WAJONG:
Developmental trajectory of young adult survivors with a disability benefit

Martha Grootenhuis
Heleen Maurice-Stam
Eefje Verhoof
Huib Caron

Psychosocial Department
Emma Children’s Hospital/Academic Medical Centre
Amsterdam, The Netherlands
Psychosocial development

growing-up with childhood cancer:
• increased dependency (parents, health care)
• decreased social participation (school, peers)

Psychosocial development and functioning under pressure
Assessing psychosocial development

*Course life life Questionnaire (CoL-Q)*

- psychosocial developmental milestones
- young adults: 18-30 years
- retrospectively, facts
- elementary, middle/high school, thereafter
- social-demographic outcomes (education, work, marital status)
CoL-Q domains

- Autonomy (6 items)
- Social development (12 items)
- Psycho-sexual development (4 items)
- Anti-social behavior (4 items)
- Substance use and gambling (12 items)
Autonomy development

Autonomy at home and outside the home

Did you have any regular chores/tasks at home during elementary school, such as washing dishes?
☑ yes
☑ no

At what age did you take your first vacation without adults?
☑ never
☑ 12-14
☑ 15-17
☑ 18-20
☑ 21 or older
Social development

Social contacts with peers, at school/ in leisure time

Did you feel that you belong to a group of friends during middle and/or high school?
☑ yes
☑ no

Who did you spend most of your leisure time with during middle and/or high school?
☑ with friends
☑ with brothers/sisters
☑ with parents
☑ alone
Psycho-sexual development

Love and sexual relations

At what age did you have your first girl/boyfriend?
☑ I haven’t yet
☑ 12-14
☑ 15-17
☑ 18 or older

At what age did you experience sexual intercourse for the first time?
☑ I haven’t yet
☑ younger than 13
☑ 13-18
☑ 19 or older
What do we know?

Compared to young adults without history childhood cancer

- fewer psychosocial developmental milestones
- smaller % employed, married/living together
- worse QoL


A delayed psychosocial developmental trajectory while growing-up may affect QoL and socio-demographic outcomes in adulthood.

Aim

to study associations between psychosocial developmental trajectory and labour participation in young adulthood
Hypothesis

Young adult survivors with disability benefits (WAJONG) had achieved fewer psychosocial milestones than young adult survivors without disability benefits.
Invalidity Insurance Act for Young Disabled Persons

In the Netherlands, young people who are (partially) unable to work because of a chronic disease or disability may be eligible for benefit under the scheme for young disabled persons:

- at least 25% occupationally disabled
- before the 17th birthday
- or during study (before the 30th birthday if being a student for at least six months in the year prior to the occupational disability).
## Respondents

<table>
<thead>
<tr>
<th></th>
<th>53 survivors with disability benefits</th>
<th>313 survivors without disability benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (female)</td>
<td>62.3%</td>
<td>48.6%</td>
</tr>
<tr>
<td>Age at study</td>
<td>Mean 25.1 (18-31)</td>
<td>Mean 24.3 (18-31)</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td>Mean 7.3 (0-17)</td>
<td>Mean 6.8 (0-16)</td>
</tr>
<tr>
<td>Diagnosis (CNS)</td>
<td>40.4%</td>
<td>5.4%</td>
</tr>
</tbody>
</table>
Reference group

508 young adults from general population

- 53% female
- age at study 18-30, M=24.2
Statistics

1. CoL-Q scales:
   ANOVA by group, age and gender
   ► effect size

2. CoL-Q items / milestones:
   logistic regression analysis by group, age and gender
   ► odds ratio (OR)
Results - Scales

Psycho-sexual development

Social development
Social development

- Benefits < No benefits (d=0.6; p<0.001)
- Benefits < Reference (p<0.001)
- No benefits < Reference (p<0.01)
Psycho-sexual development

- Benefits < No benefits (d=0.4; p<0.01)
- Benefits < Reference (p<0.001)
- No benefits < Reference (p<0.001)
Results – *items*

Less likely to achieve milestones compared to the Reference group

<table>
<thead>
<tr>
<th></th>
<th>With disability benefits</th>
<th>Without disability benefits</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autonomy</td>
<td>3 of 6</td>
<td>1 of 6</td>
</tr>
<tr>
<td>Social development</td>
<td>7 of 12</td>
<td>3 of 12</td>
</tr>
<tr>
<td>Psycho-sexual development</td>
<td>4 of 4</td>
<td>2 of 4</td>
</tr>
</tbody>
</table>
Results – *items*

Less likely to achieve milestones

Disability benefits

*vs*

No disability benefits
Autonomy

Paid job ≤ 18 yr (%)

- Benefits < No benefits (OR=0.4; p<0.01)
- Benefits < Reference (p<0.001)
- No benefits < Reference (p<0.01)
Autonomy

Leaving the parents home (%)

- Benefits < No benefits (OR=0.4; p<0.01)
- Benefits < Reference (p<0.001)
Social

Playing with friends – elementary school (%)

- Benefits < No benefits (OR=0.4; p<0.01)
- Benefits < Reference (p<0.001)
Social

Belonging to group of friends – middle/high school (%)

- Benefits < No benefits (OR=0.4; p<0.01)
- Benefits < Reference (p<0.01)
Social

Leisure time with friends – middle/high school (%)

- Benefits < No benefits (OR=0.4; p<0.001)
- Benefits < Reference (p<0.001)
Social

Going out to bar or disco – middle/high school (%)

- Benefits < No benefits (OR=0.3; p<0.001)
- Benefits < Reference (p<0.001)
Psycho-sexual

First time falling in love ≤ 18yr (%)
Psycho-sexual

First time sexual intimacy ≤ 18yr (%)

- Benefits < No benefits (OR=0.4; p<0.01)
- Benefits < Reference (p<0.001)
- No benefits < Reference (p<0.001)
Conclusion

An unfavourable psychosocial developmental trajectory while growing-up is related to a smaller likelihood of labour participation in adult life.

Early recognition and support are warranted.
Future research

• Research is needed on (medical) risk factors of applying for disability benefits

• Research should show whether stimulating the achievement of milestones while growing-up creates conditions for a better labour market position
Clinical implications (1)

Stimulate social participation
• activities with peers
• paid jobs

Monitoring milestones at transition points
• other school
• school to work
• paediatric to adult care

www.hetklikt.nu
Nombre: PRO password: KLiK
### Patiënt profiel EMMA

#### Lichamelijk

<table>
<thead>
<tr>
<th>Datum</th>
<th>Gegevens</th>
<th>CHAQ</th>
<th>CHAQ scores</th>
<th>CHAQ grafiek</th>
<th>PEDIQL</th>
<th>PEDIQL grafiek</th>
<th>LTO (score)</th>
<th>LTO (problemen)</th>
<th>Sessies</th>
</tr>
</thead>
<tbody>
<tr>
<td>04-03-2011</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>05-07-2011</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Het is voor mij moeilijk om meer dan één straat op en neer te lopen
2. Het is voor mij moeilijk om te rennen
3. Het is voor mij moeilijk om te sporten of lichamelijke activiteiten te doen
4. Het is voor mij moeilijk om iets zwaars op te tillen
5. Het is voor mij moeilijk om zelfstandig een bad of douche te nemen
6. Het is voor mij moeilijk om kweektejes rond het huis te doen
7. Ik heb moeite of pijn
8. Ik heb weinig energie

#### Emotioneel

<table>
<thead>
<tr>
<th>Datum</th>
<th>Gegevens</th>
<th>CHAQ</th>
<th>CHAQ scores</th>
<th>CHAQ grafiek</th>
<th>PEDIQL</th>
<th>PEDIQL grafiek</th>
<th>LTO (score)</th>
<th>LTO (problemen)</th>
<th>Sessies</th>
</tr>
</thead>
<tbody>
<tr>
<td>04-03-2011</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>05-07-2011</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Ik voel me zorgenvoor bang
2. Ik voel me verdrietig of somber
3. Ik voel me boos
4. Ik heb moeite met slapen
5. Ik maak me zorgen over wat wij zouden overhebben

#### Sociaal

<table>
<thead>
<tr>
<th>Datum</th>
<th>Gegevens</th>
<th>CHAQ</th>
<th>CHAQ scores</th>
<th>CHAQ grafiek</th>
<th>PEDIQL</th>
<th>PEDIQL grafiek</th>
<th>LTO (score)</th>
<th>LTO (problemen)</th>
<th>Sessies</th>
</tr>
</thead>
<tbody>
<tr>
<td>04-03-2011</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>05-07-2011</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Ik heb problemen om met andere kinderen op te schieten
2. Andere kinderen willen mijn vriend(in) niet zijn
3. Andere kinderen pesten mij
4. Ik kan bepaalde dingen niet die andere kinderen van mijn leeftijd wel kunnen
5. Het is moeilijk mee te kunnen blijven doen als ik met andere kinderen speel

#### School

<table>
<thead>
<tr>
<th>Datum</th>
<th>Gegevens</th>
<th>CHAQ</th>
<th>CHAQ scores</th>
<th>CHAQ grafiek</th>
<th>PEDIQL</th>
<th>PEDIQL grafiek</th>
<th>LTO (score)</th>
<th>LTO (problemen)</th>
<th>Sessies</th>
</tr>
</thead>
<tbody>
<tr>
<td>04-03-2011</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>05-07-2011</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1. Het is moeilijk om op te letten tijdens de les
2. Ik vergeet dingen
3. Ik heb moeite om mijn huiswerk bij te houden
4. Ik ga niet naar school, omdat ik me niet lekker voel
5. Ik ga niet naar school, omdat ik naar de dokter of het ziekenhuis moet

### Grafieken
- **Lichamelijk**: Grafiek toont veranderingen in lichamelijke toestand.
- **Emotioneel**: Grafiek toont veranderingen in emotioneel welzijn.
- **Sociaal**: Grafiek toont veranderingen in sociaal gedrag.
- **School**: Grafiek toont veranderingen in schoolgedrag.
Clinical implications (2)

Empowerment

*Op Koers*: psycho-educational group course for survivors of childhood cancer

- information seeking and relaxation
- social competence
- positive thinking

[www.opkoersonline.nl](http://www.opkoersonline.nl)
Clinical implications (3)

Empowerment

Job training - Emma@work:
• empower for work
• job mediation
www.emma-at-work.nl
References

Maurice-Stam H, Verhoof EJ, Caron HN, Grootenhuis MA. Are survivors of childhood cancer with an unfavourable psychosocial developmental trajectory more likely to apply for disability benefits? *Psychooncology* 2013; 22:708-714


Acknowledgement

Many thanks to the patients, families and colleagues who have contributed to this work over many years

See www.zorgvoorhetziekekind.nl

The work described in this presentation was funded, in part, by:
• Dutch Cancer Society, KIKA, Roparun
• Revalidatiefonds, UWV

for information
m.a.grootenhuis@amc.nl
h.maurice-stam@amc.uva.nl
## Results – items

Less likely to achieve milestones compared to the Reference group

<table>
<thead>
<tr>
<th>Autonomy</th>
<th>Benefits vs Reference</th>
<th>No benefits vs Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paid jobs ≤18yr</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>For the first time vacation without adults ≤17yr</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Leaving your parents home</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>
Results – items

Less likely to achieve milestones compared to the Reference group

<table>
<thead>
<tr>
<th>Social</th>
<th>Benefits vs Reference</th>
<th>No benefits vs Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least one year of membership in a sports club / competitive sports, elementary school</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Most of the time playing with friends, elementary school</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>At least one year of membership in a sports club/competitive sports, middle and/or high school</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Belonging to a group of friends, middle and/or high school</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>
Results – *items*

Less likely to achieve milestones compared to the Reference group

<table>
<thead>
<tr>
<th>Social</th>
<th>Benefits vs Reference</th>
<th>No benefits vs Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of friends, middle and/or high school ≥ 4</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Leisure time, mainly with friends, middle and/or high school</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Going out to a bar or disco, middle and/or high school</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>At least one year of membership in a sports club/competitive sports, after middle and/or high school</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>
Results – items

Less likely to achieve milestones compared to the Reference group

<table>
<thead>
<tr>
<th>Psycho-sexual</th>
<th>Benefits vs Reference</th>
<th>No benefits vs Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>First girlfriend / boyfriend ≤17yr</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>For the first time falling in love ≤18yr</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>For the first time sexual intimacy ≤18yr</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>For the first time sexual intercourse ≤18yr</td>
<td>X</td>
<td></td>
</tr>
</tbody>
</table>