

The HOLD ME TIGHT RELATIONSHIP PROGRAM for couples facing Huntington's Disease

Introduction

HD negatively affects family dynamics
 ↓
 Risk for children's healthy development

Previous study:
 Offspring of HD patients have a higher risk for an insecure attachment style
 ↓
 Higher risk for relationship problems & psychological problems

Aim & Research questions

Can we help couples during their healthy years to strengthen their relationship?

- understand what they need from each other, now & after onset of HD
- give children the best chances for a healthy development

Does the **Hold me Tight program** strengthen the relationship of couples facing HD?

- More relationship satisfaction?
- More psychological well being?
 - More resilience?

The Hold me Tight program

Intervention

- Training program based on attachment theory (the importance of relationships for well-being)
- Aims to increase the emotional connection between partners
- Understanding each other's emotional needs

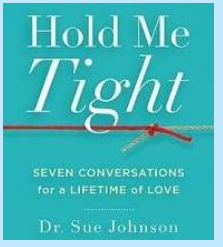
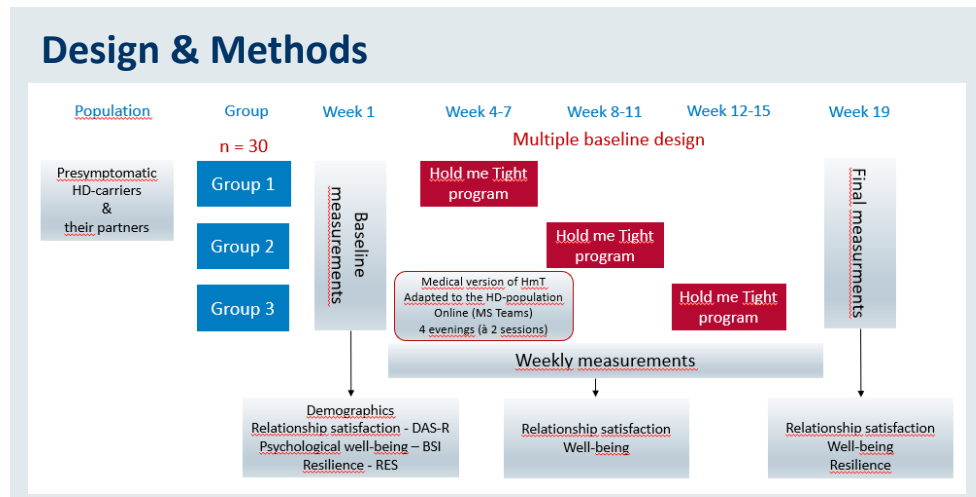
Program (8 sessions)

- First session: understanding attachment in childhood and adulthood
- Seven themes for conversations between partners (with videos, exercises & homework)

Medical groups

- Evidence based and effective in the general population
- Special versions for medical populations (cancer patients, heart patients)
- **Adaptation for the HD population:** sharing experiences on how HD affects relationships

'Are you there for me when I need you?'

Results

Participants (n = 30)
 15 male, 15 female
 Age, M; 41.7y (26-61)
 Relationship duration, M; 16.1y (3-42)
 Children, yes/no; 23/7
 Education lower/medium/high; 7/1/22
 Time since predictive test, M; 5y (1-11)
 Calculated years to onset, M; 17.4y (7-39)

Multilevel Model	B	SE	p	
(Intercept)	-6,25	2,76	0,03	*
Week	0,61	0,11	<0.0001	***
Phase	2,8	0,68	<0.0001	***
Week:phase	-0,27	0,05	<0.0001	***

HmT program increases relationship satisfaction

Multilevel Model	B	SE	p	
(Intercept)	0,145	0,054	0,012	*
Phase	-0,070	0,020	0,001	***
Week	-0,013	0,003	<0,001	***
Phase:Week	0,006	0,002	<0,001	***

HmT program enhances well-being

Paired sample t-test	Week 1	Week 19	t	p
M (SD)	25,2 (3,27)	26,2 (6,65)	-0,669	.509

No significant increase in resilience
 2 measurements; insufficient power?

*p<.05, **p<.01, ***p<.001

Participant's comments

Exchanging experiences is pleasant, especially in this phase, before onset of HD!

Talking about HD and about what may happen in the future was not easy, but it made us stronger

The program helped us speak about difficult things together

The Hold me Tight program made me feel less lonely with my situation

Very useful and valuable! We learned new things and we know how to move forward with this

We got a lot out of it! Next weekend we will make time to continue talking

After receiving the genetic test result, we had a very difficult time in our relationship. I think the Hold me Tight program could have prevented emotional injuries

Conclusions

Results and experiences of the study indicate that the Hold me Tight program

- Is well received by couples facing HD
- Improves the partner relationship
- Contributes to better well-being

Implementing the HmT program in standard HD care may help couples understand each other's emotional needs, now and during the disease process

Acknowledgments

TARA PETZKE, Psychologist, PhD student (wrote master thesis in Health Psychology on the project)

ASHYLA DONNÉ, Psychologist (co-operated as Master student Clinical Neuropsychology)

DR. EMILIA BIJLSMA, Clinical Geneticist, LUMC

DR. MAR RODRIGUEZ-GIRONDO, Medical Statistician, LUMC

& ALL PARTICIPANTS IN THE STUDY

LUMC

Dr. Lucienne van der Meer
 Health Care Psychologist & Principal Investigator

Leiden University Medical Centre, Leiden, the Netherlands
 Dept of Clinical Genetics

l.b.van_der_meer@lumc.nl

Selected refs: Van der Meer et al, 2006, 2012, 2014, 2015 | Johnson, S.M. (2008). *Hold me tight: Seven conversations for a lifetime of love* | Spanier, 1976. Dyadic Adjustment Scale – Revised | Derogatis & Melisaratos, 1983. Brief Symptom Inventory | C.A.I. van der Meer et al., 2018. Resilience Evaluation Scale



THIS STUDY WAS FUNDED BY
Vereniging van Huntington