chronic *and* disordered

EXPLORING THE INTERSECTION OF CHRONIC ILLNESS AND EATING DISORDERS

April 4, 2025

Anita Dharwadkar RD, LDN

Anna Sweeney, MS, RD, LDN

INTRODUCTIONS

ANITA DHARWADKAR, RDN, LDN

(SHE/HER)

ANNA SWEENEY, MS, RD, LDN, CEDS-C

(SHE/HER)

PRESENTATION OVERVIEW

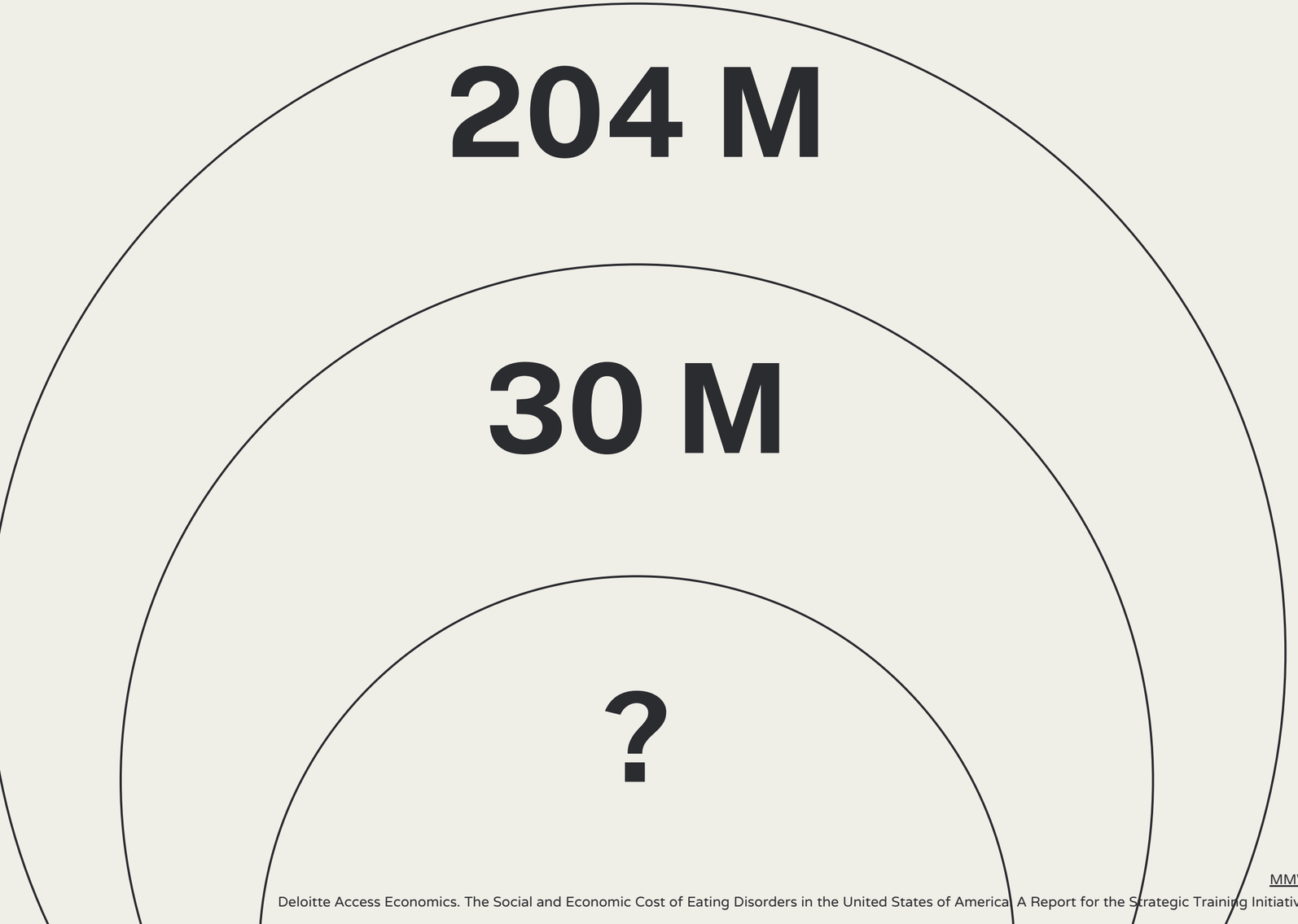
- Establishing a starting place
- The research: chronic illness and eating disorders
- Wellness & diet culture X chronic things
- Chronic illness realities
- Navigating intersectionality and intersectional loss
- The realities, possibilities, and potential pitfalls of relational care
- Case Studies, throughout
- An informal survey

chronic illness + eating disorders

*correlation? causation?

does it matter?

A STARTING PLACE



BRFSS 2019

58% of adults aged 18 to 35 reported living with one chronic illness according to the BRFSS. 22.3% reported 2+ chronic illnesses.

Phone survey adults over 18; n=67,104

CDC 2023

Six in 10 adults in the United States currently live with a chronic illness.

n = 204, 805, 604

AED 2020

28.8 million Americans will experience an eating disorder in their lives*

MMWR Morb Mortal Wkly Rep. 2022 Jul 29; 71(30): 964–970. Published online 2022 Jul 29.

Deloitte Access Economics. The Social and Economic Cost of Eating Disorders in the United States of America: A Report for the Strategic Training Initiative for the Prevention of Eating Disorders and the Academy for Eating Disorders. June 2020.

we practice weight neutral nutrition therapy

"the willingness to consider possibility requires a tolerance of uncertainty."

rachel naomi remen

CHRONIC ILLNESS, DEFINED

Chronic diseases are defined broadly as conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both.

CHRONIC ILLNESS AND EATING DISORDERS

- limited research about the *connection* between eating disorders and chronic illness
  - largely relying on research examining the experiences of children and adolescents
- endless “solutions,” for the hacking of chronic illness
  - largely relying on *not* science, vulnerable consumers, excellent marketing and healthism

Pediatric *onset* chronic illness + eating disorders

CHRONIC ILLNESS AND EATING DISORDERS

- A 2018 systemic review asking the question *"Are children with chronic illness requiring dietary therapy at risk for disordered eating or eating disorders?"*

- 86 studies about *diet-treated* chronic illness
  - diabetes, cystic fibrosis, celiac disease, gastrointestinal disorders, and inflammatory bowel diseases and disordered eating using Medline and PsychINFO
  - "children" are defined as ages 0 to 21

Conviser, J. H., Fisher, S. D., & McColley, S. A. (2018). Are children with chronic illnesses requiring dietary therapy at risk for disordered eating or eating disorders? A systematic review. International Journal of Eating Disorders, 51(3), 187—213

DIABETES

- 69 pieces of research examined the correlation between diabetes and eating disorders
- 57 of the 69 studies examined type one diabetes
  - children with diabetes are at an increased risk for disordered eating attitudes and behaviors than the general population, including drive for thinness, body dissatisfaction, dieting, and excessive exercise and diet pill usage for weight control.
  - insulin restriction, manipulation, or omission are used to control weight and are associated with the severity of disordered eating
    - *family conflict* about a child's diabetes was associated with increased disordered eating

Conviser, J. H., Fisher, S. D., & McColley, S. A. (2018). Are children with chronic illnesses requiring dietary therapy at risk for disordered eating or eating disorders? A systematic review. International Journal of Eating Disorders, 51(3), 187—213

CYSTIC FIBROSIS (CF)

- 9 pieces of research examined the correlation between CF and eating disorders
- children with CF are at risk for failure to thrive and malnutrition. Sufficient nutritional intake and healthy body weight is crucial for children with CF.
- children with CF are more likely to develop symptoms of AN than BD or BN symptoms
    - disordered eating prevalence, even if no official diagnosis is made, was elevated in children with cystic fibrosis than controls

Conviser, J. H., Fisher, S. D., & McColley, S. A. (2018). Are children with chronic illnesses requiring dietary therapy at risk for disordered eating or eating disorders? A systematic review. International Journal of Eating Disorders, 51(3), 187—213

CELIAC DISEASE

- 5 pieces of research examined the correlation between celiac disease and eating disorders
  - the majority of the studies found that with females, the rate of eating disorders was higher in those with celiac disease than in the general population. *(up to 4x as prevalent)*
  - studies did not demonstrate increased eating disorder prevalence in males with celiac disease than the general population.
    - an average of 9.87 years between onset of celiac disease and the onset of eating pathology

Conviser, J. H., Fisher, S. D., & McColley, S. A. (2018). Are children with chronic illnesses requiring dietary therapy at risk for disordered eating or eating disorders? A systematic review. International Journal of Eating Disorders, 51(3), 187—213

GI CONDITIONS

- 7 Studies examined the correlation between gastrointestinal disorders, IBD and eating disorders
- 97-98% of those with eating disorders had a gastrointestinal disorder. *IBS is the most common G.I. disorder in children with anorexia.*
  - females with BN who experienced G.I. issues as children, were younger when they started binge eating and had more severe binge eating behavior as compared to controls
  - children with IBS had more disordered eating attitudes than children with IBD and controls

Conviser, J. H., Fisher, S. D., & McColley, S. A. (2018). Are children with chronic illnesses requiring dietary therapy at risk for disordered eating or eating disorders? A systematic review. International Journal of Eating Disorders, 51(3), 187—213

CHILDHOOD CHRONIC ILLNESS AND EATING DISORDERS SUMMARY

- Diet-treated chronic illnesses are associated with disordered eating habits and eating disorders during childhood
  - Diet treated chronic illnesses require children to focus on their intake and nutrition to optimize health outcomes, but are also associated with disordered eating and eating disorders
    - The onset of type one diabetes, cystic fibrosis and celiac disease is more likely to occur before the development of disordered eating behaviors.
    - IBS is likely to occur before the onset of disordered eating
    - Disordered eating is more likely to occur before the onset of IBD

GENES & CELIAC DISEASE

- Genome wide association studies (GWAS) have identified genetic regions involved in immune regulatory mechanisms associated with celiac disease
  - Overrepresentation of genes involved with type two diabetes and anorexia are associated with celiac disease
    - Small intestinal biopsies of 144 children with celiac disease and 154 controls examining 36 genes involved with type two diabetes and four genes associated with anorexia nervosa
    - 11 genes were expressed differently in patients with celiac disease as compared to controls were *associated with diabetes*
    - *2 genes* were found to be associated with anorexia nervosa and celiac disease
- Share genetic factors involved in CD, DM type 2, and anorexia suggest a common underlying molecular pathway for these conditions

Mostowy J, Montén C, Gudjonsdottir AH, Arnell H, Browaldh L, Nilsson S, et al. (2016) Shared Genetic Factors Involved in Celiac Disease, Type 2 Diabetes and Anorexia Nervosa Suggest Common Molecular Pathways for Chronic Diseases. PLoS ONE 11(8): e0159593.

POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME

POTS is one of a group of disorders that have *orthostatic intolerance* as their primary symptom. POTS is a condition in which reduced volume of blood returns to the heart after an individual stands up from a lying down position.

- Symptoms include lightheadedness, fainting, and rapid heartbeat
- These are symptoms what are *often associated* with eating disorder experiences
- Diagnosis typically occurs between age 15 and 55, mostly affecting biological females

Benjamin, J., Sim, L., Owens, M. T., Schwichtenberg, A.,Harrison, T., & Harbeck-Weber, C. (2020). Postural orthostatic tachycardia syndrome and disordered eating: Clarifying the overlap.Journal of Developmental & Behavioral Pediatrics, 42(4), 291–298.

POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME

Postural Orthostatic Tachycardia Syndrome and Disordered Eating

- Retrospective chart review of 96 adolescents and young adults with POTS (ages 12-22)
  - The demographic qualities that increase risk of POTS are the same qualities that increase the risk of an eating disorder: being an adolescent, bio female, white, and having perfectionist tendencies.
    - eating disorder diagnosis is more delayed among youth with chronic pain, and often therefore those with POTS, leading to a poorer treatment quality.
    - 1% of adolescents experience POTS

POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME

- Adolescents with POTS have an increased risk for developing an eating disorder
  - Disruption in eating patterns
  - Delayed gastric emptying
  - Avoidance of specific foods as treatment can lead to under eating
- Orthostatic intolerance leads to a *heightened level of nervous system arousal* and central sensitization which can result in an increased risk for development of disordered eating.

POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME

- 75% of the youth in the study with POTS reported engaging in *restrictive eating* while more than 50% of them experienced *weight loss* since diagnosis
  - 4 times more likely to endorse food allergies, 13 times more likely to have celiac disease, have a high or low BMI, and abnormal ferritin or vitamin D levels than the general population.
  - increased risk of ARFID than any other eating disorder diagnosis. This is likely due to their symptoms of abdominal pain and nausea, which can lead to food restriction.

Adult onset chronic illness + eating disorders

ENDOMETRIOSIS

Epidemiological and Genetic Associations of Endometriosis With Depression, Anxiety, and Eating Disorders

- Does pleiotropy contribute to the association of endometriosis with depression, anxiety & eating disorder?
- 202,276 unrelated female participants. Genotypic and phenotypic information from genome stats of 5 countries.
- Genetic Study of 8,276 women with endometriosis and 194,000 women without (controls)

Koller, D., et al (2023). Epidemiologic and genetic associations of endometriosis with depression, anxiety, and eating disorders. JAMA Network Open, 6(1).

ENDOMETRIOSIS

- Findings
  - Endometriosis was associated with increased odds of eating disorders, depression, and anxiety. The results were significant even after controlling for age, body mass index, socioeconomic status, age at menarche, length of menstrual cycle, irritable bowel syndrome, contraceptive medications, and several pain-related phenotypes.

  - When accounting for these variables, eating disorders were associated with the highest odds of endometriosis compared to anxiety and depression

Koller, D., et al (2023). Epidemiologic and genetic associations of endometriosis with depression, anxiety, and eating disorders. JAMA Network Open, 6(1).

POLYCYSTIC OVARIAN SYNDROME

Body image distress increased in women with PCOS and mediates depression and anxiety

- Cross-sectional study with 189 women with PCOS and 225 without PCOS (control), 18-50 year-olds
- Participants self-reported body image distress using validated surveys
- Women with PCOS have increased body image distress, depressive, and anxiety symptoms after being adjusted for age, BMI, race, pregnancy history, and income and employment.

Alur-Gupta, S., Chemerinski, A., Liu, C., Lipson, J., Allison, K., Sammel, M. D., & Dokras, A. (2019). Body-image distress is increased in women with polycystic ovary syndrome and mediates depression and anxiety. Fertility and Sterility, 112(5).

CYSTIC FIBROSIS (CF)

- *Evaluating healthcare providers experiences, practices and recommendations for cystic fibrosis patients with disordered eating, a qualitative analysis*
  - 17 healthcare providers recruited from the cystic fibrosis foundation listserv interviewed by phone
  - Semi structured questions related to disordered eatings, interventions, screening messages and/or protocols
    - Patients with CF have energy needs that are 30 to 40% higher than controls
    - Most prominent disordered eating behavior observed by providers was misusing pancreatic enzyme medication (53%), food restriction (47%), skipping meals (29%)
    - 53% of healthcare providers reported not having policies or procedures for disordered eating among cystic fibrosis patients.

Darukhanavala A, Merjaneh L, Mason K, Le T. Eating disorders and body image in cystic fibrosis. J Clin Transl Endocrinol. 2021 Nov 26;26:100280. doi: 10.1016/j.jcte.2021.100280. PMID: 34917482; PMCID: PMC8646158.

MULTIPLE SCLEROSIS

- *The relationship between risk for eating disorder and health-related quality of life in patients with multiple sclerosis*
  - This study was performed cross-sectionally.
    - The study population consisted of 78 patients with MS who were followed up by the neurology department of a training hospital at Ankara city center.
  - Results showed that the risk for an eating disorder was relatively high in patients with MS
    - Found in a previous study, 9.1% of patients with MS had disordered eating behaviors.
    - Dysphasia contributing to EDs
    - Higher body dissatisfaction compared to individual w/o MS

BelgÜzar, K., & AyŞegÜl ,The relationship between risk for eating disorder and health-related quality of life in patients with multiple sclerosis GÜlhane TIp Derg 2015;57: 36- 40

JOINT HYPERMOBILITY

- *Joint Hypermobility and Clinical Correlates in a Group of Patients With Eating Disorders*
  - JHM is more prevalent in females and younger people
  - JHM has been also related to neuropsychiatric conditions such anxiety disorders and neurodevelopmental disorders such as autism and ADHD
- Participants were men and women clinically diagnosed with an ED at an outpatient ED unit of a hospital.
- Used various surveys and questionnaires

Baeza-Velasco, C., Seneque, M., Courtet, P., Olié, É., Chatenet, C., Espinoza, P., Dorard, G., & Guillaume, S. (2022, January 12). Joint hypermobility and clinical correlates in a group of patients with eating disorders. Frontiers in psychiatry.

JOINT HYPERMOBILITY (JHM)

- Results
  - A high proportion of patients with EDs were positive for JHM using the Beighton score,
  - AN most frequent ED in those with JHM
  - Participants with JHM had less cognitive rigidity compared to the control
    - May be due to structural brain differences
  - Many symptoms that present as a result of JHM is related to GI/food intake which make it more likely for ED to develop.

Baeza-Velasco, C., Seneque, M., Courtet, P., Olié, É., Chatenet, C., Espinoza, P., Dorard, G., & Guillaume, S. (2022, January 12). Joint hypermobility and clinical correlates in a group of patients with eating disorders. Frontiers in psychiatry.

GASTROPARESIS

- *Avoidant/restrictive food intake disorder symptoms are frequent in patients presenting for symptoms of gastroparesis*
- Food avoidance and dietary restriction are often initiated by patients or prescribed by providers for symptom management
  - Feeding and eating disorders (FED): include a spectrum of eating-related cognitions and behaviors that result in medical consequences, psychosocial impairment, and distress.
- Participants were those seeking a specialist for gastroparesis management

Burton Murray, H., Jehangir, A., Silvernale, C. J., Kuo, B., & Parkman, H. P. (2020). Avoidant/restrictive food intake disorder symptoms are frequent in patients presenting for symptoms of gastroparesis. Neurogastroenterology & Motility, 32(12)

GASTROPARESIS

- Results
  - 55% of patients with symptoms of gastroparesis had clinically significant FED symptoms, particularly ARFID.
  - 22% met criteria for other FEDs driven by body shape/weight concern.
  - Recommend that providers screen patients with gastroparesis/dyspepsia symptoms for ARFID symptoms before prescribing dietary management strategies.

Burton Murray, H., Jehangir, A., Silvernale, C. J., Kuo, B., & Parkman, H. P. (2020). Avoidant/restrictive food intake disorder symptoms are frequent in patients presenting for symptoms of gastroparesis. Neurogastroenterology & Motility, 32(12)

WHAT MAKES THOSE WITH CHRONIC ILLNESS MORE SUSCEPTIBLE TO DISORDER?

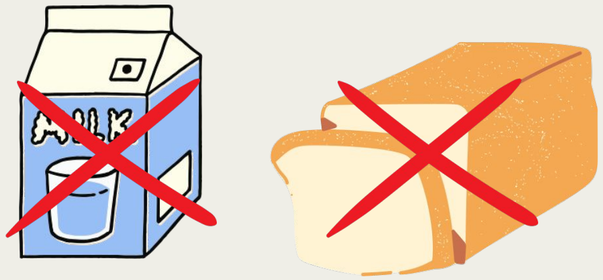
- particular vulnerabilities to cure-ish thing
- sense of responsibility & obligation
- lack of clinician curiosity
- desire for *possibility*

HEAL THYSELF

- Chronic illnesses preceded Stephen Bratman's coining the word ‘orthorexia,’ in 1996
  - Excessive preoccupation with healthy eating has only been amplified with Dr. Google and smartphones and social media
  - Management of chronic illness has only become more challenging in the era of *fake health news* and influencer derived wellness.

Dunn, Bratman Eating Behaviors 21 (2016) 11–17

DIET FIXES FOR “HEALTH”



ANTI

INFLAMMATORY

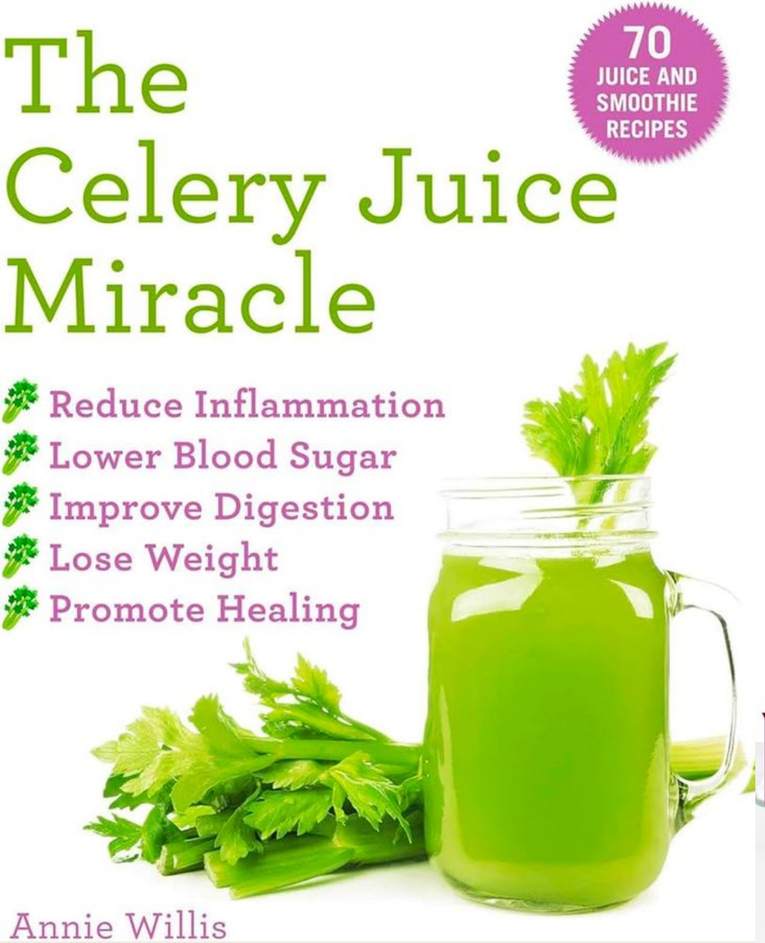
CARNIVORE

NASTY GREEN JUICE

INTERMITTENT FASTING

NO SUGAR

LOW CARB


The Celery Juice Miracle
70 JUICE AND SMOOTHIE RECIPES
Reduce Inflammation
Lower Blood Sugar
Improve Digestion
Lose Weight
Promote Healing
Annie Willis


BENEFITS YOU'RE
MISSING
from a
DAIRY FREE DIET


HOW TO
GET RID OF
BELLY BLOAT
IN UNDER
3 HOURS


Top Health Benefits of Beetroot Juice:
Weight Loss
Reduces Blood Pressure
Improves Athletic Performance
Anti-Inflammatory
Reduces Cancer Risk
Diabetes Management
© www.medindia.net

THE WELLNESS CULTURE GARBAGE FIRE

- Challenging for all of us
- More challenging for humans with less access, more illness, and fewer layers of privilege
- *Chronic illness realities*, but first a reminder from Kimberlé Crenshaw

INTERSECTIONALITY AND INTERSECTIONAL LOSS

Think for a moment about your intersecting identities.

How often are you conceptualizing care based on client's intersecting parts?
How often are you thinking about privilege? Oppression? Shared intersections?
How might you navigate intersectional loss?
For yourself? With your clients?

chronic illness realities

*things you *won't* know unless you need to know them

A CHRONIC ILLNESS REALITY

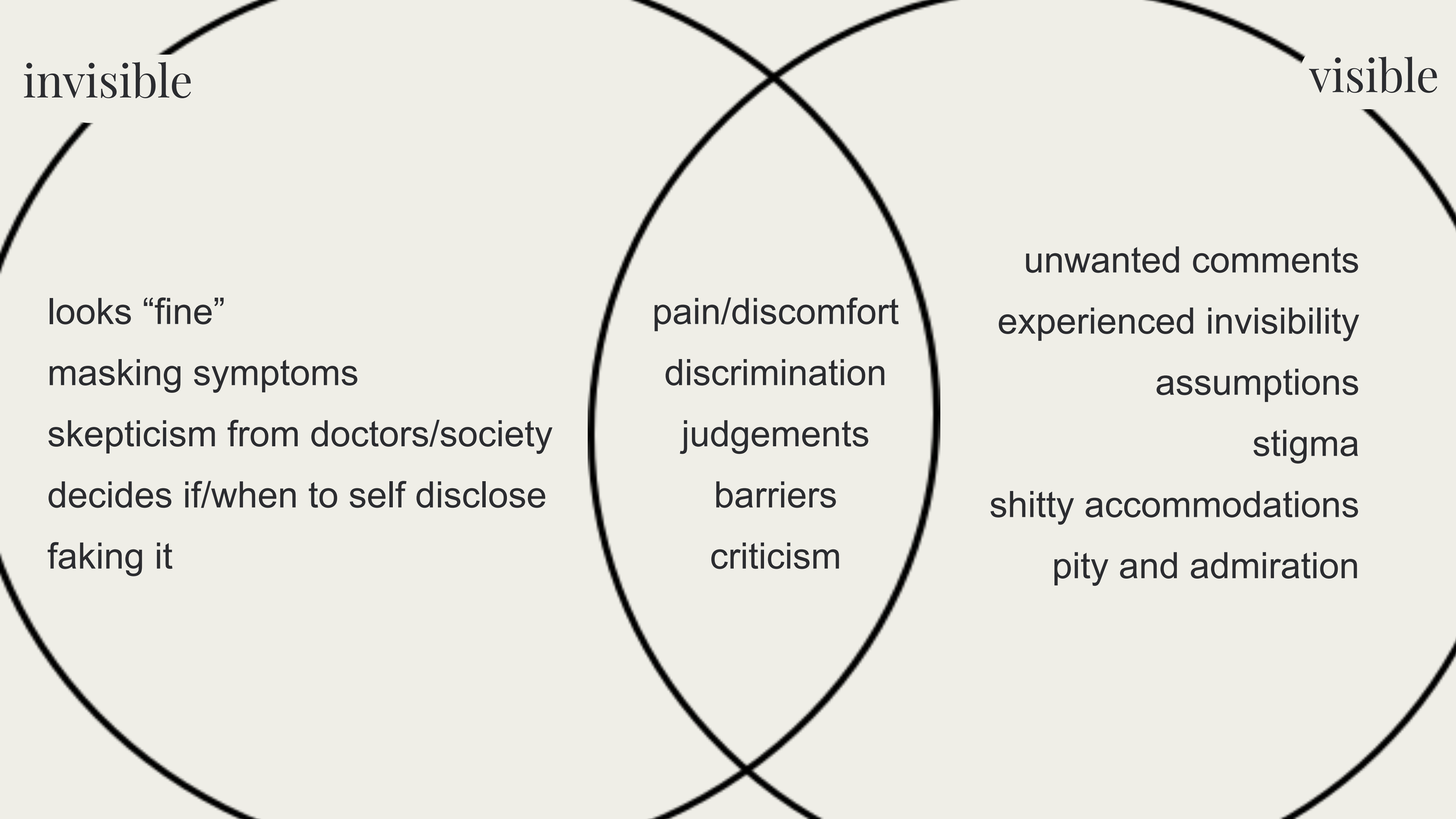
Appropriate, accurate, and timely *diagnosis* is a privilege.

Appropriate, targeted, and timely *care* is miracle stuff.

THE BURDEN OF EXTRA SELF ADVOCACY

“But you look so healthy”

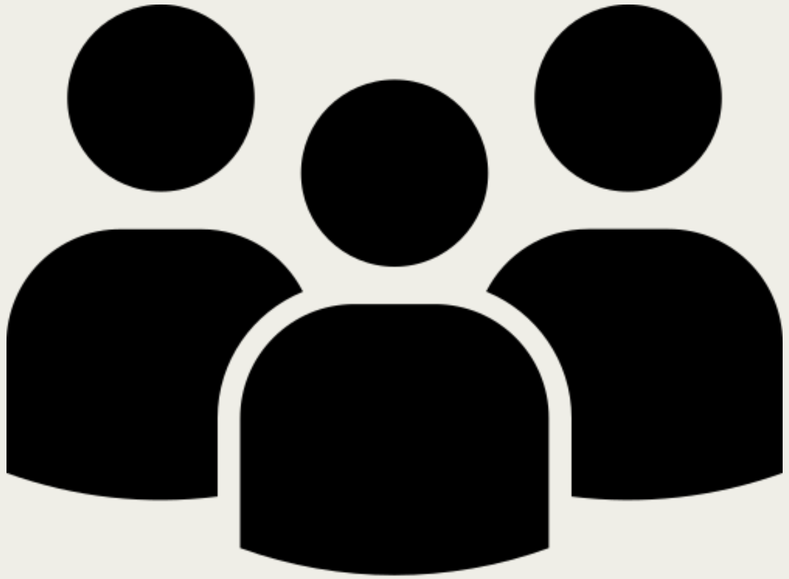
and other stupid things people say...

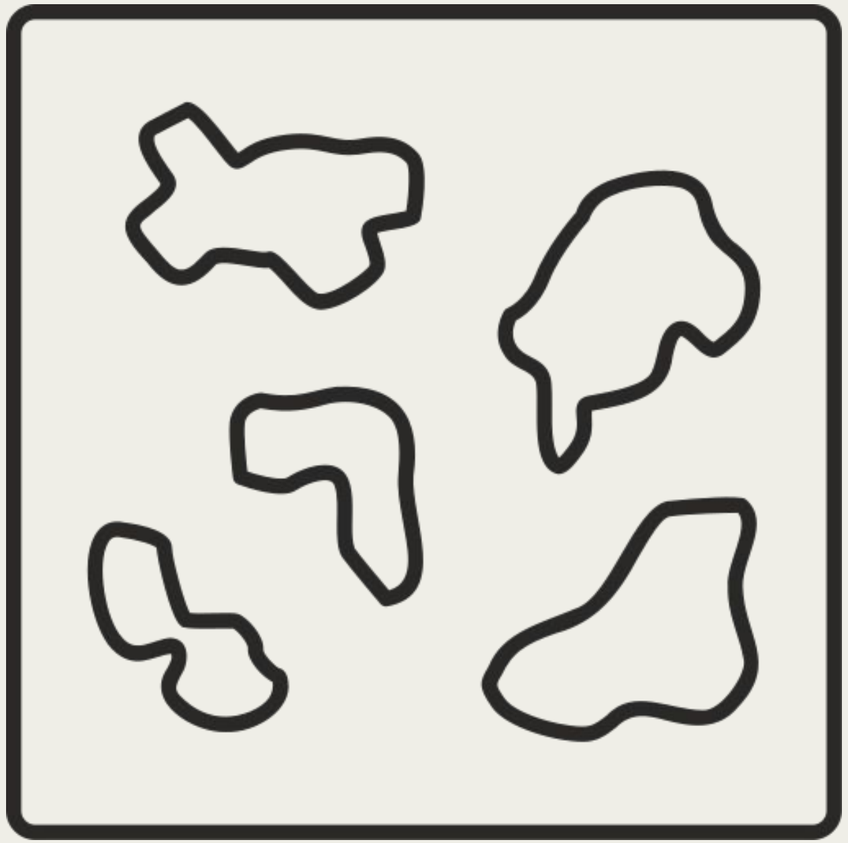

invisible
visible
looks “fine”
masking symptoms
skepticism from doctors/society
decides if/when to self disclose
faking it
pain/discomfort
discrimination
judgements
barriers
criticism
unwanted comments
experienced invisibility
assumptions
stigma
shitty accommodations
pity and admiration

THE BURDEN OF CASE MANAGEMENT

- the *necessity* of self efficacy and advocacy
- the reality and risks of gaps in care
- another intersectional opportunity or challenge
  - Who is listened to?
  - Who is able to ask questions?
  - How are needs being met?

IT TAKES A VILLAGE





PONDERING THE UTILITY OF ‘EXPERTISE’

- Client centered care
- The value of community
- The possibility in relationship

THE VALUE OF VALIDATION

I believe you.

BODY IMAGE AND CHRONIC ILLNESS, BRIEFLY

The *longest relationship* any one of us will ever have is that with our body.

- Complex relationship
- Comparison to an ideal
- Rethinking functionality
- Making room for grief

“My humanity is bound up in yours,
for we can only be human together.”

Desmond Tutu

INFORMAL RESEARCH

chronic illness x eating disorders

instagram poll active 3.18.25-3.19.25

Elimination diet, noted 27 times

cut out all grains and sugar

Only drink water

No nightshades

Eat once/day

Lose weight to avoid cancer with a known genetic mutation

go keto to "fix my brain," before entering treatment

Weight loss is the only way to address connective tissue issues

Stop eating tomatoes to cure RA

“Your food choices made this bed, change the sheets or lay down.”

THE STUPIDEST THING YOU'VE BEEN TOLD ABOUT HEALING FROM AN EATING DISORDER WHILE LIVING WITH CHRONIC ILLNESS

don’t eat sugar to cure cancer

Only eat food that your great grandmother ate

Drink coconut water

“Belly fat will kill you.” I had a tumor in my uterus.

water only fast at least one day a week

take cold showers to treat a neurological condition

"I wish all my patients had your dedication."

paleo is curative

Cut out 80% of foods to treat pcos

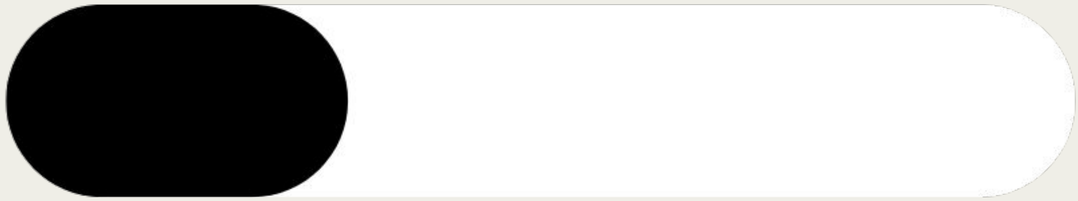
Do not eat dairy

“You should pray more” - my pcp

If you can’t exercise, don’t eat grains

CHRONIC ILLNESS X EATING DISORDER

Which came first?



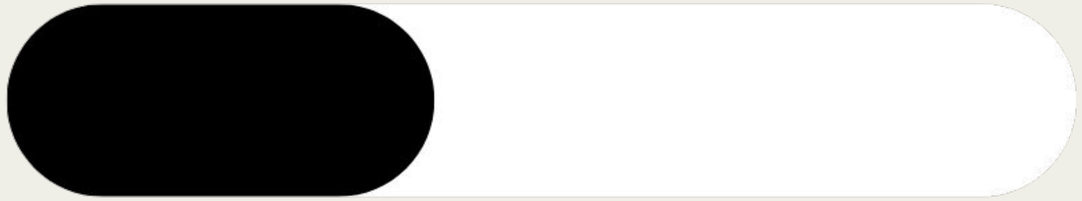
32%

chronic illness 560 vs. **eating disorder** 1,121

n=1,681

CHRONIC ILLNESS X EATING DISORDER

Has your chronic illness been addressed as part of eating disorder care?



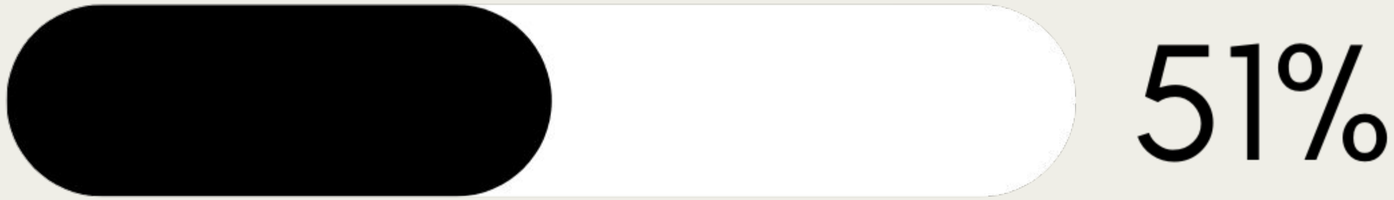
40%

yes 590 vs. no 870

n=1460

CHRONIC ILLNESS X EATING DISORDER

Do all of your providers know about *all* of your diagnosis?



51%

yes 670 no 650

n=1320

CHRONIC ILLNESS X EATING DISORDER

Has your ED + CI required you to operate as a case manager?

70%

Required you to connect specialists? **980 votes, 70%**

Been supported by *disconnected* specialists 430 votes 30%

zero votes for my specialists are a team*

n=1410

CHRONIC ILLNESS X EATING DISORDER

Has your chronic illness impacted your access to *outpatient* eating disorder support?

yes 800 v no 610 votes

n=1410

CHRONIC ILLNESS X EATING DISORDER

Has your chronic illness impacted your access to *higher* LOC eating disorder support?

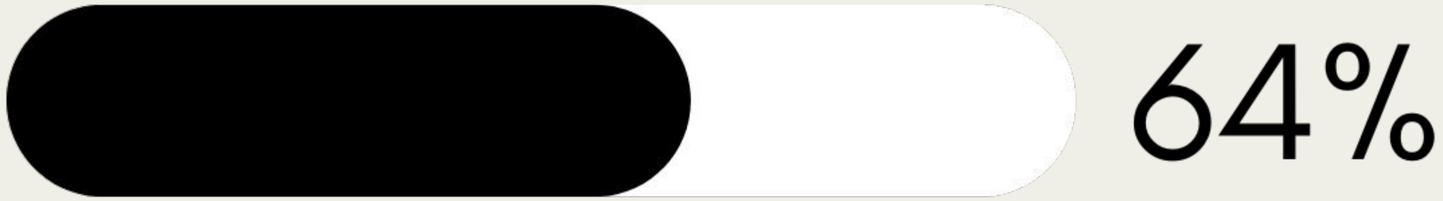
88%

yes 1204 v no 206 votes

n=1410

CHRONIC ILLNESS X EATING DISORDER

As a result of my chronic illness, my eating disorder:



my eating disorder became worse 930

my eating disorder has gotten better 190

no change 330

CHRONIC ILLNESS X EATING DISORDER

Impacted the way you use Dr. Google?

i research healing hacks 1220 vs i am not influenced 270

n=1490

HAS MANAGING CHRONIC ILLNESS

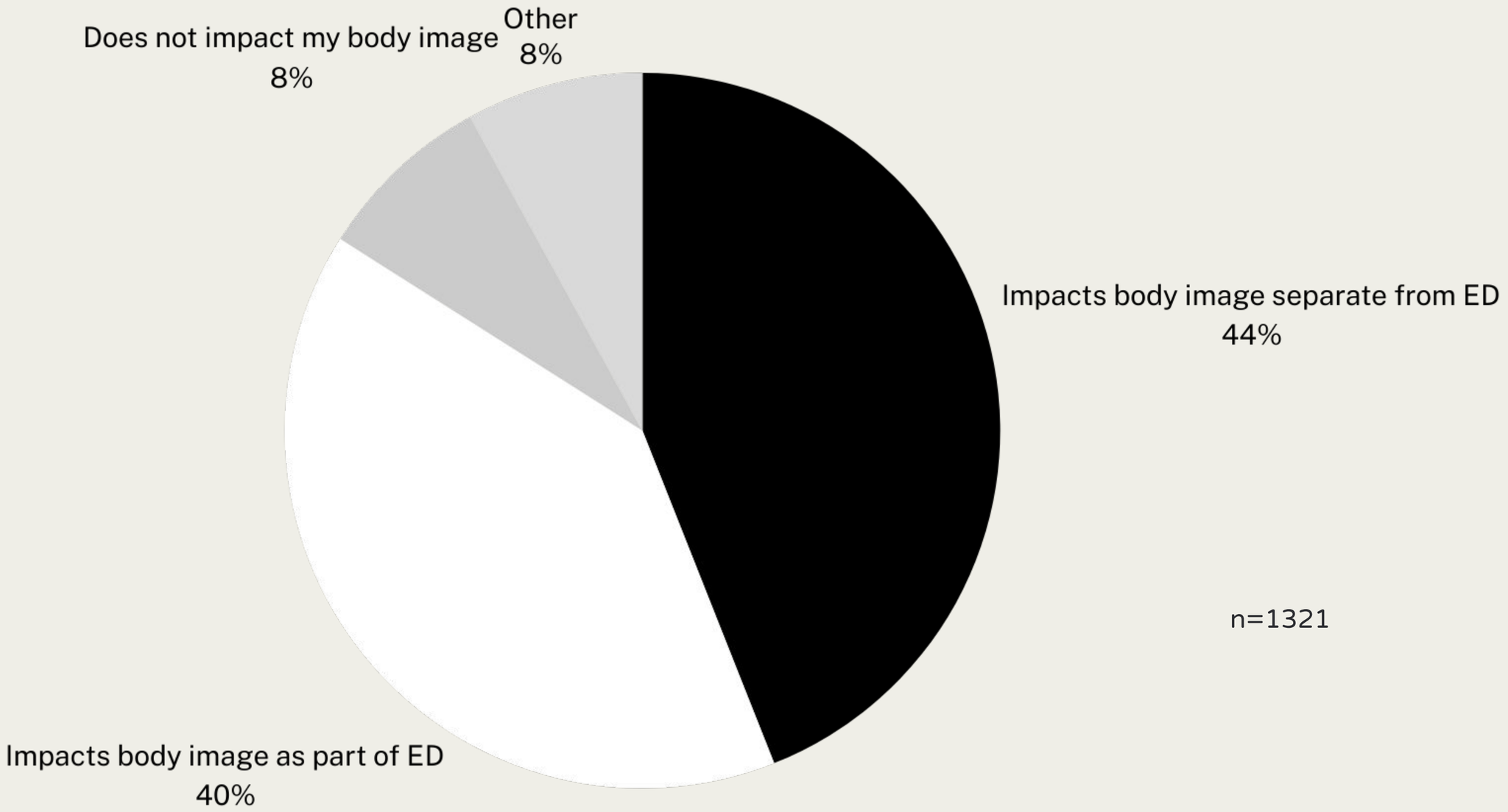
Impacted the way you interact with food?

89%

yes 1450 vs. no 180

n=1630

ED + CHRONIC ILLNESS X BODY IMAGE



n=1321

THANK YOU!

ANITA DHARWADKAR

ANITA@MARCIRD.COM

@DIETITIAN_ANITA

ANNA SWEENEY

ANNA@WHOLELIFERD.COM

@DIETITIANANNA

REFERENCES

Deloitte Access Economics. The Social and Economic Cost of Eating Disorders in the United States of America: A Report for the Strategic Training Initiative for the Prevention of Eating Disorders and the Academy for Eating Disorders. June 2020.

MMWR Morb Mortal Wkly Rep. 2022 Jul 29; 71(30): 964–970. Published online 2022 Jul 29.

Conviser, J. H., Fisher, S. D., & McColley, S. A. (2018). Are children with chronic illnesses requiring dietary therapy at risk for disordered eating or eating disorders? A systematic review. International Journal of Eating Disorders, 51(3), 187–213 .

Mostowy J, Montén C, Gudjonsdottir AH, Arnell H, Browaldh L, Nilsson S, et al. (2016) Shared Genetic Factors Involved in Celiac Disease, Type 2 Diabetes and Anorexia Nervosa Suggest Common Molecular Pathways for Chronic Diseases. PLoS ONE 11(8): e0159593.

Benjamin, J., Sim, L., Owens, M. T., Schwichtenberg, A.,Harrison, T., & Harbeck-Weber, C. (2020). Postural orthostatic tachycardia syndrome and disordered eating: Clarifying the overlap.Journal of Developmental & Behavioral Pediatrics, 42(4), 291–298.

Koller, D., et al (2023). Epidemiologic and genetic associations of endometriosis with depression, anxiety, and eating disorders. JAMA Network Open, 6(1).
Alur-Gupta, S., Chemerinski, A., Liu, C., Lipson, J., Allison, K., Sammel, M. D., & Dokras, A. (2019). Body-image distress is increased in women with polycystic ovary syndrome and mediates depression and anxiety. Fertility and Sterility, 112(5).

Darukhanavala A, Merjaneh L, Mason K, Le T. Eating disorders and body image in cystic fibrosis. J Clin Transl Endocrinol. 2021 Nov 26;26:100280. doi: 10.1016/j.jcte.2021.100280. PMID: 34917482; PMCID: PMC8646158.

Belgüzar, K., & Ayşegül ,The relationship between risk for eating disorder and health-related quality of life in patients with multiple sclerosis Gülhane Tıp Derg 2015;57: 36- 40

Baeza-Velasco, C., Seneque, M., Courtet, P., Olié, É., Chatenet, C., Espinoza, P., Dorard, G., & Guillaume, S. (2022, January 12). Joint hypermobility and clinical correlates in a group of patients with eating disorders. Frontiers in psychiatry.

Burton Murray, H., Jehangir, A., Silvernale, C. J., Kuo, B., & Parkman, H. P. (2020). Avoidant/restrictive food intake disorder symptoms are frequent in patients presenting for symptoms of gastroparesis. Neurogastroenterology & Motility, 32(12)

Dunn, Bratman Eating Behaviors 21 (2016) 11–17