



Baycrest Centre
for Geriatric Care

Health
and
Everything

Improving Quality of Life in Long Term Care

Kunin-Lunenfeld Applied Research Unit
4th Annual Conference

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- This Presentation will be available on our web site when I return
 - www.healthandeverything.org
- For more information you can write to me at
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Conflict

- Yes all the time



Interest

- Always



Dr. Steven Sabat

“Interpersonal Relationships and the Maintenance of Social Identity and Self Esteem in Long Term Care Settings”

- Attacked a received view:
 - People with Alzheimer’s have lost themselves
 - Lost their memories
 - Lost their minds
 - Lost their identity



What is Identity and Selfhood?

- John Locke
 - Identity is the sum of experiences
 - And hence of memories
- Thomas Reid
 - Identity is based on more than memory



Three Parts of Selfhood

- Personal Identity
 - I experience myself as a single entity through time, take responsibility for my actions
 - The self of personal identity persists through deterioration
- Physical And Mental Attributes
 - Can become negative while maintaining identity
 - The label of Alzheimer's pathologizes our reaction to negative characteristics
 - Results in rejecting a person's experience
 - Reinforces deterioration
- Socially constructed personae
 - We all take on many different roles
 - Requires cooperation of others
 - Assigning people the role as "patient" can debilitate them even more by interpreting what they do in a negative way
 - E.g. Wandering vs Taking a Walk



- Lots of evidence that behaviour is meaningful and rational among people with Alzheimer's but is often misinterpreted because other people attribute the patient role to them and position them negatively



Professional-Patient Relationships

- Entry into long term care is entry into an environment where normal social relationships and social personae can become immersed in insitutional and professional context and are less interpersonal



Recommendations

- Recreating personal interactions in long term care settings can help people maintain their social identity and self-esteem
 - Surfacing our unconscious prejudices can help us do this
 - We must supply support for personalizing institutional relationships



Carol Greenwood

“Quality Dining Experience: Meeting Individual Needs”

- How do we understand how people eat as disease progresses?
- Our eating patterns change as we age
- As other changes occur
- And we must accommodate to them



Entering Long Term Care

- Often there is a prevalence of weight loss, anemia, pressure ulcers
- Suspect malnutrition
- How does this happen?



Natural History of Changes During AD

- General decline in caloric intake
- Eat most at breakfast and least at dinner
- Shift from protein to carbohydrates
- Providing excess food reduces intake



Strategies to accommodate

- Large breakfast
- Nutritional Snack between breakfast and lunch
 - Worked best with heaviest and least impairment
- Capitalize on carbohydrate preference at dinner (Breakfast like foods at dinner)
 - Worked best with low BMI and more impairment



Recommendations

- We must accommodate to individual needs better
- We can recognize changes in normal eating patterns as people age in our nutritional planning
- We can Intervene earlier so that people maintain weight longer



Sudeep Gill

“Pharmacologic Treatments for Difficult Behaviours: Current Knowledge for Best Practice”

- Behavioral and Psychological Symptoms of Dementia (BPSD)
 - Symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients with dementia
- Agitation
 - Inappropriate verbal, vocal or motor activity unexplained by apparent needs or confusion
- **Unexplainable vs unexplained**



Alternatives to drugs

- ABC Charting
 - Antecedent
 - Behaviour
 - Consequences
- Modify antecedents



Alternatives to Drugs

- Education, training and support for caregivers
- Pleasant events
- Bright lights and music
- Redirection
- ID Bracelets



Drug Treatment (Last Resort)

- Clear identification of goals
- For some behaviours drugs don't work
- For others they are inappropriate
- Goals
 - Reduce distress of patient or caregiver
 - Reduce disability
 - Reduce danger to self or others



Review of Following Drugs

- **Anti-psychotics**
 - For hallucinations, delusions and aggression only
 - Use lowest possible doses
 - Monitor for adverse events
 - Discontinue after 3-6 mos
- **Antidepressants**
 - Some useful for depressed
 - But more research is needed
- **Benzodiazapene**
 - Toxic effects limit their use Antipsychotics are better
- **Anticonvulsants**
 - Some evidence but adverse events limit use
- **Cholinesterase Inhibitors**
 - Of limited use weak effects
- **Other agents**
 - Need more research



Conclusion

- Drugs as a last resort
- One size does not fit all
 - Detailed individual assessment to identify individual differences
- Drugs should be reassessed often



Barbara Bowers

- “Quality of Life and High Quality Care: Creating the Right Systems”
- Several Perspectives
 - Patients’ Perspective
 - Should include asking them
 - Personal Support Worker’s (PSW) perspective
 - Know intimate details about patients through a series of cues
 - “The way they say hello in the morning”
 - Able to see individual cues for lots of stuff
 - What they like
 - When to go to sleep



What is the Residents Perspective

- Should include asking patients
- Many Obstacles to this
 - Cannot get answer if wrong questions are asked.
 - Lower expectations can increase measures of satisfaction
 - The Baycrest interview



Quality and Relationships

- Good relationships with residents are the most critical contributor to quality
- Aspects of relationships
 - Loyalty (Respecting who you are)
 - Duration (Long Term)
 - Shared experience (increased equality)
 - Familiarity (Knowing the medical and personal)
 - Reciprocity (Should not be taken away)



Quality Based on Relationships

- Vigilance
- Attention to Detail
- Getting others to do it right
- Remembering
- Listening
- Eye contact
- Telling others
- Clearing the way
- Checking up
- Doing more than necessary
- Making exceptions



Scheduling and Patients' Wants

- Providing choices
 - When do you want to get up
 - When do you want to eat
 - When do you want to bathe or shower
- How can the institution respond?
 - Flex schedules
 - Cooperation among staff etc
 - Everyone pitches in



Recommendations

- Recognize and value PSW knowledge of the patient
- Provide support for relationships between PSWs and patients
- Help Increase patient choice
 - Possibly no need for more resources if the above are in place



Katherine McGilton

- “Quality Supervision in Long-Term Care: What Works”
- Quote of the Day

“Nursing homes often try to promote warm nurturing bonds between staff and residents while maintaining a paramilitary command structure”

Thomas 1994



- Work in ICU and Long term Care are comparable in terms of complexity
- Relationship between supervisor and direct care worker is most critical
 - Empathy
 - Reliability
 - Nurtures personal side of relationship



Work Strategies

- Supervisors knowing the residents needs and assign fair caseloads
- Mentor staff
- Can delegate
- Can get advice from Administrator
- Kept in touch with staff
- Share information



Recommendations

- Enhance capacity of supervisors
- Improve relationships with administrators
- Get rid of obstacles to supervisors doing their work



David Streiner

- “Meeting the Challenges of Measuring Quality of Life”
- Quality of Life
 - Before 1949 there was no quality of life (QoL)



- People adapt to changes in their capacity
 - Self assessed quality of life can remain high even as they deteriorate
- We choose reachable goals
 - Shoot first then draw the bull's eye



Streiner Domains of QoL

- Physical health (symptoms, treatment side effects)
- Mental health (positive well-being through distress to major disorder)
- Social health (social contacts and interactions; subjective and objectives)
- Functional health (self-care, social role functioning, etc.)

- What about the externalities?



- Housing
- SES
- Food
- Work etc
- Life satisfaction



Special Problems of AD

- What do we assess?
- Patients can't respond
- Patients with moderate AD
 - Do they understand
 - Can we believe the answers
 - Can they self assess
- How accurate are caregivers



Conclusion

- Much work to be done
- Include clients perspective
- Clarify Domains



Some Overall Impressions

- Increase our capacity to understand individual residents' perspective
 - Sadness at end of life and loss of capacity
- Enable a normalization of social relationships even in long term care settings
 - Beyond professional contacts
- Recognize how we change as we age
 - In terms of diet
 - In terms of relationships
 - In terms of identity
- Respond to individual differences across all these domains
- Pharmacological Intervention as a last resort



Residents Quality of Life

- Self assessed well-being is very reliable
- Dependent on adapting to their own situation
 - Small things can make a big difference
- Critical factor of relationship with those who are most intimate with them
 - PSWs
 - Who provide the most important intimate small supports
- Supported by supervisory staff and administration



5 dimensions of Relationship

- Amount of Direct Contact
- Continuity
- Well rounded acquaintance
- Together as equals
- Common purpose