

Autism & Suicide:

My Journey from the Brink and Back

Presented by:

Laura S. Coleman

B. A. Psychology, Emory University

Marcus Autism Center, Atlanta, Georgia

What to expect

- This presentation will discuss severe depression, psychiatric hospitalization, grief, and suicide.
- Given the heavy subject matter - If at any time you feel that you need to leave, or even if you need to step out for a just moment, **please do so.**
- **I assure you there is no judgment.** Maintaining your own mental health is paramount.
- **I am not a clinician nor expert on suicide and mental health.** While I do work in autism research, this is well outside my own area of practice.
 - **I work with clinicians and psychologists who do have this type of expertise, so if you'd like me to put you in touch with them or provide information on how to seek out professional mental health care, you can ask me.**

None of what follows is a substitute for seeking help from a mental health professional.

If you or someone you love are currently experiencing a mental health crisis, I would urge you to please seek out the care of a mental health professional, and to weigh whether or not it would be in your best interest to attend this presentation.

If you are struggling and need help, PLEASE CONTACT the Crisis Help Line by calling or texting 988.

Anyone experiencing a mental health crisis who is in need of a mental health provider, please visit: <https://findahelpline.com/i/iasp>

Disclosures

- I am an autistic adult, having been first identified as autistic while an undergraduate student, where I was subsequently referred for adult autism services at the Emory Autism Center.
- I am currently employed by the Marcus Autism Center & Emory University as a Clinical Research Coordinator for the Simons Powering Autism Research Knowledge (SPARK) Study, part of the Simons Foundation Autism Research Initiative (SFARI).
- I have received advisory funding from the Patient-Centered Outcomes Research Institute (PCORI), the Institute for Exceptional Care (IEC), and the Georgia College Transition Partnership (GCTP), among others.
- I previously participated in an Autism & Suicide Workgroup Committee with the American Association of Suicidology (AAS) from which some of this information has been adapted from.
- I have also received funding as a consultant and film participant for a documentary film currently in production on the transition to adulthood for autistic young adults.

All opinions, thoughts, and experiences shared during this presentation are solely my own, and therefore should not be construed as necessarily reflecting those of my employer, academic institution, study sponsors, or any affiliated partners.

Language

- When speaking of being a person who has a diagnosis of autism spectrum disorder, I will refer to myself and other persons who are on the autism spectrum as “autistic” predominantly, and less often may say “having autism” or “with autism.”
- This is in line with most research reflecting the majority preference expressed by those who are themselves are autistic (e.g., Kenney et al. 2016; Bottema-Beutel et al., 2021; Monk et al., 2022)—however, there are some autistic people who do prefer person-first language instead.
 - I aim to be mindful to the sensitive nature of how autistic people refer to themselves, so if I inadvertently fall back to person first language, please know that no offense is intended.
- When speaking of suicide, I will speak in terms of having “attempted suicide”, “taken one’s own life”, or “died by suicide.”
- This is in line with what has been identified as the most generally accepted language for talking about this extremely sensitive subject, which was recommended by a large sample survey study by Padmanathan and colleagues (2019).

Presentation Agenda

- **Autism & Suicide**
- **My own experience as a survivor of suicide**
- **Where to find resources**
- **Q&A**

Autism & Suicide – Estimates of Risk

- Suicide risk tends to be significantly elevated for those on the autism spectrum relative to the general population (Segers & Rawana, 2014; Hirvioski et al., 2016; Cassidy et al., 2018).
- Estimates of suicidality (i.e., those who are experiencing or have experienced suicidal thoughts, ideation, and/or behaviors) range from at least 10% to 50% of the autistic population (Segers & Rawana, 2014).
 - One systematic review found the risk of suicidal ideation for autistic persons to be as high as 72% (Hedley & Uljarevic, 2018).
- Of the total population of individuals who report being suicidal at any given time, autistic individuals are estimated to comprise at least 7.3% to 15% of those who are suicidal (Segers & Rawana, 2014).
 - Thus, autistic individuals are over-represented relative to their representation in the general population (i.e., approximately 1-2%).

Autism & Suicide – Estimates of Risk

- Autistic adults, especially those who are diagnosed later in life, have been found to be at the highest risk of experiencing suicidal thoughts and behaviors (Cassidy et al., 2014).
 - In this same study, Cassidy and colleagues (2014) found that those who were most recently diagnosed in adulthood and lacked support had the highest risk of experiencing suicidal ideation, at 66%.
- As in the general population, depression is a significant risk factor for dying by suicide in autistic people as well (Hirvikoski et al., 2016; Cassidy et al., 2014).
- Co-occurring psychiatric disorders in autistic people may also impact their risk of suicidality, with at least 70% of young individuals on the autism spectrum estimated to also have at least one or more co-occurring psychiatric conditions (Leno & Simonoff, 2020).
 - Cassidy and colleagues (2020) found co-occurring psychiatric diagnoses to significantly increase the risk of suicidal ideation and behaviors.

Autism & Suicide – Risk Factors

- The most significant risk factors for death by suicide are:
 - 1. Have one or more suicide attempts**
 - 2. Have at least one or more first degree relatives who died by suicide**
 3. Currently experiencing a major depressive episode, especially one that includes suicidal ideation
 4. Experienced at least one or more painful and/or traumatic life events(See Jamison, 2000; Joiner, 2005).
- **An autism spectrum disorder diagnosis is itself a risk factor for suicide** (Chen et al., 2017).

Autism & Suicide:

Warning Signs for Suicide in
Autistic People

Morgan & Maddox (2020; see also Morgan et al., 2021) identified the following as **warning signs** for suicide in autistic people:

1. Sudden or increased withdrawal from friends, family, and society; lack of enjoyment in previously enjoyable activities/interests.
2. Has no words/unable to communicate that one's in acute distress
3. Currently experiencing a traumatic event
4. Marked increase in rate and/or severity of self-harm
5. Focused on suicidal talk, ideation or death-related topics (not related to a typical focused interest)
6. Perseverative thoughts, ruminating thoughts that cause the person distress/despair
7. Seeking means or making plans for attempting suicide or suicidal rehearsal; fantasizing about suicide
8. Increased substance use (alcohol or other drugs)
9. Expressing hopelessness, that they have no purpose in life, no reason for living.
10. Increase in anxiety or agitation; worsening levels of anxiety and/or depression
11. Either unable to sleep or sleeping excessively
12. Feeling trapped, that they have no way out
13. Exhibiting rage, uncontrolled anger, or a desire to seek revenge
14. Acting recklessly or engaging in risky activities, increased impulsivity
15. Dramatic changes in mood
16. Giving away prized possessions or seeking long-term care for pets

If you or a loved one on the autism spectrum are experiencing these warning signs, **please seek out a mental health professional as soon as possible.**

If you think that you yourself or a loved one are at immediate risk of suicide, CALL 911 or go to your nearest emergency room.

Having been on the other side of this, it is NOT an enjoyable experience to be hospitalized, but I'm grateful beyond words to be alive today.

So even when I myself did NOT want to go, I thank God that those who loved me took this action to keep me safe.

Autism & Suicide – Why?

- Reid (2022) proposes that The Interpersonal Theory of Suicide (Joiner, 2005) may provide a useful framework to better understand suicide and autism.
- The Interpersonal Theory of Suicide posits that perceived burdensomeness and thwarted belonging may lead to suicidal ideation.
 - Perceived burdensomeness – “Everyone would be better off without me.”
 - Thwarted belonging – “I don’t have anyone in my life who cares about me.”
- Conditioning oneself to overcome the natural survival instinct, i.e. “a fear of death”, can cause suicidal ideation to escalate to suicidal behaviors and actions.

Autism & Suicide – Why?

- Suicide as the endpoint of chronic “psychache” has been proposed by psychologist and pioneering suicidologist Edwin Shneidman (1998).

The suicidal act occurs when the severity of one’s psychic pain—termed “psychache”—exceeds a person’s capacity to endure it.

- Ozawa-De Silva’s (2021) proposed Relational Theory of Meaning is another framework that may help make sense of why autistic people are especially vulnerable to suicidal ideation and behaviors.

There are other theories and frameworks that are beyond the scope of this presentation that I would be happy to share with anyone who may be interested.

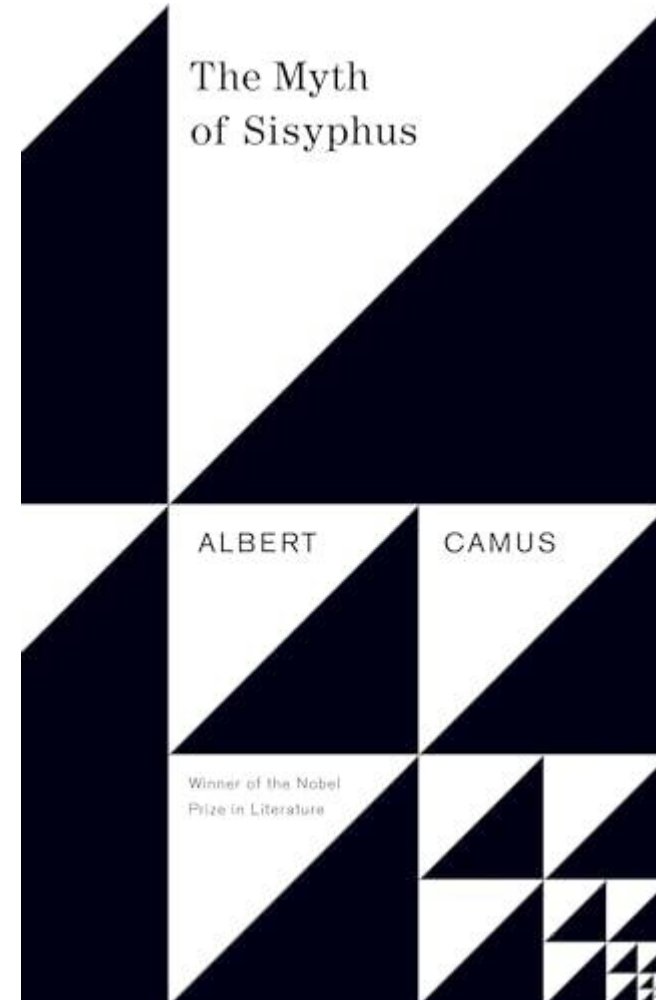
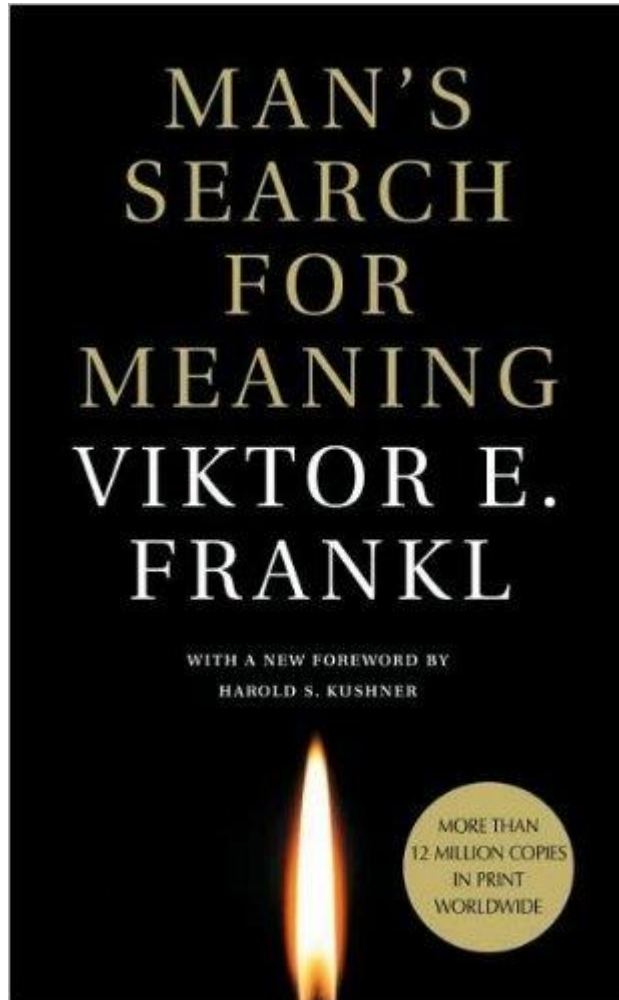
SoS – Survivors of Suicide

- “Survivor of Suicide” – One who has lived through the loss of a family member, loved one, or significant other to suicide.
- Can also indicate that one has survived their own attempt to end their life, so there are two distinct meanings to terming oneself a survivor of suicide.
- Thus, one can be a “survivor of suicide” in a doubled sense—that is, having experienced both.
- If you’re looking for support for being a fellow survivor, you can find local SoS meetings here:
<https://elunanetwork.org/resources/survivors-of-suicide-sos-group-finder>

SoS – Survivors of Suicide

- About being a Survivor of Suicide in both senses → Going back to the slide about the highest risk factors for death by suicide –
 - **Those who have survived both (i.e., their own attempt(s) and the suicide of a close family member) are at the highest risk of one day dying by suicide themselves (Jamison, 2000).**
 - ***So please remember that taking care of your mental health is absolutely vital if, like me, this describes you or a loved one.***
- If you're in the Atlanta area, you can find The Link Counseling Center's Survivors of Suicide 2024 Group Meetings Calendar here:
<https://www.thelink.org/sos-group-calendar> .
- Going to this group when I experienced my own loss was pivotal in helping me make it through, so I cannot recommend SoS highly enough for those who have experienced this type of loss.

Autism & Suicide – My Story



Viktor Frankl's Search for Meaning

- His story offers a lifelong case study of Nietzsche's oft-quoted saying, "***He who has a Why to live for can bear almost any How.***"
- Reiterates that the absolute worst case scenario can happen to you, and yet, ***you can still survive this***—and with enough patience, perseverance, and luck, you may find a life well worth living at the end of it.

Camus – Why should one live, when the human condition is inherently absurd?

“There is but one truly serious philosophical problem, and that is suicide. Judging whether or not life is worth living amounts to answering the fundamental question of philosophy. All the rest...comes afterwards.”

“...people...[pretend] to believe that refusing to grant a meaning to life necessarily leads to declaring that it is not worth living.”

Camus insists, however, that even if one’s life appears to be devoid of meaning, this does NOT mean it is not worth living.

Camus – Why should one live, when the human condition is inherently absurd?

*“Thus I draw from the absurd three consequences, which are my revolt, my freedom, and my passion. By the mere activity of consciousness I transform into a rule of life what was an invitation to death—**and I refuse suicide.** I know, to be sure, the dull resonance that vibrates throughout these days. Yet I have but a word to say: **that it is necessary.**”*

The Ultimate Conclusion of *The Myth of Sisyphus* – To Embrace the Absurd by Choosing to Live

To Camus, despite the absurdity that is inextricable from being human, *we must embrace the absurd by choosing to live.*

He proposes we do this by revolting against the proposition of living a life of meaningless repetition, embracing the freedom to live our lives according to our own values and beliefs, and drawing from what gives us passion to propel us forward as we live out each day.

This is what it means to embrace the absurdity of life—by ultimately rejecting suicide, choosing instead to live.

Questions & Discussion

Resources

- Warning Signs of Suicide for Autistic People: An autism-specific resource based on research findings and expert consensus. (2021). PDF available here: <https://988lifeline.org/wp-content/uploads/2023/01/Warning-Signs-Resource-Sept-2021-2.pdf>
- Crisis Supports for the Autism Community. (2018). PDF available here: <https://apd.myflorida.com/mentalhealth/docs/Autism-Crisis-Supports.pdf>
- Autism Resource for Warning Signs of Suicide: Considerations for the Autism Community. (2020). PDF available here: <https://apd.myflorida.com/mentalhealth/docs/Autism-Warning-Signs-3.pdf>
- Autistica Autism Resource on Suicide for Crisis Workers (2020). PDF available here: <https://www.autistica.org.uk/downloads/files/Crisis-resource-2020.pdf>

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Recommended Reading

- **Susan Rose Blauer, *How I Stayed Alive When My Brain Was Trying to Kill Me: One Person's Guide to Suicide Prevention*. First published 2003, Quill Publishing.**
- Iris Bolton (with Curtis Mitchell), *My Son, My Son: A Guide to Healing After Death, Loss, or Suicide*. First published 1983, Bolton Press Atlanta.
- **Albert Camus, *The Myth of Sisyphus and Other Essays*. First published 1955, Alfred A. Knopf.**
- Nick Durbin, *The Autism Spectrum and Depression*. First published 2014, Jessica Kingsley Publishing.
- Emile Durkheim, *Suicide: A Study in Sociology*. Translation by John A. Spaulding & George Simpson. First published 1951, The Free Press.
- **Viktor E. Frankl, *Man's Search for Meaning*. First published 1959, Beacon Press.**
- Kay Redfield Jamison, *Night Falls Fast: Understanding Suicide*. Published 2000, Vintage International.
- Eric Marcus, *Why Suicide: Questions & Answers About Suicide, Suicide Prevention, and Coping with the Suicide of Someone You Know*. Revised, published 2010, HarperOne.
- Edwin S. Shneidman, *The Suicidal Mind*. First published 1998, Oxford University Press.

*I **most highly recommend** the **bolded books in blue** for those who are currently struggling or know someone struggling with suicide. These three books specifically helped me make it through.

Interested in my work? Find more info below.

- For those who are interested in learning more about the work I do in autism research with **SPARK**, please visit our study's website: sparkforautism.org
- To connect with our Atlanta SPARK Clinical Site's team, our site's URL is https://sparkforautism.org/?code=atlanta&on_site=true
- More information about autism research and how SPARK contributes to advancing autism research forward can be found here: <https://sparkforautism.org/portal/page/autism-research/>
- All of SPARK's research publications to date can be found here: <https://sparkforautism.org/portal/page/research-publications/>
- For more information about the documentary film that I recorded myself giving this talk for:
 - The name of the film project is ***Beyond the Cliff: Navigating Autistic Adulthood***. The film's home page can be found here: <https://bdkproductions.com/beyond-the-cliff/>
 - A teaser of the film is linked here: <https://vimeo.com/852498436/f8c220f09a?share=copy>

Thank you for attending!

Laura can be reached at:

Email: laura.suzanna.coleman@emory.edu

Phone: 404-785-9467

Slides will be disseminated after the conference that will include references and resources referred to during the talk.