TRAINING TOPIC 1 - PERSONHOOD & IDENTITY

Introduction

Personhood and individual identity are at the heart of person-centeredness. Each one of us wants to be seen and known as the unique person we are. As providers, our daily challenge (opportunity?) is asking the questions and creating the environment that allows each resident to feel invited and safe in sharing meaningful details about themselves and how they see themselves and want others to see them -- even as their physical, mental, emotional, or social health may be changing in significant ways. True person-centered care, across departments, cannot be achieved without deeply knowing each resident.

Personhood & Identity

Successful care planning conversations require a genuine attempt to make all participants feel included and empowered to speak up and to feel that their requests, suggestions, ideas, and opinions matter. American culture has long undervalued the process of growing old and the contributions that we all continue to make to our communities as we age. The result is that older people feel less visible and less worthy, particularly if our aging is accompanied by changes in our physical and cognitive abilities, as it often is for nursing home residents.

We all have internalized the ageism that exists in American society and, as a result, extra effort and attention must be paid to counteracting and avoiding the many ways that older people experience a lack of worthiness. The material in this section is designed to heighten awareness of the care team to what it means to be a person with a unique identity and, despite age or declining health, still has opportunities to experience daily life events in ways that matter to each individual.

Personhood Summary

Transitions into Long-Term Care Settings

Concepts of personhood and identity include how we see ourselves and how we see ourselves in relation to how others view us or behave towards us. Individuals moving into long-term care often have experienced significant losses in the form of declining health, cognition, or a physical limitation. Transitioning into a care setting can be a jarring shift in our identity since we are no longer able to fully care for ourselves without assistance. We know that others may see us differently than in previous times during our lives and this results in longing to “feel known” by staff and other residents so we can feel connected to them.

Putting this into practice:

Case scenario

An 89-year-old retired university professor is admitted after safety lapses at home where she lived alone but with family support. She is moderately forgetful. She has a walker, but hates using it and often does not. She fell at home several times without injury. She is an admitted introvert, spends long hours reading, is dismissive of group activities and angry about having to leave her home; she doesn't want to be around "all these old people". She refuses to have meals in the dining room and has only come out of her room reluctantly when staff insist.

Practice tips

Consider the major adjustment she is making personally and professionally and her emotional state (e.g., anger).

Meeting the needs of residents and regulations

The resident has a right to a dignified existence, self-determination, and to be treated with respect and dignity. Staff must help residents maintain or enhance their self-esteem, self-worth, and incorporate their goals, preferences, and choices. Staff must also consider residents' physical limitations, assure communication, and maintain respect. (Regulatory requirement F550 – Resident Rights / Exercise of Rights).

Agency and Decision-Making Autonomy

As "persons", we have legal rights, agency, and moral accountability and an innate human need for autonomy and self-determination. Humans need to feel that we can make our own choices and exercise volition with a sense of competency to carry out the choices we make. Self-determination is the internal motivation we all feel to take action aligned with our own free choice and sense of purpose. Autonomy is the ability to "govern oneself"; to have control over one's physical and emotional self.

In long-term care, autonomy includes decisional autonomy, the ability and access to make decisions about aspects of daily life, and executional autonomy, the ability to carry out one's decisions and preferences. All persons - even those with cognitive changes - should have the opportunity to participate in care and service decisions and express preferences according to their ability. Self-determination and autonomy in long-term care must accommodate each resident's need to transition into and adapt to what might be a radically different environment. Supporting each resident in adapting safely, securely, and with feelings of trust and wellbeing is critical.

Putting this into practice

Case scenario

A school superintendent was discharged from the hospital with a leg fracture and admitted to post-acute rehab. His anticipated length of stay is 27 days. The patient wishes it was half the time and has expressed his desire to rehab at home. Patient has no cognitive impairment and feels humiliated by having to be in rehab. He feels there is no one with whom to have meaningful conversation. He feels he has to lower his standards due to the environment. He is surrounded by patients that are cognitively impaired and/or have a much higher acuity of care. He feels 'out of place.' He wants to stay busy, however, due to his immobility and range of motion challenges, is limited in his choice of activities. He was offered BINGO and was humiliated at the thought of 'playing a game.'

Practice tips

As you prepare to visit with the new resident, reflect on any notes from previous records and/or pre-planning visits with your team. Recognize the importance of first impressions. Prior to you entering the resident's room, they have already had multiple interactions. Take time to explain staff roles and their importance to the team.

Interaction with the resident: knock on the door, enter with permission, introduce yourself, greet the resident using their preferred name, and start the conversation about something that will capture their interest (e.g., school, academics, favorite subject, etc.).

A positive resident experience is the result of multiple factors and interactions throughout the resident journey. Ask the resident, "What do *you* hope we accomplish today?" It is important to have pre-visit planning to keep visits organized and certainly involve them in their care decisions. You can enhance the resident experience through practical steps, such as expanding visit options. In this scenario, provide a visit summary, and *thank* the resident for the opportunity to be part of their care team. This way you establish a sense of trust, continue the ongoing dialogue, and establish a plan of care. Think about it – you have also set expectations for your relationship by discussing communication and follow-up plans.

Meeting the needs of residents and regulations

The resident has a right to a dignified existence, self-determination, and to be treated with respect and dignity. Staff must help the residents to maintain or enhance their self-esteem, self-worth, and incorporate their goals, preferences, and choices. Staff must also consider residents' physical limitations, assure communication, and maintain respect. (Regulatory requirement F550 – Resident Rights / Exercise of Rights). The resident has the right to be informed of, and participate in, his or her treatment, including: (1) The right to be fully informed in language that he or she can understand of his or her total health status, including but not limited to, his or her medical condition. (Regulatory Requirement F552 - Right to be Informed/Make Treatment Decisions).

The resident has the right to participate in the development/implementation of his or her person-centered plan of care, including identifying who should be included in the care planning process; requesting care plan meetings; requesting care plan revisions; participating in establishing goals and outcomes of care as well as any other factors related to the effectiveness of the care plan; being informed in advance to changes to the care plan; seeing the care plan – including the right to sign off on it after a significant change has been made. (Regulatory Requirement F553 - Right to Participate in Care Planning). A personalized, homelike environment recognizes the individuality and autonomy of the resident, provides an opportunity for self-expression, and encourages links with the past and family members. The intent of the word "homelike" in this regulation is that the nursing home should provide an environment as close to that of the environment of a private home as possible. (Regulatory Requirement F584 - Safe/Clean/Comfortable/Homelike Environment).

Sudden or Undesired Life Changes & Difficulty Adapting

How well we adapt to sudden, undesired, or significant changes in our being or in our environment often depends on coping behaviors we have used in our adult lives. Individuals consciously or unconsciously strive for continuity -- of activity, of environments, of identity, of worldview. Learning about a resident's strategies in times of stress or transition for maintaining key elements of continuity in their sense of self (e.g., self-efficacy, empowerment) helps support them in a wholly unfamiliar environment.

Putting this into practice

Case scenario

Mr. Jackson, who is living with dementia (his spouse was his primary caregiver), has recently moved into a nursing home. He is navigating a new living environment resulting in expressions of frustration and social isolation. The unfamiliar surroundings have triggered anxiety and stress, causing Mr. Jackson to react to

interactions with staff, routines, or foods and surroundings that are unfamiliar. Additionally, he is constantly trying to go into other resident's rooms or leave the nursing home. Mr. Jackson is overwhelmed and confused by having a new and different caregiver each day let alone every eight hours.

Practice tips

Prepare residents for care planning conversations. A week or a few days before the care planning meeting, talk with the resident. Questions that could be asked include:

- What makes you feel valued or worthy?
- What helps you be willing to share your opinion?
- What makes you feel better about yourself?
- What helps you cope with stress or adversity?
- What helps you want to engage with day-to-day activities or try new things?
- Would you feel comfortable/or be willing to share [any of the above] in your care plan meeting on [insert date]?

Meeting the needs of residents and regulations

A resident who is diagnosed with dementia must receive the appropriate treatment and services to attain or maintain their highest practicable physical / mental / psychosocial wellbeing. The necessary care and services must be person-centered and reflect the resident's goals. Meaningful activities must address the resident's customary routines, interests, preferences, and choices to enhance their well-being. (Regulatory requirement F744 – Treatment / Service for Dementia). A personalized, homelike environment recognizes the individuality and autonomy of the resident, provides an opportunity for self-expression, and encourages links with the past and

family members. The intent of the word "homelike" in this regulation is that the nursing home should provide an environment as close to that of the environment of a private home as possible. (Regulatory Requirement F584 - Safe/Clean/Comfortable/Homelike Environment).

How to Use with Direct Care Staff

Formal In-Service Training

The material in this module can be used in formal in-service training or orientation sessions. Feel free to use case scenarios from your own community for added emphasis and relevance. Ask staff to reflect on their own experiences, for instance, with stressful life transitions or health or life changes that caused them to feel that others perceived them differently.

Informal Reminders of Personhood Concepts in Daily Care

-Daily Huddles
-All Team Meetings
-Clinical and Non-Clinical Team Meetings
-Quality Circles / Learning Circles

Additional Resources

Person-Centered Care | CMS.
https://www.cms.gov/priorities/innovation/key-concepts/person-centered-care

Wellbeing Toolkit – Ariadne Labs.
https://www.ariadnelabs.org/resources/downloads/wellbeing-toolkit/

The Patient Dignity Inventory.
https://dignityincare.ca/en/the-patient-dignity-inventory.html

Williams, K., Coleman, C. Changing Talk (CHAT) Implementation Toolkit.
https://www.kumc.edu/documents/chato/Changing%20Talk%20Online%20Training%20%28CHATO%29%20Implementation%20Toolkit.PDF

PELI-Nursing Home-MDS 3.0 Section F-Version 2.0 | Preference Based Living.
https://www.preferencebasedliving.com/for-practitioners/practitioner/assessment/peli-questionnaires/peli-nursing-home-mds-3-0-section-f-version-2-0/

Atchley, R. C. (1999). Continuity and adaptation in aging: Creating positive experiences. Johns Hopkins University Press.

Higgs, P., & Gilleard, C. (2016). Personhood, identity and care in advanced old age. Policy Press.

TRAINING TOPIC 2 - RECOGNIZING HUMAN POTENTIAL IN LATE LIFE

Introduction

Humans change and grow throughout our lives, even as we arrive in late life and prepare to die. Each person at every stage of life has innate human potential that can and should be nurtured. Some scholars define human potential as growth towards our *true selves;* thus, how each person defines or expresses their capacity to grow in late life is unique. The concept of human potential relates to the positive aspects of humanity and the ability and opportunity for personal growth and to be our best and true selves. The idea of this "upside of the human experience" has been studied from many perspectives and many disciplines, but fundamentally relates to our collective human desire to "be virtuous and to grow".

What does human potential mean for an aging person?
Recognizing and attending to each resident's human potential is an essential element of person-centered care and one which takes on added importance as each resident nears end-of-life. As our human population grows older, scholars have explored what human potential and wellbeing mean in late life. American culture has historically considered aging as a period of decline and deterioration, rather than embodying growth and opportunity. However, current trends are recognizing the potential for growth even in late life. It may take many forms, including activities and reflections that support making sense of one's life, or acts of creativity, exposure to the arts and music, or reflecting on existential matters. Psychologists consider this a stage of human development and, accordingly, long-term care staff may wish to look for ways to support late life resident well-being.

Moving into a nursing home can make people feel like they don't have control over their lives. Things they used to have control over, like who they live with, what they eat, and who can come into their living space, are suddenly not in their control. All of this can lead people to turn inward and stop learning and creating like they used to.

How is it different for older people?
Human potential is most often used to talk about children or aspiring athletes, looking to maximize their performance and skills. Human potential is relevant for older adults too. There is a common misconception that once you reach old age, you no longer grow - your personality and interests stay the same. Studies have shown that older adults continue to grow and change right up until death. Old age provides unique opportunities to learn and grow. For many, retirement is the first time they do not have to work full time to support themselves. This allows people freedom to pursue hobbies and try new things that they couldn't try earlier in life. Unlike adolescents, many older adults have a stronger sense of self and more stable

relationships. This means that older adults might be more comfortable "going against the flow" and challenging old ideas in new ways. Some scholars think this is why so many revolutionary thinkers, like Gandhi, Copernicus, and Nelson Mandela, did their most influential work later in life. Below, we outline three important concepts related to human potential with short case studies designed to help you and your colleagues use these ideas in practice.

Narratives for aging - Creativity

Creativity is intimately tied to our human potential; engaging in creative activities can offer meaning and purpose, put us in a state of flow, and elevate mood. There is a misconception that as we get older we no longer want to be creative, but as noted, some of the most creative thinkers did their best work at the end of their lives. While the ways that individuals can and want to be creative may change over the life course, creativity benefits everyone. Creating opportunities for creative engagement supports human potential. People living with memory loss are able to express their strengths when engaged in creativity. These activities reflect resilience. The Activity department plays a role in providing quality of life opportunities for engagement through interview and observation. It is a journey of discovery. Activities have been defined as any endeavor, other than routine ADLs, in which a resident participates that is intended to enhance their sense of well-being and to promote or enhance physical, cognitive, and emotional health. When we think of activity engagement, we often think of creativity.

Putting this into Practice

Case scenario

Ms. Albert, who is living with dementia and is non-verbal, is a resident at a nursing home. Her family shared during the assessment process that she was not engaged in anything at home and generally stayed in bed all day. During the first few months, the family brought in a few personal things, including a painting. When staff discussed the painting, it was shared that Ms. Albert had painted it. She was brought into the BINGO game on multiple occasions and the Activity staff provided Ms. Albert with painting materials while the other residents played. After several different attempts of providing painting materials on different days, Ms. Albert started to paint. She painted landscapes, birds, and then painted BINGO cards. Activity staff paid close attention to Ms. Albert's satisfaction: smiling, eye contact, and nodding her head. When staff asked if she wanted to play BINGO instead during one of the sessions, she nodded her head and was given a card. She was able to play the game successfully. After that she was out of bed daily and participated in the activities offered.

Practice tips

Key concepts for staff: creative potential, patience and persistence, close attention to resident cues

The staff practiced effective communication strategies with the resident which included patience. Engagement may not happen at once and the staff recognized this. Conducting a full assessment and continually assessment will help in understanding the person better as a human and help them reach their full potential.

Discussion Questions

1) Who are the residents who are hardest to engage? What are the ways you can find out about or watch for opportunities for creative engagement?
2) How do you and your team learn about each resident's interests beyond what might be in their bio? What are the ways you can use that information to support residents to be more creative?

Meeting the needs of residents and regulations

A resident who is diagnosed with dementia must receive the appropriate treatment and services to attain or maintain their highest practicable physical / mental / psychosocial well-being. The necessary care and services must be person-centered and reflect the resident's goals. Meaningful activities must address the resident's customary routines, interests, preferences, and choices to enhance their well-being. (Regulatory requirement F744 – Treatment / Service for Dementia and F679 - Activities).

Sense Making: Gerontranscendence

Many people think it is a normal part of aging to be depressed by death, but studies show that many older people do not dread dying. It's completely normal to have occasional sad thoughts about death, but a constant and persistent fear of death could be a sign of a deeper underlying problem like depression or anxiety. It could also be a sign that this individual has not been able to fulfill important life goals or go through the meaning-making process (like sharing life stories) in the way they wanted to.

Putting this into Practice

Case scenario

Ms. Nowak, is living with the risk of aspiration and is alert, oriented x3 and able to make her needs known. She has no family living or friends who support her. She has failed her swallowing evaluations and receives her nutrition through a g-tube. She was found eating bird seed and rabbit food at night in the activity room. She was also found sneaking food off the tray left in the hallway. After counseling on multiple occasions, Ms. Nowak expressed her desire to eat and understood the risks and benefits of potential aspiration pneumonia risks. Ms. Nowak signed the necessary

forms and enjoys eating meals with the other residents. She happily lived for six months before passing away from aspiration pneumonia. Before she passed, she shared how happy she was.

Practice tips

Key concepts for staff:

Towards the end of life, everyone wants to "make sense" of everything we have and haven't done in life. Working in long-term care, we have an opportunity to help residents find this peace. It may require some creativity on our part. What works for one resident might not work for another. Additionally, the rules and regulations within your nursing home may make it feel harder to honor residents' needs and wishes. However, cases like Ms. Nowak show how powerful simple changes can be for helping people write their own stories.

Discussion Questions:

1) What are some things we often don't allow residents to do in our facilities, but that we enjoy ourselves?
2) Have any current or former residents shared their goals, wishes, or preferences that are important to them as they approach death? If so, are there any that would be good for your whole team to know?

Meeting the needs of residents and regulations

The resident has a right to a dignified existence, self-determination, and communication. The resident has the right to be fully informed in advance by the physician or other practitioner or professional, of the risks and benefits of proposed care, of treatment alternatives or treatment options and to choose the alternative or option he or she prefers. (F550, Resident Rights, F552, Planning and Implementing Care)

Constraints on Human Potential [Injustice, Inequity, Trauma]

Many residents arrive in long-term care having experienced often long-standing injustices, unequal or disparate treatment, or social or other marginalizations arising from intersections of age, ability, gender, race, sexual orientation, ethnicity, religion, class, or other non-dominant identities. Inequities often lead to internalized beliefs of being less valued or less worthy which, in turn, can be barriers to establishing new relationships in the community or participating in meaningful activities. The challenge for staff is to explore and understand each resident's historical and current views on growth opportunities and what stands in the way of taking advantage of them in later life.

Putting this into Practice

Case scenario

Joan Jones, recently widowed and living alone at home, began to show signs of confusion and unsafe activity (e.g., leaving the stove on) that alarmed her two adult children. Without talking to her about it, the children arranged to move her into the nursing home. Staff conversations with the adult children revealed a long history of emotional abuse by Joan's late husband and suspicions of occasional physical abuse. Joan was a homemaker all her life with a short stint as an elementary school teacher when her children moved out of the house. After a year or two, her husband insisted she stop working. Joan is submissive to her children but perks up in 1:1 conversations with certain staff. She denies interests or abilities and prefers to self-isolate, even when encouraged to meet other residents.

Practice tips:

Key concepts for staff: Understanding historic oppression and injustice, empowerment to re-engage with potential for positive engagement.

People deal with the anger, resentment, and frustrations of past oppression and trauma in different ways. Some people like to talk through it, while others do not, and people may change how they want to process trauma, especially as they age. Someone may have kept their trauma hidden for decades, but may process it in a new way as they age. This is a key part of human potential. The goal is for staff to understand 1) how a resident's past experiences of injustice, trauma, or oppression impact any current feelings of resignation, disengagement, or disempowerment, and; 2) how best to support them in feeling more personally empowered and inclined toward purposeful engagement, however they define that.

- Help residents recall and honor past positive activities and accomplishments and find ways to reconnect with them.Use conversation guides on how best to discuss and contextualize past oppression and marginalizations.

Discussion Questions:

- Have you had residents who need special attention or care because of previous injustices? How have you given that special care?
- Moving into a nursing home can make people feel like they've lost a lot of control. What are some ways we as a team can help residents keep more control over their space and body? Review concepts of *personhood* in the prior module.

Meeting the needs of residents and regulations

Each resident has the right to be treated with dignity and respect. All activities and interactions with residents by any staff, temporary agency staff, or volunteers must focus on assisting the resident in maintaining and enhancing their self-esteem and self-worth and incorporating the resident's goals, preferences, and choices. When providing care and services, staff must respect each resident's individuality, as well as honor and value their input. (F550 Resident Rights)

Increasingly diverse demographics among nursing home residents require nursing homes to provide culturally competent care. Cultural competency, which includes language, and cultural preferences, and other cultural aspects such as thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups, is an important aspect of person-centered care. These elements influence the beliefs surrounding health, healing, wellness, and the delivery of health services and are critical to reducing health disparities. (F699 Trauma-Informed Care)

Additional Resources

Live Oak Institute Cultivating Culture Change. http://liveoakinstitute.org/

O'Hern, K. (n.d.) The Path to Purposeful Engagement A Guide for Implementing a Community Approach to Purposeful Engagement That Residents Drive and Direct. https://www.pioneernetwork.net/wp-content/uploads/2021/03/The-Path-to-Purposeful-Engagement.pdf

Caring Across Generations - You Are Not Alone. (2016) https://caringacross.org/

Ryan, R., & Deci, E. (2001). On Happiness and Human Potentials: A Review of Research on Hedonic and Eudaimonic Well-Being. Annual Review of Psychology, 52, 141-166. http://dx.doi.org/10.1146/annurev.psych.52.1.141

Cohen, G. (2006). Research on Creativity and Aging: The Positive Impact of the Arts on Health and Illness. Generations: Journal of American Society of Aging, 30(1), pp. Langmann, E. (2022). Vulnerability, Aging, and Health: is it helpful to label older adults as a vulnerable group in health care? Medicine, Health Care and Philosophy (2023) 26:133–142 https://doi.org/10.1007/s11019-022-10129-5.

Ryff, C. D. (2018). Well-being with soul: Science in pursuit of human potential. Perspectives on Psychological Science, 13(2), 242-248.

McFadden, S., & Basting, A. (2010). Healthy Aging Persons and Their Brains: Promoting Resilience through Creative Engagement. Clinics in Geriatric Medicine, 26(1), 149-161

Matz, C., Sabbath, E., & James, J. B. (2020). An integrative conceptual framework of engagement in socially-productive activity in later life: implications for clinical and mezzo social work practice. Clinical Social Work Journal, 48, 156-168.

Wadensten, B. (2007). The theory of gerotranscendence as applied to gerontological nursing–Part I. International Journal of Older People Nursing, 2(4), 289-294.

TRAINING TOPIC 3 - AGEISM IN LONG-TERM CARE

Introduction

To avoid ageism, health care staff should adopt an individualized, person-centered care approach that defines non-ageist practices and attitudes and acknowledges the need to eliminate ageism in practice.

Ageism in Systems

Ageism is a widespread cultural phenomenon involving making both positive and negative generalizations (stereotypes) about older people. The underlying belief that drives ageism is that it is bad to be old, and good to be young. Ageist beliefs can influence our thinking, even if we do not act on them. However, ageist thinking and beliefs often do lead us to act in ways that reinforce these beliefs.

Powerful, cultural norms of ageism in our society have been absorbed unknowingly by many people, including the residents themselves and family members. What does this mean? Sometimes older people hold negative views of their own aging and/or of other older people, and sometimes family members hold negative views of their own aging and/or aging in general. It is critical to involve residents and family members in your organization's journey towards age inclusion so they can support the autonomy of older adults and contribute to a person-directed approach to care for residents.

Elderspeak

Language carries and conveys meaning which feeds assumptions and judgments that can lead to the development of stereotypes and discrimination. Elderspeak is an inappropriate simplified speech register that sounds like baby talk and is used with older adults, especially in health care settings. Research has shown that nursing staff extensively use elderspeak (infantilizing communication) in conversations with older adults in long-term care settings, especially during care providing activities of daily living. Elderspeak is perceived as patronizing and can precipitate communication breakdown and problem behaviors for cognitively intact elders.

Putting this into Practice

Case scenario

A new team member in memory care feels the only way the resident will cooperate with ADLs is 'baby talk.' This team member will use oversimplified language, infantile terms (e.g., baby, sweetie, honey), and/or a rhythmic tone of voice that a person might use for a child. The resident has verbally expressed to the team member that she does not appreciate being 'talked down to as a child' and finds her language 'degrading and condescending.' As a result, the resident has filed a complaint and requested this team member to not be involved in any of her care.

Practice tips

- Address people by their preferred name.
- Treat older adults like adults. Just because they are 'older' does not mean they want to be treated like a child.
- Match your communication to the person, not their age range.
- Use a normal tone at a normal pace.
- Avoid adjustments in your rhythm, sound, sentence structure, and meaning, such as a high-pitched, overnurturing voice and use of inappropriate terms of endearment (e.g., sweetie, honey).

Meeting the needs of residents and regulations

The resident has a right to a dignified existence, self-determination, and to be treated with respect and dignity. Staff must help the residents to maintain or enhance their self-esteem, self-worth, and incorporate their goals, preferences, and choices. Staff must also consider residents' physical limitations, assure communication, and maintain respect. (Regulatory requirement F550 – Resident Rights / Exercise of Rights)

Microaggression

A microaggression is a subtle, often unintentional, form of bias. Microaggression often takes the shape of an offhand comment, an inadvertently painful joke, or a pointed insult. For example, a person might comment that for an older person, they hear well or ambulate quickly without challenge or use of a cane or walker. Individuals may not have intended to offend anyone, but the comment (or action) still reminds the person who receives the microaggression that they are not fully accepted or trusted in their nursing home. People are often well-intentioned, and they want to consciously promote equality, but unconsciously they may act differently.[1]

Putting this into Practice

Case scenario

Mr. Smith resides in the nursing home and enjoys an active lifestyle. Visitors and other family members frequently make comments to him such as, 'Wow, you walk so well without any assistance! I wish my dad was in good physical shape like you!' While Mr. Smith tries to embrace the so-called compliment, he later tells staff he finds this talk offensive and insulting. Mr. Smith said other staff members hear people talk to him this way, but they never say anything hence the reason it still occurs. Mr. Smith asks you if staff are trained in how to recognize this type of ageist behavior.

1 https://www.psychologytoday.com/us/basics/microaggression

Practice tips

- Instead of dwelling on what makes a person different (e.g., person's gender, age, race, etc.)., notice it and move on.
- Try to avoid making a comment that highlights the difference as it may come across as insensitive. Meet*ing the needs of residents and regulations*

The resident has a right to a dignified existence, self-determination, and to be treated with respect and dignity. Staff must help the residents to maintain or enhance their self-esteem, self-worth, and incorporate their goals, preferences, and choices. Staff must also consider residents' physical limitations, assure communication, and maintain respect. (Regulatory requirement F550 - Resident Rights / Exercise of Rights)

Additional Resources

State Operations Manual Appendix PP -Guidance to Surveyors for Long Term Care Facilities Transmittals. (2023) https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Downloads/Appendix-PP-State-Operations-Manual.pdf

Gendron, T., Cimarolli, V., Inker, J., Rhodes, A., Hennessa, A., & Stone, R. (2021). The efficacy of a video-based intervention to reduce ageism among long-term services and supports staff. Gerontology & Geriatrics Education, 42(3), 316-330. https://doi.org/10.1080/02701960.2021.1880904

Gendron, T. G., Welleford, E. G., Inker, J., & White, J. T. (2016). The language of ageism: Why we need to use words carefully. The Gerontologist, 56(6), 997-1006.

Psychology Today. Microaggression.
https://www.psychologytoday.com/us/basics/microaggression

Shaw, C. A., & Gordon, J. K. (2021). Understanding elderspeak: an evolutionary concept analysis. Innovation in Aging, 5(3), igab023.
https://doi.org/10.1093/geroni/igab023

Washington, E., Birch, A., Roberts, L. (2020). When and how to respond to microaggressions. Harvard Business Review.
https://hbr.org/2020/07/when-and-how-to-respond-to-microaggressions

TRAINING TOPIC 4 - DIGNITY OF RISK IN LONG-TERM CARE

Introduction

Person-centered care, that is care that focuses on an individual's values, wishes, and preferences for everyday living and care, is the guiding force for meaningful care delivery. When person-centered care is delivered, individuals experience a more positive sense of worth, well-being, and quality of life. Literature supports the notion that preferences for care and activities remain relatively stable for older adults living in nursing homes, thus can be identified, and incorporated into plans of care. Yet, challenges exist when trying to incorporate resident preferences into plans of care. A few examples of these challenges include the physical/cognitive ability of residents to participate in care discussions, family involvement (or lack of involvement) in care planning, and risk perceptions of the care team.

The Concept of Dignity of Risk-Taking in Older Adulthood

Successful plans of care target improvements in the residents' dignity while living in the nursing home community. Dignity for nursing home residents is based on internal factors, such as their perceived self-worth, and external factors such as what they are willing to participate in and/or how they are treated by others.Persons living with dementia represent more than half of the nursing home population and are at greatest risk to lose dignity in care processes due to their diminished autonomy, altered sense of self-worth, lack of social roles, and limited interactions with others..

Caregivers can support a resident's dignity by assisting residents to maintain as much autonomy as possible in decision-making around their care and activity preferences, even when there is a potential risk to their health and safety.. This will require a degree of risk-taking that must be carefully managed by the care planning team. In doing so, this can result in personal growth and an improved quality of life that we seek for our residents. Thus – there is dignity in risk-taking for nursing home residents, even those with dementia, when they are afforded their individual right to express autonomy through risk-taking.

Nursing home staff have identified the need to engage in risk-taking to support resident preferences around the following:

- Food and fluid intake
- Showering and bathing
- Toileting
- Sleep timing
- Use of adaptive equipment
- Walking and ambulation
- Transferring from bed to chair and back

- Leisure activities
- Spending time alone and/or with others

Supported Decision Making with Persons Living with Dementia
Care planning in the nursing home community is a decision-making process . Persons living with dementia (PLWD), like anyone else, desire to be involved in decisions around their care processes yet are often left out of the decision-making process. Studies have indicated that PLWD, like their older adult counterparts, have stable preferences for care and activities such as those listed above . However, the involvement of a PLWD in the decision-making process varies, with final decisions about treatment and care made most often by family caregivers, with or without the involvement of the resident. In the nursing home environment, residents expect the support of nursing home staff to help them participate in decision-making around their preferences and expect families to support these decisions by providing tangible items, time, and advocacy.

Mitigating Potential Liability and The Risk of Harm

All residents can be supported in making decisions around their care using standardized procedures. Care planning and documentation of the care planning process is one way to mitigate potential risks of harm to the resident, the caregiver, and the organization, in support of safe and dignified resident care. As an emerging best practice, nursing home staff can use the decision-making in aging and dementia for autonomy (also known as DIGNITY) procedure to manage risk-taking that is required to support preferences for care and activities. This process currently involves the following steps:

1. Assessing and tracking resident preferences to identify potentially “risky” preferences.
2. Assessing and care planning health and safety risks associated with the “risky” preference.
3. Determining the impact of honoring the “risky” preference on the residents’ quality of life.
4. Documenting preferences that involve health and safety risk.
5. Engaging residents and families to mitigate the risks.
6. Working with organizational leadership and regulators to support resident preferences.

Putting this into Practice

Case Study

Cory is a 67-year-old single widowed woman living in the nursing home for about six months now with progressive dementia, and diabetes with bilateral above the knee amputations. Cory has been more withdrawn recently, not attending activities, tearful and requesting more frequent snacks between meals. Nursing home staff denied Cory her requests attempting to redirect the conversation because they are concerned that the frequent snacking will increase Cory's blood sugars, in addition to the concern that she will gain weight. This situation worsens as Cory is now beginning to refuse care such as blood sugar checks, bathing, and assistance with toileting.

Practice Tips

- Consider that you may have just identified an important and meaningful preference of Cory to snack between meals that carries a risk to her health or safety and enact a standard protocol, such as DIGNITY, to support risk-taking.
- Initiate a conversation with Cory to clarify why she is refusing care and what her preferences are for snacking between meals.
- Engage Cory, her family representative, and the interdisciplinary care team to evaluate the potential upsides and downsides of honoring Cory's request to snack between meals.
- Engage Cory, her family representative, and the interdisciplinary care team to weigh the potential of Cory's quality of life increasing with the risks of actual harm to Cory if the preference is honored.
- Make a shared decision with Cory, her family representative, and the interdisciplinary care team how to move forward with the preference (honor as is, compromise, or not honor but offer alternatives).
- Develop a plan to move forward with the shared decision using prompts from Honoring Preferences when the choice involves risk: a process for shared decision-making and care planning resource.
- Document and enact the plan by sharing the care plan amongst all involved.
- Determine when the plan will be evaluated for success and/or changing needs.

Meeting the Needs of Residents and Regulations

According to CMS regulations, the resident has the right to:

- Choose activities and schedules (Tag F242) F679 - Activities Meet Interest/ Needs of Each Resident
- Interact with members of the interdisciplinary team, friends, and family both inside and outside the care community (Tag F172 and Tag F242) F550 - Resident Rights/Exercise of Rights (communication with and access to persons and services inside and outside the facility or nursing home)

- Make choices about aspects of his or her life in the care community that are important to him or her (Tag F242)
- Participate in care planning (Tag F280) - F553 - Right to Participate in Planning Care
- Refuse treatment (Tag F155) - F578 - Request/Refuse/Discontinue Treatment
- Both quality of care (Tag F309) and quality of life (F240) that recognizes each individual and enhances dignity. F684 - Quality of Care
- Achieve the highest practicable level of well-being (Tag F309)
- The same rights as any resident of the United States (F151)

The resident has a right to a dignified existence, self-determination, and to be treated with respect and dignity. Staff must help the residents to maintain or enhance their self-esteem, self-worth, and incorporate their goals, preferences, and choices. Staff must also consider residents' physical limitations, assure communication, and maintain respect. (Regulatory requirement F550 - Resident Rights / Exercise of Rights)

Additional Resources

State Operations Manual Appendix PP -Guidance to Surveyors for Long Term Care Facilities Transmittals. (2023) https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Downloads/Appendix-PP-State-Operations-Manual.pdf

Honoring Preferences When the Choice Involves Risk. (2020) https://www.preferencebasedliving.com/for-practitioners/practitioner/care-integration/honoring-preferences-when-the-choice-involves-risk/

Green House Podcast: Elevate Eldercare - Green House Project. (2021). https://thegreenhouseproject.org/podcast/

Clarke, C., Wilkinson H., Keady J., Gib C. (2011). Risk Assessment and Management for Living Well with Dementia.

References

Behrens, L., Anderson, H., Kowalchik, K., Mogle, J., Jones, J. R., Van Haitsma, K., Hodgson, N., & Boltz, M. (Accepted). "I'm not a risk taker": Risk Perceptions of Nursing Home Residents with Dementia. *Alzheimer Disease and Associated Disorders*.

Behrens, L., Van Haitsma, K., Brush, J., Boltz, M., Volpe, D., & Kolanowski, A. M. (2018). Negotiating risky preferences in nursing homes: A case study of the Rothschild person-centered care planning approach. *Journal of Gerontological Nursing*, 44(8), 11–17. https://doi.org/10.3928/00989134-20171206-02

Behrens, L. L., Boltz, M., Kolanowski, A., Sciegaj, M., Madrigal, C., Abbott, K., & Van Haitsma, K. (2020). Pervasive risk avoidance: Nursing staff perceptions of risk in person-centered care delivery. *The Gerontologist*, 60(8), 1424–1435. https://doi.org/10.1093/geront/gnaa099

Behrens, L. L., Madrigal, C., & Dellefield, M. E. (2023). Assessment of nursing staff learning needs around person-centered risk management in nursing homes. *Journal of Gerontological Nursing*, 49(2), 7–12. https://doi.org/10.3928/00989134-20230106-02

Ibrahim, J. E., Holmes, A., Young, C., & Bugeja, L. (2019). Managing risk for aging patients in long-term care: A narrative review of practices to support communication, documentation, and safe patient care practices. *Risk Management and Healthcare Policy*, 12, 31–39. https://doi.org/10.2147/RMHP.S159073

Jacelon, C. S., Connelly, T. W., Brown, R., Proulx, K., & Vo, T. (2004). A concept analysis of dignity for older adults. *Journal of Advanced Nursing*, 48(1), 76–83. https://doi.org/10.1111/j.1365-2648.2004.03170.

Kansas State University Center on Aging. (2024). Kansas Department of Aging and Disability Services PEAK Guidebook: Quality Improvement through Person-Centered Care. https://www.hhs.k-state.edu/aging/research/peak20/2024-25/PEAKguidebook2425.pdf

Miller, L. M., Whitlatch, C. J., & Lyons, K. S. (2016). Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia* (London, England), 15(5), 1141–1157. https://doi.org/10.1177/1471301214555542

Torossian, M. R. (2021). The dignity of older individuals with Alzheimer's disease and related dementias: A scoping review. *Dementia* (London, England), 20(8), 2891–2915. https://doi.org/10.1177/14713012211021722

Van Haitsma, K., Crespy, S., Humes, S., Elliot, A., Mihelic, A., Scott, C., Curyto, K., Spector, A., Eshraghi, K., Duntzee, C., Heid, A. R., & Abbott, K. (2014). New toolkit to measure quality of person-centered care: Development and pilot evaluation with nursing home communities. *Journal of the American Medical Association*