A Person Centred Approach to Being with Older Adults with Dementia

Kathy McGilton, RN, PhD
Senior Scientist, Toronto Rehabilitation Institute-UHN
Associate Professor, Lawrence S Bloomberg,
Faculty of Nursing, University of Toronto

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UHN Toronto Rehabilitation Institute

Objectives for the Presentation

1. Learn how different philosophical approaches influence care
2. Understand responsive behaviors
3. REAP: A person centred approach to care

Biomedicalization of dementia (Lyman, 1989)

- Neglect of the social component of dementing illness.
- While we wait for a cure, care occurs in social settings and relationships that are seldom examined are looked at in regard to their contribution to dementia.
- Reliance upon the biomedical model to explain the experience of dementing illness overlooks the social construction of dementia and the impact of treatment contexts and caregiving relationship on disease progression

Biomedicalization of dementia (Lyman, 1989)

Most of the research is focused on the troublesome or challenging behavior problems attributed to disease progression.

Dementia is:

1. pathological, an abnormal condition of CI,
2. caused by progressive deterioration of brain regions that control memory, language, and other intellectual functioning and
3. not curable

Treatment

- Within this paradigm behaviours are a direct result of changes in the brain and, therefore, must be treated with medical/clinical interventions
- Neuroleptic drugs
- Mechanical restraints
- Control disruptive behaviors

(Andrews, 2006)

Physical Restraints

However, physical restraints have been determined to be harmful and do not necessarily prevent falls and treatment disruptions

(Evans and Strumpf, 1990;Evans, Wood & Lambert, 2003; Capezuti, 2004).

Alternative Paradigm

- Algase and his colleagues (1996) developed the "Need-Driven Dementia-Compromised Behaviour (NDB)" model which conceptualises responsive behaviours as the outcome of various needs, particularly unmet needs, that residents with dementia may experience but have difficulty expressing.
- From this perspective, "disruptive" behaviours in persons living with dementia are viewed "as meaningful because they arise in pursuit of a goal or as an expression of a need" (Colling, 1999, p. 28).
- Consistent with this perspective, other researchers have suggested that "challenging" behaviours may be a form of communication for persons with dementia (Innes & Jacques, 1998) and a way that individuals with dementia seek to express themselves (Sabat and Harré, 1992).

Responsive Behaviors

- "Responsive" behaviours can reflect a response to (or way of communicating) an unmet need or to a discomfort with something in the immediate setting such as the physical body (e.g., urinary tract or other infection), social environment (e.g., boredom, invasion of space), or the physical environment (e.g., lighting). (Dupuis, personnel communication, 2008)

- This conceptualisation requires that we find better ways of understanding what persons with dementia are trying to communicate and suggests that interventions may be needed that address and change the environment (e.g., how we approach persons with dementia during care, lighting within the facility, etc.).

Prevalence of Responsive Behaviors

Estimated 75% - 90% of persons with dementia will have some responsive behavior

- Aggression
- Agitation
- Withdrawal
- Wandering

Impact of Responsive Behaviors

- Impairs quality of life (Samus et al, 2005)
- Distressing to patients
- Distressing to caregivers
- Increase risk of nursing home placement (Chan, Kasper, Black & Rabins, 2003)
- Challenges occur during interactions

Outcomes of Understanding Responsive Behaviors

- Improve quality of life
- Decrease patient and caregiver distress
- Reduce caregiver stress
- Improved quality of work life for staff
- Increased recognition of how unmet needs can result in the development of responsive behaviors (i.e. physical body (e.g., urinary tract or other infection), social environment (e.g., boredom, invasion of space), or the physical environment (e.g., lighting).
- Better Interactions

New Approach Required

This conceptualization requires that we find better ways of understanding what persons with dementia are trying to communicate and suggests that interventions may be needed that address and change the environment (e.g., how we approach persons with dementia during care, lighting within the facility, etc.).

New Approach Required

- As a result, assessments and interventions need to be focused on the meaning behind the behaviour rather than the behaviour itself.

- Potential antecedents include: discomfort, unmet needs or desires, lack of activity or boredom, untreated delirium, environmental noises, response to touch or invasion of privacy

(Cohen-Mansfield, 2001; Dupuis & Luh, 2005).

The Theory of Unmet Needs

- Belief that most responsive behaviors is a persons attempt to communicate a “unmet need”
- We need to find this un
- Assess for basic needs
  - Pain
  - Thirst
  - Grief
  - Loneliness

Regulation Developer at the MOH&LTC

"We think using this terminology (i.e. responsive behaviors) lays the groundwork for major systemic change in terms of how we view person's behaviors in LTC Homes in the future – and consequently, how they are served."

Responsive Behaviors Strategies

- Assessment, reassessment, identification of behavioural triggers, whether cognitive, physical, emotional, social, environmental, or other and management techniques and interventions.

- Strategies and interventions to prevent minimize or respond to the responsive behaviors.

Person Centred Care Approach

- Understand the person as unique with individual characteristics, needs, values, beliefs and preferences, and respond to their needs by tailoring care (McCormack, 2003)
- An understanding of their personal circumstances
- Translation of this value into widespread practice is a commonly recognized as a challenge.

A Person Centred Model of Care to Guide our Approach to Being with Persons with Dementia (REAP)

1. Relating Well
2. Environment
3. Abilities Focused
4. Personhood

Relating Well

(McGilton, 2004)

Reliability is defined as the caregiver being dependable in caregiving. This involves the caregiver both protecting the individual from the unpredictable and tolerating negative feelings without responding negatively in return.

Relating Well

Empathy refers to the care giver recognizing the needs of another and identifying with the wishes and particularities of the individual through being sensitive to the person's expression (bodily and verbal).

Relating Well

Relating well behaviours include, but are not limited to the following: maintaining close proximity, utilizing various forms of touch that are comfortable for the client, sitting beside the person, hesitating in care when necessary, being flexible, acknowledging the client's subjective experiences, and giving verbal reassurances.

Relating Well Study

(McGilton et al., Alzheimer Society of Canada)

- During each care giving situation, an association was exhibited between the caregivers' performance of relational behaviors and the residents' positive affect or mood.
- We found that the staffs' RBS scores (Relational Behaviour Scale) were significantly positively correlated with residents' pleasure during morning care.
- Based on the residents' negative affect AARS (apparent affect rating scores) outcomes, we found that lower RBS scores correlated consistently and statistically significantly with the items anxiety, fear and sadness across the three care giving situations in the three facilities.

Relating Well

- These significant findings clearly indicate that residents in the care of staff not relating effectively expressed more observable negative affect.

- Furthermore, this result implies that residents, even with severe dementia, use their affect to communicate their anger or discomfort with the care received.

(McGilton et al., Aging and Mental Health, 2011)

Relating Well: Helping the Person with Dementia Communicate (AD society)

- Never interrupt a person who has dementia when he or she is trying to communicate an idea because this distraction may cause them to lose their train of thought.
- Never contradict or argue with a person with dementia
- Must be sensitive to the limited understand and comprehension of the person
- Look a the emotional meanings and subtexts behind statements made by person with dementia. As an example, persons waiting for their mothers are most likely feeling lonely, insecure and fearful

Relating Well:
Helping the Person Understand You (AD Society)

- When communication with a person who has dementia, avoid open ended questions. Offer a yes or no question or a choice between no more than two items
- If a person with dementia does not understand the question, repeat it or rephrase it.
- Persons with dementia need more time than the average person to process a question
- Most importantly, simple expressions of caring communicate to any person that they are loved and appreciated.
- A smile speaks volumes to a person with dementia.

Relating Well: Case Example

- Call her by her preferred name
- Daily verbal reminders of where she is and why, date
- Consistent team members working with her
- Calm voice and body language
- Speaking to her right ear (as left ear has decreased hearing)
- One step verbal commands
- Eye contact and “gentle” touch for physical cueing

- (Toronto Rehab-UHN Staff Case Example)

Environment-Person Models

(Lawton, 1989)

- Lawton's model of environment-person relations proposed a dynamic interaction between the person and environment, the behavioral outcomes of which is determined by the 'competence' of the person and the 'demand characteristics' of the environment.

- A positive fit exists when person (competence) and environment (demands and opportunities) are in a state of equilibrium. The fit needs renegotiation when either the environment changes (relocation) or the person changes (illness, losses in motor skills, etc.).

Environment-Person Models

(Lawton, 1989)

- High environmental press refers to stimulation in the environment that exceeds the competence of the individual.
- Low environmental press refers to stimulation in the environment that is below the competence of the individual.
- It is important than to interpret behaviors of residents with respect to these environments, rather than to personal characteristics or the disease.

Environment-Person Models

(Lawton, 1989)

Strategies

- Dementia decreases the threshold for stress or stimuli from the environment.
- Must manipulate the physical and social environment to meet the unique needs of a person with dementia.

Environment-Person Models

(Lawton, 1989)

- Social Environment
- Scheduling daily therapy sessions so there is a balance between a person's high arousal and low arousal states is an example of how we can manipulate the environment.
- Greater than 1.5 hours of activity associated with agitation (Kovach et al., 2004)

Environment-Person Models

(Lawton, 1989)

Physical Environment

- Physical access, temperature, color, and placement of furniture are all environmental factors that can be adjusted

Environmental manipulation: Case Study

- Low vision strategies – lighting, contrast, de-clutter for safety, using large print
- Orientation signage: calendar, patient room, wayfinding signs
- Difficult finding her way: room located close to nursing station
- Consistent activities spread out throughout the day
- Reduce noise in room

Abilities Focused Care:

Wells and Dawson (2002)

- The goal of Abilities-Focused Care is that the patient maintain and use retained abilities as long as possible

- Abilities-Focused Care is not based on symptoms or pathology per se but is based on an understanding of the neuro-psychological changes which are caused by dementia in the areas of : Language, Attention, Memory, Movement, Sensation, and Perception

Abilities Focused Care

- We learn how the clinical features, that is, the signs and symptoms of the disease, affect particular human abilities to carry out day to day life activities (Dawson, Wells and Kline, 1992).

- If we can identify and promote retained abilities and/or compensate for lost abilities, they can enable the individual.

Abilities Focused Care

SELF CARE ABILITIES:

1. Voluntary Movements
2. Spatial Orientation
3. Purposeful Movements

SOCIAL ABILITIES

1. To give and receive attention
2. To engage/participate in conversation
3. Humour appreciation

Abilities Focused Care

INTERACTIONAL ABILITIES

1. Comprehension Abilities
    a) Verbal Comprehension
    b) Reading Comprehension
2. Expression Abilities

INTERPRETIVE ABILITIES

1. Recognition
2. Recall
3. Feeling States

Abilities Focused Care

For bathing, dressing, eating, grooming, and toileting the following abilities are required:

- Voluntary movements
- Purposeful movements
- Body spatial orientation
- Focus attention
- Conversation

Abilities Focused Care

Example:

- Ideomotor Apraxia: A disconnection between the mind and the body (i.e. the mind may understand an action to be taken but cannot get the message to the body)

- Threatens the ability to start an action or initiate an activity. The person agrees to do something but takes no action.

  You ask: Would you like to eat now?

  Person's response: Says yes but doesn't do anything

- Body needs to be cued independently of the mind.

Abilities Focused Care

Possible inappropriate action HCP takes:

- Doing activity for the person
- HCP tries to find ways to enhance cooperation
- Speaking too simply to person

Possible thoughts the HCP has:

- Person unable to undertake action
- Person uncooperative
- Person doesn't understand request

Excess disability is a result and dependency in the activity occurs

Abilities Focused Care

Practical Application

Visual object cue (ASK)

(i) Show the objective to the individual and ask him/her to show you how to use them

Visual action cue (DEMONSTRATE)

(ii) Demonstrate the use of the objects and ask the person to copy your actions.

Body object cue (SHOW)

(iii) Place the object in person's hand and ask patient to use them.

(iv) Do the task for the client (DO)

Abilities Focused Care: Case Study

- Maximizing remaining sensory abilities (hearing and vision)
- Focus on functional activities vs standard exercises.
- Consistent daily team communication and encouragement of Mrs. D in “what she can do”
- Consistent performance of independence and care activities with Mrs. D by all team members

Personhood

(Kitwood, 1997)

- Gaining insights into the subjective world of dementia
- Through accounts of what people with dementia have written
- Individuals will vary greatly in what they experience, according to their personality and biography

Personhood

- Knowing the person involves becoming familiar with the individual, that is, gaining knowledge of a person's life and times.
- Nurses must seek to round out their knowledge of each client's life and times. At times this may involve partnering with families to gain needed knowledge.
- Finding out what makes them tick (Galik, Resnick, & Pretzer-Aboff, 2009)

Personhood

- To know the person also involves understanding his/her culture, that is, the particular beliefs, values and biases that have been learned, and how these affect the way that person views and responds to the world.
- Awareness of the individual and his/her life circumstances may assist nurses to predict which individuals may potentially be high-risk and how they may express their needs.

Personhood: Case Study

- Lifelong sensitivity to temperature changes:
  - Noted increased anxiety and agitation when cold
  - use of warm blankets for comfort and ensuring warmer temperature as a strategy
- Recognition of past roles/activities:
  - performed “admin” activities in nursing station for nurses
  - talking to her about her past interests/roles (staff and volunteers)
- Daughter asked to stay for the first day – good way to get to know the patient

Putting it all together

- The REAP Model involves assessing the abilities of clients with dementia and getting to know the individual client and their likes and dislikes and unmet needs.
- Based on this assessment staff are called on to manipulate the environment to meet their cognitive abilities, while relating to them based on their knowledge of their abilities, who they are, what they like, and how they respond.

Current research

Using the REAP model focused on rehabilitating clients with cognitive impairment in rehabilitation settings

- **McGilton, K.S.**, Davis, A., Naglie, G. Mahomed, N.,Flannery, J. , Jaglal, S., Cott, C., & Stewart, S. (2013). Evaluation of patient-centered rehabilitation model targeting older persons with a hip fracture, including those with cognitive impairment. BMC Geriatrics, 13(1), 136. doi: 10.1186/1471-2318-13-136

Questions?

Contact Information:
kathy.mcgilton@uhn.ca