

# *Acceptance and Commitment Therapy for Pediatric Sickle Cell Disease*

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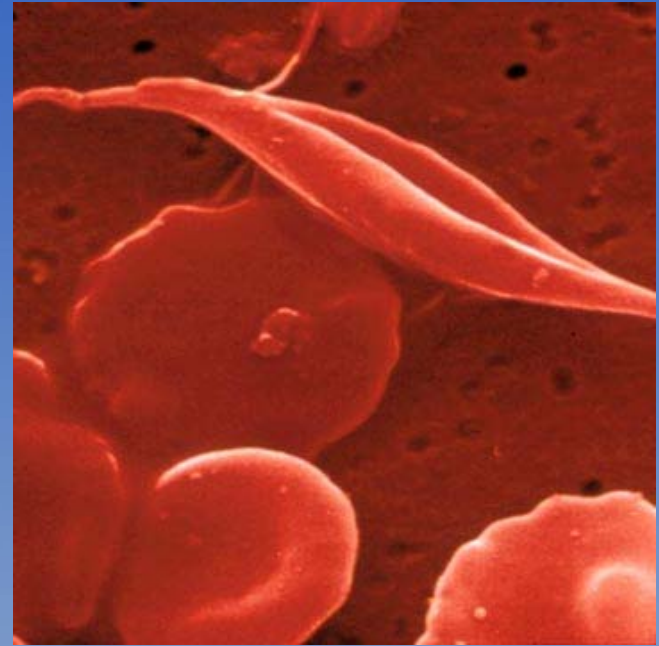
*Samen Nog Beter 2*  
April 23, 2010

# *Agenda*

- Pediatric Sickle Cell Disease (SCD)
- Acceptance and Commitment Therapy (ACT)
- Preliminary data on our ACT for SCD program

# *Sickle Cell Disease (SCD)*

- SCD is a genetic blood disorder with a number of symptoms



# *Common SCD Symptoms*

Jaundice

Back pain

Arm and leg pains

Foot swelling



Fatigue

Breathlessness

Joint pain

## *Sickle Cell Disease (SCD)*

- SCD is a genetic blood disorder with a number of symptoms
- Adolescents with SCD are at risk for medical, neuropsychological, and psychosocial problems
- There is a pressing need for effective and practical psychosocial approaches to manage pain and improve functioning and quality of life
- The parents are in danger of heightened stress and maladjustment

## *SCD Treatments*

- Reviews suggest that psychosocial and pain treatments for pediatric SCD are sparse and limited (Anie & Green, 2002; Chen, Cole, & Kato, 2004)

# *Acceptance and Commitment Therapy (ACT) for SCD*

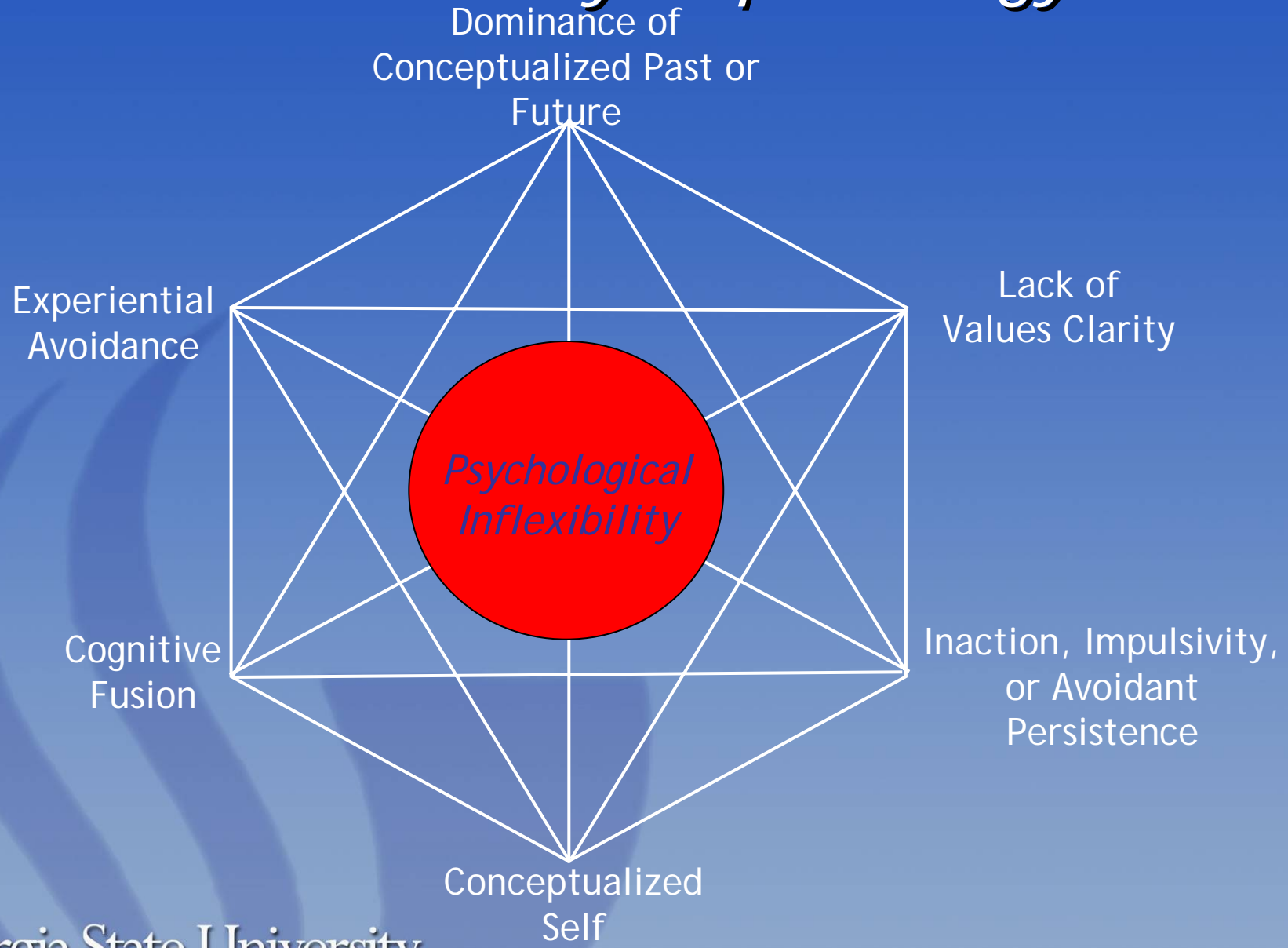
- ACT incorporates acceptance, mindfulness, and behavior change strategies to increase psychological flexibility
- Parallels the *Serenity Prayer*
  - God grant me the serenity to accept the things I cannot change; courage to change the things I can; and wisdom to know the difference (Reinhold Niebuhr)



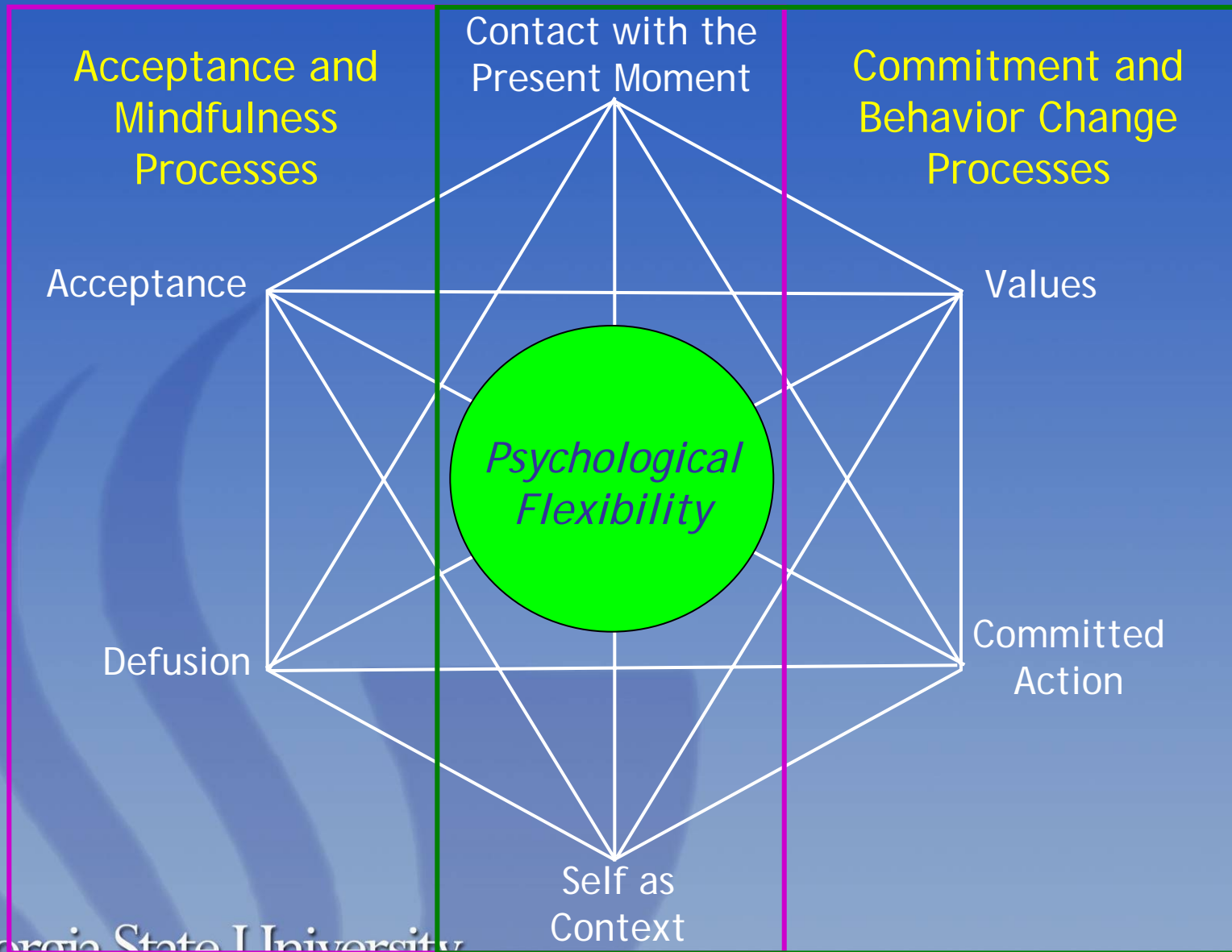
*Let's Discuss the Relations among  
Thoughts, Feelings, and Behaviors -  
What can you Control?*



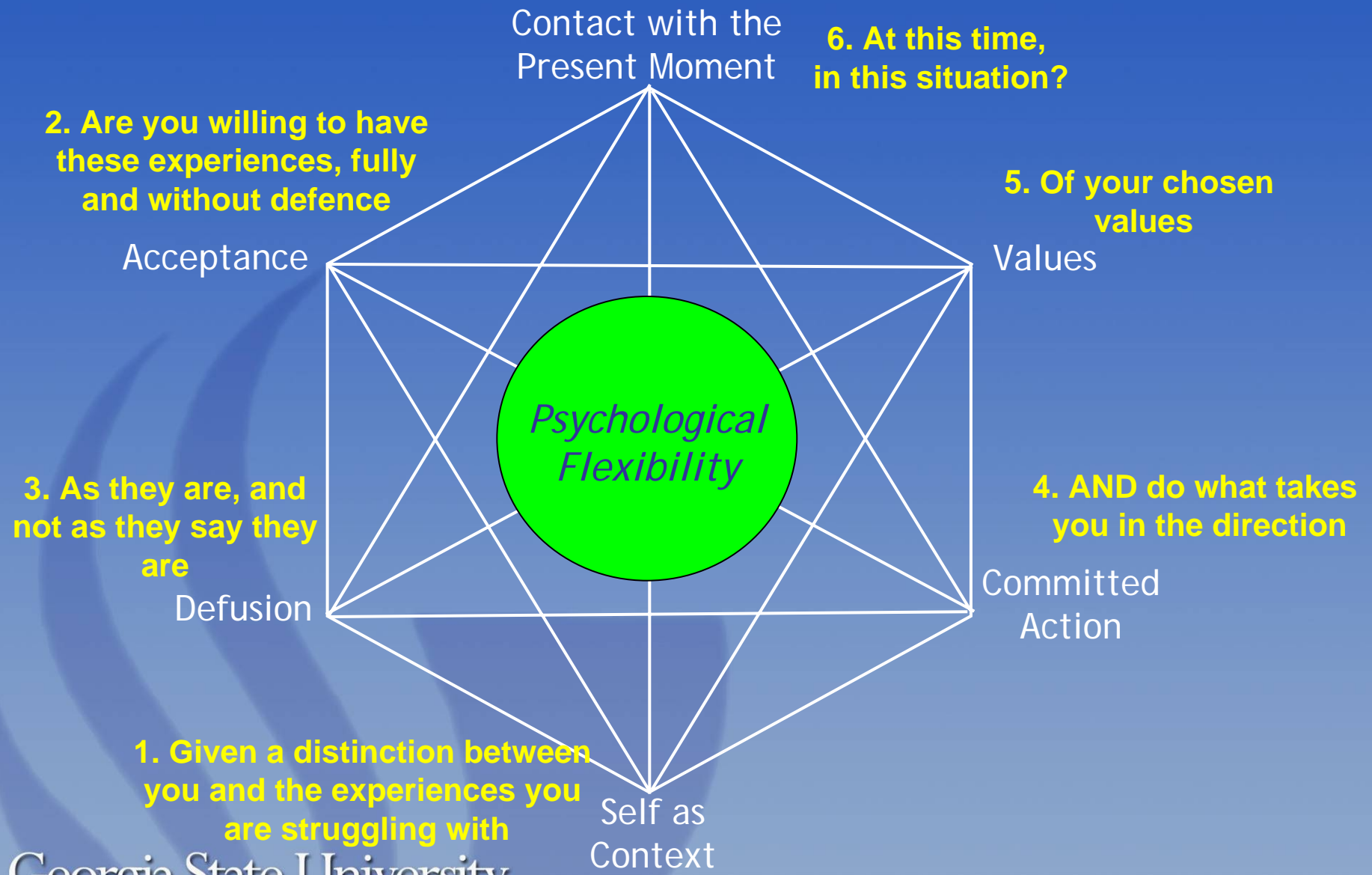
# *ACT View of Psychopathology*



# *ACT Approach to Treatment*

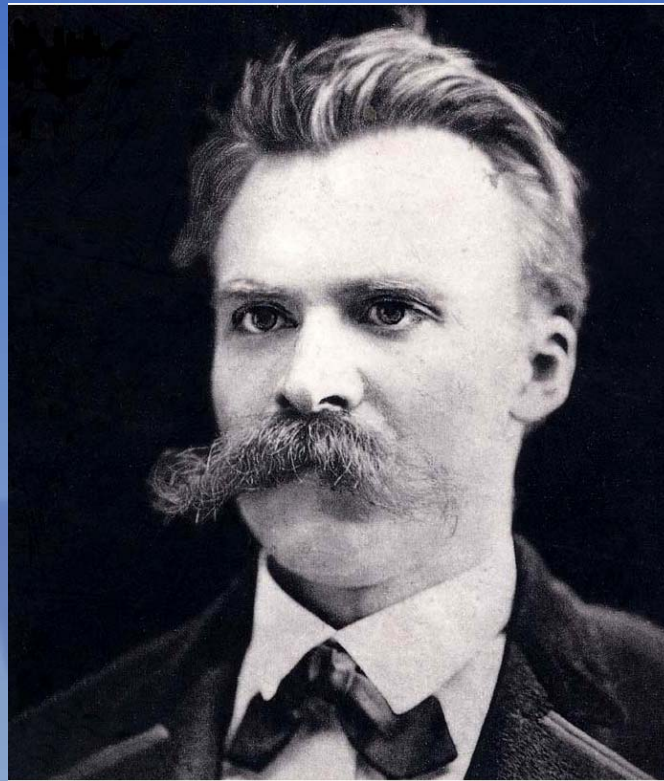


# ACT Approach to Treatment



*“He who has a why to live can bear almost any how.”*

Friedrich Nietzsche

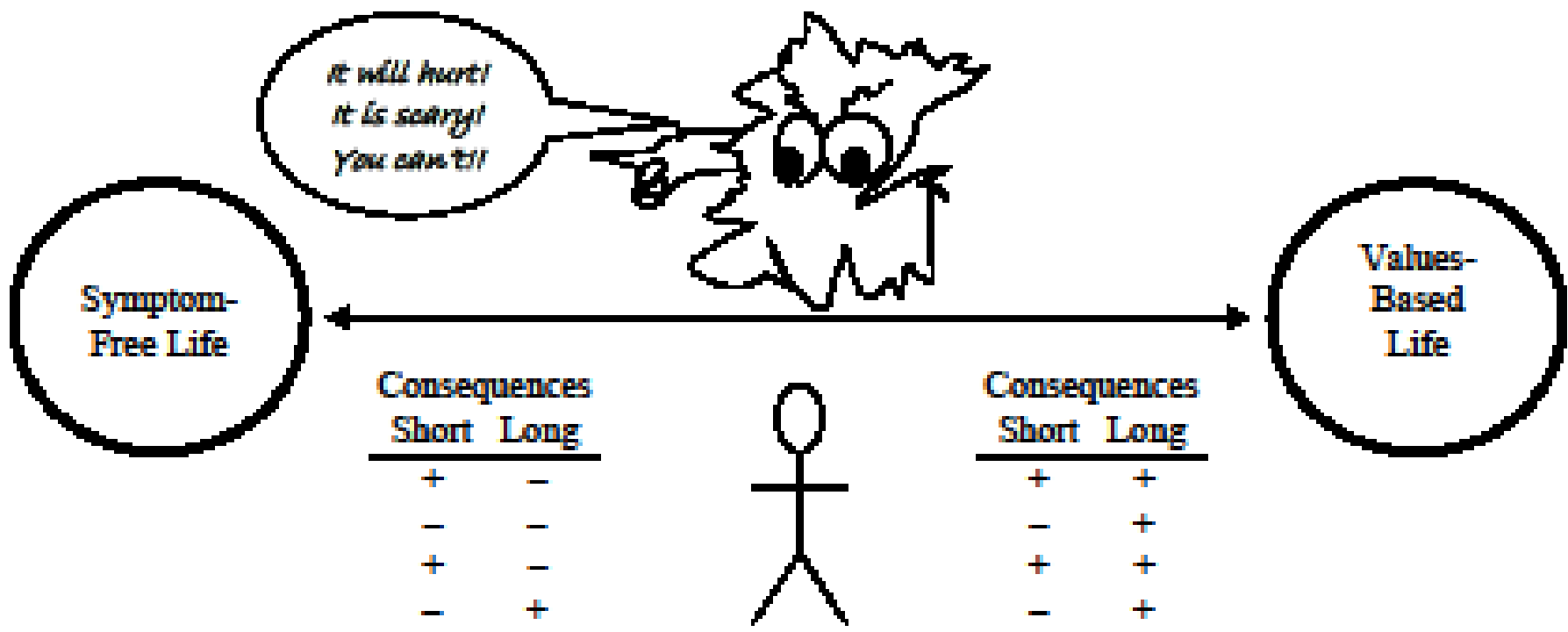


# *ACT for SCD Pilot Data - If Interest and Time*

- Descriptive study
- Single-Subject Study
- Group Study

# *Treatment Program - Let's Try it Together (Samen Nog)*

- Rationale and Overview (Life line; Spiral)





## *Treatment Program (cont.)*

- Rationale and Overview (Life line; Spiral)
  - Why are you here?
- What gets in the way of living?



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## *Treatment Program (cont.)*

- Rationale and Overview (Life line; Spiral)
  - Why are you here?
- What get in the way of living?
- Values (Collage)

FAMILY FRIENDS SCHOOL LEARNING

HEALTH SPIRITUALITY HOBBIES

CHILDREN OUTDOORS ART FITNESS

WIFE HUSBAND VOLUNTEER

JOB RELIGION



PARTNER



## *Treatment Program (cont.)*

- Rationale and Overview (Life line; Spiral)
  - Why are you here?
- What gets in the way of living?
- What is important to you?
- Where do you want to be in the future?

Me in 2015



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## *Treatment Program (cont.)*

- Rationale and Overview (Life line; Spiral) - Why are you here?
- What gets in the way of living?
- What is important to you?
- Where do you want to be in the future?
- How can you live the life you want? (Bus, Milk, Blocker, Invite on ride)
- What can you do right now? (Index cards)
- Please share your values, goals, and barriers.  
Let us know your immediate plans



## *Concluding Comments*

- There are data that ACT approaches are helpful for adults and pediatric chronic pain patients
- We have preliminary data to support ACT for SCD symptoms
- I argue that this approach might be useful for a number of pediatric conditions, where the emphasis would be to live a vital life *with* a challenging condition

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# *ACT for SCD Pilot Data*

## *Cross-sectional Data*

- *Participants* - 28 12- to 18-year-olds with SCD
- *Measures*
  - Pain (PedsQL PPQ)
  - Acceptance and psychological flexibility (CIAQ-A; AFQ)
  - Anxiety (SAS)
  - Quality of Life (PedsQL)

# *Cross-sectional Data*

- *Results*

- Higher pain positively correlated with anxiety and lower quality of life
- Acceptance and psychological flexibility positive correlated with lower anxiety and higher quality of life

- *Conclusion*

- Acceptance and psychological flexibility might impact anxiety and quality of life

## *Case Study*

- *Participant* - 17-year-old male with SCD and his mother
- *Present problem* - Fatigue, low energy, poor grades, lack of independence
- *Treatment* - 8 sessions of ACT-oriented behavioral therapy (e.g., embracing unchangeable barriers with 'SCD Monster'; establishing value-derived behavioral goals)



## *Case Study - Measures*

- *Teen Measures* - Quality of life (PedsQL, pre-post); SCD symptoms and values diary (Severity and Interference, Valued Activities)
- *Parent Measures* - Adjustment (BSI-18, pre-post), teen functional disability, Interference and values diary

## *Case Study - Results*

- Adolescent - Modest improvement from reported high pre-functioning; significant behavioral improvement; significant improvement in value-consistent living
- Mother - Significant improvement on teen functioning (0-60 scale; 36 pre to 7 post); approximately 20% improvement in living consistently with values

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## *Group Study*

- *Participants* - 2 (14-year-old; 17-year-old; boys; each with mother and father)
- *Presenting problem* - SCD symptoms interfering with life); teen issues around independence; homework complaints
- *Measures* -
  - Teen - Pain, Disability, Acceptance, Values, Quality of Life; Daily diary
  - Parent - Child disability, QoL. Acceptance, Values, Adjustment

## TEEN DAILY DIARY

**At the end of each day, please either email or leave a phone message for Dr. Cohen with your name and scores for each question below.**

**Email: [LLCOHEN@GSU.EDU](mailto:LLCOHEN@GSU.EDU); Phone: 404-413-6318**

1. How severe were your SCD symptoms (pain, fatigue, etc.) today?



0 = No Symptoms      2      4      6      8      10 = Severe Symptoms

For the next questions, please provide a score of 0-5 based on the scale below to indicate how much **SUCCESS** you have had in living according to your values.

For each of the areas of life below, consider how you most want to live your life. This is personal and different for everyone - there are no right or wrong answers. Please rate how **SUCCESSFUL** you have been living according your values TODAY. These questions are not asking how successful you want to be but how successful you have been TODAY.



0	1	2	3	4	5
Not at all Successful	Slightly Successful	Somewhat Successful	Moderately Successful	Very Successful	Extremely Successful
					<b>SUCCESS</b>
					<b>At Living Your Values</b>
2. Family – taking care of relationships with parents, brothers/sisters, and other relatives, such as grandparents					
3. Friends – spending time with friends, being supportive, or whatever being a friend means to you					
4. Boy/girl friends – dating, spending time with a girlfriend or boyfriend, having a close or special relationship with a partner.					
5. School/work/education – attending school, keeping up with education, working or preparing for work or a career					
6. Health – keeping fit and healthy and physically able to do activities					
7. Growth and learning – learning new skills and ideas, being aware of world events, becoming an independent person, looking after yourself.					
8. Spirituality/Religion – honoring and practicing my beliefs, attending services, praying					

**Thank you!**

**Please do not forget to call or email with your name and scores at the end of each day to Dr. Cohen**



## PARENT DAILY DIARY

**At the end of each day, please either email or leave a phone message for Dr. Cohen with your name and scores for each question below.**

Email: [LLCOHEN@GSU.EDU](mailto:LLCOHEN@GSU.EDU); Phone: 404-413-6318

1. How much did you worry about your teenage child today?



0 = No Worries about Teen	2	4	6	8	10 = Severe Worries about Teen
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For the next questions, please provide a score of 0-5 based on the scale below to indicate how much **SUCCESS** you have had in living according to your values.

For each of the areas of life below, consider how you most want to live your life. This is personal and different for everyone - there are no right or wrong answers. Please rate how **SUCCESSFUL** you have been living according your values TODAY. These questions are not asking how successful you want to be but how successful you have been TODAY.



0	1	2	3	4	5
Not at all Successful	Slightly Successful	Somewhat Successful	Moderately Successful	Very Successful	Extremely Successful
					<b>SUCCESS</b> At Living Your Values
2. FAMILY: Participation in your relationships with your parents, children, other close relatives, people you live with, or whoever is your "family."					
3. INTIMATE RELATIONS: Being the kind of partner you want to be for your husband/wife or closest partner in life.					
4. FRIENDS: Spending time with friends, doing what you need to maintain friendships, or providing help and support for others as a friend.					
5. WORK: Engaging in whatever is your occupation, your job, volunteer work, community service, education, or your work around your own home.					
6. HEALTH: Keeping yourself fit, physically able, and healthy just as you would most want to do.					
7. GROWTH AND LEARNING: Learning new skills or gaining knowledge, or improving yourself as a person as you would most want.					
8. SPIRITUALITY/RELIGION - Honoring and practicing my beliefs, attending services, praying.					

**Thank you!**

**Please do not forget to call or email with your name and scores at the end of each day to Dr. Cohen**

## *Group Study - Preliminary Results*

- Participants identified specific behavioral goals (e.g., consistent homework schedule; walk without crutches)
- Subjective report via phone is positive; data collection is underway



# References

- Dahl, J. C., & Lundgren, T. L. (2006). *Living beyond your pain: Using Acceptance and Commitment Therapy to ease chronic pain*. Oakland, CA: New Harbinger.
- Hayes, S. C., & Greco, L. A. (2008). *Acceptance and mindfulness treatments for children and adolescents: A practitioner's guide*. Oakland, CA: New Harbinger Publications.
- Hayes, S. C., Strosahl, K., & Wilson, K. G. (1999). *Acceptance and Commitment Therapy: An experiential approach to behavior change*. New York: Guilford Press.
- McCracken, L. M. (2005). *Contextual Cognitive-Behavioral Therapy for chronic pain*. Seattle, WA: International Association for the Study of Pain.
- Wicksell, R. K., Ahlqvist, J., Bring, A., Melin, L., & Olsson, G. L. (2008). Can exposure and acceptance strategies improve functioning and life satisfaction in people with chronic pain and whiplash-associated disorders (WAD)? A randomized controlled trial. *Cognitive and Behaviour Therapy*, 37, 169-182.
- Wicksell, R. K., Dahl, J., Magnusson, B., & Olsson G. L. (2005) Using acceptance and commitment therapy in the rehabilitation of an adolescent female with chronic pain: A case example. *Cognitive and Behavioural Practice* 12, 415-423.
- Wicksell, R. K., Melin, L., Lekander, M., Olsson, G. L. (2009). Evaluating the effectiveness of exposure and acceptance strategies to improve functioning and quality of life in longstanding pain - A randomized controlled trial. *Pain*, 141, 248-257.
- Wicksell, R. K., Melin, L., & Olsson, G. L. (2007). Exposure and acceptance in the rehabilitation of adolescents with idiopathic chronic pain - a pilot study. *European Journal of Pain*, 11, 267-274.