The Role of Families and Natural Supports on Mitigating Loneliness and Other Negative Outcomes

National Assertive Community Treatment (ACT) Virtual Consultation Meeting

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Presented by Bette Stewart

Evidence-Based Practice Consultant/Trainer

bmstewart@som.umaryland.edu

Learning Objectives: You will be able to identify...

how loneliness is a contributing factor to higher morbidity rates among the general population and specifically among individuals diagnosed with serious mental illness;

why developing a collaborative relationship with family members and other natural supports is essential for recovery;

how stigma, shame, guilt, fear and misunderstanding of mental illness impacts families and can hinder their support and connection;

possible strategies for engaging families through empathy, education, and hope.

Families are the Original Natural Supports: Survival Depended on it!

The Surgeon General's Report on Loneliness

The physical health consequences of poor or insufficient connection include:

- 29% increased risk of heart disease,

- 32% increased risk of stroke, and,

- 50% increased risk of developing dementia for older adults.

Lacking social connection increases risk of premature death by more than 60%.

"We now know that loneliness is a common feeling that many people experience. It's a feeling the body sends us when we need something we need for survival is missing."

Our Epidemic of Loneliness and Isolation: The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community. 2023
https://www.hhs.gov/sites/default/files/surgeon-general-social-connection-advisory.pdf

Premature death of 10 – 25 years among individuals with serious mental illness

Vulnerabilities

- Severity of symptoms
- Deficits in social skills
- Smoking
- Psychiatric medications
- Poor nutrition
- Obesity
- Sedentary behavior
- Alcohol & drug use
- Stigma
- Unemployment
- Unhoused
- LIMITED FAMILY AND SOCIAL RESOURCES

Fiorillo A, Luciano M, et al. Reducing the mortality gap in people with serious mental disorders: the role of lifestyle psychosocial interventions.

Increased Morbidity and Mortality

"The rates of mortality from these diseases for the SMI population are several times those of the general population."

- Cardiovascular diseases
- Diabetes (including related conditions such as kidney failure)
- Respiratory diseases (pneumonia, influenza)
- Infectious diseases

Understanding Isolation & Loneliness

Social Isolation

- *"Social Isolation is objectively having few social relationships, social roles, group memberships, and infrequent interaction."*

"Lacking social connection can increase the risk for premature death as much as smoking up to 15 cigarettes a day."

The Surgeon General's report, 2023

Loneliness

- *"Loneliness is a subjective internal state. It is the distressing experience that results from the perceived isolation or unmet need between an individual's preferred and actual experience."*

Masi CM, Chen H-Y, Hawkley LC, Cacioppo JT. A Meta-Analysis of Interventions to Reduce Loneliness. Pers Soc Psychol Rev 2011 Aug;

Family Isolation and Loneliness

Many articles focus on building natural supports with co-workers, organizational groups, identifying common interest groups, etc.

Many ACT participants already have contact with their family. Some may even live with family.

Not everyone has negative familiar relationships, but for those who do…

Even when families have experienced mental illness with their relative for years, they still may not understand why their relative behaves the way they do.

"Adults across the globe rate their social relationships, particularly with family and close friends, as the most important source of meaning, purpose, and motivation in their lives."

The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community

" *When meaningful social connections are severed or unavailable it affects behavior.*"

"*...the only thing worse than suffering a serious illness is suffering it alone.*"

The New York Times, How social isolation is killing us. Dhruv Khullar, 12/2016

- Families may…

  - have no prior knowledge of behavioral health symptoms.

  - misinterpret symptomatic behaviors as willful.

  - become frustrated and angry causing a disruption of the relationship.

  - withdraw their support.

- Research supports…

  - family education and support directly improves individuals' recovery and reduces relapse rates.

  - very few families receive ANY illness information or support.

  - families engaged as part of the treatment team can provide long-term supports.

Reducing Loneliness through Connection

"...family support can contribute to reducing stigma and promoting open conversations about mental health within the family and society at large.'

"Listening without judgement, expressing care and understanding, and providing reassurance are essential components of effective family support."
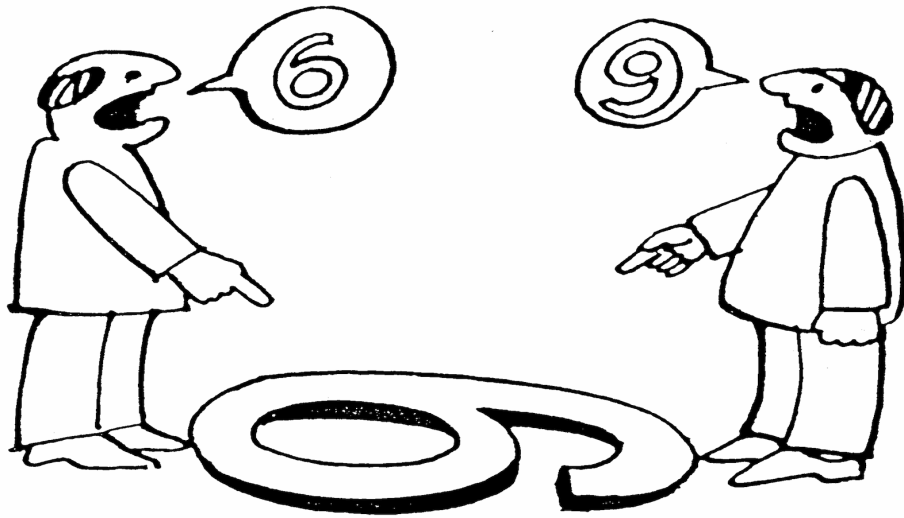
Hhtps://mentalhealthcenterorg/family-support-in-mental-health-treatment/

The Keys to Understanding Families

- Empathy
- Education
- Knowing what to offer and when
- Support
- HOPE

Empathy

"The intimate comprehension of another person's thoughts and feelings, without imposing our own judgement or expectations."
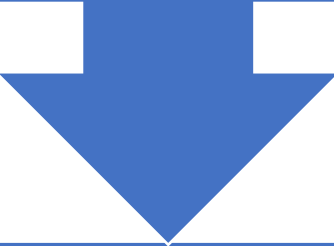
Hope and Empathy

- Families hold onto the hope that their relative will recover when they understand the illness and have support.

- To outsiders, families may appear to be disinterested.

- Families are more likely to engage with providers who can empathize with their fears or concerns about risks and returning symptoms.

Understanding family burden

Subjective Burden is...

The *psychological reactions* faced by caregivers as feelings of loss, anxiety, embarrassment, and stigma.

The functioning level of the individual is the main determinant of subjective care and includes how the caregiver perceives the burden.

(https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4601079/#)

Examples

- "It was devastating...we were angry, scared, embarrassed, and were confused with no clue about what to do. When she became psychotic, the bottom fell out of our lives." -JA (parent)

- "I get angry sometimes at my cousin and his wife for having so many children and not taking care of them or themselves.

- "She moved back in with her baby to our parents' house. We, once again, began the downhill slide into chaos.

- "...my sister stopped visiting, and even now will not go to visit my mother at the house if my brother is there." -MS

Understanding family burden

Objective Burden is...	Examples

"the family-felt burden brought on by the individual's behavior and respective consequences on careers, financial health and leisure; the time and finances devoted to care."

(https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4601079/#)

- *"The day to day is very challenging to deal with, mostly for my mother because she is his primary caretaker." -NA*

- *"Also, the rest of the family was not protected from my brother's behavior." -NA*

- *"He cannot be left alone overnight even though he is 22 years old. I am unable to go on a vacation unless someone can stay with him." -LS*

What you may see when working with families

Family discord

Loss of social support

Shame and guilt

Distrust of the MH system

Financial insecurity

Fear

Hyper-vigilance

Effective Engagement with the Family System

Requires understanding, empathy, and respect along with these practical strategies:

- Lessen anxiety and develop appropriate expectations.

- Suggestions for dealing with practical issues,

- Help with management of symptomatic behavior.

- General and specific education about mental illness and treatment.

Helping Families to be Supports

- Emotional support
- Learning problem-solving and coping skills
- Learning effective communication skills
- Learning about stress-vulnerability
- Reducing stress

- Improved mental and physical health
- Improved relationship with family member and staff
- And reduces the impact of stigma through support and education

Successful collaboration with families...

- "Family work can only be implemented if it is considered a shared goal of all members of a clinical team and/or mental health service, including the leaders of the organization."

- "Everyone must believe the value in collaborating, to see the value."

- Eassom E, Giacco D, Dirik A, et al. Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. *BMJ Open 2014;4:e006108.*

15 Principles of working with families

- Ensure everyone is on the same page

- Pay attention to clinical and social needs of client

- Provide optimum medication management

- Listen to families' concerns

- Explore family members' expectations

Dixon L, McFarlane W, Lefley H, et al: Evidence-based practices for services to families of people with psychiatric disabilities. Psychiatric Services 52:903-910, 2000

15 Principles of working with families

- Assess strengths and limitations of family's ability to support the person
- Help resolve family conflict by responding sensitively to emotional distress
- Address feelings of loss
- Provide relevant information at appropriate times
- Help improve communication among family

Dixon L, McFarlane W, Lefley H, et al: Evidence-based practices for services to families of people with psychiatric disabilities. Psychiatric Services 52:903-910, 2000

…15Principles in working with families

- Provide training in problem-solving techniques

- Encourage family members to expand their social support network

- Be flexible meeting family needs

- Provide family with resources

- Provide an explicit crisis plan

Dixon L, McFarlane W, Lefley H, et al: Evidence-based practices for services to families of people with psychiatric disabilities. Psychiatric Services 52:903-910, 2000

Basically…

- Listen to what families are saying.

- You don't have to "fix" things, sometimes listening with empathy is all that is needed.

- Respect where families are in their process of emotional recovery, some may never accept the fact their relative has a brain disorder, may never let go of their expectations of their relative.

- Give them what they need at whatever stage they are in but provide the empathy to let them see they can move forward.

- **And never give up the hope of recovery!**

Building collaboration that works

It takes teamwork.
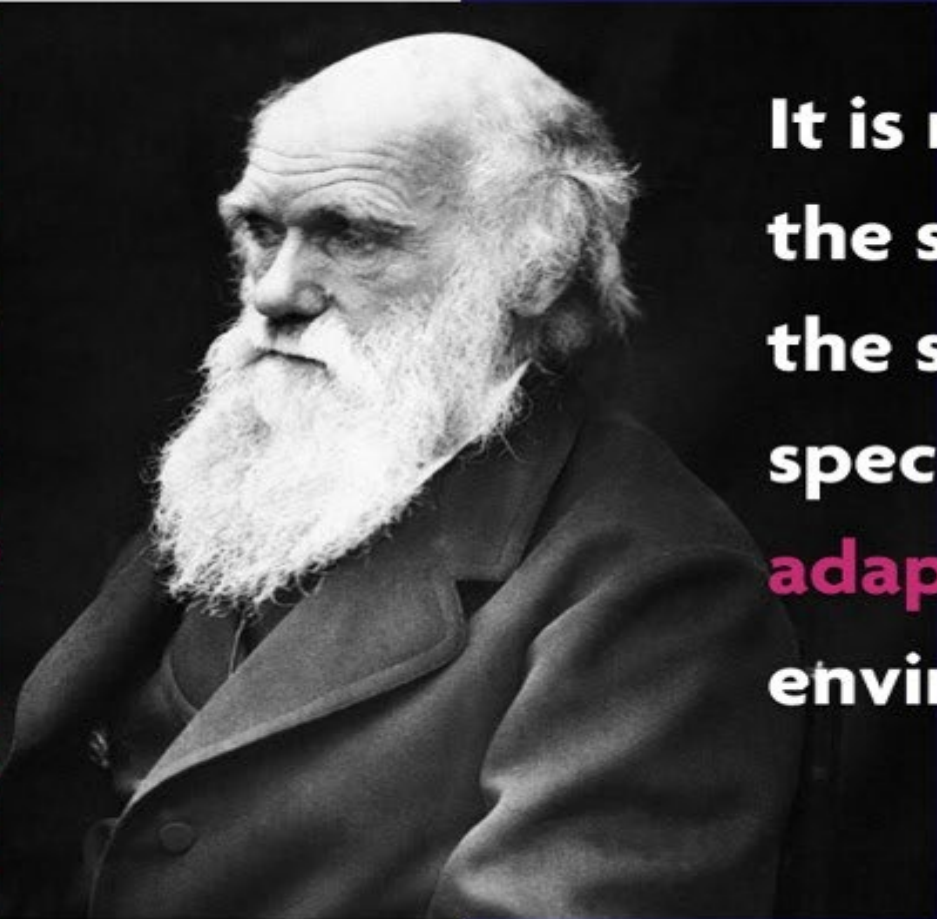
It takes time, empathy, understanding, and education.

It can be done!

Original Natural Supports

"Family members that attend self-help groups reported improvement in the relationships with mentally ill family members"

(Heller, Roccoforte, Hsieh, Cook, Pickett, 1997)

It is not the most intellectual of the species that survives; it is not the strongest that survives; but the species that [...] is able best to **adapt and adjust** to the changing environment in which it finds itself.

—*Charles Darwin*

Thank You!

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