Living in Community
*Embracing People with Dementia*

Cordula Dick-Muehlke, Ph.D.
CORDULA CARES
Consulting in Aging & Dementia

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**Our Time Together**

- Explore cultural metaphors for dementia and their impact
  - Sources and causes of stigma
  - How stigma feels
  - Dementia-related stigma in senior living communities
  - Negative consequences of stigma
- A framework for reducing stigma
  - Seven antidotes to dementia-related stigma
- Developing dementia-friendly senior living communities
  - Steps to becoming a dementia friendly
  - What others have done
  - What will you do?

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**Metaphors**

- Extend our knowledge of the world
- Create a new reality and describe that new reality at the same time
- Impact attitudes and behavior

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Military Metaphors Can . . .

- Enhance the morale of patients and health care professionals
- Activate the drive towards health
- Impose order on a disordered world
  - Help patients understand, communicate about, and symbolically control the illness
- Create a shared understanding
- Mobilize human, economic, and social resources for research

As summarized in Nie, J-B., et al. (2016). American Journal of Bioethics, 10, 5-11
Multiple Negative Consequences
Of Military Rhetoric in Biomedicine

• Pulls on primordial instincts
  • Creates fear, engenders the image of an enemy and impels aggressive responses
  • Precludes “higher” thought processes and wiser responses
• Reinforces the biomedical model
• Limits one’s experience and understanding of the illness experience
• Implies that winning the war is only a matter of fighting hard enough

As summarized in Nie, J-B., et al. (2016). American Journal of Bioethics, 10, 3-11

Multiple Negative Consequences
Of Military Rhetoric in Biomedicine

• Can hinder health care professionals and society as a whole in caring for individuals with chronic conditions
• Is inherently masculine, power-based, and paternalistic
• Has been used to justify unethical research

As summarized in Nie, J-B., et al. (2016). American Journal of Bioethics, 10, 3-11

How Metaphors Impact the Illness Experience
In Dementia

A military trope “overmobilizes, overdeshines, and it powerfully contributes to the excommunicating and stigmatizing of the ill.”

Susan Sontag

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Dr. Alois Alzheimer

Ich hab mich verloren.
Auguste Deter
May 16, 1850 – April 8, 1906
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Peculiar fibrillary changes of the nerve cells – early stage
Peculiar fibrillary changes of the nerve cells – terminal stage
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Our goal . . . to call attention to our belief that senile as well as presenile forms of Alzheimer are a single disease, a disease whose etiology must be determined, whose course must be aborted, and ultimately a disease to be prevented.

Robert Katzman

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The War on Alzheimer’s Disease

What Are We Fighting Against?

• Alzheimer’s disease compromises most valued attributes of the individual
  • Reasoning, productivity, self-reliance

• Cognition and self-consciousness central in philosophical conceptions of personhood
  • Loss of cognition equated to loss of self

Language of Dehumanization Fuels the War

Dementia
• Unraveling of the self
• Slow death of the mind
• Living death
• Never-ending funeral
• Thief of the mind
• Long goodbye

Person with dementia
• A shell of the former self
• Dead already
• Unaware
• Physically here, emotionally gone
• Labelled with negative attributes and behaviors
  • Aggressive
  • Difficult
  • Burden
  • Wanderer

Alzheimer’s Disease Threatens Personhood

• Alzheimer’s disease compromises most valued attributes of the individual
  • Reasoning, productivity, self-reliance

• Cognition and self-consciousness central in philosophical conceptions of personhood
  • Loss of cognition equated to loss of self

Media Fuels the War

<table>
<thead>
<tr>
<th>Frame</th>
<th>Description</th>
<th>Language and Images</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dualism of mind and body</td>
<td>Person (spirit/soul) is gone, but body remains</td>
<td>Empty shell, sieve, flickering light</td>
</tr>
<tr>
<td>Invader</td>
<td>Dementia is a thief who steals a person’s life – an enemy</td>
<td>Thief, invader, demon, monster</td>
</tr>
<tr>
<td>Faith in science</td>
<td>Medical science is the only solution</td>
<td>Illness, diagnosis, treatment, cure</td>
</tr>
<tr>
<td>Fear of degeneration and death</td>
<td>Dementia is a death sentence times of indignity</td>
<td>Living dead, Apocalypse, decrepitude</td>
</tr>
</tbody>
</table>

Van Gorp, B. (2012). Social Science and Medicine, 74, 1274-81
Media Fuels the War

<table>
<thead>
<tr>
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</thead>
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<tr>
<td>Reversed roles</td>
<td>• People with dementia become childlike and are a burden</td>
<td>• Dependent child</td>
</tr>
<tr>
<td>No 'quid pro quo'</td>
<td>• Real “victims” are those around the affected person</td>
<td>• Heavy burden to bear</td>
</tr>
<tr>
<td></td>
<td>• Carers take over everything with nothing in return</td>
<td>• Collateral damage of dementia</td>
</tr>
</tbody>
</table>

Van Gorp, B. (2012). Social Science and Medicine, 74, 1274-81

Media Fuels the War

• With images that shape our consciousness and lead us to feel terrified and powerless¹
  • An unstoppable natural or monstrous force that affects individuals in an extreme way
    – Silent tsunami, wave, rising tide, flood of Biblical proportions
    – Monster, invader, alien, demon
    – Time-bomb, enemy, terrorism
    – Silent epidemic
    – Darkness cast against the light of medical advances
    – Leave behind “victims” and creates “burden”


Social Media Fuels the War

• In a sentiment analysis of 77,008 tweets publicly available tweets across 10 days in 2014¹
  • 31,150 (40.5%) used dementia-related keywords
    – Alzheimer, alz, dementia, demented, cognitive, old-timers, memory loss, senile and senility
  • Tweets were classified as from a private vs. organization user and rated on 5 dimensions
    – Metaphorical, informative, personal experience, joke, and ridicule
  • 6,582 (21.1%) tweets used dementia-related terms in a stigmatizing way
  • Among private users, 51.1% of tweets were stigmatizing


Lack of Knowledge Compounds the Problem

• How dementia literate are we?
  • Dementia literacy refers to knowledge about the causes, symptoms, evolution, and treatment of dementia
  • In a review of 40 studies examining dementia literacy¹
    – 19 (47.5%) found the public had poor to very limited knowledge about AD/dementia
    – Another 17 (42.5%) found fair-to-moderate knowledge
    – Only 4 (5%) found good knowledge
  • Lack of knowledge and symptoms is even lower in minorities²

¹ Cahill, S., et al. (2015). Alzheimer’s Disease & Associated Disorders, 29, 256-75
Cultural Misconceptions About Dementia

- A normal part of aging
- A form of mental illness
- A result of fate
- Retribution for past sins of self, family, or ancestors
- An imbalance in the body’s complementary forms of energy (yin and yang)
- Contagious
- Due to stress from acculturation difficulties

The Downside
Of Cultural Metaphors for Alzheimer’s Disease

Alzheimer’s Disease
Feared Most by Older Americans

Alzheimer’s Disease Facts & Figures 2014
Alzheimer’s Association

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Alzheimer’s Disease

A Diagnosis of Social Exclusion

- Individuals with dementia are sequestered, outside the “people club”1
- Sources of social disenfranchisement in AD2
  - In social contexts, from difficulties people with memory loss and their families have accepting/understanding cognitive changes
  - In political contexts, by focusing on the negative implications of AD to increase funding for biomedical research
  - In scientific contexts, by reducing affected persons to biological and behavioral symptoms in order to find a cure


Stigma

- στίγμα is a common Greek noun meaning “a mark, dot, puncture,” or generally “a sign”
- στίγμα referred to the mark cut or burned into a person’s skin to identify the individual as a slave, criminal or traitor
- Today, stigma is primarily defined as
  - A mark of disgrace associated with a particular circumstance, quality, or person1
  - A mark of shame or discredit: stain2

1 Concise Oxford English Dictionary
2 www.merriam-webster.com/dictionary/stigma

How Stigma Feels

Think of a time in your life when you felt isolated or rejected for being seen as different from other people.

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On Trying to Fake It

“"I didn’t want people to know because I think they would see me as different; I have told very few people, just close trusted friends. I didn’t want to be seen as different before I had to be. “My main interest has been not to have people notice about me... [I’m] not ready to be seen as different, not able to contribute, as dense. So far I’m kind of a closet person. But I think they are beginning to wonder. I can fake it some of the time. I think it changes the way they view me. I don’t want it. All of our friends are somewhat backing off.”

Rhoda in 2012, at age 72
Diagnosed with amnestic MCI

Roth, E. G., et al. (2016). Gerontologist, 56, 868-76

Stigma Extends to Senior Living Communities

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Stigma in Multi-Level Senior Communities

• Interviews with 367 individuals, including residents, family members and staff of 7 multi-level communities revealed

  • Stigma of place
    – Areas of highest care were labelled by staff and residents
      • “Back/Down/Over/Up There”
      • “The Dark Side,” “The Twilight Zone,” “God’s Waiting Room”
    – Places where cognitively impaired persons lived were especially derided

  • Stigma in the social environment
    – Resident discomfort with differences, particularly in cognition, lead to shunning

1 Roth, E. G., et al. (2016). Gerontologist, 56, 868-76

Consequences of Stigma

- Delayed Diagnosis
- Concealment of Diagnosis
- Isolation, Social Exclusion
- Loss of Self-Esteem (“Self-Stigma”)
- Shame, Embarrassment, Depression
- Hesitation to Use Services
- Under-Recognition of Caregivers (“Stigma by Association”)
- Disparities in Access to Care and Services (“Public Stigma”)

Impact of Alzheimer’s Disease on the Person

- Disease
  - Neuropathology
    - Cognitive decline
    - Functional impairments
    - Behavioral and psychological changes

- Losses
  - Autonomy
  - Self-esteem
  - Mastery
  - Roles
  - Identity
  - Friends

- Outcomes
  - May be expressed verbally or non-verbally
    - Depression
    - Despair
    - Hopelessness
    - Feeling useless

- Illness Experience
  - Social Consequences
    - Stigmatizing, hypercognitive culture
    - Dehumanizing approaches to communication, support, and care
    - Exclusion, isolation

- Cure
  - or at least control

- Healing and Hope
Living in Community
Embracing People with Dementia

We can’t cure dementia yet
BUT WE CAN ALL CURE THE STIGMA

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Which Viewpoint Will You Choose?

<table>
<thead>
<tr>
<th>Frame</th>
<th>Counter Frame</th>
</tr>
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<tbody>
<tr>
<td>Person (spirit/soul) is gone, but body remains</td>
<td>Individual remains a whole person who loses cognitive abilities but retains his/her identity and humanity</td>
</tr>
<tr>
<td>Dementia is a thief who steals a person’s life – an enemy</td>
<td>An inopportune visitor that can be adapted to</td>
</tr>
<tr>
<td>It is possible to live well with dementia</td>
<td>It is possible to live well with dementia</td>
</tr>
<tr>
<td>Medical science is the only solution</td>
<td>Answers/solutions beyond medical science</td>
</tr>
<tr>
<td>Individual treated as a patient</td>
<td>Individual treated as a person first</td>
</tr>
<tr>
<td>Dementia is a death sentence</td>
<td>Life is a gift</td>
</tr>
<tr>
<td>Fear of indignity</td>
<td>Joy can be found in the moment</td>
</tr>
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A Framework for Combatting Stigma
Seven Antidotes

Van Gorp, B. (2012). Social Science and Medicine, 74, 1274-81
Seven Antidotes to Stigma

- Expanding personhood
- Appreciating individual uniqueness
- Developing capacity for empathy
- Recognizing interdependence in all creation
- Embracing and growing from living with dementia
- Living well with dementia is possible
- Realizing hope beyond cure, i.e., as eradication of Alzheimer’s disease

“The we are not human beings having a spiritual experience. We are spiritual beings having a human experience.”

Teilhard de Chardin
If you have met one person with dementia, you’ve only met one person. That is, each individual will talk, act, remember, and behave differently. Not simply because of what stage of dementia they are in, but because they are who they are. Unknown

Developing Empathy

Take the Perspective of the Person

Dementia is a shift in the way a person experiences the world.

Allen Power, M.D.
It is far more important to know what person the disease has, then what disease the person has.

Hippocrates

Empathy Involves Listening Fully

Ears - to hear
Eyes - to see
Mind - to think
Heart - to feel

Undivided attention - to focus

Valuing Interdependence

The whole idea of compassion is based on a keen awareness of the interdependence of all these living beings, which are all part of one another, and all involved in one another.

Thomas Merton
Growing Through Diminishments

Having Alzheimer’s disease made me face ultimate realities, not my bank account. My money, my job, and other parts of my life were trivial issues that restricted my growth, my spiritual growth. Alzheimer’s disease transferred me from what I call the trivial plane to the spiritual or personal plane. I had to face the absolute horror of the ‘A’ word, and I began a dialogue with my existence, a dialogue with my life and my death.


Pat Summit
On Embracing Decline

“Above all, I know that Alzheimer’s has brought me to a place that I was going to arrive at someday anyway. With or without this diagnosis, I was going to experience diminishment. We all do. [And] I know God doesn’t take things away to be cruel. He takes things away to lighten us. He takes things away so that we can fly.”

People
March 18, 2013
Living in Community
Embracing People with Dementia

Living Well With Dementia is Possible

Steve, Howard, and Richard
On Life After the Diagnosis

“You have to learn your limitations so you can expand your horizons”.
Steve, age 58, in 2012
Diagnosed with MCI

“There is life after Alzheimer’s disease; it is up to each one of us as to how we make it happen.”
Howard, age 76, in 2006
Diagnosed with AD

“Everybody, especially if entering into this, lose the fear. That’s one of the most important things, lose the fear and find your life. Look for happiness and find where you can give and receive and move forward.”
Richard, at age 66, in 2009
Diagnosed with MCI

Making a Good Life with Dementia Possible
It’s Up to All of Us

Realizing Hope Beyond a Cure

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16
Hope Beyond Cure

• Many types of hope are possible at the end of life
  • For a cure, for survival, for comfort, for dignity, for intimacy, for salvation . . .
  • Hopelessness is “not the absence of hope, but attachment a form of hope that is lost”¹
• Our challenge when facing dementia and death is to diversify and redirect hope
• Within relationships we can expand hope and discover other purposes in life


Transformational Relationships in Dementia

• Transformational relating
  • Compassionate, empathic listening
  • Supporting expression of feelings
  • Promoting acceptance
  • Enjoying the present
  • Emphasizing strengths
  • Being with
  • Doing together
  • Creating joy

Although the world is full of suffering, it is full also of the overcoming of it.”
— Helen Keller

Dementia Friendly Senior Living Communities

How Do We Get There?

What is a Dementia Friendly Community?

• “A place where people living with dementia are supported to live a high quality of life with meaning, purpose and value.”
  Alzheimer’s Australia

• “A place where individuals with dementia are
  • Able to live good lives.
  • Have the ability live as independently as possible.
  • Continue to be part of their communities.
  • Are met with understanding.
  • Are given support where necessary.”
  Wisconsin Healthy Brain Initiative
Living in Community  
*Embracing People with Dementia*

### Becoming Dementia Friendly  
*In Your Senior Living Community*

1. **Define problem**
2. **Gain organizational “buy-in”**
3. **Engage resident and other partners**
4. **Create a vision**
5. **Develop a plan**
6. **Start somewhere**
7. **Evolve**


### Step Questions to Ask

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<th>Step</th>
<th>Questions to Ask</th>
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<tbody>
<tr>
<td>Defining the problem</td>
<td>What community issues exist related to dementia?</td>
</tr>
<tr>
<td>Gaining organizational “buy-in”</td>
<td>Do leaders in your community see this as a problem? Are they willing to make it a priority?</td>
</tr>
<tr>
<td>Engaging residents and other partners</td>
<td>Who internally and externally cares about reducing dementia stigma in your community? How can they help?</td>
</tr>
<tr>
<td>Creating a vision</td>
<td>How do you – leadership, residents, and partners – envision the senior living community?</td>
</tr>
<tr>
<td>Developing a plan</td>
<td>What will you do by when?</td>
</tr>
<tr>
<td>Start somewhere</td>
<td>What's doable now that you can take action on?</td>
</tr>
<tr>
<td>Evolve</td>
<td>What have we learned? Do we need to adapt our plan?</td>
</tr>
</tbody>
</table>

### What Others Have Done

- **Education to increase resident knowledge of dementia**
  - Causes, symptoms, progression, treatment and care
  - Skills to enhance communication skills and respond compassionately to behaviors

- **Buddy Program**  
  *Channing House, Palo Alto, CA*  
  - Cadre of cognitively healthy residents regularly visit peers with dementia in skilled nursing
  - Buddies share positive experiences and benefits with others

- **Joyful Hearts Choir**  
  *Front Porch Communities, Glendale, CA*  
  - Cognitively healthy resident volunteer to act as choir partners for residents with dementia
  - Replication of the community-based Giving Voice Chorus within senior living, www.givingvoicechorus.org

- **Living Well With Dementia Storytelling**  
  - Engage residents living positively with MCI or early dementia to share stories of their experience with your community a large
    - Involve a professional to support cognitively impaired residents as they prepare and share experiences

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What Others Have Done

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- Living Well With Dementia Storytelling
  - Engage residents living positively with MCI or early dementia to share stories of their experience with your community a large
    - Involve a professional to support cognitively impaired residents as they prepare and share experiences

Hand in Hand

- Staff education
  - Covering causes, symptoms, progression, treatment and care of dementia
  - Emphasizing person-centered approaches
    - The seven antidotes to stigma
  - Preparing them to lead by example

Where Will You Start?

*Brainstorming Ideas to Reduce Stigma in Your Senior Living Community*

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