SA23- Addressing the Needs and Challenges of Younger Adults in LTC

Saturday, March 24
4:00 PM- 5:30 PM

Session Description

This session will examine differing needs and risks associated with younger residents in LTC. Speakers will discuss reasons for the growth of this population, and associated challenges as LTC facilities and staff adapt to individuals who may be very long-term residents whom are tech savvy, may retain considerable physical or cognitive capacity, and also may retain interests or personality traits that can be very difficult to manage in a traditional SNF setting.

Learning Objectives
Describe common medical conditions affecting younger residents and psychosocial correlates of these conditions.
Identify risks that may be associated with younger residents and a strategy to mitigate them.
Develop a care plan to address psychosocial issues of younger residents including activity and risk management components.

Presenter(s): Rebecca Ferrini, MD, MPH, CMD; Robert Gibson, PhD, JD

Presenter(s) Disclosures: All speakers have reported they have no relevant financial relationships to disclose.
Younger Adults in Long Term Care: Meeting the Challenge and Setting the Standard
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Speaker Disclosures
Dr’s Ferrini and Gibson have no financial relationship(s) to disclose.

Learning Objectives
By the end of the session, participants will be able to:
• Identify different needs of younger and older residents.
• Have greater awareness of conditions leading to SNF placement in younger and older resident groups
• Be aware of medical differences in younger and older residents, e.g., comorbidities, and conditions leading to admission.
• Recognize regulatory and rights issues more common with younger adults.

A growing concern
• Younger adults, age 18-64 are the fastest growing subpopulation in long term care.
• 20 years ago, those under age 65 were 8% of long term care, now they are 16%.
• Younger adults have longer lengths of stay, are more often funded by Medicaid, and have widely variable needs.

On the Cutting Edge
• Edgemoor has a higher number of younger adults and more experience.
• We led a group representing the USA to develop a toolkit to help others care better.
• There was little literature on younger adults, so we pooled our stories and experiences to develop best practices.

What are pillars of success?
1. Know the residents well.
2. Know the regulations well.
3. Influence behavior through relationships.
4. Work as interdisciplinary team.
KNOW ME FIRST
Younger Adults are different than older adults in their needs and wants.

How do they get into nursing homes?
- Developmental disability.
- Gradual decline due to neurodegenerative disorders (MS, HD).
- Sudden change in lifestyle (accident).
- Long term mental illness and associated decline.
- Long term poor behaviors (drug addiction, poor self care, smoking, alcohol) culminating in cognitive loss, physical abilities and decline.

Meet Martin
Martin suffered a traumatic spinal cord injury resulting in quadriplegia. He now is developing limited use of the upper extremities, but is totally dependent. He is withdrawn, angry and irritable, and complains frequently about staff. He is sure he doesn’t belong with all these old people in the SNF.

A disability in a younger patient has different meaning— a life interrupted with loss of a future they can readily imagine

Younger people are different than older ones...
Psychologically, socially, developmentally, medically, and cognitively

Knocked off course...
Develop may be stunted by drug use, negative lifestyle choices, drugs, and chronic illness.
In many cases, it is their behavior and maladaptive relationships that led to SNF placement.
Generation Differences

- One big difference between younger and older people is the time they grew up in—what was happening in the world, what music they like, what they expect.
- Another difference is their stage of development: younger people are separating from parents and making their own way, and creating new families and identities, older people are experiencing a gradual, expected decline.

Unique medical problems to younger adults

- Fertility and birth control
- Sexually transmitted diseases (though this is a growing problem in the elderly as well)
- A lack of comorbidities
- More physical strength
- Substance abuse may be more prominent

Know the concerns and preferences of younger adults

- Night owls
- I want to get out of here
- Fashion ideas
- Social media, technology
- Minor children
- Goals for the future (education)
- Ideas about privacy
- Different expectations, entitlements
- Different attitudes toward tube feeding and cognitive loss and code status

“Knowing” includes understanding decision making capacity: U-CARE

- Do they Understand the issue?
- Are they Consistent in their responses/wishes?
- Can they Appreciate the likely consequences of courses of action?
- Are they able to Reason effectively?
- Can they Express a position?

Try Aid To Capacity Evaluation (ACE)

1. Medical Condition:
2. Proposed Treatment:
3. Alternatives:
4. Option of Refusing Proposed Treatment (including withholding or withdrawing proposed treatment):
5. Consequences of Accepting Proposed Treatment:
6. Consequences of Refusing Proposed Treatment:
7a. The Person’s Decision is Affected by Depression:
7b. The Person’s Decision is Affected by Psychosis:

INSTRUCTIONS FOR SCORING

1. Domains 1-4 evaluate whether the person understands their current medical problem, the proposed treatment and other options (including withholding or withdrawing treatment). Domains 5-6 evaluate whether the person appreciates the consequences of their decision.
2. For domains 1-6, if the person responds appropriately to open-ended questions, score YES. If they need repeated prompting by closed-ended questions, score UNSURE. If they cannot respond appropriately despite repeated prompting, score NO.
3. For domain 7, if the person appears depressed or psychotic, then decide if their decision is affected by the depression or psychosis. For domain 7a, if the person appears depressed, determine if the decision is affected by depression. Look for the cognitive signs of depression such as hopelessness, worthlessness, guilt, and punishment. For domain 7b, if the person may be psychotic, determine if the decision is affected by delusion/psychosis.
Really understand the regulations and rules

Younger Adults push the limits of regulations not designed for them.

§483.10 Resident Rights are strained with younger adults

- §483.10(a)(1) A facility must treat each resident recognizing each resident’s individuality. The facility must protect and promote the rights of the resident.
- §483.10(b) Exercise of Rights. The resident has the right to exercise his or her rights as a resident of the facility and as a citizen or resident of the United States.
- §483.10(e)(2) The right to retain and use personal possessions...
- §483.10(e)(3) The right to reside and receive services in the facility with reasonable accommodation of resident needs and preferences...

Younger adults often focus on rights

- §483.10(f)(1) The resident has a right to choose activities, schedules (including sleeping and waking times)...
- §483.10(f)(2) The resident has a right to make choices about aspects of his or her life in the facility that are significant to the resident.
- §483.10(f)(4) The resident has a right to receive visitors of his or her choosing at the time of his or her choosing...
- §483.10(g)(6) The resident has the right to retain and use a cellular phone at the resident’s own expense.
- §483.10(h)(1) Personal privacy includes accommodations, medical treatment, written and telephone communications, personal care, visits, and meetings of family and resident groups...

Regulations mandate both autonomy and safety.

- Assessment and care planning identifies the optimal balance between the need to protect and the exercise of autonomy in each individual situation.
- Capacity assessment is key to finding the balance between autonomy and safety for each individual.

My rights end where your rights begin

- Resident Rights are important, but not unlimited. Rights of one individual cannot impinge on the rights of another (staff or resident).
- Your right to wear tight pants is limited by my right to be free from injury at work and my right not to be forced into doing something that may cause you harm.
- Your right to have your hair styled cannot override his right to have his meal or his brief change timely.

“All your needs and some of your wants”

- Identify the difference between needs and wants or preferences.
- Reframe potential limits to choices/rights invoking the rights of other residents.

Your right to get up when you want is limited by our need to feed other residents from 12-1 p.m.
Influence Behavior Through Relationships:

It works better than education, force, begging, threatening or punishing.....

Relationship Stages

- Initiating
- Maintaining
- Repair/Recovery
- Ending

With Younger Adults, Relationships Tend to be Long-Term

- Length of stay is longer for younger adults-conditions are more chronic, and health is better.
- Discharge options are reduced—in short, you will likely know each other for a long time.
- Invest in these long term relationships for the benefit of staff and the resident.
- Be careful you do not reinforce negative behavior.

Goal is mutual relationship between staff and residents but with appropriate boundaries.

- Like a friend but we get paid and they are paying
- There has to be some “like”
- Unhappy staff pollute a therapeutic environment
- Be aware of potential for parental transference (authoritarian, nurturing, lenient)
- Staff are not interchangeable: if “oil and water”—do your self a favor and do not assign

Past Trauma impacts behavior.

- Resident/staff relationships may be impacted by past trauma.
- In cases of abuse, residents may be prone to interpreting our actions as threatening, hostile or negative.
- May evoke reactions, good and bad, in us as caregivers.

Avoid threats or punishments

- It is common to want to tell the younger adult ..
- “If you don’t like it here, maybe we can find a better place for you.”
- DON’T DO IT!
- You can’t find another place! Try...
- “We are frustrated now. But I know if we keep working at it we can find a solution we can both live with. I am committed to having you here and working this out.”
Gender/Sexual Identity

- Acceptance of LGBTQ persons may be an issue for some staff – younger adults may be more open about their sexuality.
- Reactions to LGBTQ individuals may have encountered discrimination and negative reactions in past relationships.
- Increased risk of trauma or substance abuse

Empathetic listening—nonviolent communication

- Much communication is unintentionally “violent”
- Empathetic listening may include:
  - Observations—describe what is seen without judgement
  - Feelings—emotions (and they don’t include “attacked”): sad, frustrated, weak….
  - Needs—we share the same needs—connection, order, control
  - Requests—asking not demanding

Work as Interdisciplinary Team

- More perspectives = more solutions
- Honor staff as well as resident needs/perspective
- Unhappy staff will never create happy residents.
- Don’t sabotage the team with nonbelief, siding with the resident, or impractical solutions
- Listening first before problem solving
- Establish an environment of trust so you can hear the truth and innovation/creativity can flourish.

Let’s practice solving problems

- Manipulative, demanding, use of profanity.
- Substance abuse, drug seeking (prescription drugs more often the “drug of choice”).
- Frequent complaints or demands.
- Noise, clutter, night-owl schedules.
- Non-adherence, pushing the limits.
- Challenges with technology that they know more about than we do.
- Poor curb appeal.
The framework we recommend

- Understand their individual perspective.
- Know the regulations.
- Assess capacity
- Develop and nurture the relationship to influence behavior (relationship-based influence versus “compliance”).
- Be clear about staff roles and responsibilities.
- Through engagement and meaning, get to win-win.

“No Male Staff!”

- Susie insists that she cannot have males look at her body because she is young and because she has had bad experiences in the past.
- Can you accommodate her request?

Can we accommodate preference for one-gender staff?

YES
- Dignity issue
- We can relate to her request
- How hard can it be—we have lots of female staff?

NO
- Discriminatory hiring and assigning of work
- Coverage for breaks, absences
- Violates rights of others when certain staff are pulled away

One approach—make it a careplan request with assessment, IDT review and formal response.

We have reviewed your preference with an interdisciplinary team, the reasons for your request, your facility and the other areas where your preferences are honored.

We have:
- Accommodated your preference in your primary assigned staff.
- Listed your preference on your care plan.
- Notified you that we can accommodate your preference at least some of the time.
- Offered you roommate or C.N.A. preferences.
- Assured you that we will do our best to try to have the staff that you want.
- Assured you that we will have qualified staff to meet your needs.
- Informed you of the difficulty of honoring all your preferences in our daily living environment as we do not discriminate due to the race, gender, religion or sexual orientation of our staff, or violate the rights of staff and other residents to have their staff pulled away to accommodate a preference of another.

If your preference cannot be accommodated, you prefer to:

- Have two staff to provide care.
- Have a shower with clothing covering private areas
- Refuse care/pericare until a person with the preferred characteristic is available
- Emergency care only
- Note: refusing/delaying care may result in bad outcomes; staff has discussed these with you and you are aware of the risks.
Demanding Resident

- Maria is a young woman with quadriplegia who wants to look beautiful. She has many exacting requirements for care preferences, consuming the time of staff caring for her. They are burning out and sometimes she or they get injured putting on clothing that is too tight. Staff rotate on and off her care every week and she manipulates them to spend more time by threatening to report them for abuse.

The framework we recommend

- Understand their individual perspective.
- Know the regulations.
- Assess capacity
- Develop and nurture the relationship to influence behavior (relationship-based influence versus “compliance”).
- Be clear about staff roles and responsibilities.
- Through engagement and meaning, get to win-win.

Strategies to manage those who insist.

- Consistent assignments
- High support for staff “in the trenches”
- Make “keeping a staff member relationship” a care plan goal
- Set and enforce limits with the justification that accommodation of her preferences denies other residents’ necessary medical services

Behavioral care plans are not behavioral contracts

Martin again

- Martin purchased a power chair from Craigslist—it is a captain type chair and he needs pillows on the side to hold his trunk up. He operates it quickly but has not hit anyone (which he believes is a testament to his skill). He goes out of the facility without signing out and neighbors complain as they fear he will be taken advantage of and sometimes is in the street. He gets sunburnt and has cigarette burns in his clothing.

The framework we recommend

- Understand their individual perspective.
- Know the regulations.
- Assess capacity
- Develop and nurture the relationship to influence behavior (relationship-based influence versus “compliance”).
- Be clear about staff roles and responsibilities.
- Through engagement and meaning, get to win-win.
Power Wheelchair—operation/storage and transfer to the chair is a privilege that can be lost

- Require MD order and assessment
- Assessment for safe operation (driving test, Statement of Understanding)
- Re-evaluation with problems—don’t put a delirious person in a power chair!
- Rules for safety
- Rules for space—clutter—power wheelchairs are large!

Leaving Grounds Unaccompanied

- Duty to protect, but still a right – how do you balance?
- Capacity assessment
- Functional assessment
- Risk sharing—statement of understanding
- Document, and document again. Reassess with any change. Make sure you clarify the difference between wandering, elopement and leaving unaccompanied.
- Document the struggle between what you think is safe and what you recommend with the reality of resident rights.

Surprise!

Staff are checking on Maria. They knock and enter and note a visitor is in bed with her having sex. She is a quadriplegic with no volitional movement and you last saw her up in her power chair. She calls out when you enter, “Oh my God!” and he tells you to “get out!”

The framework we recommend

- Understand their individual perspective.
- Know the regulations.
- Assess capacity
- Develop and nurture the relationship to influence behavior (relationship-based influence versus “compliance”).
- Be clear about staff roles and responsibilities.
- Through engagement and meaning, get to win-win.

Sexuality in nursing homes must involve planning

Watch for liaisons—if staff are companionable with residents, they can learn a lot about what is happening.

- Separate and investigate
- Assessment of mutuality: Do you know want to be here?
- Assessment of Capacity: Do you know what you are doing?
- Assure no exploitation or abuse
- Address health and safety issues
- Identify role of facility, staff and family—when, what is needed from staff, how to assure privacy

Donald

- 28 years old with diagnosis of developmental disability, obesity and schizophrenia, Donald lacks verbal fluency, but gets easily irritated, especially if redirected or hearing “no.” He repeats the same phrase over and over. If he does not like the response, he may throw his feces or water, hit, pinch or even bite, and even though he sits in a wheelchair, he has been known to stand up suddenly and chase staff.
The framework we recommend

- Understand their individual perspective.
- Know the regulations.
- Assess capacity
- Develop and nurture the relationship to influence behavior (relationship-based influence versus “compliance”).
- Be clear about staff roles and responsibilities.
- Through engagement and meaning, get to win-win.

Aggression is far more frightening and dangerous in the young

- Always begin with assessment—what is diagnosis, triggers, propensities?
- What can be done?
  - Verbal de-escalation
  - Avoid triggers
  - Environmental interventions
  - Continuum of force: Defensive tactics
  - 911

Younger residents complain about gossip, while furiously engaging in it.

- Martin hangs around the nursing station and listens in on conversations. People tell him things! He sometimes likes to tell you what other residents are doing, but gets annoyed that “there is no privacy here.” He had a girlfriend for a while and wanted staff to keep it a secret. He wanted to know why Sally got three weeks off to go to the Filipines while Mary’s time off request was denied.
Getting to win-win with younger adults means letting people “grow-up” in your facility.

- Martin was admitted to your facility 7 years ago after an auto accident. He was so challenging those first 4 years, complaining about staff, being verbally aggressive, lashing out and calling the state—he often had staff in tears. He has grown up a lot in the last years, but he feels staff can never let go of the “old him.”

Encourage transformative experiences

- Education: However, it is also a hassle—arranging care, food, transportation, financing, and who is going to help them study?
- Friendships: developing peer-to-peer or peer-to-staff or outside relationships
- Romance: can change attitudes
- Development of new skills/role—mouth painting, running an activity, fixing your facility computers.
- Electronics—allows a connection to the outside world.
- Hope/goals (e.g. discharge)

Prepare to Develop new skills

Capacity assessment, documentation, learning about electronics and power chairs and regulations, setting boundaries, listening, negotiating, conflict management, and keeping one-step ahead.

Pearls

- Consistent assignments are key—do all you can to promote that relationship as primary
- Focus on listening: Seek first to understand
- Avoid authoritative strategies or too much telling/reminding/ or educating….
- Tell a positive story

Once you have them, be prepared to be challenged

Know what you are getting into BEFORE you admit.

Questions?

For additional questions, sample forms and policies, or copies of materials, please contact: Rebecca.ferrini@sdcountry.ca.gov