

The Effect of Stigma on Access to Care and Services

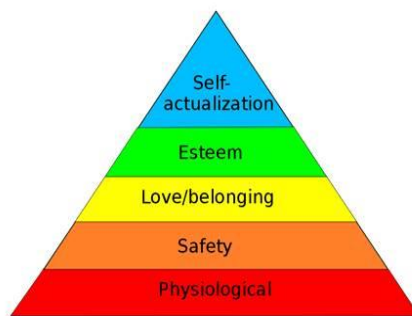
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#DementiaCareSummit

A Holistic View on Nomenclature Terminology Lexicon Jargon Taxonomy Words

- **Definition: Holistic** (in medicine)
 - "Characterized by the treatment of the whole person"
- **Takes into account mental and social factors**
 - Not just the physical symptoms of a disease



Maslow, A.H. (1943)
Image Source: <https://en.wikipedia.org/>

“In Their Words”

- **Stakeholder Group: People Living with Dementia**
 - Men and women
 - AD and related dementias
 - Varying ages represented
- Survey responses
- Web conference



Source: <https://www.stakeholdermap.com>

Dementia - Through the Lens of Disability

- **Stigma** – Being perceived as
 - Different from others
 - Unintelligent
 - Mentally ill
 - Of reduced worth
- **Resulting in:**
 - Social isolation
 - Reduced input in care preferences
 - Lower self-esteem
- **Disability laws (i.e. ADA) confer certain rights:**
 - Special considerations of different behavior
 - Accommodations
 - Coverage of healthcare costs
 - Legal liabilities
- **Cultural sensitivity**
 - Evolution of terminology
 - i.e. replacing mental retardation with intellectual or learning disability

The General Public and Dementia

• Public (mis-) perceptions

- It's a psychiatric condition, not medical
- Cognitive impairment is normal part of aging
- Dementia = Alzheimer's

IN THEIR WORDS

- People think of it as mental illness, **insane**, impaired reasoning, **deranged** or lunacy.
- conjures up the stigma of someone who is unable to speak, feed themselves, **sits in a wheelchair and is unaware of their surroundings.**
- The public clearly **avoids any discussion of "dementia"** because it's frightening.
- Many have **caricature idea** involving an elderly individual with memory loss and behaviors regressed to infancy.

Reduce Stigma, Increase Well-Being

• Perception evolves through research, education, advocacy

- These all hinge on **effective communication**

• Desired outcomes

- Earlier diagnosis
- Easier access to care and services
- Increased participation in research
- Increased education and support for those diagnosed
- Improved sense of well-being for those living with dementia

IN THEIR WORDS

- I think many perceive the diagnosis as an "all or nothing" experience. Perhaps understanding that **there is still meaning to life while living with dementia** may change perception.
- **Education, Education, Education**
- Careful public education. Straightforward **definitions of each disease, and POSSIBLE symptoms**, and relaxation view of various outcomes of the disease. Start with "disease" and then pass to possible symptoms.

Stigma and Clinical Care

- **Patient perspectives can delay seeking a diagnosis**

- Denial
- Procrastination
- Rejection of family concerns

- **Physicians can impact how well (or poorly) a diagnosis is received**

- Personal attitude (i.e. “therapeutic nihilism”)
- Effective communication skills
 - At risk status
 - Etiology v. syndrome
- Medical model vs. holistic approach

IN THEIR WORDS

- My older sister has Alzheimer's and she **NEVER admitted** that she had “memory problems.”
- With a diagnosis, the doctor is the front line and should explain the disease to patients in **simple, accurate terms**. The problem is that **many doctors are incapable of this**.
- Extremely important to know and understand the diagnosis and specific processes. **We want more than Wikipedia summaries**.
- I feel that it is extremely important to understand the **disease and processes** - not only to have a sense of the changes that lie ahead (physical, emotional, spiritual, etc.) and to make plans, but in terms of **being able to tap into emerging therapies and opportunities to participate in research**.

Obstacles to Accessing Services and Support

- **Stigma from needing dementia services**

- **Service providers use different terms**

- Community-based services
- Government agency programs

- **Different terms to promote dementia services**

- Memory disorders
- Alzheimer's disease
- Dementia

- **Caregiver support programs**

- Dementia-specific vs. disease-specific

- **People living with dementia**

- Memory clubs/café
- Early-onset Alzheimer's groups

IN THEIR WORDS

- Unless it says, “for AD and other dementias”, **I think only of AD”**
- My experience has been when something is for those diagnosed Alzheimer's and should I inquire, **I am often told that I need to be living with Alzheimer's in order to receive the service** etc.
- In such a case, **I think such a clinical program applies only to those with Alzheimer's**.

Ethical Considerations – New Research Definitions of AD Continuum

- **Psychological, Emotional and Social Impact**

- Diagnostic counseling (i.e. sibling to genetic counseling)
- Protecting the privacy of those with “at risk” status
- “Coming out of the closet”

- **Policy Implications and Civil Rights**

- Driving
- Employment
- Housing
- Insurability

SOURCE:

Alzheimer Europe: Discussion paper on ethical issues linked to the changing definitions/use of terms related to Alzheimer’s disease, 2016

Nomenclature in Dementia Services Research

- **Research Classifications Needed**

- The different types of treatments and care practices
- The characteristics of people who benefit from them
- The kinds of problems each one has been shown to reduce or resolve.

- **Stakeholders include:**

- Funders
- Providers
- Users

- **Terminology needs to be easy to understand across all stakeholder groups**

Evidence-Based Treatments and Care Practices

- Professional support
- Psycho-educational
- Behavior management/skills training
- Counseling/psychotherapy
- Self-care/relaxation techniques

Gitlin et al., (2015), Maslow (2012)

Research Participation

- **Terminology can influence recruitment**
 - Potential participants and/or their study partners may not recognize studies they qualify for
- **Denial is a barrier in recruitment and can complicate participation**
 - Including using the word dementia during assessments
 - Risk of 'revealing' a diagnosis that is forgotten or not shared

Consulting Merriam-Webster – or J.K. Rowling

- **Dementia (noun)**
 - A chronic or persistent disorder of the mental processes caused by brain disease or injury and marked by memory disorders personality changes, and impaired reasoning
 - Synonyms: Mental illness, madness, insanity, derangement, lunacy
- **Demented (adjective)**
 - Suffering from dementia
 - Informal: driven to behave irrationally due to anger, distress or excitement
 - Synonyms: mad, insane, deranged, psychotic, out of one's mind, crazed, lunatic, unbalanced, unhinged, disturbed, non compos mentis



"Dementor" from
Harry Potter series
(Image: Raising Creativity,
YouTube)

Consulting Merriam-Webster

- **Interventions**

- Action taken to improve a situation, especially a medical disorder: "two patients were referred for surgical intervention"
- An occasion on which a person with an addiction or other behavioral problem is confronted by a group of friends or family members in an attempt to persuade them to address the issue: "as her health worsened, her daughters considered staging an intervention"

- **Treatments**

- Medical care given to a patient for an illness or injury: "I'm receiving treatment for an injured shoulder"

- **Care practices**

- None

Being Mortal (Epilogue) by Atul Gawande

- "We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being..."
- "...I never expected that among the most meaningful experiences I'd have as a doctor – and really, as a human being – would come from *helping others deal with what medicine cannot do*, as well as what it can."

Recommendations

- Establish a **federally-led working group**, reporting to the Advisory Council on Alzheimer's Research, Care and Services, comprised of representatives from government, patient advocacy (including people with dementia and caregivers), clinical, scientific, industry and regulatory stakeholder groups, plus communications and public health experts, and leaders from other fields that addressed comparable nomenclature challenges.
- Identify and **review existing market research** done by dementia stakeholder organizations on the public's understanding of dementia and related disorders.
- As it pertains to **preclinical and prodromal diagnoses of AD and ADRD**:
 - Research the **cost/savings benefits of earlier classifications** on the dementia continuum
 - Identify **potential risks (i.e. psychosocial, emotional and social impact)** of delivering these diagnoses, and educational and support needs to maximize well-being.
 - Identify **policy implications and civil rights issues**, including privacy of at-risk status, employment, housing insurance, access to goods, services, healthcare and support.
 - Identify **professional education implications** for the medical and caring workforce.
 - Identify unique, **age-appropriate services needed by younger adults** diagnosed as at-risk.

Recommendations (continued)

- Recommend **research needed to further define and/or address public knowledge gaps** perpetuated by confusing terminology, terms that perpetuate stigma and isolation and address terminology-related barriers to early diagnosis, access to care and services, and research participation.
- Identify and **test public health education strategies** to a) increase public understanding of the syndrome of dementia, b) the varying underlying causes of dementia, c) destigmatize the concept of dementia and d) reduce social isolation of people with dementia and the family caregiver after the diagnosis
- Identify the **best opportunities for early nomenclature changes**, what stakeholder groups must be convened to establish proposed changes, what are the **top challenges**, and identify strategies to make incremental progress.