adulthood. As a result, pediatricians see more adolescents than ever before. These adolescents, sometimes with severe chronic disorders, need to prepare themselves for adult life.

How do these young people themselves experience life? Acquiring a chronic illness has often been described in terms of biographic disruption. But for those growing up with congenital disorders, an unhealthy body is the norm. An important developmental task in adolescence is the formation of self-identity. How does a chronic disorder influence the development of self-identity in adolescents?

SLIDE 3 On Your Own Feet

This research wants to give a voice to adolescents (12-19 years of age) with chronic disorders who are being treated at the Sophia Children's hospital, Rotterdam, The Netherlands. In this presentation, my focus is on the attitude of adolescents towards their illness and the evaluation of their life and future.

SLIDE 4 Aim & sample of the research

The aim of the total study is to map adolescents' attitudes and preferences for health care, and investigate their competencies required to enable adolescents to independently direct their own treatment (self-management) and to function as an adult health care consumer. Various qualitative research methodologies have been employed. The research was followed by a large quantitative study in which health preferences and competencies of adolescents with chronic disorders were explored. Here, I will focus on the results from the interviews with 31 adolescents (12-19 years).

SLIDE 5 Interview study

We used a sample of 31 adolescents with various congenital and acquired disorders randomly selected from the total population of Erasmus MC–Sophia (12-19 years). We conducted semi-structured, in-depth interviews using an interview guide (topic-list). All interviews were digitally recorded and literally transcribed. Qualitative data-analysis consisted of constant comparison and was assisted by use of a computer program called Atlas.Ti.

SLIDE 6 characteristics of participants

There were almost as many boys as girls in the study population. Mean age was 15.4 (sd 2,1). All are regular visitors to the children's hospital. Half of them visits the OPD at least three times a year; 25% is treated by more than one specialty. Almost half of them also have been admitted to hospital at least once, 12% is admitted on a regular basis. They have a great variety of chronic disorders having different impact on daily life and warranting various treatment regimes. One third is seriously affected by their illness. We also interviewed some adolescents with a limited life expectancy due to serious cystic fibrosis, or Duchene's Muscular Dystrophy.

SLIDE 7 Results: A normal life

If you ask adolescents with chronic disorders about themselves and about their lives, they always stress their normality. Most of them strongly agree with the statement *"I am like everyone else, my illness is something extra"*. If asked to specify the differences with

healthy peers, most young patients deny that there are any. Perhaps the only difference they see is that they have an illness which they have to take care of, while the others don't. But most stress that this does not set them apart from their healthy peers. Only few admit that they indeed feel 'being different'. This is usually accompanied by the desire to be normal, to be living without disease. They seem not happy with their dysfunctional bodies.

SLIDE 8 Results: Optimistic views on future

Therefore, disclosure of their health status remains a sensitive issue. Some say they have no problems with disclosing their illness to everyone around them. But many others will not talk about it to strangers and only reveal the illness to close friends.

Only a minority of patients knows about patient organizations and only a few have experienced contact with fellow patients. Many adolescents, however, expressed interest in meeting fellow patients through the hospital. The ones that have are usually positive about the contact with fellow patients.

With regard to their views of the future: Most hold optimistic views about their futures, most think that their dysfunctional bodies will not limit their careers and prospects for the future, only a small minority worries about the future or deny risk of serious impairments or even death, such as Katja who does not want more information about her condition: *"because they only say I will die young. But that is not so, not for me"*. The general optimism is in sharp contrast to the reality of the life of young adults living with chronic disorders in the Netherlands: more drop out of education, less are unemployed and they have less career opportunities and experience more difficulties finding a partner and having a family.

SLIDE 9 Why normalization?

In the interviews we observed a strong tendency **to normalize** living with a chronic disorder. How can normalization be explained? Having a chronic health problem is fairly uncommon at a young age. So we see normalization as a coping strategy to deal with the 'abnormal'. Most adolescents have a strong fear of being 'set apart', being excluded from peers and peer activities. A lot of adolescents have experienced pestering and being treated as 'different' and this caused them a lot of agony.

The result in most cases is that adolescents prefer not to think of their illness: they do not wish to be associated with it ("*dis-association*"). In some cases this could be labeled as **denial** (as in the quote of Jolanda). She is not very compliant to her therapy; she *"goes her own way"*. She even changes her treatment if she wishes to do so. Most adolescents however, think denial to be dangerous and stupid. They normalize their lives to make as a strategy to make their lives more bearable, a **positive adaptation** to difficult circumstances. Their chronic condition is a constant reality, which they cannot escape from. It is the only reality they know; therefore chronic illness does not disrupt, but rather constitutes their every day life. They try to live their lives as normal as possible, in order to prevent the illness from taking over their life. By incorporating the chronic disorder in their self identity, negative feelings of being different are being managed and resolved. Thus, not trying to think about it, is not always denial, as Arjo teaches us, it is a strategy to deal with reality as an undeniable fact.

SLIDE 10 Conclusions

An important consequence of the strong desire to be normal and the strategy employed by adolescents with chronic disorders to normalize their life is that they do not put the illness at the center of their lives. Life is more important than therapy; they will adjust

therapy to life and not vice versa. Doctors tend to think the other way round: they put therapy first.

However, it is good to realize that any treatment which disrupts normalcy sets them apart from peers or discloses their health condition is likely to be unpopular. Many would rather miss a dose than a drink with friends. Doctors should not only be aware of the risk of non-adherence, but should be more open to discuss these sensitive issues and should try to seek solutions which support young people with chronic conditions in their strive to lead a normal life. The positive, optimistic views of young people with chronic conditions have a positive effect on their experienced quality of life. And indeed, quality of life IS more important than strict adherence to treatment!