PARTNER PERSPECTIVE

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Shared Risk in Assisted Living: Awakening a Sleeping Giant

Providing person-centered care is the core philosophy of assisted living, an industry serving more than one million older adults across 32,000 communities in the United States (National Center for Health Statistics, "Data From the National Post-acute and Long-term Care Study [NPALS]," Apr. 7, 2025, https://bit.ly/NCHS-NPALS). Drawing on agreed-upon constructs, the national Center for Excellence in Assisted Living at the University of North Carolina (CEAL@UNC) defines person-centered care and policies as those that promote "quality of life, privacy, choice, dignity, inclusion and independence as defined by each individual and those who know them best." Central to these tenets is the right of a resident to choose to engage in preferred activities — including activities that entail risk.

In assisted living, resident risk is shared and often is intertwined with liability issues, regulations, and family member concerns, among others. These factors may result in protective policies and practices that are intended to minimize harm, yet they restrict resident choice. Four examples can illustrate how risk-mitigation strategies in assisted living and well-intentioned practice and policy can paradoxically clash with residents' dignity, agency, and well-being. In all these examples, the advantages and disadvantages can be quantified and evaluated, but the research has yet to be done.

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1) Diet: The freedom to choose what to eat is more than a nutritional decision — it is a core expression of independence (*J Hum Nutr Diet* 2014;27:152–161). However, more than half of assisted living residents have chronic conditions that may call for therapeutic or otherwise restrictive diets, including the 58% of residents with hypertension, the 33% with heart disease, and the 16% with diabetes (NPALS 2025). Although individually tailored dining programs can reduce medical symptoms (*Can J Diet Pract Res* 2020;81:186–192), overly restrictive diets may prompt residents to refuse meals due to lack of appeal based on personal choice, leading to undernutrition and weight loss (*Diabetes Care* 2016;39:308–318).

2) Mobility and Falls: Falls are the leading cause of injury death among adults over 65 years of age (Centers for Disease Control and Prevention, "Older Adult Fall Prevention," https://www.cdc.gov/falls/about/index.html). More than 50% of assisted living residents require assistance with transfers or ambulation, and over 27% experience at least one fall a year (NPALS 2025). Although increased physical activity can promote strength and mobility and help prevent falls (*J Clin Med* 2020;9:2595), staff concerns regarding injury may result in residents being passively incentivized to remain seated for extended periods (*Int J Environ Res Public Health* 2020;17:6415). Families, too, fear risks to physical safety and may discourage unaccompanied walks, inadvertently limiting residents' mobility (*West J Nurs Res* 2023;45:105–116).

3) Medication Management: The most frequent support needed by assisted living residents is managing an often-complex medication regimen; this management sits at the intersection of regulation, organizational policy, and personal choice. Although staff assistance may reduce medication errors, restrictive practices such as prohibiting self-administration or storing medications out of residents' reach can encourage residents to self-medicate with over-the counter medications (e.g., pain relievers), which could result in dangerous drug duplications (*Gerontologist* 2009;49:463–473).

4) Dementia and Cognitive Impairment: Almost 45% of assisted living residents live with dementia, and an even higher proportion experience cognitive impairment (*Health Aff [Millwood]* 2014;33:658–666). For these residents, decision-making opportunities may be restricted under the assumption that declining cognition is driving behaviors rather than true preferences (*JBI Evid Synth* 2021;19:1583–1621). Everyday activities including eating, walking, and taking medications may be labeled as "risky" based solely on a diagnosis. And, though they are intended to provide a safe environment that avoids risks such as elopement, the presence of locked memory care units inherently limits resident autonomy (*Health Aff Sch* 2025;3:qxaf053).

The Reality of Risk

Negotiating and embracing risk is a constant throughout our lives, from learning to ride a bicycle to deciding whether to get married (and to whom) or resigning from a C-suite position to pursue one's life passion. Growing older, no matter where someone lives, does not remove the right to choice. In fact, honoring choice is so universal a value that it is embodied in the World Medical Association's Physician's Pledge as "I will respect the autonomy and dignity of my patient."

However, there are legal and practical limitations to honoring choice in long-term care — take, for example, a nursing home successfully sued for $200 million after the falling death of a 92-year-old woman who had "slipped away" from her group ("Jury Awards $200 Million Verdict in Pinellas Nursing Home Death Case," *Tampa Bay Times*, Jan. 13, 2012, https://bit.ly/PinellasCase). Regardless of the cause, headline-generating lawsuits such as this may evoke fears of liability among even the most vigilant operators.

Additionally, communities must on occasion comply with regulations that are not strictly aligned with person-centered principles or they may risk state-levied admissions restrictions, fines, or licensure revocation (*Med Care Res Rev* 2022;79:731–737). These factors result in some feeling there is little choice but to embrace more restrictive and "safer" practices and policies.

Shared Risk Agreements: A Path Forward

Despite the challenges to enabling risk in assisted living, there are paths to negotiate shared risk that involve practice, policy, and research.

Practice and Policy: Agreements related to shared risk, sometimes called negotiated risk, have long been proposed as a framework to reconcile tensions between preventing harm, limiting liability, and honoring resident autonomy. Whether formalized in writing or understood informally, these agreements invite residents, their support systems, clinicians, administrators, and care staff to collaboratively identify acceptable risk that respects individual preference while maintaining safety and regulatory compliance. Written agreements, when integrated into regular assessment and care planning, serve as useful tools that provide clear communication of not only the expressed preferences of residents but also the process of negotiation and final

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- Remember that both pressure injury prevention and wound healing rely on adequate nutritional intake. Nutritional assessments should be prompt and effective, taking into consideration the extra calories, protein, and micronutrients required for wound healing.
- If a resident has skin failure due to multiple organ system diseases and/or a combination of vascular disease and nutritional deficit, make sure these items are addressed by providers.
- If a resident is in the process of dying, educate the family to manage their expectations realistically. This can include a palliative, symptom-oriented approach or entry into a hospice program while avoiding hospitalizations and aggressive or invasive tests and treatments.

Overall, pressure injury prevention and treatment involve a coordinated, facility-wide system of care that includes risk assessments, care planning, and reassessment to adjust interventions as the resident's condition changes.

Summary

Pressure injuries, historically viewed as indicators of poor care quality in nursing homes, are increasingly recognized as complex medical conditions that are not always preventable. Regulations in long-term care have evolved to accommodate the reality of pressure injury occurrence, but practitioners need to be aware of this complexity and provide documentation of prevention efforts. Pressure injury prevention and treatment involve a multidisciplinary process that includes physicians, advanced practice providers, nurses, nutritionists, social workers, and therapists. Practical strategies for frontline practitioners include implementing prevention measures, addressing nutritional needs, documenting clinical complexity, and providing family education during end-of-life care.

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Scabies

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For cases of classic scabies, staff and other residents or visitors who have had prolonged, direct skin-to-skin contact should be treated. For crusted scabies, staff, residents, and visitors who have had contact with infected individuals or their fomites be should be treated, regardless of symptoms. Treatment also is recommended for the household members of the staff who are undergoing treatment for scabies (CDC, "Public Health Strategies for Crusted Scabies Outbreaks in Institutional Settings," May 8, 2024, https://bit.ly/4eNZyA6).

5. Maintain communication. The facility should ensure rapid communication.

- Establish a process of communication for identifying and notifying exposed residents, staff, and their household members.
- Educate the staff about the anticipated signs and symptoms and advise them to report to the facility when they occur.
- Communicate with laundry services to ensure that they are aware of the potential transmission.

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agreement (Assisted Living Workgroup, "Assuring Quality in Assisted Living: Guidelines for Federal and State Policy, State Regulation, and Operations," April 2003, https://bit.ly/ALWG-2003).

Shared risk in clinical and supportive care may entail shifting from a compliance mindset to one of adherence. Compliance implies a top-down hierarchy where assisted living residents follow recommendations from "those who know best" without question. By contrast, adherence acknowledges residents' active role and responsibility in managing their own health, challenging unilateral definitions of "risk" and requiring active negotiation and mutual understanding (*HCA Healthc J Med* 2023;4:219–220).

Research: Despite the promise of shared risk agreements, concerns exist surrounding their use, variability, and unknown efficacy. Some argue these agreements serve as Trojan horses: they are essentially a disguised liability waiver to shield inadequacies of care (*J Health Care Law Policy* 2007;10:287–337, https://bit.ly/Carlson2007). Conversely, others feel they expose operators to an unacceptable level of liability. It is hard to counter these arguments when there is little empirical evidence regarding the use and outcomes of shared risk agreements in assisted living and a lack of consensus regarding their standard principles. At the same time, there exists potential to develop measurement tools to assess the cost-benefit of control/accepted risk, but such a metric, and related research, does not exist.

CEAL@UNC: Awakening the Sleeping Giant of Shared Risk

Shared risk in assisted living received heightened attention in the 1990s, resulting in varying forms of community and industry association formats; some states have incorporated them into regulations (*N C Med J* 2010;71;164–167). However, since the early 2000s there has been remarkably little dialogue related to the topic and a surprising dearth of evidence, meaning that long-standing challenges related to shared risk remain dormant and unresolved.

The concept of shared risk is central to the person-centered hallmark of assisted living. It lends itself to research and to research-informed practice and policy to improve the well-being of the people who live and work in assisted living. Therefore, CEAL@UNC is engaging its diverse Strategic Advisors and Research Core Affiliates to better understand the current realities, challenges, and promises of shared risk in assisted living. For those interested in learning more about this and other initiatives, we welcome your visit to theceal.org, or contact CEAL@office.unc.edu.

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