



OCD, Disability, & Me:
Exploring the Intersections
between Chronic Illness,
Research Gaps, & Help-
Seeking Behavior

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Meet Our Team.



Jessie Birnbaum



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Objectives

- Learn how to explain the overlap of OCD & co-morbid chronic illness/disability
- Learn how OCD & chronic illness/disability influence one another
- Learn how to help clients with health anxiety & chronic illness/disability
- Hear personal testimonials
- Learn how clinicians can better support their clients with OCD & chronic illness/disabilities

OCD
Symptoms
Begin

2002

Diagnosed
with
OCD

2014

Severe
Headaches
Started

2020

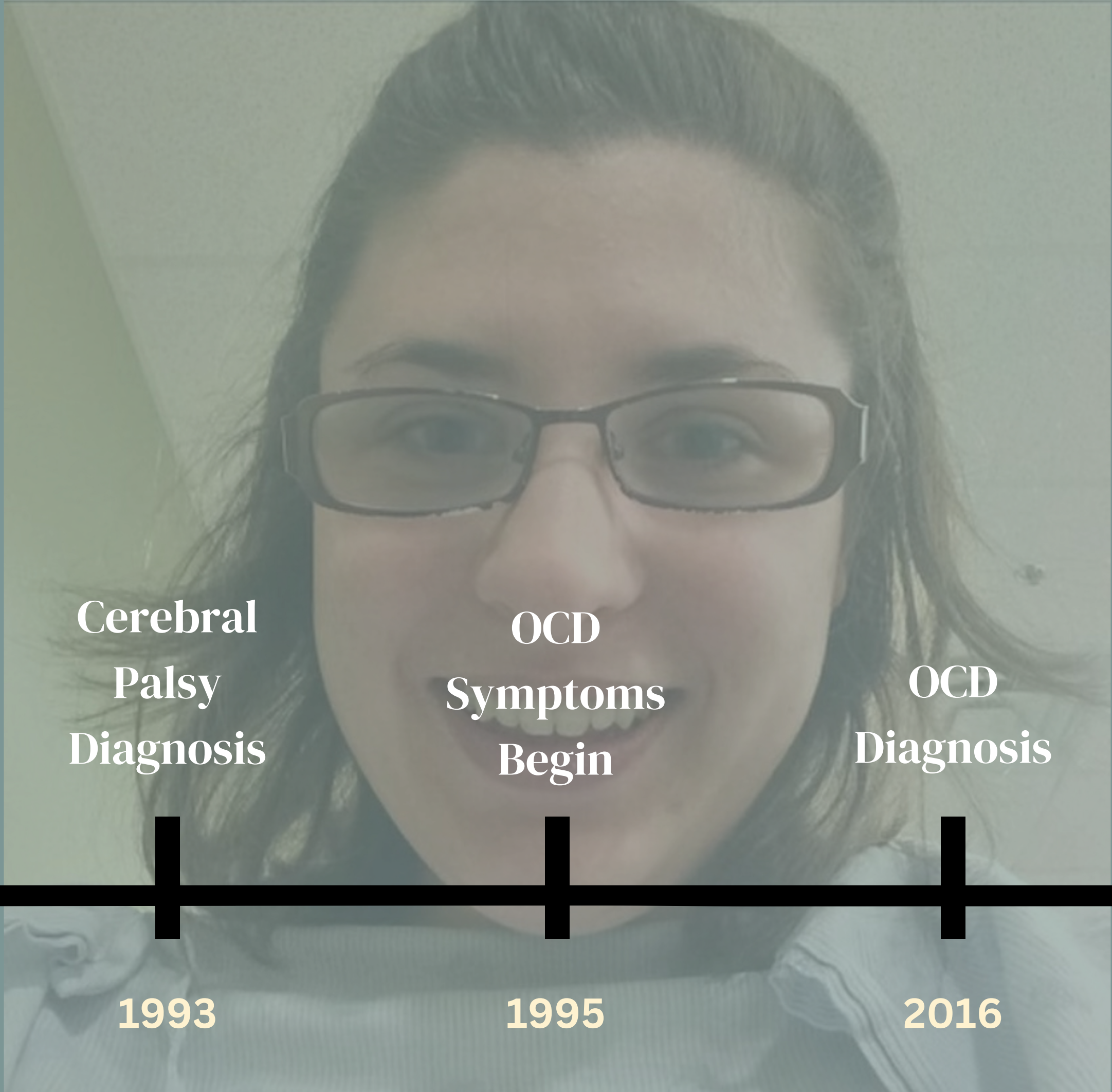
Diagnosed
with Crohn's
Disease

2021

Traveled to
the Mayo
Clinic

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Premature
Birth

1992

Cerebral
Palsy
Diagnosis

1993

OCD
Symptoms
Begin

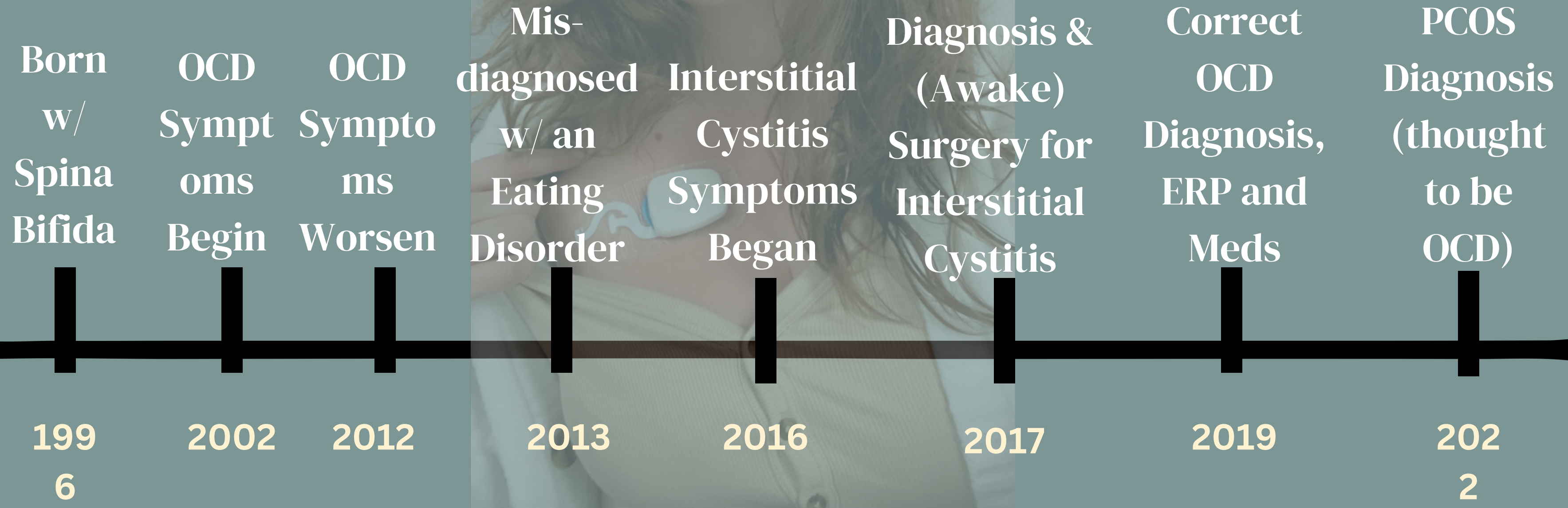
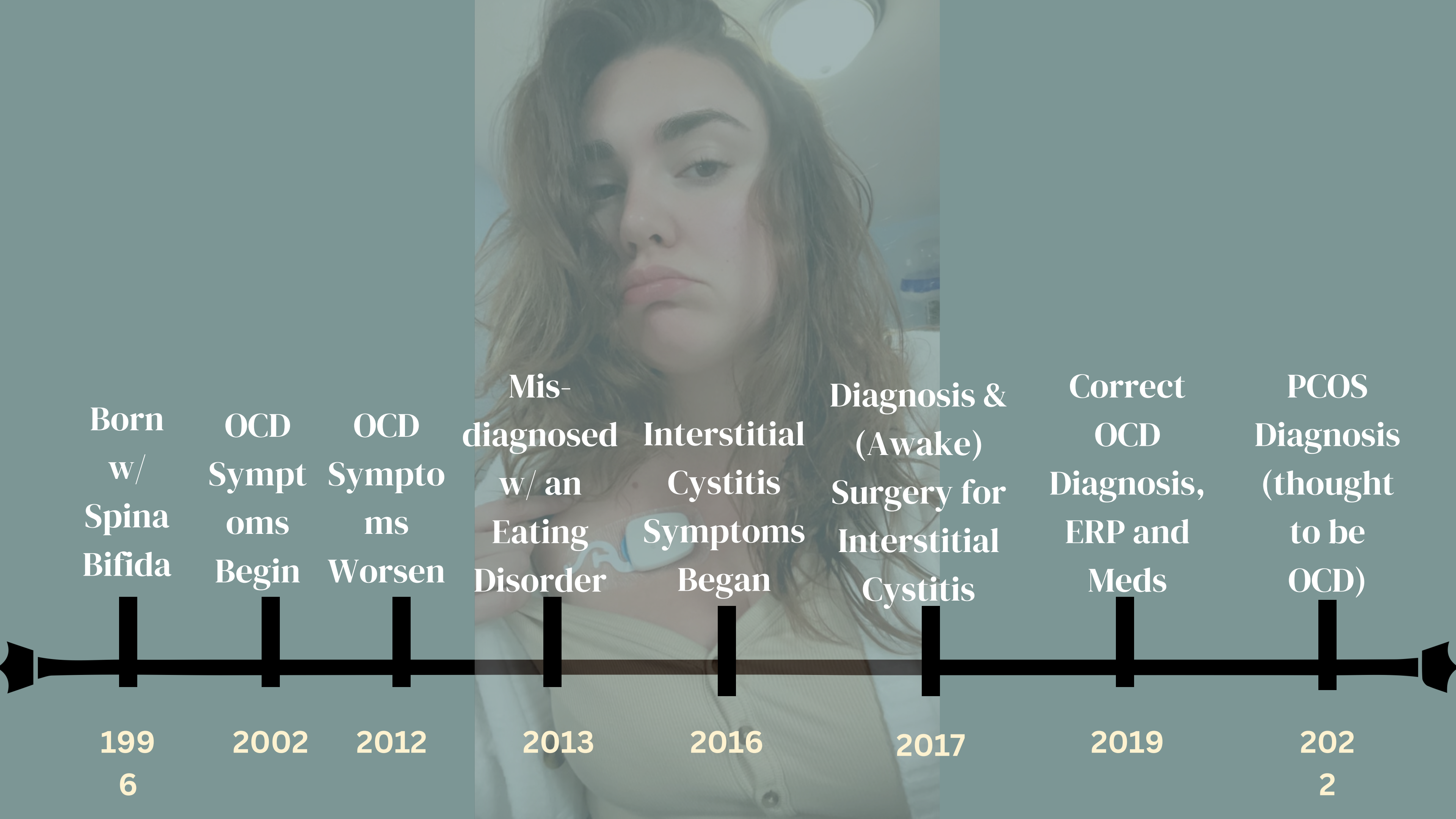
1995

OCD
Diagnosis

2016

Begins ERP
Treatment for
the First Time

2017



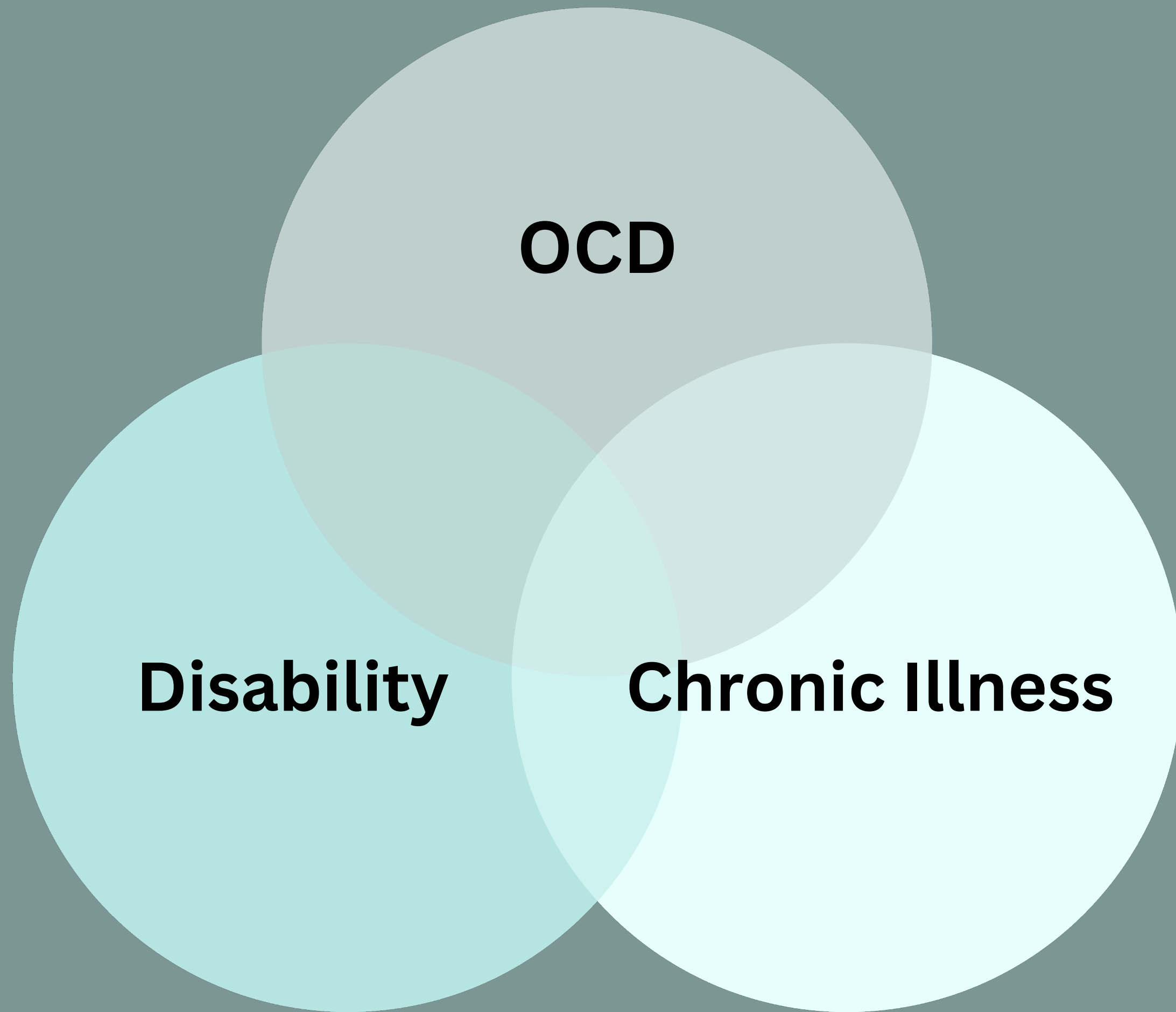
Definitions

Chronic Illness

Conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both.

Disability

Any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities and interact with the world around them.



OCD

Disability

Chronic Illness

Stigma





Research Gaps



AGE DIFFERENCES



GENDER DIFFERENCES



LGBTQIA+ DISPARITIES

Research Gaps



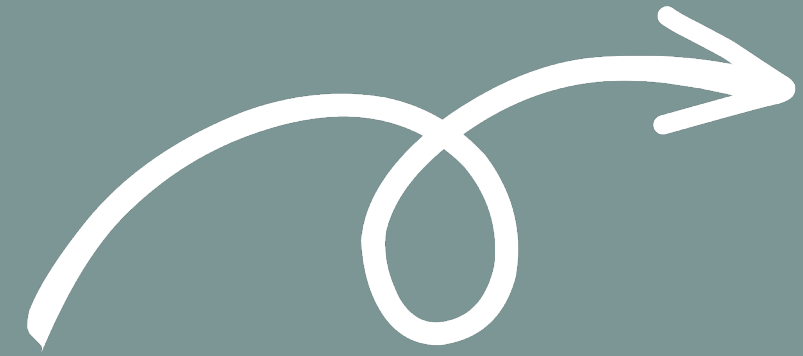
RACE & ETHNICITY DIFFERENCES



(UNDER)FUNDING



HELP SEEKING BEHAVIORS



Chronic Illness x OCD



**"This journey was long
and difficult
where it shouldn't
have been"**

**"It can be hard to
know when
something is a
serious problem"**

**"My chronic illness and the
traumatic medical
experiences I've had really
fueled and worsened my
OCD"**

**"It makes
everything
more complex"**

**"My chronic illnesses
have made some of
my worst fears come
true, and that has
fueled my OCD".**

Complications to ERP

- ROCD with Doctors
- Health Anxiety
- Medication
- Second Opinions
- Google/Research
- Flares/Exhaustion



Higher Levels of Care

"Sadly I was discriminated against for having a disability when I was seeking OCD treatment. I was at a point in my life where it was 'do or die' and I was ready to get help, although no-one was willing to help me"

Distinguishing Health Anxiety from Chronic Illness



**Getting diagnosed with OCD
"was actually an easier
experience because I was
validated from the start and not
dismissed"**

**"I find that having a diagnosis of
Crohn's disease makes medical
professionals believe me more now;
it is seen as a serious and 'legitimate'
physical illness so doctors are more
willing to run tests and not dismiss
things, at least not as much as they
used to"**

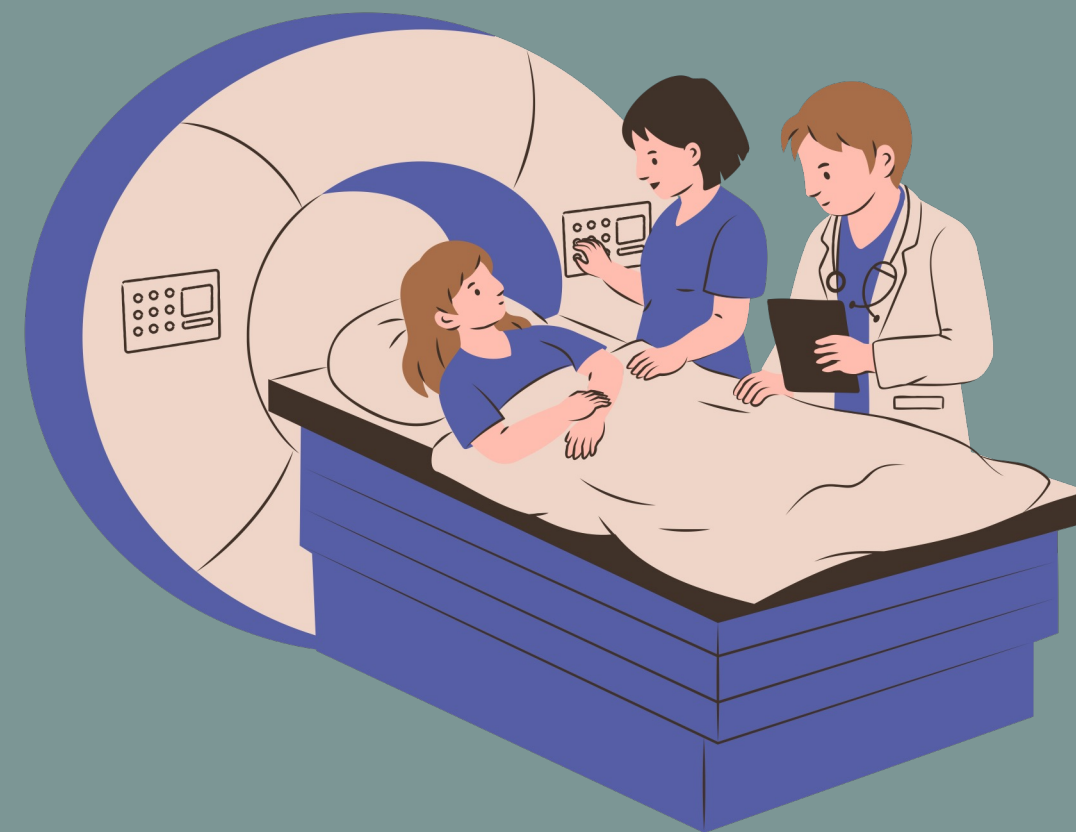
**"A lot of my chronic illness
physical disability includes
things that are not testable so in
lieu of an actual diagnosis they
just say it's OCD"**

**Doctors "often assume it's 1) my
health anxiety acting up 2) side
effects from psych meds. Both
of these are unhelpful at best
and traumatic at worst"**

Rule Out the Medical and Communicate with Other Doctors



ERP helping with chronic illness



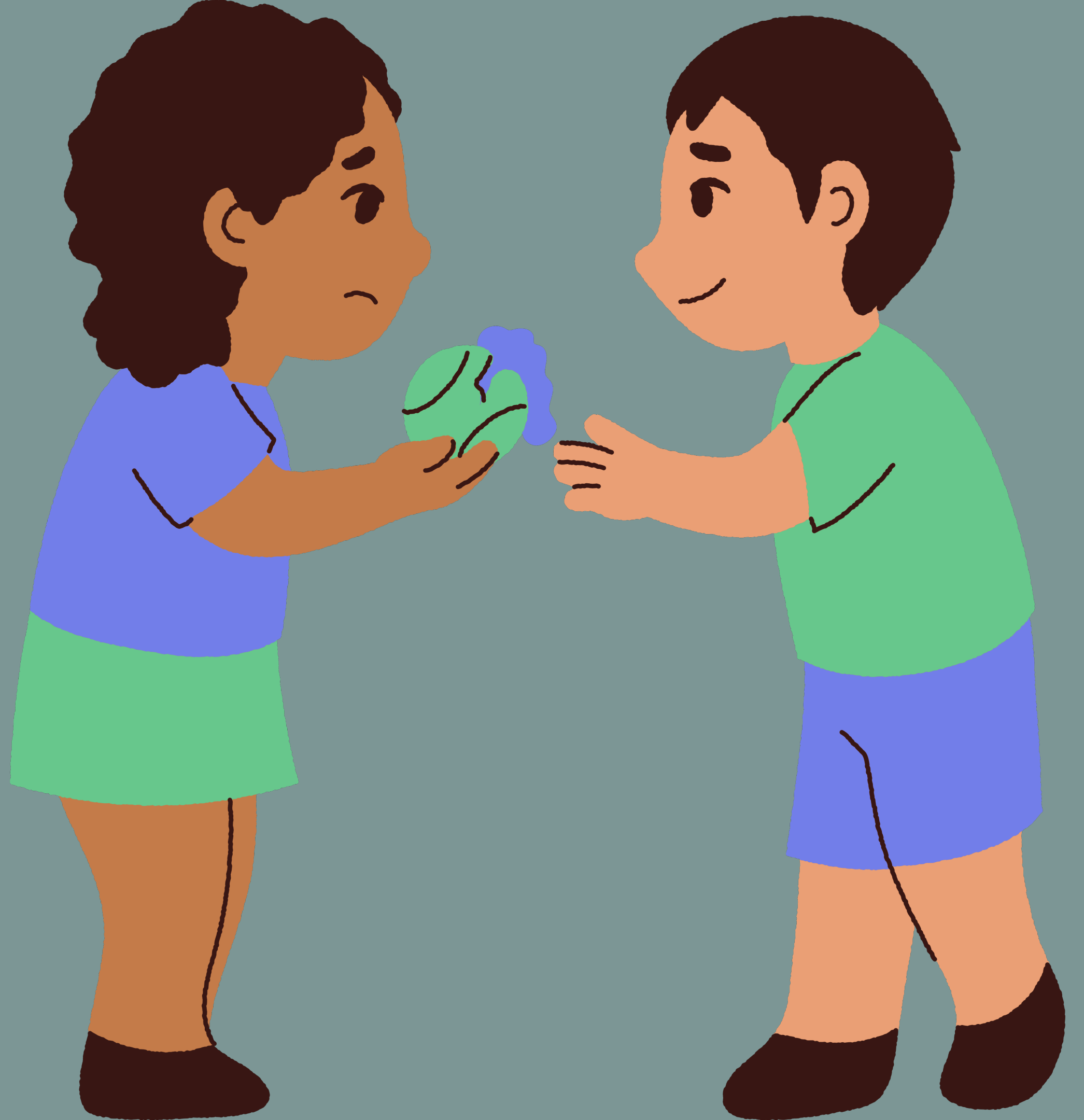


Clearly
Define
Your Role
in Their
Care

"I've gone months with treatable painful conditions bc I was so determined to "not give in to a compulsion" by seeking medical care. I view this as being a result of mental health specialists insisting and reinforcing that everything was OCD when I actually had separate medical issues"

"I feel that most therapists are really compassionate about chronic illness, though I do feel I have to teach them a lot about it"

Using Self as Instrument





How do we
make ERP
more
accessible?

(From a client
perspective)

Our Recommendations

- Make ERP Accessible
- Avoid Timelines
- Other Modalities (ACT)
- Grey Space - practice what you preach!

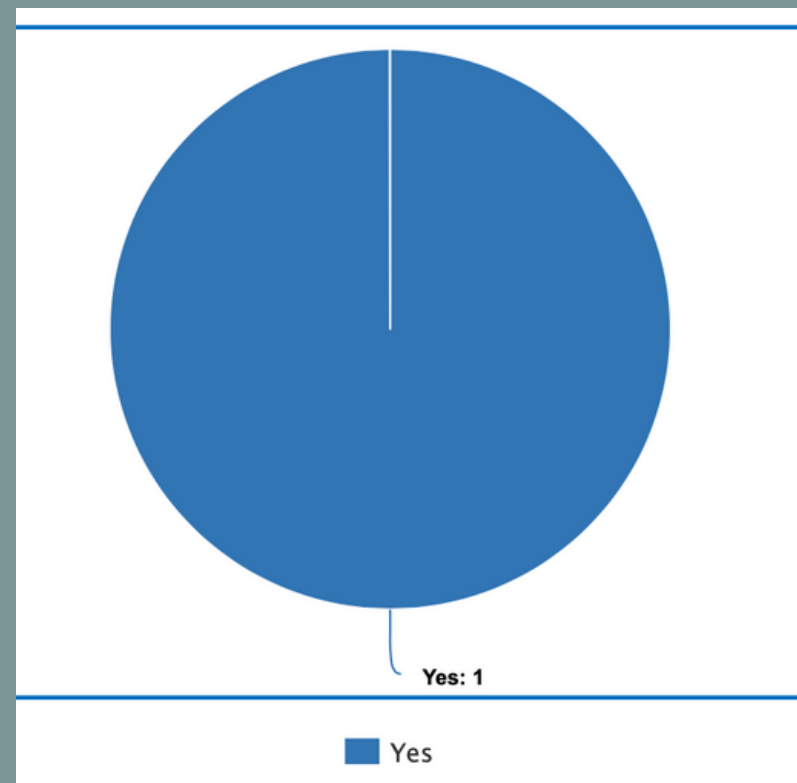


Advice from SIG Members

- Validate
- Use Dialectics
- Stay Open Minded
- Treat Fairly
- Acknowledge the Unknown
- Be Willing to Learn



"Have you ever felt invalidated by a medical professional when seeking treatment for either your disability/chronic illness or your OCD?"



Validation

"In my case, knowing that my doctors will believe me and run the tests when I tell them that something feels off has reduced my OCD health anxiety symptoms"

"Don't invalidate medical conditions by attributing everything to anxiety!"

"Don't invalidate the patient"

"Believe patients and please run all necessary tests before you say it's anxiety"

Dialectics

**"Know it can be
both
mental and
physical"**

**"Make sure your patients know
that you can hold these two truths
at the same time: My patient has
OCD that causes distressing and
excessive health anxiety AND my
patient has a chronic physical
illness that needs to be monitored
and treated"**



Open- Mindedness

"Learn what it is and unlearn stereotypes"

"It's okay not to know if your patient's symptoms are due to chronic illness, or due to their OCD, or some combination of them both"

"Admit what you don't know, run the tests, and build trust/rapport with your patients"

"Each case is individual, complex, and should be treated without using black-and-white thinking"

"Be open minded and willing to learn"

Fairness

"Give all equal opportunity to take life back from OCD - we are all deserving no matter our differences or how challenging our case may be"

"You and your patient are not failing if you cannot distinguish OCD from physical chronic illness flares without testing"

"Listen to us and don't look down on us"

"Don't judge or base a decision to accept someone to treatment based on them being different"

Closing Thoughts



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References

- Pinciotti, C. M., Smith, Z., Singh, S., Wetterneck, C. T., & Williams, M. T. (2022). Call to action: Recommendations for justice-based treatment of obsessive-compulsive disorder with sexual orientation and gender themes. *Behavior Therapy*, 53(2), 153–169. <https://doi.org/10.1016/j.beth.2021.11.001>
- Siantz, E., & Aranda, M. P. (2014). Chronic disease self-management interventions for adults with serious mental illness: A systematic review of the literature. *General Hospital Psychiatry*, 36(3), 233–244. <https://doi.org/10.1016/j.genhosppsych.2014.01.014>
- Hooten, W. M. (2016). Chronic pain and mental health disorders. *Mayo Clinic Proceedings*, 91(7), 955–970. <https://doi.org/10.1016/j.mayocp.2016.04.029>
- Mestre-Bach, G., & Potenza, M. N. (2023). Cyberchondria: A growing concern during the COVID-19 pandemic and a possible addictive disorder? *Current Addiction Reports*, 10(1), 77–96. <https://doi.org/10.1007/s40429-022-00462-3>
- Hedman, E., Ljótsson, B., Axelsson, E., Andersson, G., Rück, C., & Andersson, E. (2017). Health anxiety in obsessive compulsive disorder and obsessive compulsive symptoms in severe health anxiety: An investigation of symptom profiles. *Journal of Anxiety Disorders*, 45, 80–86. <https://doi.org/10.1016/j.janxdis.2016.11.007>
- Fernández de la Cruz, L., Kolvenbach, S., Vidal-Ribas, P., Jassi, A., Llorens, M., Patel, N., Weinman, J., Hatch, S. L., Bhugra, D., & Mataix-Cols, D. (2015). Illness perception, help-seeking attitudes, and knowledge related to obsessive-compulsive disorder across different ethnic groups: A community survey. *Social Psychiatry and Psychiatric Epidemiology*, 51(3), 455–464. <https://doi.org/10.1007/s00127-015-1144-9>
- Verhaak, P. F. M., Heijmans, M. J. W. M., Peters, L., & Rijken, M. (2005). Chronic disease and mental disorder. *Social Science & Medicine*, 60(4), 789–797. <https://doi.org/10.1016/j.socscimed.2004.06.012>
- Hansen, M. S., Fink, P., Frydenberg, M., Oxhøj, M.-L., Søndergaard, L., & Eriksen, M. (2001). Mental disorders in medical inpatients and the association to severity of illness, self-rated physical disability, and Health Perception. *Psychosomatics*, 42(1), 41–47. <https://doi.org/10.1176/appi.psy.42.1.41>
- Pinciotti, C. M., & Orcutt, H. K. (2021). Obsessive-compulsive symptoms in sexual minorities. *Psychology of Sexual Orientation and Gender Diversity*, 8(4), 487–495. <https://doi.org/10.1037/sgd0000437>
- Robinson, K. J., Rose, D., & Salkovskis, P. M. (2017). Seeking help for obsessive compulsive disorder (OCD): A qualitative study of the enablers and barriers conducted by a researcher with personal experience of OCD. *Psychology and Psychotherapy: Theory, Research and Practice*, 90(2), 193–211. <https://doi.org/10.1111/papt.12090>
- Vuong, T. M., Gellatly, J., Lovell, K., & Bee, P. (2016). The experiences of help-seeking in people with obsessive compulsive disorder: An internet survey. *The Cognitive Behaviour Therapist*, 9. <https://doi.org/10.1017/s1754470x1600009x>
- Tausig, M. (2013). The sociology of chronic illness and self-care management. *Research in the Sociology of Health Care*, 247–272. [https://doi.org/10.1108/s0275-4959\(2013\)0000031013](https://doi.org/10.1108/s0275-4959(2013)0000031013)
- Pinciotti, C. M., Wadsworth, L. P., Miron, L. R., Riemann, B. C., & Leonard, R. C. (2022). Transgender and gender diverse patients in intensive mood disorder treatment: A comparative examination of clinical presentation and treatment outcomes. *Behavior Therapy*, 53(5), 1062–1076. <https://doi.org/10.1016/j.beth.2022.05.004>
- Hathorn, S. K., Lochner, C., Stein, D. J., & Bantjes, J. (2021). Help-seeking intention in obsessive-compulsive disorder: Predictors and barriers in South Africa. *Frontiers in Psychiatry*, 12. <https://doi.org/10.3389/fpsy.2021.733773>
- Mahintorabi, S., Jones, M., & Harris, L. (2017). Exploring professional help seeking in practicing Muslim women with obsessive compulsive disorder washing subtype in Australia. *Religions*, 8(8), 137. <https://doi.org/10.3390/rel8080137>

References continued

- Fernández de la Cruz, L., Kolvenbach, S., Vidal-Ribas, P., Jassi, A., Llorens, M., Patel, N., Weinman, J., Hatch, S. L., Bhugra, D., & Mataix-Cols, D. (2015). Illness perception, help-seeking attitudes, and knowledge related to obsessive-compulsive disorder across different ethnic groups: A community survey. *Social Psychiatry and Psychiatric Epidemiology*, 51(3), 455–464. <https://doi.org/10.1007/s00127-015-1144-9>
- Picco, L., Abdin, E., Chong, S. A., Pang, S., Vaingankar, J. A., Sagayadevan, V., Kwok, K. W., & Subramaniam, M. (2016). Beliefs about help seeking for mental disorders: Findings from a Mental Health Literacy Study in Singapore. *Psychiatric Services*, 67(11), 1246–1253. <https://doi.org/10.1176/appi.ps.201500442>
- Ayers, S. L., & Kronenfeld, J. J. (2007). Chronic illness and health-seeking information on the internet. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 11(3), 327–347. <https://doi.org/10.1177/1363459307077547>
- García-Soriano, G., Rufer, M., Delsignore, A., & Weidt, S. (2014). Factors associated with non-treatment or delayed treatment seeking in OCD sufferers: A review of the literature. *Psychiatry Research*, 220(1–2), 1–10. <https://doi.org/10.1016/j.psychres.2014.07.009>
- Belloch, A., del Valle, G., Morillo, C., Carrió, C., & Cabedo, E. (2008). To seek advice or not to seek advice about the problem: The help-seeking dilemma for obsessive-compulsive disorder. *Social Psychiatry and Psychiatric Epidemiology*, 44(4), 257–264. <https://doi.org/10.1007/s00127-008-0423-0>
- Goodwin, R., Koenen, K. C., Hellman, F., Guardino, M., & Struening, E. (2002). Helpseeking and access to mental health treatment for obsessive-compulsive disorder. *Acta Psychiatrica Scandinavica*, 106(2), 143–149. <https://doi.org/10.1034/j.1600-0447.2002.01221.x>
- Felton, B. J., & Revenson, T. A. (1987). Age differences in coping with chronic illness. *Psychology and Aging*, 2(2), 164–170. <https://doi.org/10.1037/0882-7974.2.2.164>
- Sodi, T., & Phethi, T. (2017). Influences on help-seeking pathways among people with chronic illness and disease in a rural South African community. *Journal of Psychology in Africa*, 27(3), 286–289. <https://doi.org/10.1080/14330237.2017.1321863>
- Fullana, M. A., Mataix-Cols, D., Caspi, A., Harrington, H., Grisham, J. R., Moffitt, T. E., & Poulton, R. (2009). Obsessions and compulsions in the community: Prevalence, interference, help-seeking, developmental stability, and co-occurring psychiatric conditions. *American Journal of Psychiatry*, 166(3), 329–336. <https://doi.org/10.1176/appi.ajp.2008.08071006>
- Subramaniam, M., Abdin, E., Vaingankar, J. A., & Chong, S. A. (2012). Obsessive-compulsive disorder: Prevalence, correlates, help-seeking and quality of life in a multiracial Asian population. *Social Psychiatry and Psychiatric Epidemiology*, 47(12), 2035–2043. <https://doi.org/10.1007/s00127-012-0507-8>
- Simonds, L. M., & Elliott, S. A. (2001). OCD patients and non-patient groups reporting obsessions and compulsions: Phenomenology, help-seeking, and access to treatment. *British Journal of Medical Psychology*, 74(4), 431–449. <https://doi.org/10.1348/000711201161091>
- Wheaton, M. G., Sternberg, L., McFarlane, K., & Sarda, A. (2016). Self-concealment in obsessive-compulsive disorder: Associations with symptom dimensions, help seeking attitudes, and treatment expectancy. *Journal of Obsessive-Compulsive and Related Disorders*, 11, 43–48. <https://doi.org/10.1016/j.jocrd.2016.08.002>