Marriage and Dementia

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Winds of Change are Blowing

- Texas State’s goal is to change the stigmatizing & commodification of elders & PWD.

- This process involves a fundamental change in the way doctors give diagnosis, ending the labels/stigma’s that go with dementia etc.

- In families, social services and long term care, our challenge is providing fundamental rights & citizenship to PWD.

- Love and Dementia: How to Support a Couple Coping with Memory Loss

  Common Challenges of Couples:
  - Taking on more responsibility;
  - Decline in health for the caregiver;
  - Personality changes;
Algorithm for Diagnosis of Dementia

Memory Problems

Yes

SAD

Yes

Depression

No

Exclude

Reversible

Dementia

No

Mild Cognitive

Impairment

No

Loss of

Function

No

Abrupt Onset

Stepwise Progression

Yes

Vascular

Dementia

No

Other Vascular

Disease

Behavioral

Disturbance

Parkinsonism

Yes

Frontotemporal

and

Lewy-Body

Dementias

No

Alzheimer’s

Disease

Dementia vs. Pseudo Dementia

“**Dementia:** a shift in the way a person experiences the world around her/him.”* Dr. Power

- Alzheimer’s Disease (AD)
- Vascular Dementia
- Lewy Body Disease
- Frontal-temporal Dementia
- Korsecoffs Syndrome
- Pick’s Disease
- Creutzfeldt-Jakob Disease
- AIDS related Dementia
- Huntington’s Diseases

**Pseudo Dementia:**

- Depression
- Fatigue
- Intoxication
- Infections/Illnesses
- Metabolic Disorders
- Nutritional Disorders
- Vascular Problems
- Tumors
- Psychiatric Disorders

*Power, A. Dementia Beyond Drugs. In a Strange Land….People with Dementia and the Local Church. Malcolm Goldsmith. 4M Publications 2004*
Non-Linear Models of Alzheimer’s Disease

FACTOIDs: Marriage & Dementia

- 30 Million PWD worldwide, 75% of U.S. PWD live in community
- Spouses of PWD put in more hours of care (e.g. bathing, feeding, toileting—reported by 65% sampled) than others;
- Spouses represent 62% of caregivers living with non-institutionalized family members with dementia;
- Caregivers age 75+: men & women offer equal amounts of care but wives are more likely than husbands to suffer from high stress during care giving.
- Wives take on an emotional role while husbands an instrumental role in caregiving;
Economics

• **Assisted living.** In 2012, the average cost for basic services in an assisted living facility was $3,477 per month, or $41,724 per year. 72% of assisted living facilities provided care to PWD. In facilities that charged a different rate for PWD, the average rate was $4,619 per month, or $55,428 per year, for this care.

• **Nursing homes.** In 2012, the average cost for a private room in a nursing home was $239 per day, or $87,235 per year. The average cost of a semi-private room in a nursing home was $214 per day, or $78,110 per year.

“Dementia was not in our plans!”

Dementia is not something a person has chosen! Persons with dementia (PWD) are citizens, they have done nothing wrong, they deserve to have full rights!


• Result:
• Avoidance
• Not Experienced
• Fear
• Lack of
• understanding
• Discounted

Some “family” or “friends” stop coming around after the label “Alzheimer’s” is given to your spouse
What partners experience with PWD prior to & after dementia diagnosis

**Prior to diagnosis:**
- Memory loss
- Difficulty performing familiar tasks
- Vocabulary changes, usually shortens
- Disorientation to time & place
- Poor or decreased judgment/abstract thought
- Misplacing things
- Changes in mood, behavior, personality
- Loss of initiative
- Americans want a “diagnosis” or label given to symptoms.

**After Diagnosis:**
- Role Changes with family members
- People treat you different
- Short term amnesia while long term memory remains intact
- Speech skills change, gradually going through time travel (Trip back in time)
- Some skill change (e.g. handling money, driving etc.) but some remain, its depends on what you focus upon as a spouse! (Strengths or weaknesses)
- Intimacy changes—huge increase (e.g. frontal temporal dementia) or decrease (other diseases like Vascular dementia etc.). Ongoing sexual challenges with couples).
• Stigma is socially discrediting in a particular way: (Goffman 61). The association of age with senility>
cartoon

• Thornicroft (2014) has 3 elements to stigma: 1) problems of knowledge (ignorance), 2) problems of attitude (prejudice), 3) problems of behavior (discrimination).

• PWD are unjustifiably rendered shameful, excluded & discriminated against. 'WPA, World Health Org. 15’

• Stigma involves labels, stereotypes, separation, low social power/status & discrimination. Link and Phelan 11
10 recommendations to overcome stigma
by World Alzheimer’s Report 2013

1. Educate the public
2. Reduce isolation of PWD
3. Give PWD a voice (full citizenship)
4. Recognize the rights of PWD & their spouses (caregivers)
5. Involve PWD in their local communities.
6. Support & educate informal & paid caregivers
7. Improve the quality of care at home & in care homes
8. Improve dementia & geriatric training of primary healthcare physicians
9. Call on governments to create national Alzheimer’s disease plans
10. Increase research into how to address stigma, more money toward caregiving vs. finding a cure.
Couples at Home

- Worldwide, PWD mostly live in their own homes, often with family (e.g. Latinos). The financial, social & therapeutic benefits of family have been extensively documented, not only for PWD but also for society as a whole (Ehrlich & Associates 2013).

- Studies show that caring for PWD is stressful. “Caregiver burden” is greater than other chronic conditions (Patterson et al., 1998; Etters et al., 2008). De la Cuesta, 2005).

- Social involvement differs by country. There is high involvement in Scandinavia, Netherlands & Switzerland & low involvement in southern & central Europe. Instead there are extended filial obligations where the family are legally obligated to support their frail elders both socially & economically. However, among the general public, caregiving is perceived as a responsibility of the family even if caregiving predominantly is a female task (Haberkern & Szydlik, 2010).
Couples in Long Term Care

- Dementia is running about 75% in nursing homes & 50% in Assisted Living communities in America.

- Institutionalization of a spouse does not appear to relieve spousal caregivers from care burden. Spousal caregivers report greater increases in care burden & depressive symptoms as compared to other caregivers up to 12 months after placement in a care facility (Gaugler, Mittelman, Hepburn, & Newcomer, 2009).

- Spouses remain involved in care, albeit with a change in intensity & type of care provided (Gold, 1995; King et al., 1991). A dementia diagnosis contributes to a higher level of spousal involvement in caring for a partner resident in a care facility (Mirante, 2004).
We’re “together but apart.”

• Hemingway & Associates (2014) found a central theme in the analysis of interviews was ‘together but apart’. Institutionalization created a physical separation between spouses, & yet spouses remained involved in the care. The theme ‘together but apart’ was evident in partners describing their relationships with facility staff & how staff described their interactions with spouses. ‘Together’ largely represented the positive & affirming aspects of the relationships.

• Rather than focusing on the burden of care, spouses identified the affirming experience of ongoing connections & physical presence of their mates. The togetherness with staff was experienced as a rewarding fellowship, & spouses regarded staff in an overall positive light. Negative aspects of the experience of caring for an institutionalized spouse were captured by the term ‘apart’. In broad terms, ‘apart’ was attributed to larger aspects of the healthcare system & U.S. government policies. Case study: Mike age 45 and his wife Jo Ann
“The ‘Alzheimerization of dementia’….”
Dr. Tom Kitwood (originator of person centered care).

• Defocus on labels: “I….now can see my reluctance to apply the term dementia to my wife as a way of protecting the specificity of Jo Ann from the generality of the named condition.” Anonymous.

• “Expect PWD to do better than they are; it helps them to become better; but don’t be disappointed when they are not; it helps them to keep trying”;

• PWD need a voice & a choice, life goes on as normal as possible but with alterations along the way.

• Keep your couple identity (Bisbee 2013)

• Japanese change dementia (chi=foolish, stupid, losing your reasoning) to Ninchi (meaning cognition disorder).

• Whitehouse neurologist in U.S.: “Brain aging” or “accelerated brain aging.” Keeps it positive with patients, identify what they CAN do…..
“My partner is Dr. Jekyll & Mr. Hyde”

Dr. Whitehouse gives an account of a couple—the husband Dementia & PD was a nice, former NFL football star. Yet many family members feared he would turn into “Mr. Hyde.” Our expectations and how we act toward PWD can either turn them into Dr. Jekyll or Mr. Hyde. The emotions of others affect PWDs moods.

“Whether a PWD exaggerates their worst features or their best often depends upon the circumstances they are in and especially the type of caregiver they have.” His wife was a loyal & attentive caregiver. She viewed her husband’s condition as an opportunity to enrich & deepen their relationship on different terms, & did her best to create an environment that would best accommodate & stimulate her husband” (Baikie, 2002)
Co-constructed couplehood & stigma

• “I just consider it the problem of the person who holds the opinion – rather than mine. But if encountered too often, it saps morale. I belong to other groups that are minorities locally but this is one where my competency is in question.” PWD, spouse.

• Molyneaux & Associates (2012) found that couples reminisced together on the history of their relationship, most notably about the ‘good old days’. This challenges the assertion of Svanstro¨m and Dahlberg (2004) that PWD are unable to reflect on their past and focus only on the present. Co-constructed accounts of couplehood are valuable not only when researching couples experiences with dementia but also in their clinical assessment, this involves: normalizing, externalizing, sharing the experience & reframing the experience in light of the past treatment.

“I’ve armed myself with information and research about AD by reading lots of books & articles. I think information & knowledge is the best defense against stigma.” Physician with AD, USA
“Whatever happens, we will go through this together. I will be there.”

Michael French — a smart, good-natured, hardworking man — had become someone his wife Ruth felt she hardly knew. He threw away tax documents, got a ticket for trying to pass an ambulance & bought stock in companies that were obviously in trouble. Once a good cook, he burned every pot in the house. He became withdrawn & silent, & no longer spoke to his wife over dinner. That same failure to communicate got him fired from his job at a consulting firm. Infuriated, his wife considered divorce. But in 2007, she found out what was wrong. Because Mike had trouble speaking, he consulted a neurologist.

When they got the diagnosis, Mrs. French asked the Dr., “How do we treat it?” “It’s brain atrophy,” he replied. His wife’s thoughts of divorce evaporated. Instead, she told her husband: “Whatever happens, we will go through this together. I will be there.” From then on, the silence at the dinner table no longer troubled her. It did not seem personal anymore. He was not refusing to talk; he simply could not. Her anger melted into sadness!
Better to view it as changes in relationship than losses in relationship

- Although the nature of the relationship between caregiver & PWD is considered to be a relevant factor, the nature of the marriage has received relatively little research.

- Impact: reduced shared activities, loss of emotional support from spouse & a diminution in the quality of verbal communication between the couple.

- The impact may affect morale of caregiving spouses & their perception of changes in marital intimacy & satisfaction. In caregiving, marriage & intimate relationships need to be taken into account.
Impact of diagnosis on Partner

- Diagnosis affects every aspect of marriage, including intimacy. Partners often move from being a lover to a caregiver, taking on more & more of the responsibility for the PWD care (Bailkie, 2008; Snyder, 2002; Harris & Sterin, 1999; Sherman, 1998).

- Dementia changes the expression of intimacy & sexuality, yet this important part of the marital relationship, particularly in the very early stages of the disease, has not been well studied (H. Poole, PhD, unpublished data, 2003; Mayers & McBride, 1998; Ballard, C.G. et. al., 1997).
“My wife was 75 when she received the diagnosis. I can recall she had been gradually demonstrating each of the 10 warning signs of AD for 20 years. Her behavior was one of the reasons I was contemplating divorce. I finally understood that the arguments & dysfunctional relationship that I had with her. My irritation at her forgetfulness & tendency to repeat questions, her arguments with all of the family, were due to AD that had been creeping within her for so many years without anyone in the family realizing. If our daughter had knew back then she was actually struggling with AD, she wouldn’t have made fun of her repetitive questions. We both would have dragged her to the nearest place she could engage in physical activity or community work, which would have stimulated her brain and made her feel empowered and valued.”
60% of caregivers report that the PWD had shown at least one negative sexual behavioral change during dementia.

25% of male PWD had shown behaviors of always wanting sex. It seems to have little impact on whether couples continue to have intercourse when compared with the general aging population.

10% of caregivers experienced positive sexual changes.

33% of PWD found expressions of tenderness towards the caregiver increase. Of those still at home, at 3 years from the onset of dementia, 46% continued to practice intercourse, at 5 years the number was 15 couples (41%), and at 7 years it had declined to 7 couples (28%).

Dementia did not affect significantly the general atmosphere of the marriage.
Maintaining intimacy in early dementia (Harris, 2009)

- Harris added to our knowledge base relating to marital intimacy of couples dealing with early-stage dementia in 3 ways:
  - Providing a model that distinguishes how couples respond to changes in their marital relationship around the expression of intimacy;
  - Pinpointed positive coping strategies that helped couples cope with the changes in the marital relationship. Ex. flexibility, a humor, acceptance, & using family & emotional support);
  - Developed recommendations for the need for good open communication between the couples, as well as with their healthcare providers.
Intimacy at different levels

Harris’ (2009) study found a typology of 2 overall types, for both PWD & caregivers.

1. This group felt that though there was less sex, they had actually grown closer & more intimate on other levels. This is somewhat similar to the conceptual framework on intimacy of Moss & Schwebel (1993).

They talked about psychological intimacy, commitment, & other expressions of intimacy. They still found much satisfaction in their marital relationship.
Mixed findings

2. This group had both limited feelings of intimacy. They expressed a great deal of frustration, anger, & disappointment with the changing relationship.

Most of the time, the couples in Harris’ (2009) study were aware of each other's feelings & fell into the same type; however, there were a couple of cases in which the PWD & spouse were at odds, not in tune with others feelings (N = 3). Three people with dementia believed that there were no changes, though their spouses did not agree. This incongruence might be due to the diagnosed individuals' lack of awareness. Some were cognizant of other positive changes that occurred in their marriage & within themselves--including growth & reconfirming of their commitment.
• What is most often studied are “problem” sexual behaviors of or issues with PWD (e.g. late stage dementia in residential care settings). In my consults I deal with this a lot.

• Intimacy is an integral part of a couple's life & can be a major contributor to their quality of life. Indeed, when memory is gone, it is this intimacy that may provide an important bridge to the past.

• Discuss: Conjugal visits etc.
Doctors talking to couples about sex

Wife: “In a good relationship [patient-doctor], the doctor should be able to bring up the topic of sex with the couple.

Doctors can ask: How's your relationship? How is your sexual relationship? Do you want to talk about it? Is there anything I can do?”

Husband: “I'm thinking about my family doctor. He's concerned & that. But, he doesn't have the time. And so, he's unable to give you the time. Maybe the basics, maybe to hear you out, maybe able to give at least a "heads-up," with the things that you're facing. So that when you run into it, it's not a negative.

My doctor said, "Here's the Viagra." I just think if he's a good professional he’d look beyond just the physical things that you are going to have to deal with [sexuality].”
Crisis: Opportunity for spiritual development--selflessness, unconditional love

- In my focus groups, a wife says, “Well. I think my husband has to work harder. He keeps track of everything that I'm supposed to do. You know, he had to take on responsibility of things that I might forget. *His day has become my day.*”

- Husbands struggles: “My wife’s busy. She'll get grouchy at times & I understand--she's carrying the major load. The responsibilities used to be mine!” "Being dependent is the hardest thing for me to do, to be suddenly dependent.” “My wife & I have changed roles throughout our marriage.”
Role Reversal

• Some caregivers experienced the opposite effect from what was described. They had to acquire and learn new and additional roles in their relationships. A husband states. "You reprogram & learn. You learn things that you never thought you'd have to, like makeup. How do you get your wife to take a shower?"

• Another husband stated, “And part of the change in my mind is that it's a little bit more of a father-daughter than it used to be. Probably because there are little things that I have to take care of that she would have taken care of before. Things that make you start to feel more like a father-daughter connectedness than a married couple on an equal level.”
Carving out new definitions of couplehood

- **Wife:** "We enjoy ourselves. We have really good times. It's not the life we had planned. 'Flexible Are Us' is what I say all of the time."

- **Husband:** “It's been a journey. So when she was first diagnosed, other than the brief short-term memory issues, she was herself. Our relationship was the same. It wasn't father-daughter. It was just that we knew something was coming upon us. As time progressed, I probably had to assist her more. That's been a growing issue. She's always been a very independent, so she resists. But she knows she needs it. So we're fighting through how to love and respect one another. Yet there's some things I need to do to insure her safety and well-being. How do I become the spouse that is fair to the definition of spouse today that can still provide that respect? That's difficult knowing that fine line.”
Couple Coping Strategies (Johnson, 2015; Harris, 2009)

- Religious beliefs,
- Acceptance of their spouses' condition,
- Finding some humor,
- Emotional support & release (e.g. “Mostly I cry on the inside. Periodically I tell him, I am having a meltdown. I have it; then I go on my way”),
- Family or Friends support,
- Being flexible,
- Exercise,
- Respite Care/Day Care
- Gero Counselor
Young PWD

- Rostad & Associates (2013) study subjects revealed the following 4 themes:
  - entrapment by circumstances,
  - loss of humanity,
  - Having faith, hope & willpower,
  - the desire to ensure one’s quality of life.

- These themes provide an understanding of the experiences of younger PWD who live at home. The theme of preserving hope & willpower rebuts prejudices that life with AD diminishes a PWD humanity. PWD autonomy & self-determination should not be ignored.
This study examined a newly developed intervention, Acquiring New Skills While Enhancing Remaining Strengths (ANSWERS), for caregiving spouses of PWD. ANSWERS used a strength-based approach combining educational skills (used with caregivers) & cognitive rehabilitation skills training (traditionally used with PWD) into a single protocol for addressing the dyad’s care issues & needs. Key domains include:

- effective communication;
- education about dementia & memory loss
- managing memory;
- staying active &
- recognizing emotions & behaviors.

It focused on outcomes for caregivers (Judge et al., 2013).
ANSWERS: Training for Spouses

Intervention-given caregivers had decreased care-related strain as indicated by lower emotional health strain, marital strain, role issues, higher caregiving skills & improved well-being (less depression & anxiety).

Implications:

**ANSWERS** was a strength-based approach for selecting, developing, & implementing care goals, as well as teaching caregiving spouses educational & cognitive rehabilitation skills for addressing care needs (Judge et. al., 2013).
Dementia villages: Couples living Holland, Switzerland, U.S. (coming)
Websites & Stress Assessment

- Take the Family Caregiver Distress Assessment:
  - www.caregiverstress.com

- dementiacentre@stir.ac.uk
- http://www.linkedin.com/groups/Alzheimers-Care-Home-4043518?trk=myg_ugrp_over

LinkedIn.com groups:
Cutting Edge Dementia Therapy Network;
Advocates for Person Centered Care;
Alzheimer's reading room.
Texas State University—register for the first M.S. in Dementia & Aging Studies program (online) in America, Dr. Patti Guiffre at 512-245-8983

Questions?

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