



THE PSYCHOLOGY OF DUCHENNE



Kempenhaeghe
Centre of neurological
Learning disorders

Jos Hendriksen, PhD
Clinical child psychologist





Psychosocial Adjustment in Males with Duchenne Muscular Dystrophy: Psychometric Properties and Clinical Utility of a Parent-report Questionnaire

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Neuropsychiatric Disorders in Males With Duchenne Muscular Dystrophy: Frequency Rate of Attention-Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder and Obsessive-Compulsive Disorder

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Objective The primary aim of this study was to establish the psychometric properties and clinical utility of the Personal Adjustment and Role Skills Scale (PARS-III) for assessing psychosocial adjustment in males with Duchenne muscular dystrophy (DMD). **Methods** The parents of 287 male patients with DMD aged 5–18 years completed the PARS-III and Revised Rutter Scale. **Results** The α coefficients and factor analysis indicated good reliability and validity. Overall psychosocial adjustment was positively associated with increases in age. A clinical cutoff score for screening in the DMD population is also reported. **Conclusions** The PARS-III is a reliable and valid index of youth psychosocial adjustment and can be used for both clinical screening and research purposes.

Key words Duchenne muscular dystrophy; psychosocial adjustment; questionnaire



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Neuromuscular Disorders xxx (2012) xxx–xxx



www.elsevier.com/locate/nmd

Meeting report

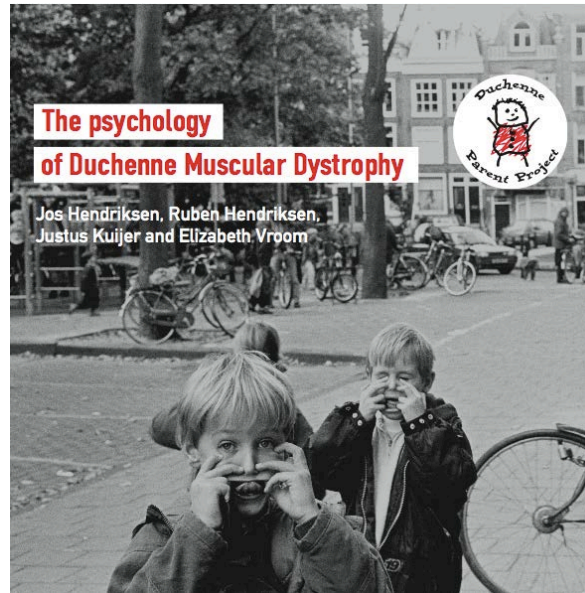
Transition in Duchenne Muscular Dystrophy: An expert meeting report and description of transition needs in an emergent patient population
(Parent Project Muscular Dystrophy Transition Expert Meeting 17–18 June 2011, Amsterdam, The Netherlands)

D.G.M. Schrans^{a,*,1}, D. Abbott^{b,1}, H.L. Peay^{c,1}, R.F. Pangalila^{d,1}, E. Vroom^{e,1}, N. Goemans^{f,1}, J.S.H. Vles^{a,g}, A.P. Aldenkamp^{a,g}, J.G.M. Hendriksen^{a,g,1}



Are Males With Duchenne Muscular Dystrophy at Risk for Reading Disabilities?

Jos G.M. Hendriksen, PhD^{*1} and Johan S.H. Vles, PhD, MD²



Information about intelligence, learning, behavior and other psychological aspects of this muscle disease for parents, siblings, teachers, paramedics.



Starting point:

The **average boy** with Duchenne does not exist. Every boy/young man is unique with his own strenghts and deficits.

Is there **a characteristic psychological profile** of boys/young men with DMD, with potential deficits in cognition, communication, behavior, and psychosocial functioning?

Muscle and Brain

NEUROLOGISCHE LEER- EN ONTWIKKELINGSSTOORNISSEN



introduction

THERE IS BRAIN INVOLVEMENT IN DMD

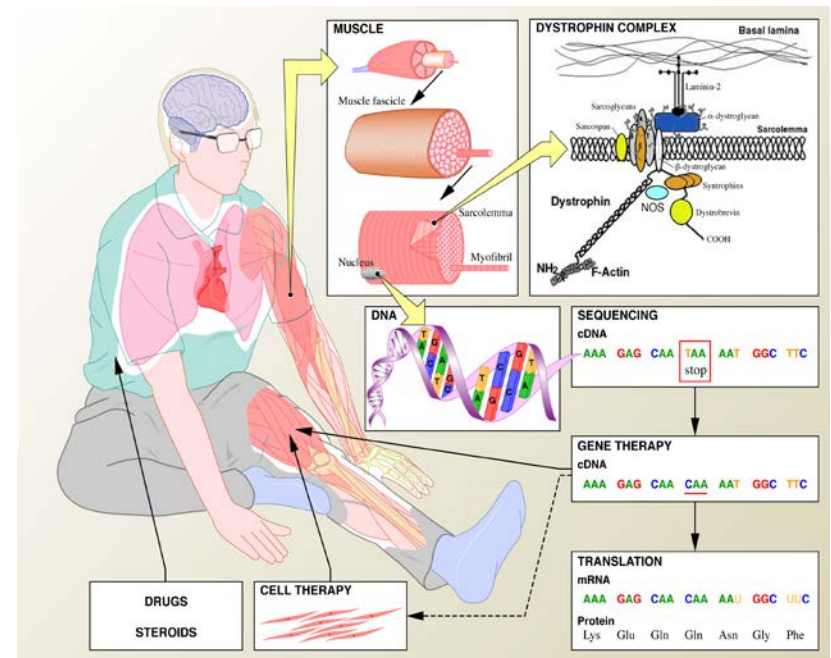
Duchenne Muscular Dystrophy and Brain Function

J.L. Anderson¹, S.I. Head² and J.W. Morley³

¹Childrens Hospital, Westmead, Sydney,

²School of Medical Sciences, University of New South Wales, Sydney,

³School of Medicine, University of Western Sydney, Sydney, Australia

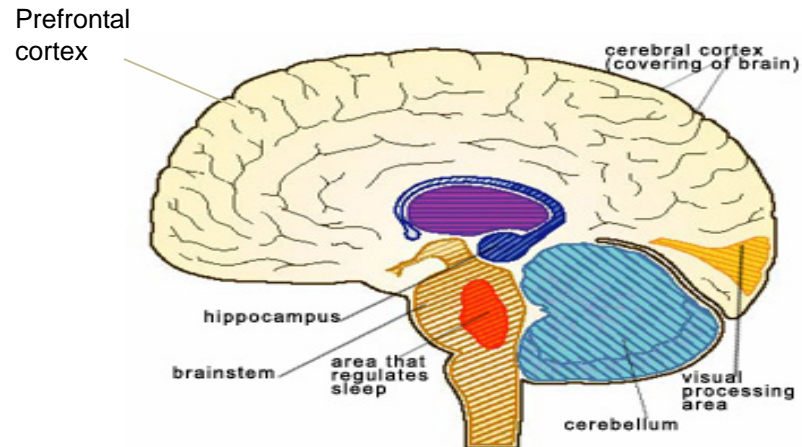


introduction

Depletion of brain dystrophin:

Brain area Cognition

- Hippocampus memory
- Cerebellum automatisisation
- Prefrontal cortex ... planning/organisation



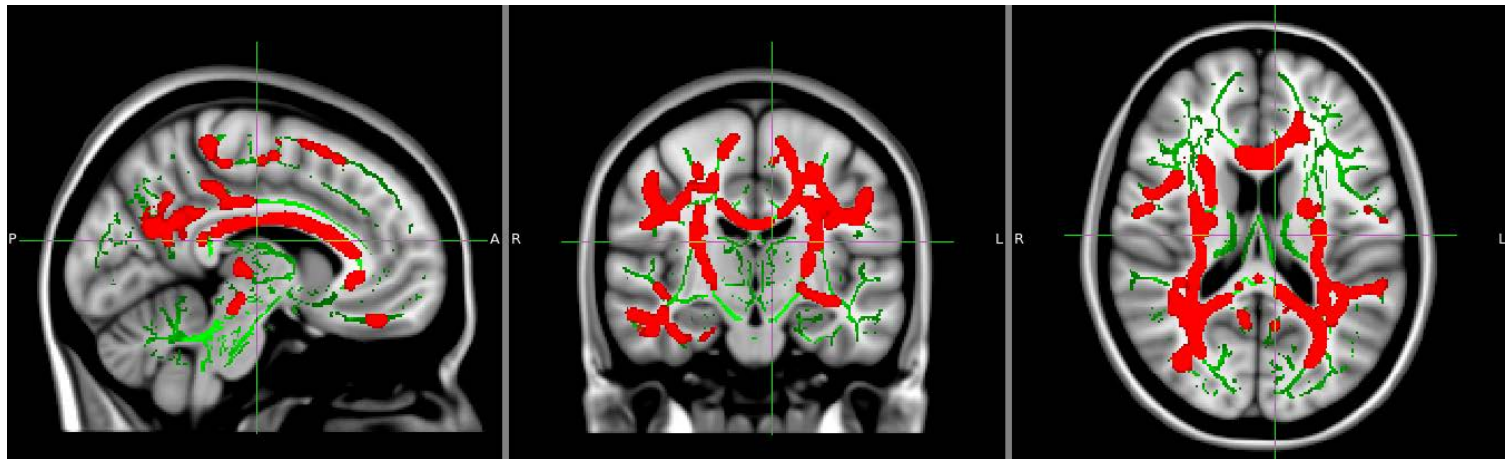


Leiden - Kempenhaghe research project:

structural brain abnormalities

30 DMD boys + 20 Controls

6+3Tesla 3D T1 and diffusion tensor imaging scans
and neuropsychological testing were obtained





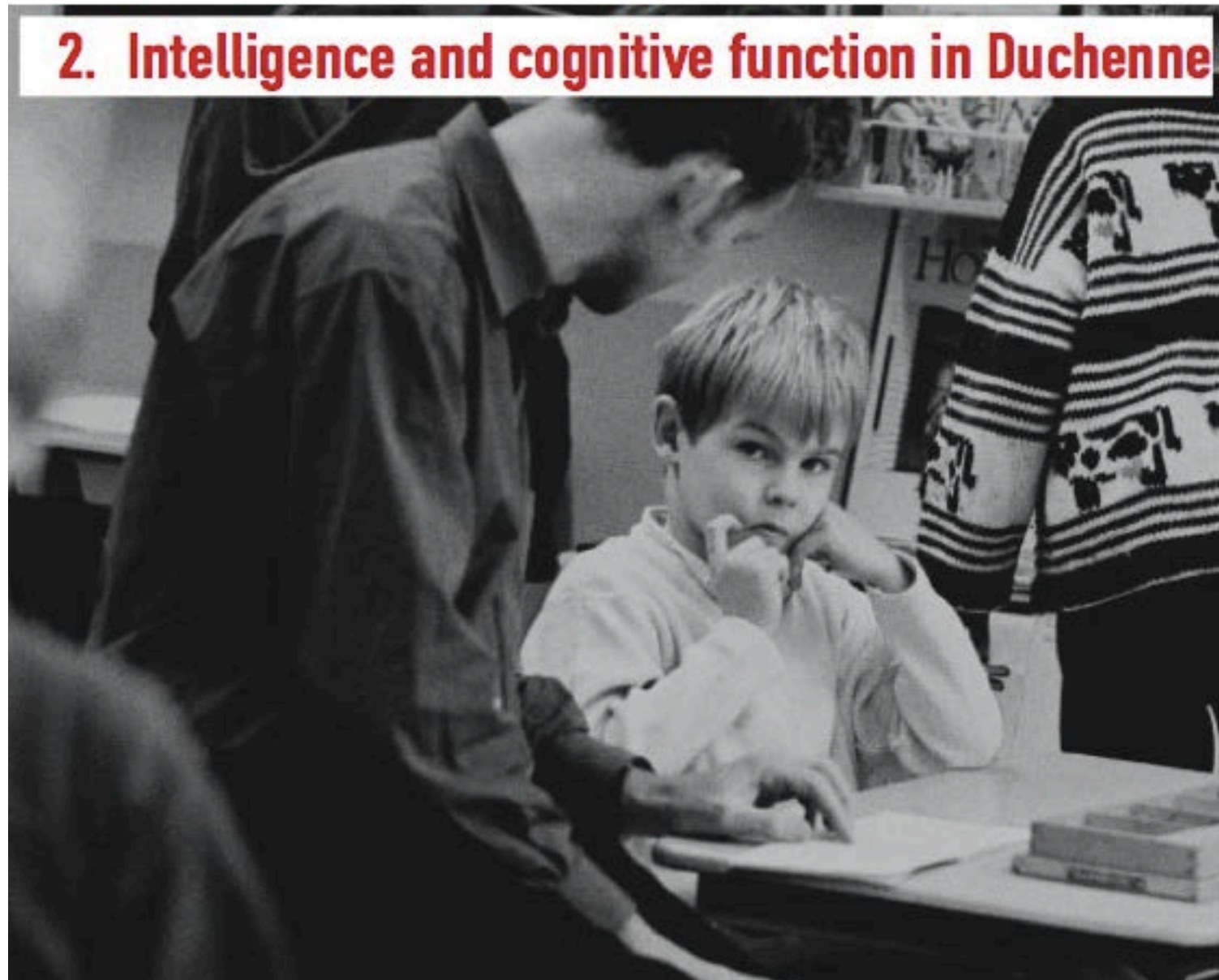
FOUR PSYCHOLOGICAL TOPICS:

1. Intelligence and cognitive functions
2. Psychosocial adjustment & coping
3. Neuropsychiatric comorbidity
4. Transition into adulthood



2. Intelligence and cognitive function in Duchenne

PART 1:



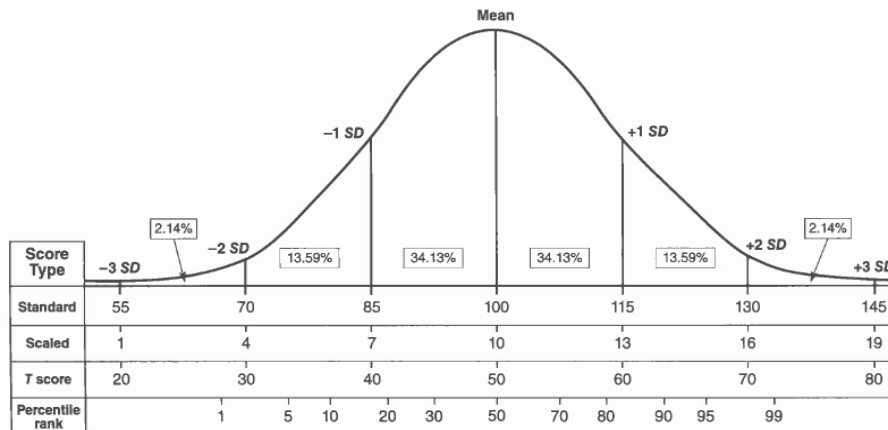


Intelligence

"An individuals ability to adapt and constructively solve problems in the environment" (David Wechsler)

Intelligence

Interpretation of Evaluation Results



<70	retarded
70-85	low
85-115	normal
115-130	high
>130	very high



Cotton et al 2001

Intelligence and Duchenne muscular dystrophy: Full-Scale, Verbal, and Performance intelligence quotients

Sue Cotton* BBSc (Hons) Grad Dip App Sc, Faculty of Health Sciences;
Nicholas J Voudouris PhD;
Kenneth M Greenwood PhD, School of Psychological Science, Faculty of Science, Technology and Engineering, La Trobe University, Victoria 3086, Australia.

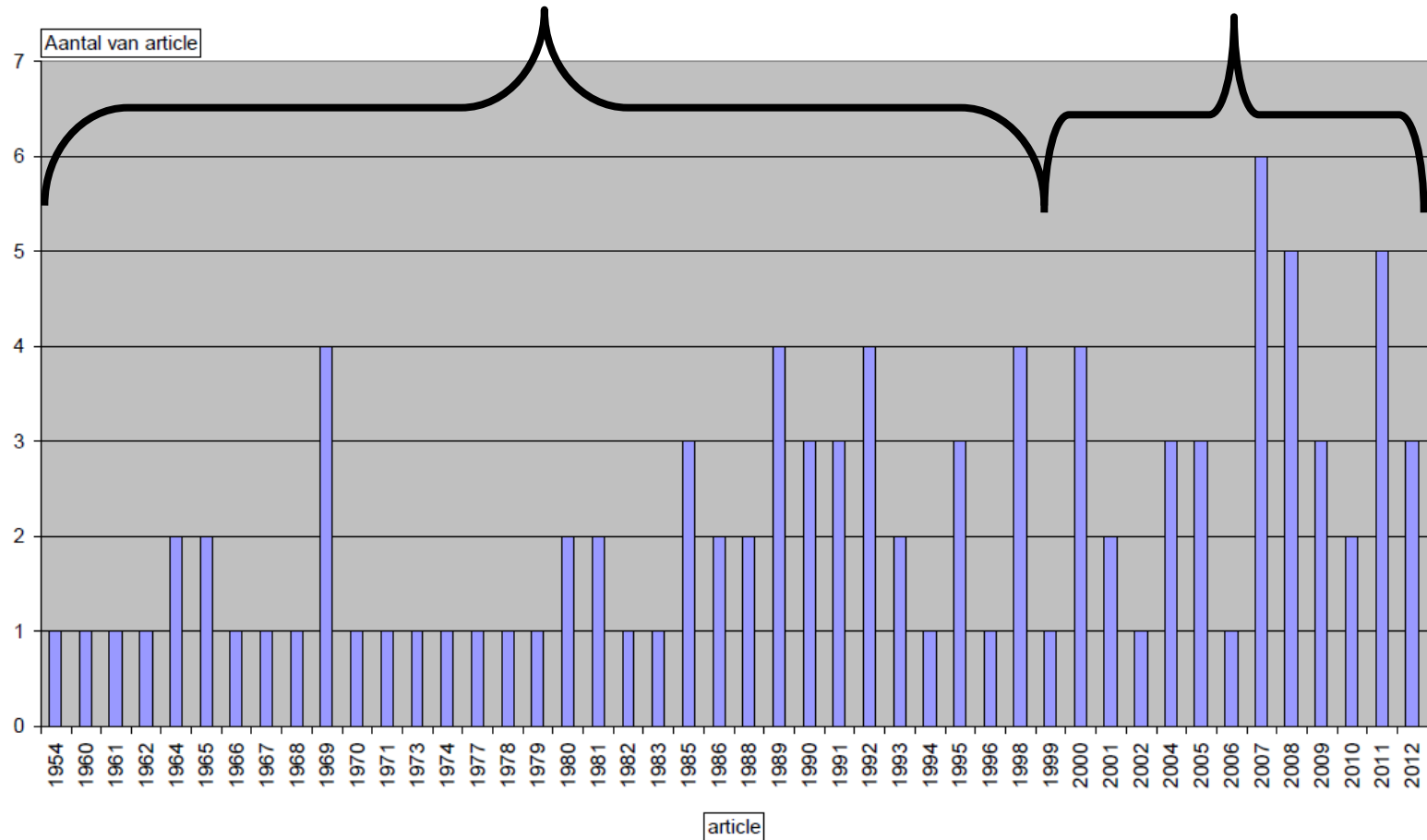
Intelligence

Annotation

Hendriksen & Schrans 2012 review

Intelligence

38 studies





Hendriksen & Schrans 2012 review

77 studies between 1954 and 2012

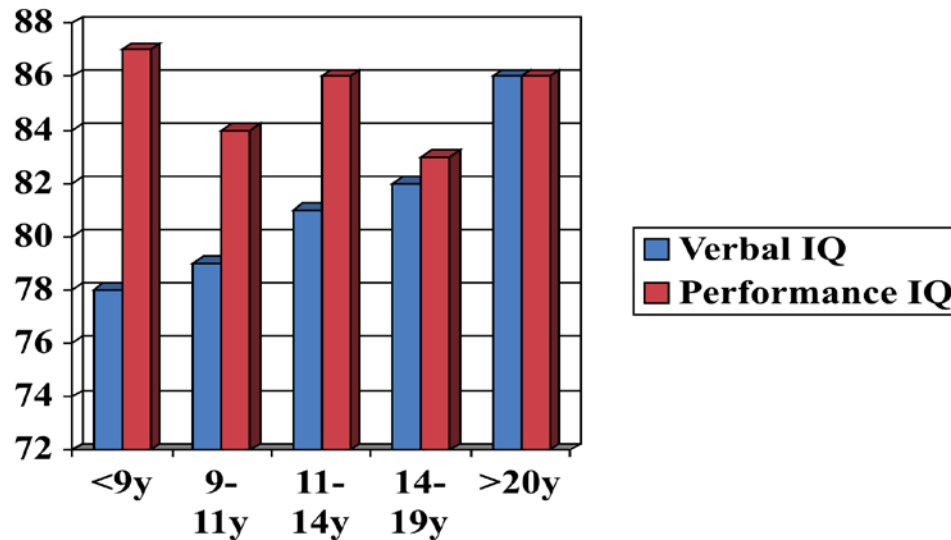
11 studies using Wechsler scale (N= 377:
295 not included in the Cotton review)

Intelligence

Wechsler Total IQ	88 (Cotton 80)
Wechsler Performance IQ	93 (Cotton 85)
Wechsler Verbal IQ	88 (Cotton 80)

Association between IQ and age (Cotton 2005)

Intelligence



VIQ improves with age:

<9 years: Mean = 78

>20 years: Mean = 86

GROWING OUT OF DEFICIT

As boys grow older they grow out of a verbal deficit



Child neuropsychology

Strengths and deficits



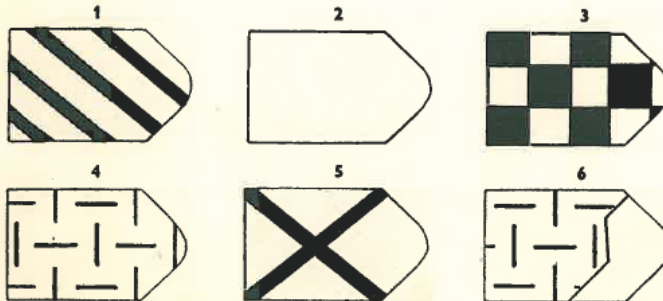
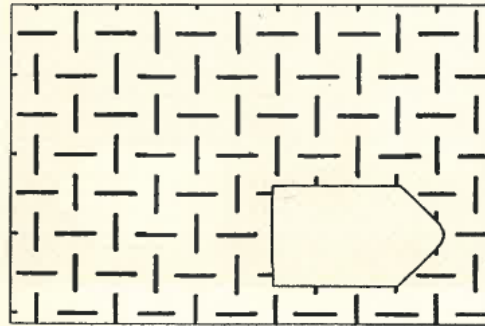
COGNITIVE FUNCTIONS

Profile of strengths and deficits ?

Raven progressive matrices

SET A

A1



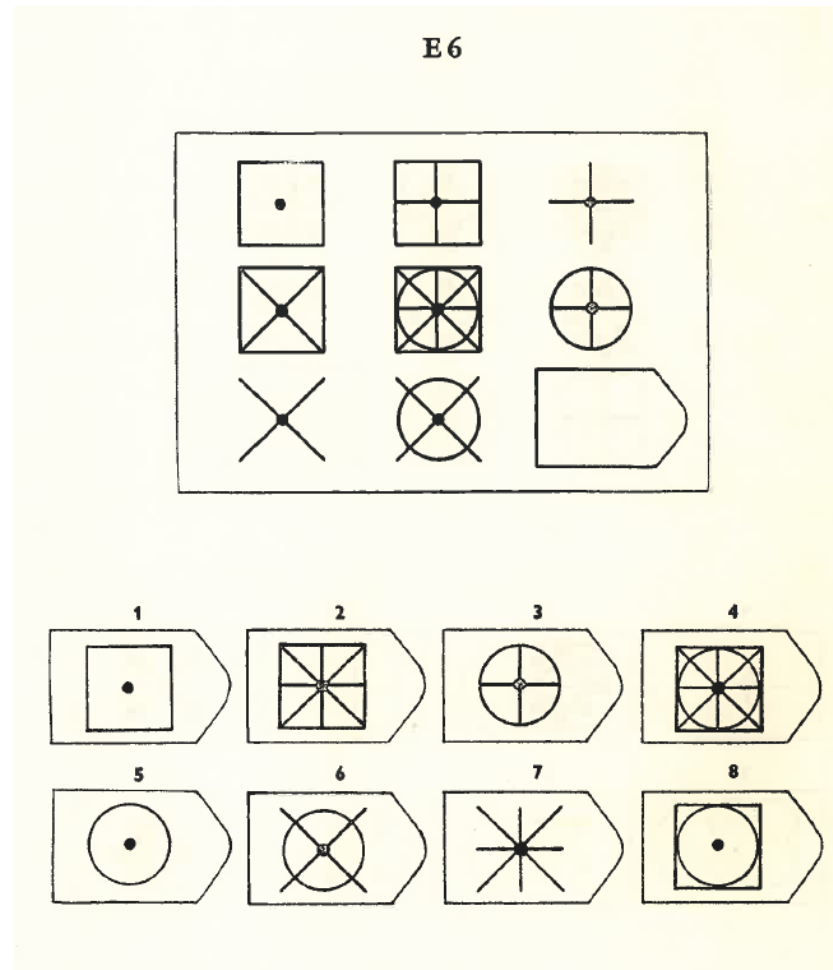
Logical reasoning:
DMD boys do not
differ from their
controls

Strengths and deficits

Look at the pattern carefully: which of these pieces goes in there?

Raven progressive matrices

Strenghts and deficits



Look at the pattern carefully: which of these pieces goes in there?



Boy 9 years

Strenghts and deficits





WEAKNESS: Expressive Language

- Delayed language development;
- Language fluency (on command speech) may be more affected;
- This may result in poor reading performances (40% in DMD)

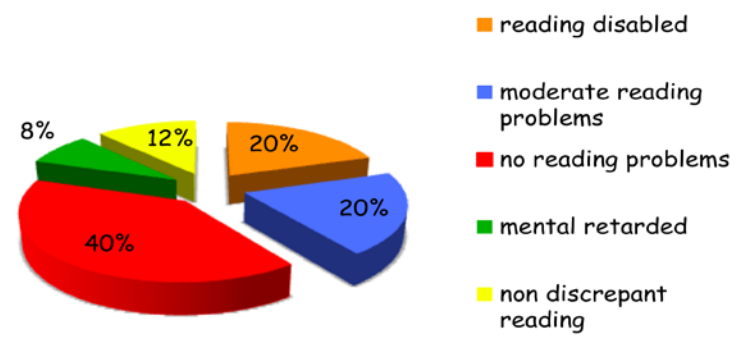
Strengths and deficits



Are Males With Duchenne Muscular Dystrophy at Risk for Reading Disabilities?

Jos G.M. Hendriksen, PhD*¹ and Johan S.H. Vles, PhD, MD²

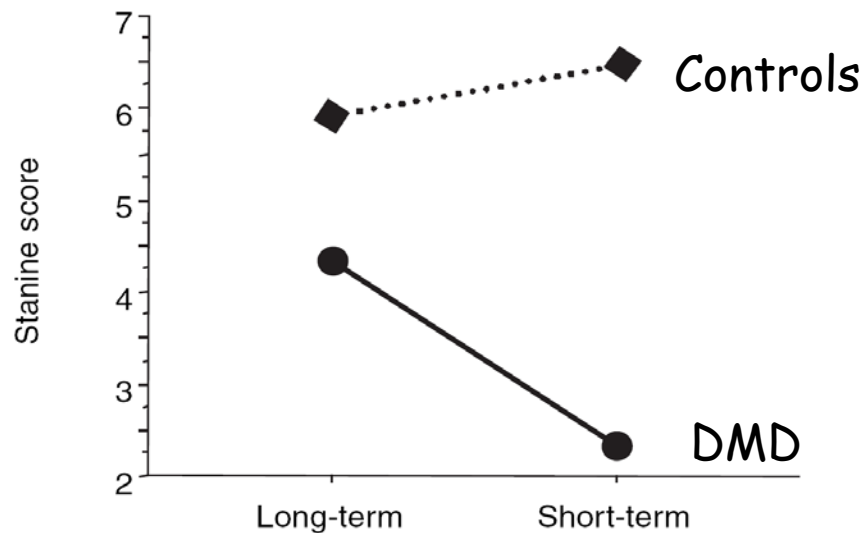
Reading in DMD



Short term memory deficits

Wicksell et al (2004):

The short term memory deficits might play a critical role in the cognitive impairment and intellectual development.

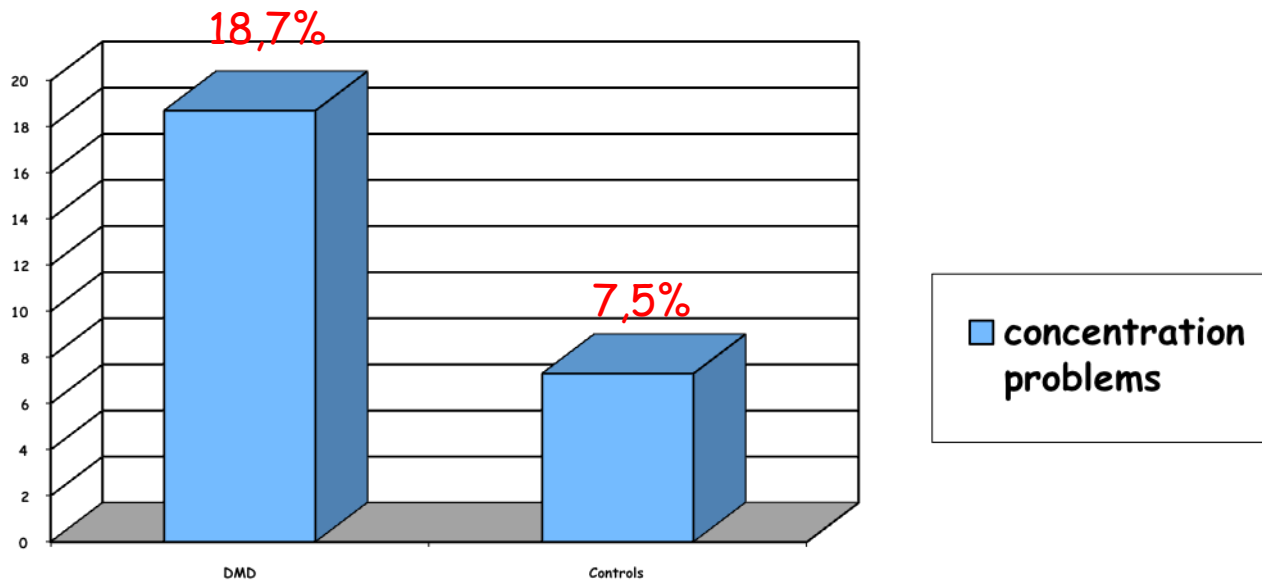




Attention problems: incidence

Strengths and deficits

Hendriksen & Vles, N=351 (DMD boys)





Cognitive profile: a summary

Strengths and deficits

Weaknesses

expressive language
working memory
attention

Strengths

visuospatial
rote memory





Education

Majority of the boys visit normal school
(Holland N=216)

62% normal school

8% school for disabled children

5% school for mentally retarded.



www.leraar24.nl/video/2735



4. Psychosocial adjustment and normal behavior problems in Duchenne

PART 2:





Behaviour in developmental perspective

Normal development

Normal stressors

First school day

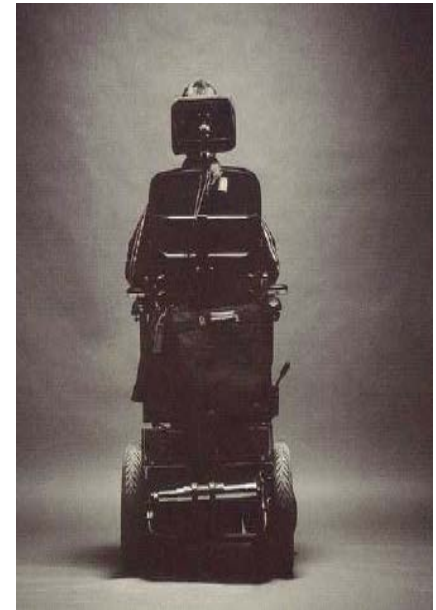
First bad grade

Being rejected

Falling down

Become wheelchair dependent

Illness related stressors





DMD and coping

How do boys and young men with duchenne adjust to their illness?

Journal of Pediatric Psychology Advance Access published July 22, 2008

Psychosocial Adjustment in Males with Duchenne Muscular Dystrophy: Psychometric Properties and Clinical Utility of a Parent-report Questionnaire

Jos G. M. Hendriksen,^{1,2,3} PhD, James T. Poysky,⁴ PhD, Debby G. M. Schrans,^{1,2} MSc,
Eric G. W. Schouten,⁵ PhD, Albert P. Aldenkamp,^{1,3} PhD, and Johan S. H. Vles,³ PhD, MD
¹Kempنهاeghe Epilepsy Centre, Heeze, ²Franciscusoord, Childhood Rehabilitation Centre, SRL, Valkenburg,
³Department of Neurology, University Hospital Maastricht, ⁴Baylor College of Medicine, Texas Children's
Hospital and ⁵Department of Psychology, Maastricht University

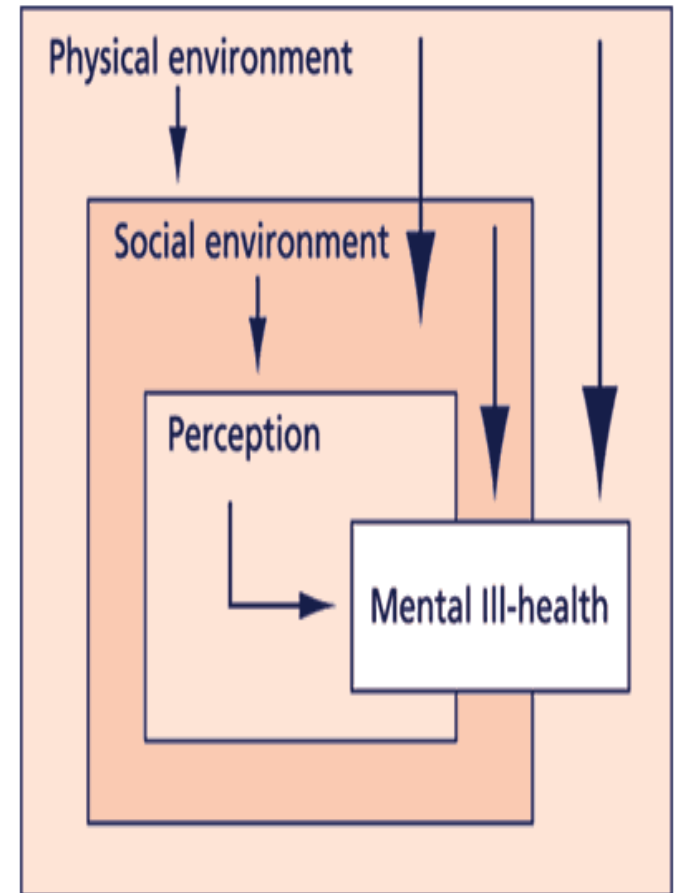


This is the first study to compare psychosocial adjustment of a large sample of patients with DMD to findings reported in males with other chronic conditions



Psychosocial adjustment

Psychosocial adjustment can be defined as the adaptive task of managing upsetting feelings and frustrations aroused by the illness, and preserving an emotional balance.



PARS-III Psychosocial adjustment

High score
reflect
better
adjustment.

During the last month, how often has your boy shown each of the following behaviours?

	Never or Rarely	Some- times	Often	Always	
1. Spent time with friends?	1	2	3	4	PEERS
2. Made friends without difficulty?	1	2	3	4	PEERS
3. Joined others of own accord?	1	2	3	4	PEERS
4. Had many different friends?	1	2	3	4	PEERS
5. Wanted help in things he could have done on own?	4	3	2	1	DEP
6. Been unable to decide things for self?	4	3	2	1	DEP
7. Asked for help when could have figured things out?	4	3	2	1	DEP
8. Asked unnecessary questions instead of working on own?	4	3	2	1	DEP
9. Done things for attention even though punished for it?	4	3	2	1	HOST
10. Flared up if couldn't have own way?	4	3	2	1	HOST
11. Become upset if others did not agree with him?	4	3	2	1	HOST
12. Ignored warnings to stop unacceptable behaviour?	4	3	2	1	HOST
13. Told lies?	4	3	2	1	HOST
14. Not responded to discipline?	4	3	2	1	HOST
15. Stayed with task or assignment until finished?	1	2	3	4	PROD
16. Made full use of abilities?	1	2	3	4	PROD
17. Done work without being pushed or punished?	1	2	3	4	PROD
18. Kept on with task even when difficult?	1	2	3	4	PROD
19. Complained about problems?	4	3	2	1	ANX/DEP
20. Seemed restless, tense?	4	3	2	1	ANX/DEP
21. Said people didn't care about him?	4	3	2	1	ANX/DEP
22. Seemed sad?	4	3	2	1	ANX/DEP
23. Said he couldn't do things right?	4	3	2	1	ANX/DEP
24. Acted afraid or apprehensive?	4	3	2	1	ANX/DEP
25. Sat and stared without doing anything?	4	3	2	1	WITHD
26. Appeared listless and apathetic?	4	3	2	1	WITHD
27. Seemed unaware of things going on around him?	4	3	2	1	WITHD
28. Shown little interest in things, had to be pushed into activity?	4	4	2	1	WITHD



Six domains of psychosocial adjustment

1. Peer relations: making friends of his own
2. Dependency: asking for help
3. Hostility: responding to discipline
4. Productivity: keeping up with tasks
5. Anxiety/depression: acting afraid
6. Withdrawal: unaware of things going on



Psychosocial adjustment

Developmental profile: overall adjustment scores



As boys grow older, they grow into better adjustment

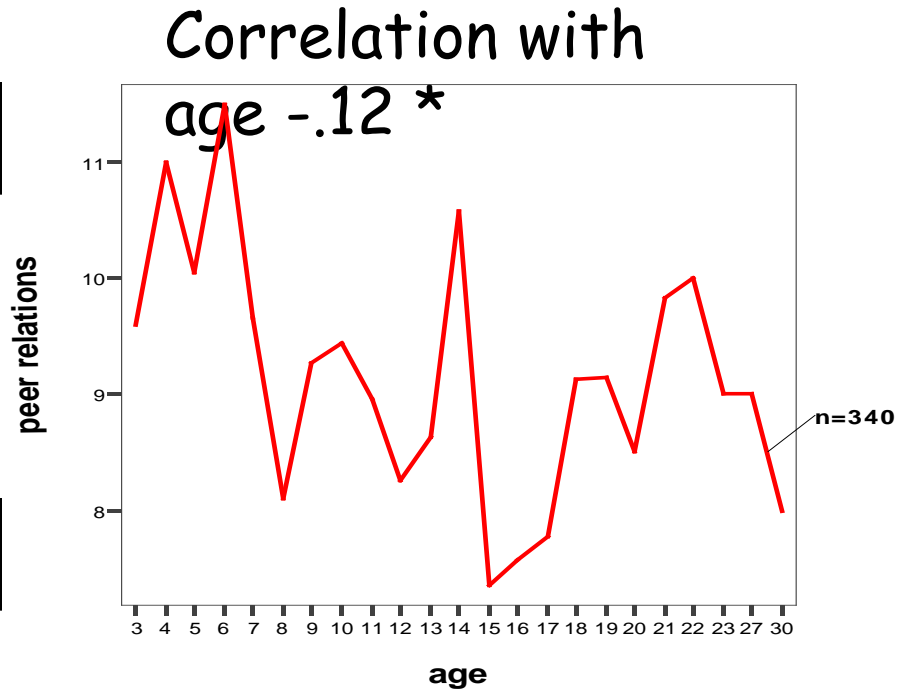
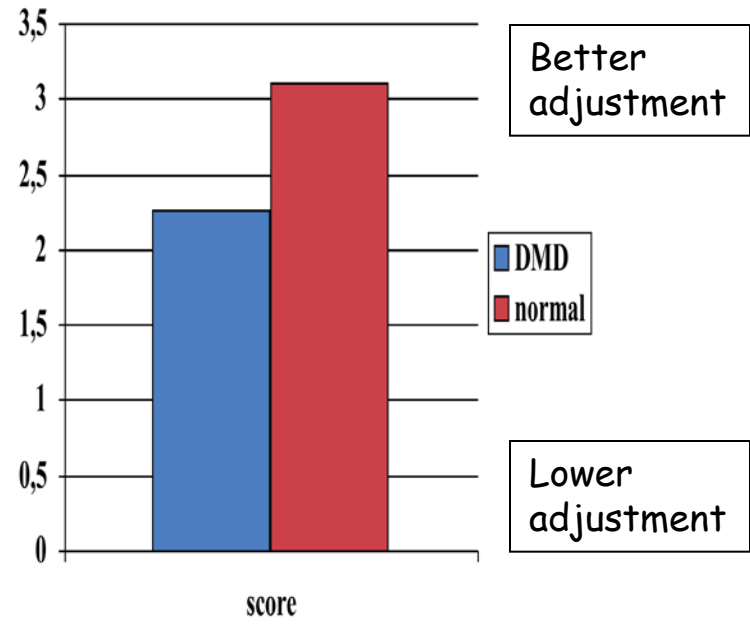


Psychosocial adjustment

1. Peer relations



Made friends without difficulty/
Joined others of own accord



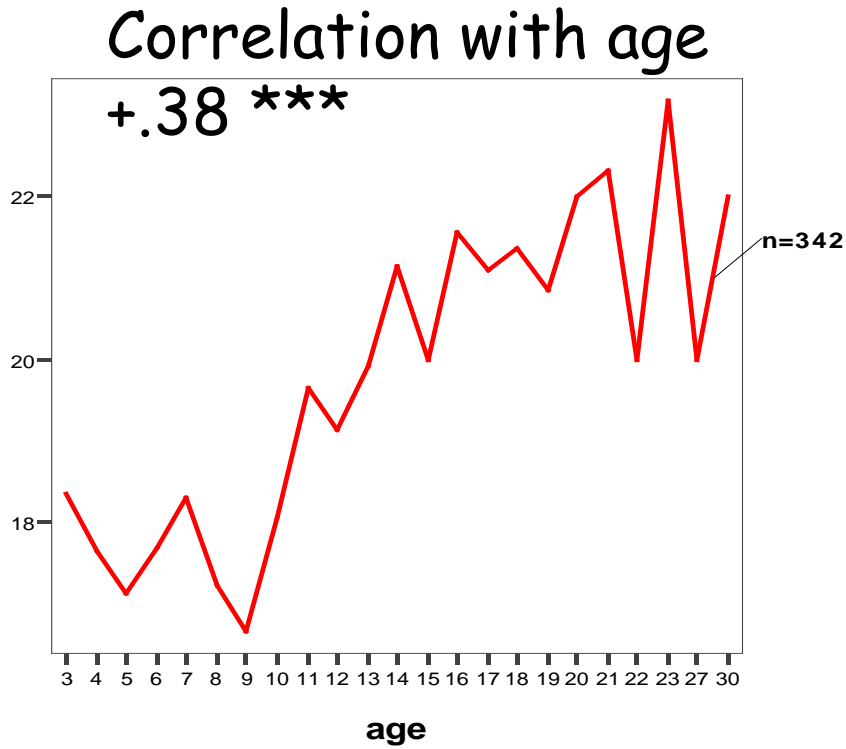
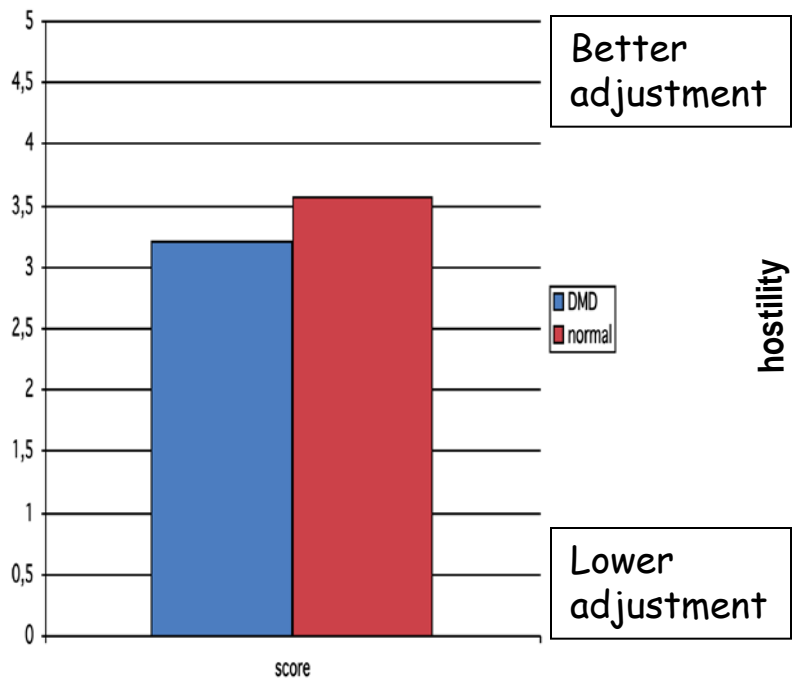


Psychosocial adjustment

3. Hostility



Ignored warnings to stop unacceptable behaviour/
Did not respond to discipline

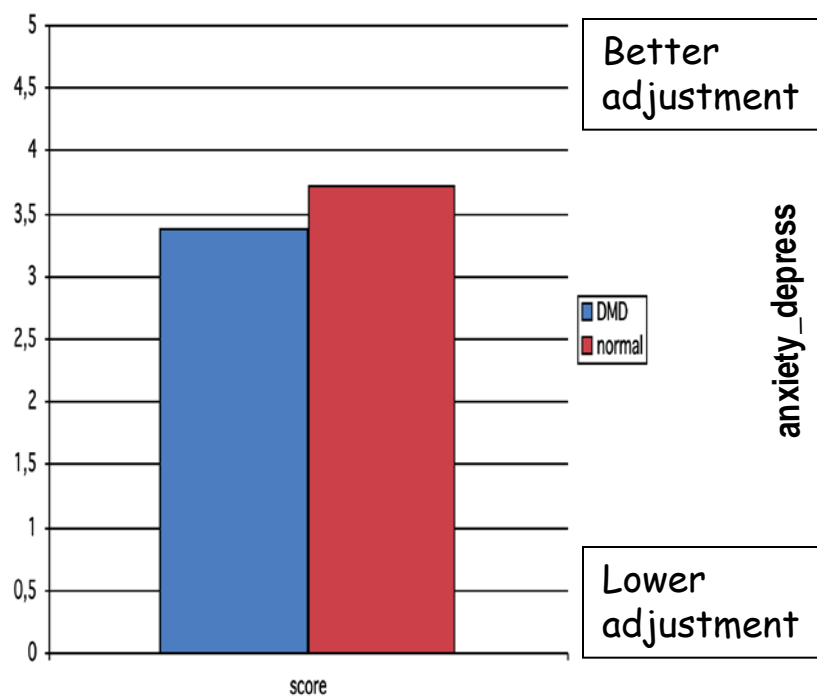




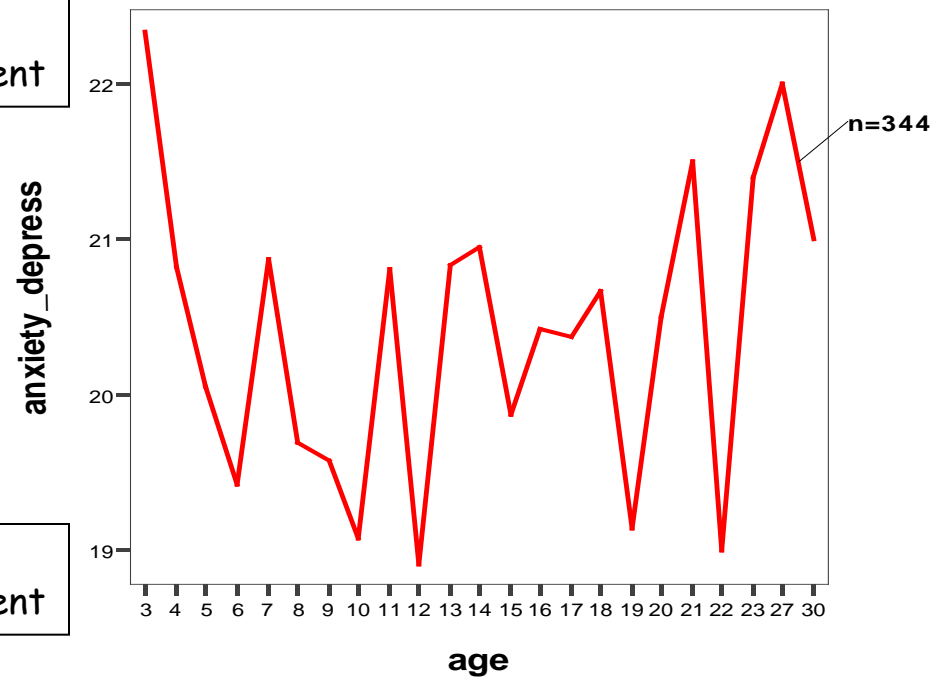
Psychosocial adjustment

5. Anxiety / depression

Said people didn't care about him/
Said he couldn't do things right



Correlation with age .04 NS





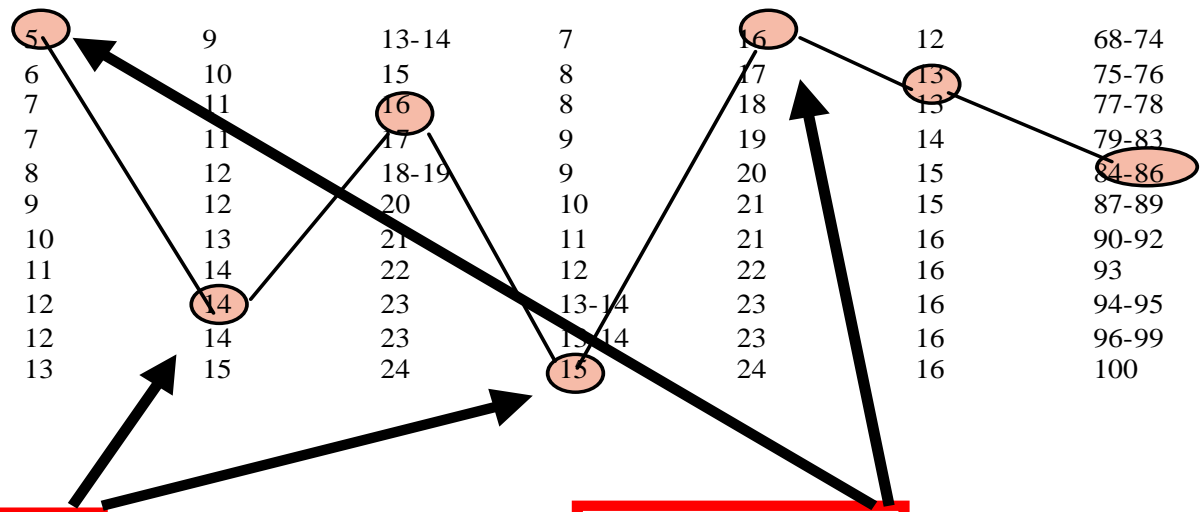
Profile of strengths and weaknesses

Percentile scores: Individual profile of domains of psychosocial adjustment

	Peer relations	Dependency	Hostility	Productivity	Anxiety/depression	Withdrawal	PARS-III Total score
Maximum score	16	16	24	16	24	16	111
Mean score	9,03	12,18	19,22	10,45	20,16	14,41	85,34
Standard deviation	1,17	2,38	4,08	2,92	3,04	1,95	12,18
Percentile 10	5	9	13-14	7	16	12	68-74
Percentile 20	6	10	15	8	17	13	75-76
Percentile 25	7	11	16	8	18	13	77-78
Percentile 30	7	11	17	9	19	14	79-83
Percentile 40	8	12	18-19	9	20	15	84-86
Percentile 50	9	12	20	10	21	15	87-89
Percentile 60	10	13	21	11	21	16	90-92
Percentile 70	11	14	22	12	22	16	93
Percentile 75	12	14	23	13-14	23	16	94-95
Percentile 80	12	14	23	13-14	23	16	96-99
Percentile 90	13	15	24	15	24	16	100

strengths

weakness



Boys with DMD do not appear to be at significant greater risk for adjustment problems than boys with other chronic conditions

Table IV. Psychosocial Adjustment Scores of Males with DMD Compared with Males with a Chronic Disease in the Study of Walker et al. (1990)

	Males with Duchenne muscular dystrophy (N=287)	Males with chronic medical condition (N=263)	One sample t-test
PARS total scale	84.43 (12.15)	85.7 (12.1)	-1.71 NS
Peer relations	8.93 (3.09)	11.2 (2.8)	-12.33***
Dependency	12.01 (2.35)	11.5 (2.8)	3.62***
Hostility	18.88 (4.11)	18.6 (4.0)	1.15 NS
Productivity	10.30 (2.87)	10.7 (3.2)	-2.36*
Anxiety/depression	20.02 (2.98)	19.1 (3.6)	5.19***
Withdrawal	14.34 (1.95)	14.4 (2.1)	-0.51 NS

*** $p < .001$; * $p < .05$; NS, not significant.



No difference in psychosocial adjustment between boys who are taking steroids (N=161) as compared with those who were not on steroids (N=118)

Exploratory Analyses

The total PARS-III scores of 161 males in our study using steroids (56%) were compared to 118 nonusers (41%). *T*-test indicated no significant difference between the two groups ($t = 1.37$; $p = .17$). Analyses of subscales indicated a small but significant difference ($t = 2.33$; $p = .02$) for the withdrawal subscale when boys using steroids ($M = 14.6$) were compared to nonusers ($M = 14.0$).



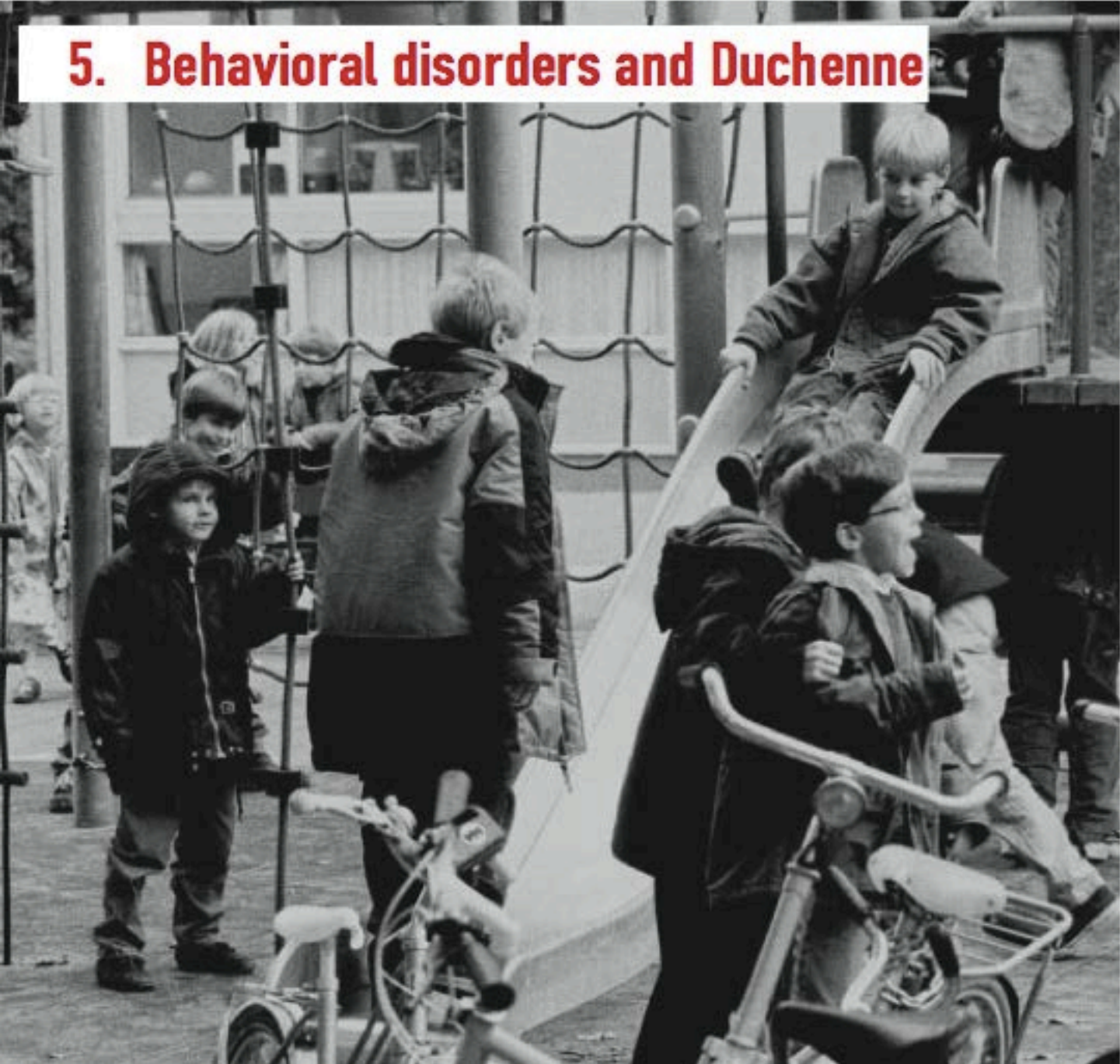
Norm referenced data suggest that a score below the cutt-off point of 72 indicates a higher risk for psychosocial adjustment.

These boys need further comprehensive evaluations.

use of the clinical cutoff that was established in this study (total score <72) will hopefully allow professionals to quickly identify patients who are at risk for having adjustment problems, and who may benefit from more comprehensive evaluations (such as clinical evaluation, pathology-focused rating scales, or neuropsychological testing).



5. Behavioral disorders and Duchenne



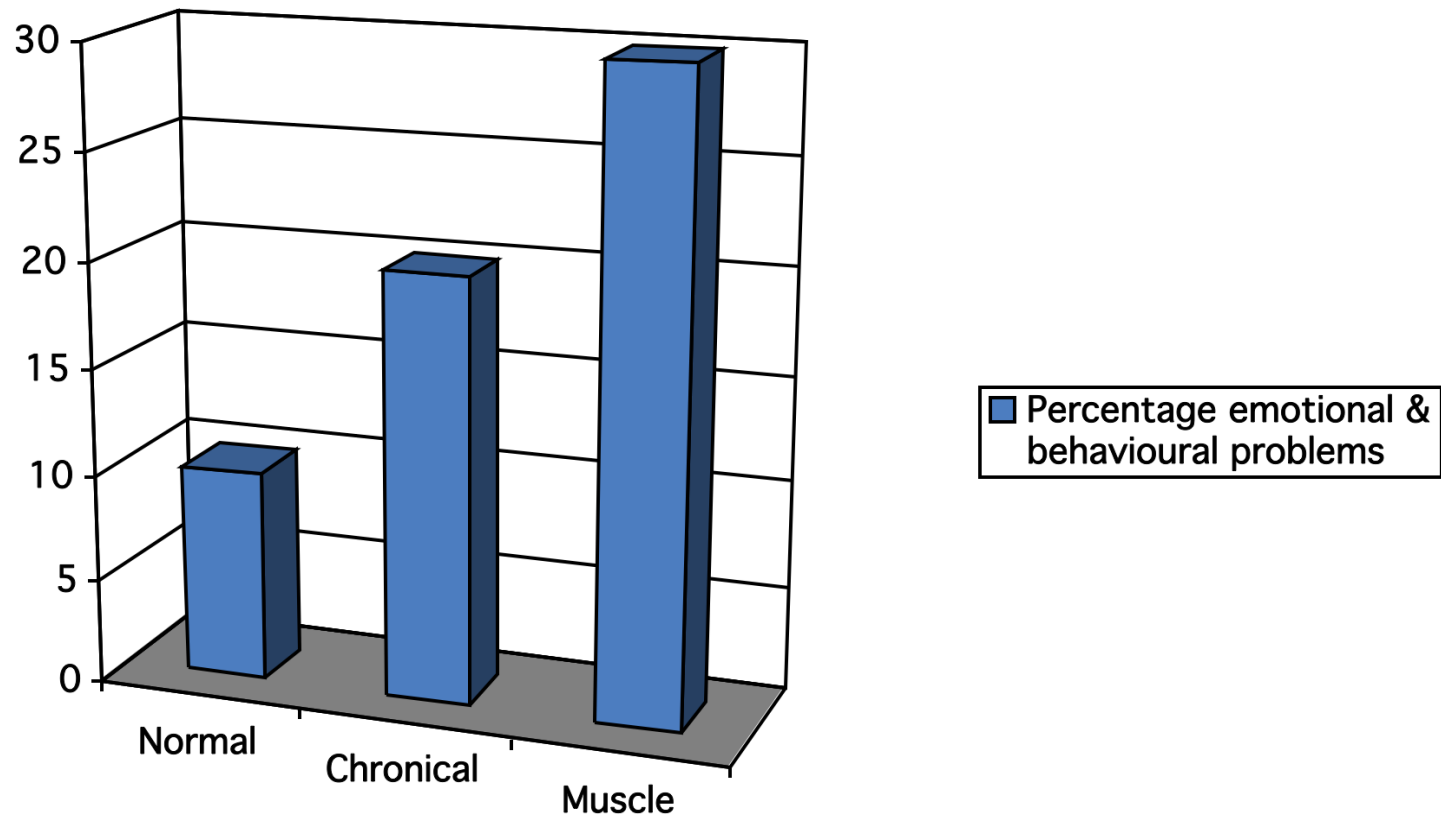


Neuropsychiatric problems:
Is there a comorbidity?

YES



Neuropsychiatry



Prevalence ASD (Autism Spectrum Disorders) in DMD

Three studies on Autism and DMD:

Wu et al (2005) =
3,7%

Hendriksen & Vles (2008)= 3,2%

Hinton et al (2009)=
15-19%

Wu, Kuban, Allred, Shapiro & Darras (2005). Association of Duchenne Muscular Dystrophy with autism spectrum disorders. *Journal of child neurology*, 20 (10): 790-795.

Hendriksen, C.G.M. & Vles, P.S.H. (2008). Neuropsychiatric disorders in males with Duchenne muscular Dystrophy. *Journal of child neurology*, 23 (5): 477-81

Hinton V& Cyrulnik SE (2009). Association of autism with dystrophinopathies. *Pediatric Neurology*, 41 (5); 339-46.

Normal population = 0,16%

Original Article

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Neuropsychiatric Disorders in Males With Duchenne Muscular Dystrophy: Frequency Rate of Attention-Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder, and Obsessive–Compulsive Disorder

Joseph G. M. Hendriksen, PhD, and Johan S. H. Vles, MD, PhD

Table 1. Prevalence Rates of Reported Neuropsychiatric Diagnoses in 351 Males With Duchenne Muscular Dystrophy and the Mean Age of the Males at the Time of the Study

	Mean Age, y (SD)	Frequency	Percentage	General Population (%)	t Value	p Value
ADHD	11.4 (3.5)	41	11.7	7	2.73	.007
ASD	9.8 (2.3)	11	3.1	0.0016	3.19	.002
OCD	10.5 (3.2)	17	4.8	2.3	2.22	.027

NOTE: ADHD = attention-deficit hyperactivity disorder; ASD = autism spectrum disorder; OCD = obsessive–compulsive disorder.

ADHD in DMD

Italian boys (Pane et al, 2012; N= 103)

DSM-IV criteria and Conners
questionnaires

ADHD/ADD = 36%

-ADHD = 18%

-ADD = 12%

-HYP = 3%

Relation with steroids?

The diagnosis of ADHD was independent of Total IQ and not associated with ambulation and steroids regime (Pane et al 2012)

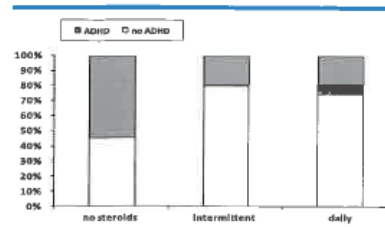


Figure 1. ADHD and steroid treatment.

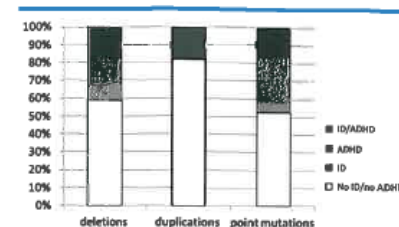


Figure 3. Type of mutations and ADHD.



DMD and ADHD in our clinic

12 boys (6.5 year) DMD with learning problems;

Verbal IQ 85; Performance IQ 104;

67% normal education,

25% repeated a grade;

6 boys (50%) with ADHD and on ritalin medication;

Positive effect ritalin in 83% (N=5).



Transition

an emerging and novel patient population

PART 4:





Amsterdam expert meeting june 2011

Transition





Available online at www.sciencedirect.com

SciVerse ScienceDirect

Neuromuscular Disorders xxx (2012) xxx–xxx



www.elsevier.com/locate/nmd

Meeting report

Transition in Duchenne Muscular Dystrophy: An expert meeting report and description of transition needs in an emergent patient population (Parent Project Muscular Dystrophy Transition Expert Meeting 17–18 June 2011, Amsterdam, The Netherlands)

D.G.M. Schrans^{a,*}, D. Abbott^{b,1}, H.L. Peay^{c,1}, R.F. Pangalila^{d,1}, E. Vroom^{e,1},
N. Goemans^{f,1}, J.S.H. Vles^{a,g}, A.P. Aldenkamp^{a,g}, J.G.M. Hendriksen^{a,g,1}

Transition



Priority of factsheets

1. Taboos (predictable but unspeakable)
2. Start early
3. Personality type
4. Medical Watershed moments

Taboos: Facilitating open conversation

This fact sheet will help you and others talk about subjects that are difficult or uncomfortable to express. Topics such as sex and romance, mortality (which is the fancy word for death), guilt that you may feel having MD, or guilt that your parents may feel in taking time for themselves over your condition, and also losing abilities you once had and how it is going to be in the future. It is ok to feel angry with MD, and also sad or bummed out. It is ok and it is normal. It is even ok to cry sometimes. What is important is that you learn how to cope, and eventually manage your own life. You will also feel happy, success, and feelings of accomplishment. Having MD is not all bad!

General tips for mom and dad:

- Start early in life.
- Initiate conversations with your child.
- Create an open environment.
- Communicate your own values.
- Listen to your child.
- Try to be honest.
- Be patient.
- Use everyday opportunities to talk.
- Don't forget friends, talk with them too!

The topics below can be tough to talk about, and the boxes at the bottom provide some answers and conversation starters so that discussion can be open and honest. Your feelings are ok; don't be afraid to share them and talk about why you feel as you do.

SEX

GUILT

MORTALITY

DECLINE
OF
ABILITY

1. Real life is NOT like the movies. You don't meet someone and end up in bed a few hours later. Time is spent going to the movies, out to eat, and getting to know someone. Sex is a difficult topic to talk about even if you are not disabled. When you begin dating, be open to talking about your feelings about sex, and what you might need help doing.
2. Guilt is around when you have a disability. Maybe you feel guilty asking people for assistance, maybe your family feels guilty about all the pressure they put on themselves to make sure you are ok. Do they ignore their own lives? Do your siblings feel guilt toward you or themselves? Remember, all feelings are normal, and it is even ok to talk about conflict and the role of everyone in your house. Everyone needs to have a life; not just you. Be patient, and talk, talk, talk.

1. Mortality is another subject that can be scary. Everyone knows that they are going to die, but not everyone believes it. As we all get older, it is something that we all think about, but love does not die. We don't stop loving someone when they pass away. All of us have limited time on the Earth. Talking about death is also healthy. Even though it is going to happen someday, people that are happy in life always have the same outlook: Do the best you can while you are here!
2. Losing ability is like going through phases of grief: anger, denial, realization, acceptance. As you go through the cycle, you understand that it happens over and over when you can't do something anymore. How to deal? Perspective. Using a power chair? Now you CAN do things by yourself that you couldn't do before. The list goes on and on.



THEME 2: Start thinking about transition early

Teach skills for independence early and start transition at the earliest developmentally appropriate time.

Transition

Individually accustomed care which should ideally be goal directed, easily accessible, simple and outpatient



THEME 3: Patient types and coping with DMD

Guide adolescents to the front seat of their own care and take an individual role in the ongoing process of transition.

Transition



"As long as I just follow doctor's orders, I don't have to worry"

Conscious & Compliant

"If my parents know what to do, it's OK"

Backseat Patient

"I take my own decisions, I will not have my illness limit me"

Self-confident & Autonomous

"Just imagine that things will go wrong later"

Worried & Insecure

Transition

Patient Types and Coping Strategies

This fact sheet is meant to guide you in being in charge of your own care. In our experience some doctors tend to talk to parents instead of the main person. This main person is you! As a result you may not be in charge of your own care. In order to force doctors to talk to you instead of your parents and in getting more independent from your parents while getting older we designed this fact sheet. It is supposed to inform you and offer practical tips in getting in charge concerning medical issues, psychological issues, and social environmental issues in your own care.

Why do we think it is important to be in charge of your own care? In explaining this we want to make a comparison with "boatsmen". The name boatman refers to the one who gives instructions to the sailors on the deck of a ship. He usually has sailed big waters and bears great storms. As with the boatman's life, the life of a man with Duchenne, is determined to the extend he is able to give instructions and organize his environment. To be able to do this in a satisfying way he needs to be recognized and be in charge of his own care.

In taking charge, you first have to ask yourself how well each profile below matches you?
- not at all, not really, a little, well, very well -

"As long as I just follow doctor's orders, I don't have to worry"

A

"If my parents know what to do, it's OK"

B

"I take my own decisions, I will not have my illness limit me"

C

"Just imagine that things will go wrong later"

D

If profile A, B or D suits you best you might use some help in getting in charge of your own care.

Our goal is to let you make your own decisions and not let your illness limit you. If you do so, you're in charge of your own care! For those of you who haven't (yet) but want to, we will give some tips.

- Stop worrying about your disease or health
- Stop thinking your disease permits you living a normal life
- If you want something to happen: be at the helm of your own care and take your own responsibility
- Accept help from others if needed or offered
- Believe that you are able to manage your own care
- Think for your self and do what suits you best; don't accept every tip or advice others give you ;)

But if you do so you'll notice the effects described alongside →

If profile C suits you best, you're already in charge of your own care. You may recognize the characteristics below. These characteristics are of great importance in getting more independent and in charge of your own life and care.

- Living easy now is more important than being completely compliant
- It's you who decides how to live; don't let your disease limit you in daily life
- Dare to discuss your own opinion with others, including medical professionals
- You are capable of doing that yourself, you know enough about it
- You want to be treated like an adult and do your own talking
- You don't need your parents for that
- No one needs to hold your hand, but you may find it convenient to get information
- This does not mean you will always use it though!



THEME 4: Medical watershed moments

Crisis = opportunity:

- Loss of daily activities;
- Repercussion of scoliosis surgery;
- Ventilator: energy and restrictions;
- From pediatric to adult care.

Transition



ONE VOICE
TO END DUCHENNE

Parent Project
Muscular Dystrophy

Duchenne with a Future

The Power to Live

Jos Hendriksen, Debby Schrans, Jelle de Jonge
Elizabeth Vroom, Pat Furlong (2011)

Documentary



Documentary





ONE VOICE
TO END DUCHENNE

Parent Project
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Duchenne with a Future

The Power to Live



Jos Hendriksen, Debby Schrans, Jelle de Jonge
Elizabeth Vroom, Pat Furlong

- Interviews with 8 Duchenne men and 5 experts
- 4 countries: USA, Danmark, Belgium, Netherlands
- 18 Discs of filming, each 45 min.

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A positive message:



Concluding remark

There is a close interrelationship between physical and psychological issues that characterize DMD;

There is urgent need for multi-disciplinary approaches in the context of contemporary medical management and improved survival

Developmental and Behavioral Disorders Grown Up: Duchenne Muscular Dystrophy

Jennifer M. Birnkrant, BA,* David S. Bennett, PhD,* Garey H. Noritz, MD,†
David J. Birnkrant, MD‡

Thank You for your attention

Jos Hendriksen:

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When parents are confronted with the diagnosis of Duchenne, it is hard for them to understand its consequences. A lot of questions arise: how will the life of our son look like?

What is the best for him? In which way is he normal and in which way is he different from others? How will he perform at school? What should we be prepared for? How do we explain it to others? What to tell them and when? Teachers and other professionals often have the same questions: how can we teach him? What to tell the other children?

This booklet has been written to answer some of the above questions. We intend to give some guidelines and support to all of them living and working with the boys at home, school or during therapy. Remember that every boy with Duchenne is unique and not all the topics to be covered will apply to all of the boys.

We will successively deal with five areas of functioning:

1. physical functioning
2. cognitive functioning (cognitive functions and intelligence)
3. learning in school
4. emotional and social functioning
5. behavioural functioning.

photography: Jutka Rona
design: Justus Kuijer



for more information:
uppmnd.org
duchenne-community.org

the psychology of duchenne muscular dystrophy

Jos Hendriksen, Ruben Hendriksen
and Elizabeth Vroom

