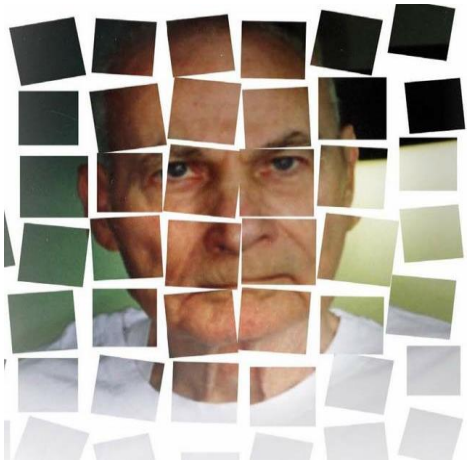
Fighting for Dignity: Prevention of Distressing and Harmful Resident-to-Resident Interactions in Dementia in Long-Term Care Homes



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May 12 2016 @ BrainXchange, Toronto, Canada

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Objectives

Identify…

1. **Consequences**

3. **Contributing factors, causes, & situational triggers**

4. Psychosocial **strategies** prevention and de-escalation

Over a Century-long Problem

"…when walking about groped the faces of other patients, and was often struck by them in return."

Auguste D. Year: 1901

Book: Lock (2013). The Alzheimer's Conundrum: Entanglements of Dementia and Aging.

Definition
Resident-to-Resident "Aggression"

"Negative, aggressive and intrusive **verbal, physical, material, and sexual** interactions between LTC residents that in a community setting would likely be unwelcome and potentially **cause physical or psychological distress or harm** in the recipient."

(Rosen, Pillemer, & Lachs, 2008; McDonald et al. 2014)

Resident-to-Resident Elder "Mistreatment" Instrument

(Teresi et al. 2013)

- Use **bad words** toward another resident
- **Scream at** another resident
- Try to **scare, frighten, or threaten** with words
- **Boss around** / tell another resident what to do
- **Hit** another resident
- **Grab** or yank
- **Push** or shove
- **Throw things**
- **Threaten** with a cane, fist, or other object
- **Kicking, biting, scratching**, or spitting
- **Going into another res room** without asking or **taking**/touching/damaging or breaking **other res personal things**

High Prevalence & Incidence

Lachs et al. (2014): *n*= 2011 residents; 10 NHs in NY;
Resident & staff interviews, chart reviews, direct observation
20% were "mistreated" by a fellow resident in past month (Verbal = 16%; Physical = 6%; Sexual = 1%; Other = 11%)

Castle (2012): 249 NHs in 10 states;
Mail questionnaire: n = 4,451 nurse aides; past 3 months
The number of resident-to-resident "abuse" cases is high

Scope Review by McDonald et al. (2015) found **high incidence: One-third of all cases of "abuse"** in LTC homes

Underreporting

"**The majority of resident-to-resident mistreatment incidents are not reported** in most nursing homes"
- Prof. Jeanne Teresi

Underreporting and poor quality of reporting are major **barriers** for prevention

MDS 3.0 doesn't identify target: Staff vs. Residents

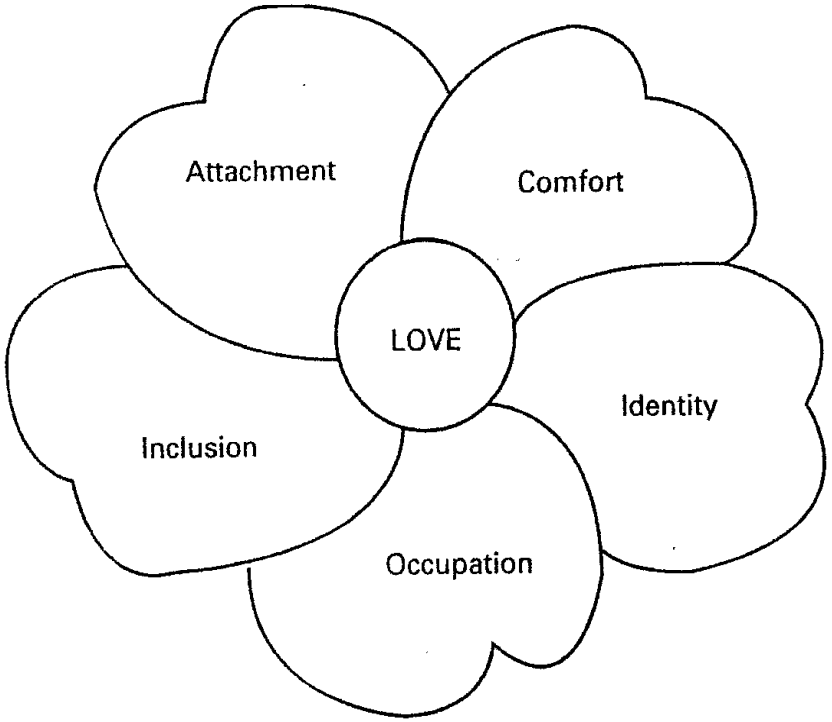
Caspi, E. (2013). M.D.S. 3.0 – A giant step forward but what about items on resident-to-resident aggression? JAMDA*, 14(8),* 624- 625.

Behavioral Expressions labeled as "Aggressive" in people with dementia are mostly…

- **Expressions of unmet human needs**
- Have **meaning, purpose, & function** *to the person…*
- Attempts at **communication** that need be explored with validation – Judy Berry, president, Dementia Specialist Consulting
- Attempts at **gaining control** over unwanted, frustrating or threatening situations
- Attempts at **preserving identity & dignity**

=> BAROMETERS for resident's tolerance to stressful stimuli…

The Main Psychological Needs of Persons with Dementia



Source: Kitwood, (1997, p. 82). Dementia Reconsidered: The Person Comes First.

Close Trusting Relationship

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Know the Resident's Early Life History

20 reasons why can be found at: http://tinyurl.com/l6p6ux4

Case Example

(Johnston, 2000)

Horticulture group activity in VA Medical Center – a group of Veterans are **transplanting blooming tulips…**

Mr. W became pale, tremulous, agitated, hyperventilated, and **pushed another resident**…

He was physically restrained and returned to the locked unit

Conversation revealed: **Became distressed on seeing the tulips**

Life history: During his army service in WWII **several of his platoon were killed** after being cornered **in a tulip field…**

Mild to Serious Consequences

Negative consequences for:
Target resident ←

Exhibitor
Residents witnessing
Care partners (staff)
Family members
Visitors
LTC home
Society

+ Substantial cost implications…

Consequences for Target Residents

- **Psychological**: frustration, anger, anxiety, fear, sadness, depression, social isolation, avoidance of activities
- **Physical:** Injuries and accidents: falls, dislocations, bruises or hematomas, reddened areas, lacerations, abrasions, fractures (e.g. hip), brain injuries
- **Deaths**: Dozens of reports in the media

Frank Piccolo

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Review of 40 Deaths due to DHRRI in Dementia

- **Nature of physical contact**: 32% push/beat-fall episode
- **Time until death** (average): 8 days (32% same day)
- **Location**: 68% inside bedrooms (19 out of 28 episodes)
- **Roommates**: 37% (15 out of 40)
- **Time:** Majority during evening (+ 3 during the night)
- **Weekends**: 62% (18 out of 29)
- **Not witnessed**: 70% (19 out of 27)

Editorial in JAMDA (January 2016):

http://www.jamda.com/article/S1525-8610(15)00640-4/pdf

Next Step…
Analyze Medico-Legal Databases

- **National Coronial Information System** (Australia)

(Murphy, Ibrahim, Bugeja, & Pilgrim, 2016: Monash University; Victorian Institute of Forensic Medicine)

- **National Violent Death Reporting System** (U.S.)

  (CDC's Division of Violence Prevention)

- **Canadian Coroners and Medical Examiner Database** (Canada)

Contributing Factors, Causes, & Triggers

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Common Causes & Triggers

- Resident history & background factors (traumas; personality; “aggression” prior to admission; poor relationships; depression)
- Physiological, medical, functional causes
  - Pain; constipation; dehydration; UTI; delirium; hallucinations; delusions
  - Specific dementias: bvFTD; TBI; CTE (Dementia Pugilistica), Korsakoff syndrome
  - Serious Mental Illness (SMI) (e.g. Schizophrenia) and PTSD
- **Factors in the physical environment ←**
- **Situational causes and triggers ←**
- **Care partners and organizational factors ←**

Contributing Factors in the Physical Environment

- **Segregation of a large number of people with dementia**

- **Large unit size and layout limiting supervision**
- **Inadequate landmarks/signage** (wayfinding difficulties)
- **Crowdedness**
- **Noisy, over-stimulating, & hectic environment**
- **Lack of privacy and private away spaces** (beyond bedroom)
- **Private vs. shared bedrooms** (conflicts b/w roommates)
- **Indoor confinement**
- **Hallways** (too narrow; “dead ends”)
- **Inadequate lighting & glare**
- **Too cold or hot**
- **TV**
- **Elevators**
- Access to **sharp/dangerous objects**

Situational Causes and Triggers

- Frustration with **being institutionalized** / **Lack of control & choice**

- **Boredom**
- **Situational frustrations** / **interpersonal stressors**
- Miscommunications and **misunderstandings**; misperceptions
- **Invasion of personal space**
- Problems with **seating arrangement**
- **Intolerance of other's behavior** (Repetitive questions; unwanted touching)
- **Taking another's belongings** / Competition for limited resources
- **Unwanted entry into one's bedroom**
- **Conflicts b/w roommates** (about "rules" for using the bedroom)
- **Racial/ethnic comments/slurs**
- Discrimination and hostility towards people who are **LGBT**

Theme: Unmet Human Needs

Care Partners & Organizational Factors

- **Biomedical…*vs*…Person-directed & relationship-based care**: Arcare, Helensvale, Australia: http://tinyurl.com/jxldwfv

- Inhumane **staffing levels** (Highly stressful working conditions)
- **Lack of training** in prevention of DHRRI in dementia & SMI
- **Lack of support and guidance** of direct care partners by managers
- New, inexperienced **& unsuitable** direct care partners
- **Tensed** and dysfunctional **relationships** b/w employees
- **Hierarchical organizational structure**
- Care partners **burnout**
- **Inappropriate approaches**, attitudes, & communication style
- **Inattentiveness** to early warning signs of distress & frustration
- Language or cultural **mismatch** (care partners-residents)

Prevention and De-escalation Strategies

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Prevention and De-escalation Strategies

We all want a magic bullet/quick fix…but the reality is…

It's the **cumulative effect of multiple factors** in the social and physical environment and factors at *all* levels of the organization and beyond – **intersect with** the resident's cognitive impairments and unmet needs – **lead to DHRRI**

It is an **endless culture change journey** requiring *fundamental* changes in practices and organizational operations & strong and ongoing commitment from all…

Prevention and De-escalation Strategies

- Strategies at regulatory/oversight, emergency, and law enforcement levels

- Procedures & strategies at organizational level ←
- Proactive measures ←
- Immediate strategies during episodes ←
- Post-episode strategies ←

Strategies at Regulatory/Oversight, Emergency & Law Enforcement Levels

- Adequate **Reimbursement / Incentive System**
- Bridge gap in **M.D.S. 3.0**
- Adequate **reporting** and **measurement tools**
- Improve **Nursing Home Compare** Website
- Build *small* PDC **Behavioral Units** (dementia; SMI)
- Understand and protect from **Sex Offenders**
- Develop discharge policy to avoid **wrongful evictions**

- Proactively address **Assisted Living** "ticking time bomb"

Strategies at Regulatory/Oversight, Emergency & Law Enforcement Levels

- **Regulations**; **Policies and Procedures** (NHs & ALRs)

RE-EXAMINE DHRRI-specific PRACTICES, DEFINE ROLES, and TRAIN:

- **Government Accrediting & Surveying Agencies** (State and Federal/CMS)
- **Ombudsman program**
- **Police officers**
- **Medical Emergency personnel**
- **APS**
- **Medicaid Fraud Control Units**
- **Coroner/Medical Examiner** Agencies

- **Death Certificates**

=> Collaboration and **timely information transfer b/w all agencies** (e.g. b/w Police & State Survey Agencies) and **b/w agencies & LTC homes**

Coordinated Inter-Agency Strategy

- *"For the cause of assuring safety in long-term care, it means **the coming together of expertise** including the appropriate government officials, community agency workers, long-term care administration, frontline staff, family caregivers, researchers…..and the media"* – Social workers Eleanor Silverberg, Angela Gentile & Victoria Brewster

- Caspi, E. (2015). Policy Recommendation: The National Center for Prevention of Resident-to-Resident Aggression in Dementia. *JAMDA, 16,* 527-534.

Critical Government Initiatives

Canada

- **Behavioural Support System** (Mobile Interdisciplinary Seniors Behavioural Support Outreach Teams). Ontario Ministry of Health & LTC: http://tinyurl.com/zalhgz9

Australia

- **Dementia Behaviour Management Advisory Service** (Australian Government Funded): http://dbmas.org.au

Strategies at Regulatory/Oversight, Emergency & Law Enforcement Levels

*"**One of the challenges** is that we have a system where it is up to nursing homes to pretty much **police themselves**"* – Professor Laura Mosqueda

"***What worries** Prof. Karl Pillemer is not that nursing homes can't find ways to reduce residents' mistreatment of each other, but that **they won't face much pressure to try***"

– Paula Span, New York Times, quoting Prof. Pillemer

Procedures & Strategies at the Organizational Level

- Address DHRRI in your **Policies and Procedures**
- Set **realistic admission and discharge criteria**
- Conduct **pre-admission behavioral assessment**
- **Employ the right people** & train and support them!!!
- Implement **consistent** ("dedicated") **assignments**
- Implement **mechanisms** for **knowing residents' life histories**
- Develop **roommate selection** and **reassignment policy**
- Strengthen **reporting policy** (Culture of blame → Learning)
- Improve ***quality*** **of documentation**
- Regularly hold **Resident & Family Council** meetings

Guiding Principle

*"*The most important principle in treating the aggressive person is the effort to **understand *the meaning* of the sequence that led to** the aggressive behavior*"*

– Prof. Jiska Cohen-Mansfield

Encouraging Research Findings

- **Early warning signs and situational triggers** can be observed in the majority of these episodes (Caspi, 2013; Snellgrove, 2013)

- DHRRI tend to **occur in patterns**

  (time of day, location, events, people, objects)

- **A small number of residents account for a large portion** of DHRRI (Malone et al., 1993; Negley & Manley, 1990; Allin et al. 2003; Almvik et al. 2007; Bharucha et al. 2008)

Proactive Measures

- "The best way to handle aggressive behaviors is **to prevent them from occurring in the first place**" – Judy Berry, president, Dementia Specialist Consulting

- "The only way to manage behaviors in persons with dementia…and I mean the only way…is to prevent them in the first place…but **unfortunately we spend most of our time reacting** to the behavior **when we should be reacting to the cause"** – Jan Garard, RN, MN Department of Human Services

Fire Inspector vs. ~~Fire Extinguisher~~ (Dr. John Brose)

Walking Group Intervention

(Holmberg, 1997)

- **Frequent and distressing RRI during early evening hours** at a care home for people with dementia…

- **Intervention**: Immediately after dinner volunteers led a 30-minute walking group for 3 consecutive days

  (Comparison: 4 days without walking groups)

- **Outcome**: 30% reduction in “aggressive” incidents during 24 hours after walking… (RRI & Resident-Staff)

Proactive Measures

- **<u>Train in caring for and communicating with people with dementia:</u>**
  1. Habilitation Therapy: http://www.alz.org/delval/in_my_Community_64433.asp
  2. P.I.E.C.E.S. Model: http://pieceslearning.com
  3. Validation Method: https://vfvalidation.org/web.php?request=index

- **Protect care partners** (e.g., Train-the-trainer non-violent self-protection techniques – TJA PSI): http://www.tjapsi.com/hc_index.htm

- **Strengthen info transfer** / Be informed about previous episodes
- **Ensure *everyone* knows residents involved in DHRRI**
- **Promote teamwork**!
- Provide **structured/consistent routine** (but be flexible…)
- Instill **empathy**/compassion **between residents**

Proactive Measures

- **Be constantly alert.** Watch residents vigilantly!
- **Identify and respond to early warning signs of distress/anxiety**
- **Be proactive!** "Stop the vicious cycle of reactivity" (Zgola, 1999)
- Regularly **move around the unit** (avoid congregating in 1 place)
- **Modify the physical environment** (dementia-friendly guidelines)
- Remove or secure **objects used as weapons**
- Ensure **content on TV** is enriching, calming, and therapeutic
- Ensure **active presence of managers** (evenings, weekends, & holidays)
- **Recruit volunteers** (e.g. **"Buddy System"** for new residents – Judy Berry)
- Install **emergency call buttons** & use **hand-held radios**
- Use **assistive technology** (e.g. Vigil Dementia System)

Meaningful Activities

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Encourage Creativity
Case Example

When **bored**…a resident with dementia engaged in "aggressive" behaviors toward other residents…

He wanted to work and feel useful…

The care team bought him **a manual lawn mower**…

He is now using it all the time to mow the lawn outside and it reduced his 'aggressive' behaviors.
"This is the best $79 I've spent." – Judy Berry

Experts' Opinion

"**Activities are the main weapon against** behavior difficulties and violent behavior" – Dr. Paul Raia

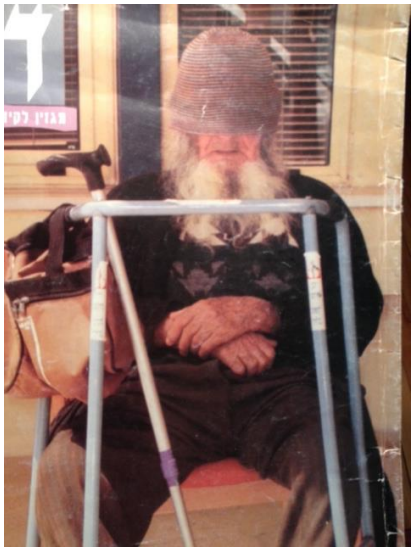
"If a person with dementia is **engaged** in a *meaningful* activity, the person **can not simultaneously be exhibiting problematic behavior"** – Dr. Cameron Camp

Unless…

Unmet medical need; fatigue; remote trigger from past; something negative in physical environment; activities not planned or delivered professionally or incompatible to resident's preferences, abilities, disabilities

But the reality is…

Most residents are **not engaged** in **activities most of the time** in NHs
(Cohen-Mansfield et al. 1992; Burgio et al. 1994; Schreiner et al. 2005; Wood et al. 2005)



Boredom = The enemy of a *subgroup* of residents with dementia!

"A resident who is at most risk of an assault is bored!"

- Administrator of a nursing home

Research Findings
Evening = Vulnerability Time Period !

- **Half** of distressing RRI episodes occurred **between 5pm – 8pm** (Donat, 1986)

- **Half** of DHRRI incidents requiring police involvement occurred **between 4pm – 10pm** (Lachs et al. 2007)

Most NHs do not offer *meaningful* activities during the evening hours. **A missed opportunity**

- **Higher** number of **direct care partners** during **evening** hours was found to **reduce distressing RRI** (Donat, 1986)

"A wise lawyer will first approach the activity director and ask: **'How did you engage the resident in a way that would have prevented the violence/injury against my client?'"**

– Dr. Paul Raia, Alzheimer's Association, MA

Immediate Strategies During Episodes

"The behavior can not be changed directly,

only indirectly by changing either ***our*** **approach or** the person's **physical environment**"

– Dr. Paul Raia

Immediate Strategies During Episodes

- "Engage in a **swift, focused, decisive, firm, and coordinated** intervention" (Soreff, 2012).
- Immediately defuse **"chain reactions.**" Anxiety is contagious!
- **Redirect resident(s) from the area**
- **Avoid overcrowding resident** (will strike if feels "cornered")
- Offer to **take a walk together**
- Distract/divert to a **different activity** or change the activity
- **Refocus/switch topic** to his/her favorite conversation topic
- Position, reposition, or change **seating arrangement**

Immediate Strategies During Episodes

- Physically and skillfully **separate residents**
- **Avoid** conversations in **loud/crowded places**
- **Slow down!**
- **Avoid approaching from behind/side**…usually from the front
- Establish **eye contact** (unless threatening/culturally inapprop)
- If he **starts to walk away, don't try to stop** him right away (Judy Berry)
- Maintain a **safe distance** (slightly beyond striking range)
- Speak at the **level of the eyes** (never above the resident)
- **Speak *with*…not *at*** the resident

Immediate Strategies During Episodes

- **Try to stay calm!** They *will* "mirror" your emotional state!
- **They'll respond to the unspoken…even if you said the right thing!** (Jan Garard)
- **Be sincere**. Many people with dementia can detect insincerity
- Be **firm and direct** (rather than angry or irritated)
- Use **short, simple, familiar words/sentences** & one-step directions
- **Never ignore their emotions**… **Encourage expression of feelings** (frustration; anger; fear) but do it in a safe way and location...

Immediate Strategies During Episodes

- Encourage **a compromise**
- **"Save face"**
- **Avoid arguing, reasoning, correcting,** or criticizing a resident with dementia
- "**Validate** the subjective truth, internal reality, & feelings of the person, no matter how illogical, chaotic, or paranoid..." (Naomi Feil, Validation Method)
- **Avoid** using **Reality Orientation** (in mid-to-late stages of Alzheimer's disease)
  Avoid questions that challenge short-term memory ("Didn't I just tell you…?")
- **LISTEN TO FEELINGS, less to facts; RESPOND TO EMOTIONS, not to the behavior**
- Identify & proactively address **underlying needs *behind* the words and behaviors**
- **Turn negatives into positives**; **Avoid** using words: **"No!" "Don't…" & "Why?"**

Immediate Strategies During Episodes

- "Never command/demand. Instead **ask for their help"** (Berry, 2012)
- **Apologize** sincerely when things go wrong…
- Ask the person for **permission**
- It is (usually) **not intentional**. Try not to take it personally!
- **Be patient** and **supportive.** They face an avalanche of losses!!!

- "If what you are doing is **not working**, STOP! **Back off – Give the person some space and time**. Decide on what to do differently. **Try again!"** (Teepa Snow). Don't leave resident(s) alone when unsafe!

- **Seek assistance** from co-workers (esp. those the resident trusts)

- Be **consistent in approach** (across staff, shifts, days, weekends)

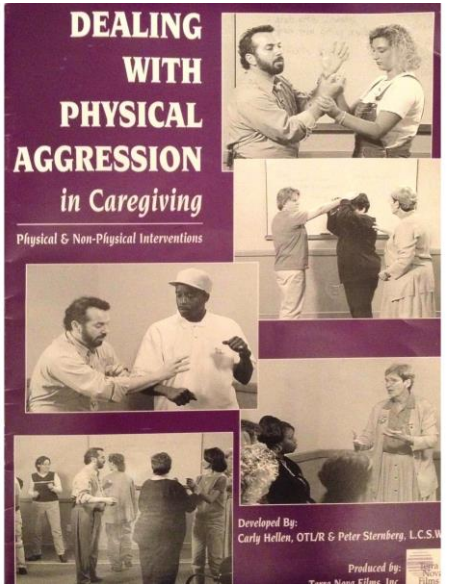
- **Promptly notify interdisciplinary team and physician** re episodes

Recommended DVD

Carly Hellen & Peter Sternberg (1999). Dealing with Physical Aggression in Caregiving: Physical and Non-Physical Interventions

Techniques demonstrated:

- Release from **a grab**
- Deflecting **a strike or a kick**
- Dealing with your **hair pulled**
- Planned containment
- Unplanned containment



Link to Terra Nova Films: http://tinyurl.com/hveq5tr

Post-Episode Strategies

- **Provide** (adult-to-adult) **reassurance!**
- Hold **de-briefing** procedures and **meetings** (a "360-degree" approach)
- **Document** sequence of events/triggers leading to DHRRI (**Behavior Log**)
- **Seek emotional support** from a trusted co-worker or supervisor
- **Consult with nurse and physician** (1st aid; evaluation of medical cause; change in meds)
- **Inform & consult with family** (timely; reliably; value their input/insights)
- Consider **change in seating arrangement** or **bedroom/roommate** assign.
- **In true emergency** (e.g. potential for immediate harm), **consider transfer** to psychiatric hospital / neurobehavioral unit **for evaluation**

Assessment is Key

Characteristics of effective individualized assessment:

- Proactive
- Comprehensive
- Interdisciplinary
- Whole person & Person-directed
- Life course perspective
- Needs-based
- Persistent / Systematic

Assessment-based "Anticipatory Care Approach"

(Prof. Christine Kovach)

What's in your quiver?

- Recognizing Early Warning Signs of Distress (Caspi)
- Behavioral Expressions Log (Caspi)
- R-REM Instrument (Teresi et al. 2013)
- Brøset Violence Checklist (Almvik et al. 2007)
- Evaluation of Urgency of DHRRI Form (Caspi)

- Interdisciplinary Screening Form (DHRRI & dementia-specific) (Caspi)

- Behavior Intervention Plan Form (adapted from Dr. Paul Raia)

Behavioral Expressions Log (*5WsIOS*)

Date	When?	Where?	Who?	Why?	Intervention	Outcome	Suggestion
_/_/_	Time	Location	Who was there?	Cause / Trigger	Describe intervention, if any	Describe outcome	Make a suggestion for future
What? Detailed description of the behavioral expression and what happened (sequence of events) BEFORE and AFTER the behavior: _____ _____							

Persistent use of the log often enables to identify patterns, causes, and situational triggers – the basis for individualized interventions

Will was hitting residents “for no reason”

(Raia, 2011)

Keeping a Behavioral Expressions log revealed:

The hitting occurred only in the activity room [Where?]
Never at night [When?]
Never struck the same person twice [Who?]
Only on sunny days but not on all sunny days [What?]
Only if he sat on one side of the room [Where?]
The sun was glaring in his eyes. He thought the residents were playing with the light switch… [Why?]

Intervention: Drawing down a shade when he is in the room
Outcome: Hitting discontinued; Psychotropic meds avoided…

Two Recommendations

1. Train all employees in DHRRI in dementia & SMI:

- Understanding
- Recognition
- Documentation
- Individualized Care Planning
- Prevention
- De-escalation

2. Low and dangerous staffing levels in many U.S. nursing homes:

Harrington et al. (2016): http://tinyurl.com/jgtt4uu

=>

Pass legislation & fund adequate staffing levels (adjust for acuity)

The Consumer Voice for Quality LTC: http://tinyurl.com/hyv3kkh

Policy Goal

"We talk about violence-free schools...

Why we don't talk about violence-free nursing homes?

What about ending violence in nursing homes as a policy goal?"

- Professor Karl Pillemer

Questions / Discussion

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DEMENTIA BEHAVIOR CONSULTING

Website: http://dementiabehaviorconsulting.com

Archival Blog:
The International Center for Prevention of DHRRI in dementia in LTC Homes:
http://eiloncaspiabbr.tumblr.com