

# Coping with uncertainty

Peter Vermeulen, PhD

Autism in Context

MAR  
11  
2021

**Autism and Mental Health  
Conference 2021**



[www.petervermeulen.be](http://www.petervermeulen.be)





**How can we play tennis?**





The brain is a  
prediction organ

And it doesn't like  
uncertainty!



VUCA

VOLATILE

UNCERTAIN

COMPLEX

AMBIGUOUS

WORLD

## Precise Minds in Uncertain Worlds: Predictive Coding in Autism

Sander Van de Cruys, Kris Evers, Ruth Van der Hallen, Lien Van Eylen,  
Bart Boets, Lee de-Wit, and Johan Wagemans  
KU Leuven

INAS



### Autism as a disorder of prediction

Pawan Sinha<sup>a,1</sup>, Margaret M. Kjelgaard<sup>a,b</sup>, Tapan K. Gandhi<sup>a,c</sup>, Kleovoulos Tsourides<sup>a</sup>, Annie L. Cardinaux<sup>a</sup>,  
Dimitrios Pantazis<sup>a</sup>, Sidney P. Diamond<sup>a</sup>, and Richard M. Held<sup>a,1</sup>

<sup>a</sup>Department of Brain and Cognitive Sciences, Massachusetts Institute of Technology, Cambridge, MA 02139; <sup>b</sup>Department of Communication Sciences and Disorders, Massachusetts General Hospital Institute of Health Professions, Boston, MA 02129; and <sup>c</sup>Department of Biomedical Engineering, Defense Institute of Physiology and Allied Sciences, New Delhi, India DL 110054

Contributed by Richard M. Held, September 5, 2014 (sent for review November 13, 2013; reviewed by Leonard Rappaport, Stephen M. Camarata, and Nouchine Hadjikhani)



# The relationship between intolerance of uncertainty and anxiety in autism: A systematic literature review and meta-analysis

Autism  
2020, Vol. 24(8) 1933–1944

© The Author(s) 2020



Article reuse guidelines:  
[sagepub.com/journals-permissions](https://sagepub.com/journals-permissions)  
DOI: 10.1177/1362361320932437  
[journals.sagepub.com/home/aut](https://journals.sagepub.com/home/aut)



Richard Jenkinson<sup>1</sup> , Elizabeth Milne<sup>1</sup> and Andrew Thompson<sup>2</sup> 

## Abstract

The association between intolerance of uncertainty and anxiety has proved robust in neurotypical populations and has led to effective interventions targeting intolerance of uncertainty. The aim of this systematic review and meta-analysis was to investigate this association in autistic people, given the high prevalence of anxiety in this population and the limited effectiveness of therapies used currently to treat anxiety in autism. A protocol was published on the Prospero database (CRD42019125315), and electronic databases were searched using terms related to intolerance of uncertainty, anxiety and autism. Included in the systematic review were 12 studies, of which 10 were included in a meta-analysis. Results showed that anxiety and intolerance of uncertainty were consistently elevated in autistic participants. Examining the correlation between these two constructs, the meta-analysis revealed a large sample-weighted effect size,  $r = 0.62$ , 95% confidence interval =  $[0.52, 0.71]$ ,  $p < 0.001$ . The strength of this association was comparable to meta-analyses conducted on neurotypical populations, and therefore, it was concluded intolerance of uncertainty may be an appropriate target for intervention for autistic individuals. However, conclusions were limited due to the small number of relevant studies that were available and due to issues with methodological quality.



# VUCA

VOLATILE

UNCERTAIN

COMPLEX

AMBIGUOUS

WORLD

more than ever now



# Living in uncertain times

## Left stranded: our new report into the impact of coronavirus

Published on 07 September 2020



- 9 in 10 autistic people worried about their mental health during lockdown
- 85% said their anxiety levels got worse





# The impact of the COVID-19 pandemic on autistic adults

Research group EXPLORA (Ghent University) has set up an online survey to investigate the effects of the current COVID-19 pandemic on the mental health and daily lives of adults on the autism spectrum. The tremendous impact of the pandemic has affected society as a whole, but this study aims to better understand how the current pandemic affects autistic adults specifically, so that tailored support and advice can be given to this group. Here we present the most societally relevant preliminary results of our ongoing study, in the hope that this will benefit the autistic community and their broader support network at this time.

The preliminary results are based on a sample of 839 participants (mean age = 38, range: 18-81; 573 female), of which 473 reported that they have a formal clinical diagnosis of autism spectrum disorder (ASD) [1]. To respect the wishes of autistic individuals, we use the term 'autistic', a term endorsed by many individuals with ASD (Kenny et al., 2016). All participants were residents of either Belgium ( $N = 467$ ), the Netherlands ( $N = 220$ ), or the United Kingdom ( $N = 152$ ). For the current report, we combined data from these three countries, but note that results were similar when analysing data for residents of the three countries separately.



# Coping with anxiety

angst en autisme



Angst en Autisme

25 abonnees

KANAAL AANPASSEN

VIDEO'S BEHEREN

HOME

VIDEO'S

PLAYLISTS

KANALEN

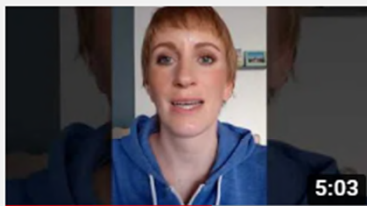
DISCUSSIE

OVER



Uploads

▶ ALLES AFSPELEN



5:03

Sanne vertelt hoe ze omgaat met de Coronacrisis

92 weergaven •  
5 maanden geleden



3:19

David getuigt hoe hij omgaat met angst en onzekerheid

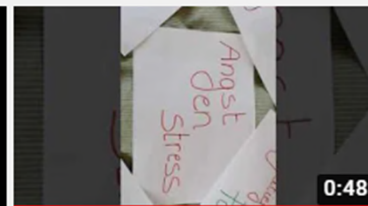
171 weergaven •  
5 maanden geleden



4:10

Minne vertelt over angst en onzekerheid

110 weergaven •  
6 maanden geleden



0:48

Loes vertelt wat angst en onzekerheid met haar doet...

101 weergaven •  
6 maanden geleden



3:13

Jari over onzekerheid en angst

113 weergaven •  
6 maanden geleden



AUTISM in CONTEXT

from neurodiversity to neuroharmony





Uncertainty is not new to us.  
We have coped with uncertainty before.

*“You have power over your mind, not outside events.  
Realize this and you will find strength.”*

Marcus Aurelius





UNCERTAINTY



WORRYING



ANXIETY / STRESS



# Managing your worries

- Plan your worry-time
- Limit the amount of uncertain input
- Contextualize to counterbalance







Will I get infected?

What about the  
restrictions?

When will this be over?

There will always be more healthy  
people than sick people

We will always be allowed to  
watch TV/play games

Every crisis has a beginning  
and an ending



### What do we NOT know?

If we will be allowed to travel for our summer vacation

When restaurants will re-open

When we will all be protected against the virus

### What DO we know?


That we're going to do nice things in our summer vacation

That we can have nice meals at home too

That we can already do things to protect ourselves







# Someday: A Story of Hope for Children

- Carol Gray

©Carol Gray, 2020. Permission is hereby granted to download, copy, re-send, share, and translate with credit to author.

# THINK

- True?
- Helpful?
- Inspiring?
- Necessary?
- Kind?



The infographic is set against a light blue background. On the left, a vertical column of five colored squares contains the letters T, H, I, N, and K in white. To the right of each letter is a question in bold blue text, followed by a more detailed question in a lighter blue font. On the right side of the infographic, there is an illustration of two women in business attire. One woman is pointing upwards with her right index finger, and the other is looking at her. Above them are two overlapping thought bubbles, one light grey and one white.

<b>T</b>	<b>IS IT TRUE?</b> Is this fact or is it really an opinion or feeling? Know & be clear before you speak.
<b>H</b>	<b>IS IT HELPFUL?</b> Does it help you, them or the situation?
<b>I</b>	<b>IS IT INSPIRING?</b> Also, does it IMPROVE on the silence?
<b>N</b>	<b>IS IT NECESSARY?</b> Would this be better left unsaid?
<b>K</b>	<b>IS IT KIND?</b> What is your motivation for communicating?





# H.A.P.P.Y.

**Happiness in Autism Personal Project for Young people**

[www.petervermeulen.be](http://www.petervermeulen.be)

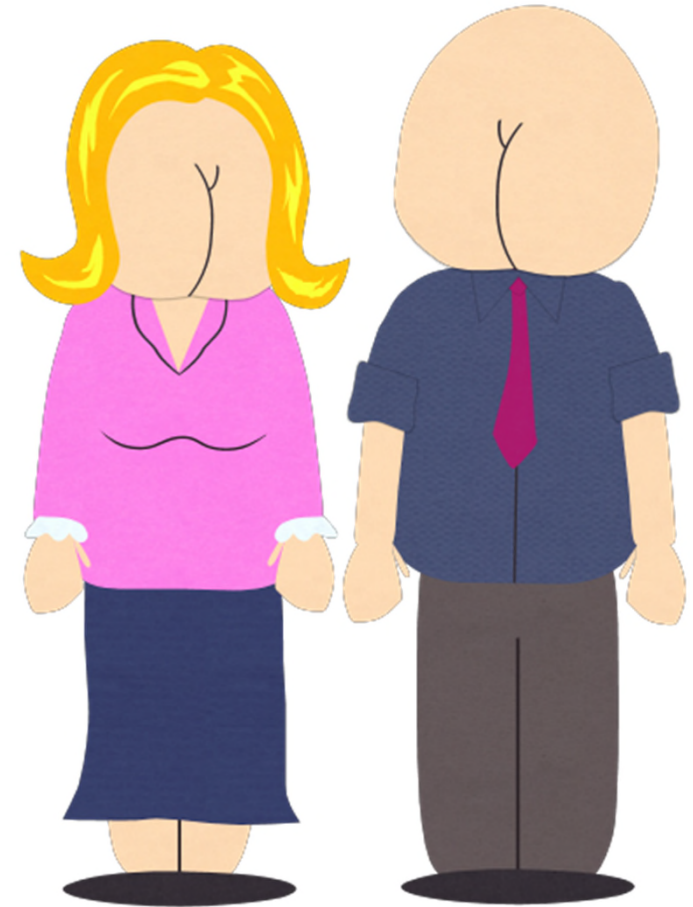


Positive diary  
Pride diary

# But person

But....

We don't know  
when we will  
be allowed to...







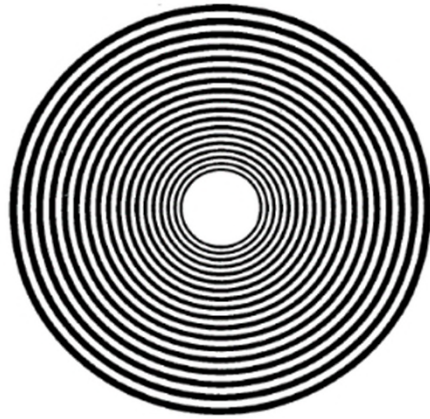
Uncertainty, stress and control

Martin Seligman





# Importance of control in stress



## URBAN STRESS

Experiments on Noise and Social Stressors

DAVID C. GLASS / JEROME E. SINGER

*New York University  
and  
Russell Sage Foundation  
New York, New York*

*State University of  
New York at Stony Brook  
Stony Brook, New York*



ACADEMIC PRESS  
New York San Francisco London 1972  
*A Subsidiary of Harcourt Brace Jovanovich, Publishers*



David Glass & Jerome Singer





Create islands of control in the ocean of uncertainty







Your Daily  
Routine  
Matters

# Routines are good for the mental health of children

Published in final edited form as:

*J Abnorm Child Psychol.* 2011 January ; 39(1): 83–94. doi:10.1007/s10802-010-9447-5.

## **Family Routine Moderates the Relation Between Child Impulsivity and Oppositional Defiant Disorder Symptoms**

**H. Isabella Lanza** and

Department of Psychology, Temple University, Philadelphia, PA, USA; Integrated Substance Abuse Programs, Semel Institute for Neuroscience and Human Behavior, University of California, Los Angeles, 1640 S. Sepulveda Blvd., Ste. 200, Los Angeles, CA 90025, USA

**Deborah A. G. Drabick**



Department of Psychology, Temple University, Philadelphia, PA, USA

Feature Articles

## **Why Routines Matter: The Nature and Meaning of Family Routines in the Context of Adolescent Mental Illness**

Femke Koome MHSc, Clare Hocking PhD & Daniel Sutton PhD 

Pages 312-325 | Published online: 19 Sep 2012

 Download citation  <https://doi.org/10.1080/14427591.2012.718245>



Controlled and  
predictable small  
variations in  
routines







Teach your brain to like surprises



**Don't try to control the uncontrollable**

*control*





# My control chart

## Things I cannot control

- The virus
- The measures
- Availability of food
- Time line exit
- The weather
- My personality
- Mr. Donald Trump

## Things I can control

- What I eat
- How often I watch the news
- When I do my chores
- When I go to bed

## Things I can control with support

- My anxiety
- My thoughts
- My free time
- My screen time
- My children
- My partner

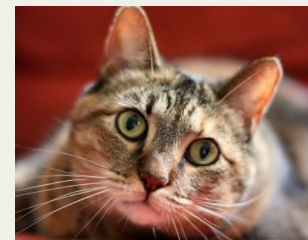


H.A.P.P.Y.

Happiness in Autism Personal Project for Young people

## What-if script

I don't know  
when my cat  
will die.



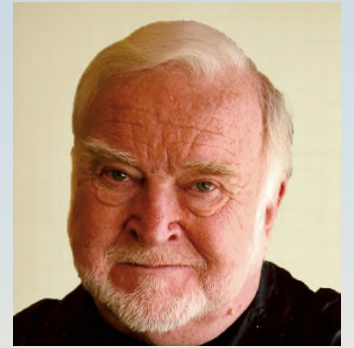
I don't know if I will be  
able to cope with the loss.

If my cat dies...

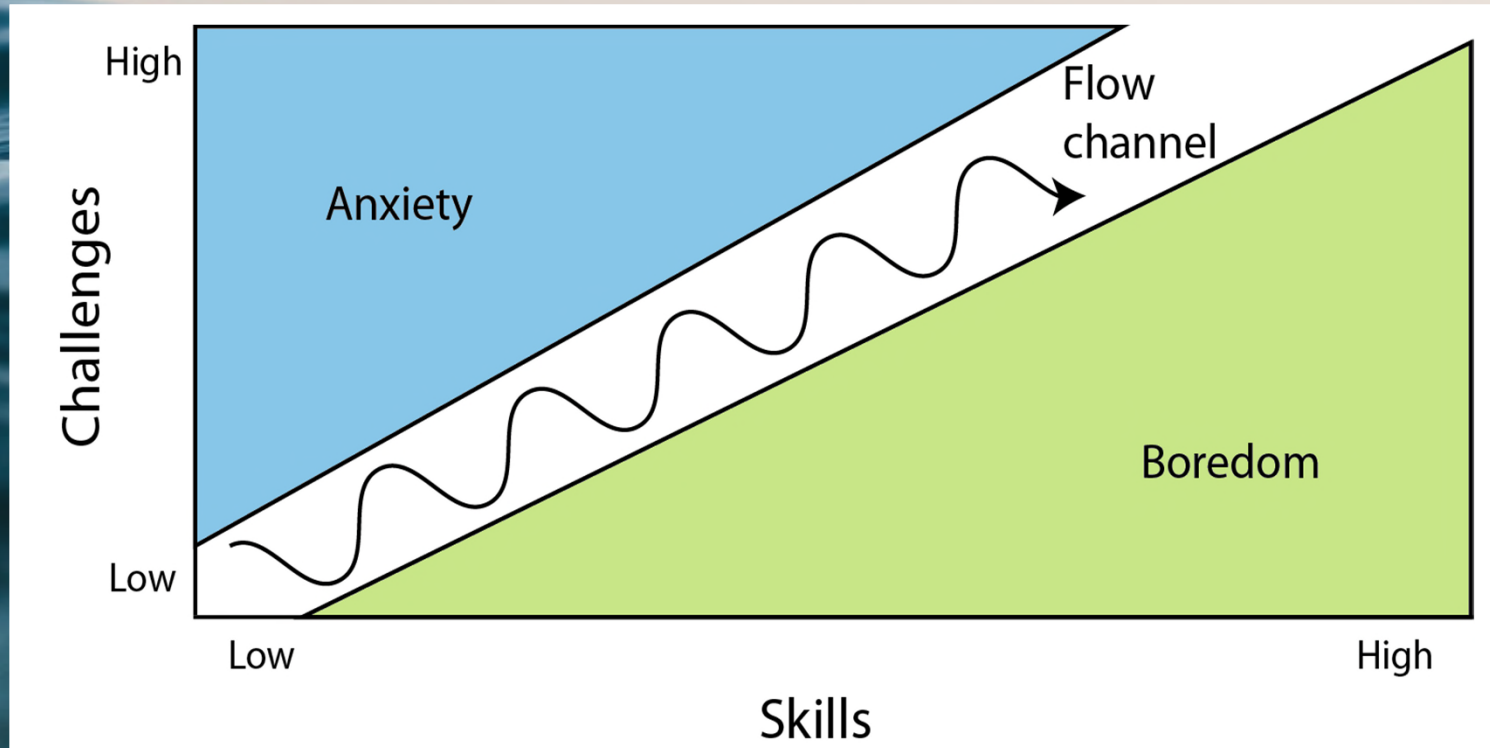
...my mum will help me to  
cope with my  
sadness.



# Distraction: flow activities



Mihaly Csikszentmihalyi





# Distraction: flow activities

- Catch your attention
- Match your interests
- Stretch your skills a bit
- Have a goal that you have chosen
- You enjoy the journey, not the end



Motivation follows action



Plan the  
well-being  
activities





# Plan everything!

- The positive thinking
- The physical exercise
- The flow activities
- The worry time
- The relaxation activity
- When you listen to/watch the news

## DAY PLANNER

\_\_\_/\_\_\_/\_\_\_

M T W Th F Sa Su

To Do List:

today I am grateful for

daily goals



appointments

breakfast

lunch

dinner

water: 

snacks

fitness

mood

Learn to embrace  
uncertainty

Fight the insecurity



This is certain:

Uncertainty is the key to  
unlocking opportunity







# AUTISM in CONTEXT

from neurodiversity to neuroharmony

[www.petervermeulen.be](http://www.petervermeulen.be)

[AUTISM IN CONTEXT](#)

[PETER IN CONTEXT](#) ▼

[YOUR CONTEXT](#)

[H.A.P.P.Y. -PROJECT](#)

[CONTACT](#)

[peter\\_autisme](#)

## THANK YOU FOR YOUR ATTENTION

