APPENDIX A: PUBLICATIONS

During the period from 2019 through 2021, the PPCLSC team and its collaborators published 52 articles on person-centered care topics in journals reaching researchers, educators, practitioners, and policymakers in the fields of gerontology, medicine, nursing, psychology and social work. For our earlier work, please visit the extensive archive on the Preference Based Living website (https://www.preferencebasedliving.com/for-researchers/researcher/).

Publications

2021


2020


Since 2019, PPCLSC team members have presented 42 papers and poster sessions to scientific and provider groups, such as the Gerontological Society of America, Alzheimer’s Association of America International Conference, Academy Health, Society for Post-Acute and Long-Term Care Medicine. Most notably, Dr. Kimberly VanHaitsma was an invited speaker at the 2020 National Research Virtual Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers sponsored by the National Institute on Aging. She reported on the state of the science on evidence-based person-centered care practices for people living with dementia and presented recommendations for future research.

Invited/Keynote/Plenary Addresses


6. Steelman, E. & Johnston, T. (Invited presenter) (September 11, 2019). Working with lesbian, gay, bisexual and transgender residents, National Church Residences, Columbus, OH.

7. Steelman, E. (June 18, 2019). Providing care and services to LGBT+ older adults: Exploring the process and the journey, LeadingAge, PA. Hershey, PA.

Chair/Discussant of Symposia


Paper Presentations

2021


2020


2019


39. Resnick, B., Kolanowski, A., VanHaitsma, K. (Co-presenter) & Galik, (March 8, 2019). Changing how care is provided to residents with BPSD: The EIT-4-BPSD intervention. Paper presented to AMDA-The Society for Post-Acute and Long-Term Care Medicine Annual Conference, Atlanta, GA.

**Poster Presentations**


42. Madrigal, C., VanHaitsma, K., Mogle, J., Fick, D., Scanlon, D., Abbott, K., & Behrens, L. Validating the Care Preference Assessment of Satisfaction Tool to Measure Quality of Care in Nursing Homes. Late Breaking Poster Presentation. Gerontological Society of America Annual Meeting, Austin, TX, November 14, 2019.
APPENDIX C: RESEARCH GRANTS

During the period from 2019 through 2021, PPCLSC’s research and scholarship was supported by 10 grants from the National Institute on Aging, the National Institute for Nursing Research, state governments in Ohio and Tennessee, private foundations, and Penn State University. This appendix gives a snapshot of our current projects and those completed within the last three years.

Current Grants

1. **Increasing the Preference-Based Care of People in Ohio’s Nursing Homes with a Special Focus on People Living with Dementia.** State of Ohio Department of Medicaid, Civil Money Penalty Funds (10/1/19-10/30/22)

   **Investigator team:** (Katherine Abbott, Alex Heppner, Miami University), (Kimberly VanHaitsma, Penn State University) (Karen Eshraghi, Sarah Humes, Abby Spector, Victoria Crumbie, Consultants)

   **Purpose:** This project builds preference based, person-centered care capacity among Ohio’s 960 nursing homes, including those with low-star ratings. The project develops materials that enhance homes’ capabilities in leadership, communication and training, as well as strengthen technological solutions for data collection and analysis to support care infrastructure. The project focuses on promoting adoption of preference assessment through education and training, as well as building sustainability through quality assurance performance improvement (QAPI) strategies that enhance daily life for nursing home residents. The project is the successor to a previous three-year grant that introduces Ohio nursing homes to the Preferences for Everyday Living Inventory and preference-based person-centered care.

2. **PA Collaboratory for Age and Dementia Friendly Care Using the 4M’s and Telehealth with Rural Communities and in Persons with ADRD.** Health Resources and Service Administration (7/1/19-6/30/24)

   **Investigator team:** (Donna Fick, Marie Boltz, Judith Hupcey, Erica Husser, Janice Whitaker, Kimberly VanHaitsma, et al., Penn State University)

   **Purpose:** This project aims to improve the health of older adults in rural medically underserved areas of Pennsylvania. The initiative develops educational programming and training that enables rural-based healthcare providers and caregivers to deliver more age and dementia-friendly care. The project is a collaborative partnership with Primary Health Network (PHN), the largest Federally Qualified Health Center (FQHC) in PA with over 45 sites; the Institute for Healthcare Improvement, Area Agencies on Aging, and the Alzheimer’s Association. The partnership implements a curriculum that focuses on the national “4Ms” Framework of an Age-Friendly Health System: 1) what Matters; 2) Medication; 3) Mentation; and 4) Mobility. Training for students and providers highlights the importance of attending to each older adult’s strengths, not just the deficits, and ways to live well with dementia.
3. **NIA IMPACT Collaboratory.** National Institute of Aging. (4/1/19-3/31/24) (PIs: Vince Mor, Brown University; Susan Mitchell, Harvard University)

*Investigator team:* (Kimberly VanHaitsma, Marie Boltz, Penn State University)

*Purpose:* The Collaboratory aims to provide the national infrastructure necessary to catalyze and support embedded pragmatic clinical trials of non-pharmacological interventions for persons with dementia. By convening national experts to provide consultation and guidance to Collaboratory-funded pilot projects and NIA-funded trials, the program has the potential to transform care delivery, quality, and outcomes for millions of Americans suffering with Alzheimer’s disease and related dementias.

4. **Person-Centered Care for Older LGBTQ Adults: A Partnership Between Penn State and Older Adults in Philadelphia,** CTSI Penn State University-Bridges to Translation Grant (2019-2022).

*Investigator team:* (Britney Wardecker and Jes Matsick, Kimberly VanHaitsma, Penn State University) (Community expert, Rabbi Erica Steelman, Independent Consultant)

*Purpose:* The PELI is a widely used, validated tool to assess older adults’ preferences for care. This pilot project builds upon the Rainbow PELI (conceived of by Steelman and developed by Steelman and Crumbie, 2017, [https://www.preferencebasedliving.com/for-practitioners/practitioner/assessment/peli-questionnaires/rainbow-peli-nh-full-version-2-0/](https://www.preferencebasedliving.com/for-practitioners/practitioner/assessment/peli-questionnaires/rainbow-peli-nh-full-version-2-0/)). This pioneering pilot project emphasizes and celebrates collaboration between academics and members of the community outside of the ivory tower. Three Penn State researchers and one community expert form the research team that work in collaboration with two Community Advisory Boards (CABs). One CAB consists of six older LGBTQ adults and the other CAB consists of six non-LGBTQ older adults. This pilot project will contribute to the development of the first comprehensive scientifically validated tool that assesses daily living preferences and embraces needs of all older adults, including the historically underserved LGBTQ community.

**Recently Completed Grants**

5. **Assessing Preferences for Communicating with Technology: A Person-Centered Approach to Managing Multiple Chronic Conditions.** Gordon and Betty Moore Foundation Patient and Family Engagement Early Career Investigator Award (11/30/2017-11/29/2021)

*Investigator team:* (Andrea Sillner, Senior Mentors: Marie Boltz, Kimberly VanHaitsma, Penn State University)

*Purpose:* This project developed and tested a new subscale of the Preferences for Everyday Living Inventory, called the P-TAC. The new subscale has been designed to strengthen technology-assisted communication among older adults receiving community-based home health services and their formal and informal caregivers. It addresses gaps in support needed to improve transitions in care for older adults with multiple chronic conditions. The project developed the P-TAC subscale by exploring contextual (person, provider and environmental) facilitators and barriers to the use of technology-assisted communication among clients, informal caregivers and organizations. The project used cognitive interviewing techniques to assure the wording is person-centered and reflects language used by older adults, informal caregivers and formal service providers.

6. **Implementing EIT-4-BPSD for Nursing Home Residents with Dementia.** National Institute of Nursing Research Grant, 1R01NR015982-01A1 (8/23/16-5/31/21)

*Investigator team:* (Ann Kolanowski, Kimberly VanHaitsma Marie Boltz, Karen Eshraghi, Penn State University) (Barbara Resnick, Beth Galik, UMD)

*Purpose:* Only a small percentage of nursing homes use person-centered practices shown to ameliorate behavioral and psychological signs of distress (BPSD) among residents with dementia. This project aimed to increase uptake of
approaches to alleviate BPSD and improve resident quality of life. Fifty nursing homes took part in the cluster randomized trial. The study evaluated whether the implementation strategy, based on the evidence integration triangle framework (EIT), promoted adoption of recommended practices to address BPSD. The study provided guidance on how to implement person-centered behavioral practices for BPSD, and developed pragmatic measures that allow researchers and providers to assess nursing homes’ progress toward this goal.

7. **The Impact of Person-Centered Care on Nursing Home Quality.** Miami University, Scripps Gerontology Center. The Patrick and Catherine Weldon Donaghue Medical Research Foundation (2020–2021)

*Investigator team:* (Katherine Abbott, Jane Straker, Miami University) (Kimberly VanHaitsma, Penn State University)

*Purpose:* The PELI is a tool that providers can use to learn about an individual’s preferences and integrate that information into their personalized care plans. In 2015, the Ohio Department of Medicaid mandated that all Medicaid certified nursing homes use the PELI to enhance person-centered care. This mandate provided the opportunity to explore whether the use of the PELI is a predictor of: 1) resident and family satisfaction; 2) clinical (e.g., pressure ulcers, falls) and care process outcomes (e.g., physical restraints, antipsychotic medication use); and 3) quality ratings (e.g., overall star rating, health inspection rating, staffing rating, quality rating, number of complaints). Stakeholder organization: Ohio Person Centered Care Coalition.

8. **The Impact of Gender Differences on Identification and Treatment of BPSD.** National Institute of Nursing Research, 3R01NR015982-04S1 (09/18/2019 – 05/31/2020)

*Investigator team:* (Ann Kolanowski, Kimberly VanHaitsma, Marie Boltz, Karen Eshraghi, Penn State University) (Barbara Resnick, Beth Galik, UMD)

*Purpose:* Previous research suggests that BPSD in men is more likely to be identified and managed. Lack of identification and management of BPSD is a gender bias that can seriously affect health outcomes for the large numbers of older women in nursing home settings. This study had three major aims. The first was to test for gender differences in identification and management of BPSD. Our hypothesis was that women would have fewer BPSD identified by staff than men, and BPSD in women would be less likely to be treated with person-centered behavioral approaches and/or psychotropic medication than men. The second aim was to test for gender differences in quality of staff/resident interactions. We hypothesized that women would have fewer positive interactions with staff and lower quality of life than men. The third goal was to qualitatively explore caregivers’ experiences with identification, documentation and management of BPSD among women and men. The goal was to probe our data to formulate testable hypotheses that, if supported, would ultimately help to improve the care delivered to the 922,480 women who reside in the nation’s 15,000 nursing homes.

9. **Implementing a Preference-Based, Person-Centered Communication Tool in Tennessee.** State of Tennessee Department of Health (7/1/19-7/30/20)

*Investigator team:* (Katherine Abbott, Alex Heppner, Miami University) (Consultant: Kimberly VanHaitsma, Penn State University)

*Purpose:* This quality improvement initiative introduced Tennessee nursing homes to Preferences for Activity and Leisure (PAL) cards, an innovative tool to promote person-centered care. PAL cards profile each resident and highlight their recreation and leisure interests based on PELI interviews. PAL cards provide an easy way to share information about residents across staff, shifts and departments. Organizations that use PAL Cards find they promote more personalized care; spark conversations between staff, volunteers and community members; and foster community connectedness. The Tennessee project offered free training and learning circles to 25 providers. The evaluation examined staff perceptions about the feasibility of creating and using PAL cards as well as the impact on residents. The project expanded on a successful pilot conducted with 35 Ohio nursing homes.
10. Incorporating the Preferences for Everyday Living into Ohio’s Nursing Homes to Improve Resident Care.
State of Ohio Department of Medicaid, Civil Money Penalty Funds (7/1/16-6/30/19)

*Investigator team:* (Katherine Abbott, Alex Heppner, Miami University) (Kimberly VanHaitsma, Penn State University) (Karen Eshraghi, Sarah Humes, Victoria Crumbie, Consultants)

*Purpose:* The PELI is a tool used to assess nursing home residents' preferences. It was selected by the Ohio Department of Medicaid as one of five quality improvement indicators as part of a pay-for-performance initiative. This project partnered with Ohio nursing homes on ways to honor residents' preferences for daily living by providing education and training on how to use information about residents' preferences to improve care. The team worked with providers to identify barriers to implementing the PELI assessment and develop solutions for long-term sustainability. Also, the project designed an app to assist providers as they collect, manage and track preference data over time.

*Internal Initiatives of PPCLSC*

**Testing a Tool to Evaluate Student Nurse Preparedness for Dementia Care.** Program for Person-Centered Living Systems of Care (1/1/20-12/31/22)

*Investigator team:* (Marie Boltz, Ann Kolanowski, Ashley Kuzmik, Janice Whitaker, Kimberly VanHaitsma, Penn State University)

*Purpose:* Penn State College of Nursing Center for Geriatric Nursing Excellence is collaborating with the University of Bradford School of Nursing (United Kingdom) to create and pilot a survey that asks nurses in the US and the UK how prepared they feel to work with people living with dementia. Survey results will inform new curricula for care of older adults living with dementia.
Understanding Roles of Research Facilitators and Facility Champions in Implementing EIT-4-BPSD in Nursing Homes. Program for Person Centered Living Systems of Care Pilot Project (11/15/17-5/23/21)

Investigator team: (Kimberly VanHaitsma, Caroline Madrigal, Karen Eshraghi, Kiernan Riley, Timothy Adekye, Ann Kolanowski, Liza Behrens, Penn State University), (Katy Abbott, Miami University)

Purpose: The aim is to study experiences and perspectives of the Research Facilitator to obtain a deeper understanding of facility goals, barriers and facilitators related to decreasing behavioral and psychological signs of distress (BPSD). The project objectives are: 1) Explore experiences and perceptions of EIT-4-BPSD Research Facilitators surrounding facility-level goal establishment and attainment. 2) Investigate the establishment and attainment of staff-directed resident-level goals and their relationship to facility goals. 3) Examine the role of the Facility Champion and members of key stakeholder groups involved throughout the goal-setting and attainment process.

Appropriateness and Feasibility of ERIC Implementation Strategies for BPSD Using the EIT-4-BPSD Approach in the Nursing Home Setting. Program for Person Centered Living Systems of Care Pilot Project. (5/3/18-5/2/21)

Investigator team: (Kimberly VanHaitsma, Ann Kolanowski, Caroline Madrigal, Penn State University)

Purpose: This study explores the participatory implementation process by evaluating the appropriateness and feasibility of using Expert Recommendations for Implementing Change (ERIC) strategies to deliver person-centered, function-focused care in the nursing home setting. The goal is to learn more about the application of implementation strategies within the context of the EIT-4-BPSD model.

Consultation on Person-Centered Research Efforts

Optimizing Mealtime Care (OPTIMAL): Development and Pilot Testing of a Person-Centered Mealtime Care Intervention for Nursing Home Residents with Alzheimer’s Disease and Related Dementias (ADRD). NIH/NIA (National Institute of Aging), K23AG066856 (9/15/2020-6/30/2024)

Investigator team: (Wen Liu, University of Iowa College of Nursing), (Consultant: Kimberly VanHaitsma, Penn State University)

Purpose: This project aims to develop, evaluate, and refine a theory-based, person-centered mealtime care intervention, Optimizing Mealtime Care (OPTIMAL), and determine its feasibility, and usefulness.

Everyday Preferences of Family Caregivers for People Living with Dementia. Alzheimer’s Society of Calgary, Calgary, Alberta, CA.

Investigator team: (Gwen McGhan, University of Calgary) (Kimberly VanHaitsma, Ann Kolanowski, Penn State University)

Purpose: The study aimed to adapt a measurement tool that can be used to ascertain what family caregivers want and need when caring for a relative living with dementia in a nursing home.
Supporting Expression of Sexuality by Older People with Dementia in Long-Term Care from a Person-Centred Care Approach. Dementia Australia Research Foundation, Queensland, AU. (2/14/19-2/13/20)

Investigator team: (Cindy Jones, Bond University) (Kimberly VanHaitsma, Penn State University)

Purpose: Staff caring for older adults living with dementia often find the topic of sexuality challenging and see the expression of sexuality as a problem rather than as an expression of need. This project aimed to help providers create care environments that are supportive of expression of sexual preference, need and desire by adults with dementia. The project developed and evaluated a tool that helps providers improve their understanding as well as create policies and care practices that promote a more affirming response toward the expression of sexuality by people living with dementia.

Translation and Pilot of the Preferences for Everyday Living Inventory (PELI) in Long-Term Care.
Foundation Wohlfahrtspflege North Rhine Westfalia, Germany. (7/1/17-6/30/19)

Investigator team: (Martina Roes, University of Witten) (Kimberly VanHaitsma, Penn State University)

Purpose: The PELI is a questionnaire phrased in conversational language that asks older adults about their preferences for social contact, personal development, leisure, living environment and daily routine – information that provides the cornerstone for person-centered care. This project translated the PELI into German and developed new items needed to make the instrument culturally relevant to older adults receiving long-term services and supports in Germany. The project followed international best practices for translation and cultural adaptation and tested the PELI-D’s reliability and feasibility in three care settings. The initiative provides a model for researchers and clinicians who wish to customize and apply the PELI as part of the movement toward more person-centered care globally.
APPENDIX D: CARE PARTNER RESOURCES

Through ongoing, close research partnerships with providers, the PPCLSC team and collaborators at Miami University Scripps Gerontology Center have created more than 100 resources -- training videos, intervention kits, tip sheets, webinars and Quality Assurance and Performance Improvement programs -- to advance the practice of preference-based, person-centered care. With provider input, we tested and refined each resource to assure ease of use by a diverse workforce that includes administrators, activity and life enrichment directors, social workers, nurses, physicians, direct care workers, and advocates.

The first section of this appendix highlights three multi-site initiatives and a new online training course as well as the companion resources offered to participating providers. The second section lists an array of tools we co-developed and shared with long-term services and supports providers to spread best practices in preference-based, person-centered care.

Initiatives to Improve Quality and Strengthen Provider Capacity in Preference-Based, Person-Centered Care

**PAL Card Quality Improvement Project**
Preference for Activity and Leisure (PAL) cards give staff a fast and easy way to learn about a resident’s background and most important preferences, providing an at-a-glance view of a resident’s background and priorities, and facilitating conversations and activities in any setting. During the pandemic, PAL cards supported staff in providing person-centered care during rapidly changing times in the nursing home setting. The Preference Based Living team led two PAL Card Quality Improvement Project studies in Ohio and Tennessee, serving 23 residential communities for older adults.

Along with virtual coaching, participating sites received:

- Assessment interviews: PELI PAL Card Interviews (see Pragmatic Assessment Tools), https://www.preferencebasedliving.com/pal-cards/
- Tip sheets:
  - PELI PAL Cards: Communication Preferences Key, https://www.preferencebasedliving.com/pal-cards/peli-pal-card-communication-preferences-icon-key/

**IPPI Quality Improvement Project**
Our evidence-based Individualized Positive Psychosocial Intervention (IPPI) builds relationships and enhances person-centered care for older adults living with dementia. This intervention helps direct care workers tailor one-on-one activities to resident interests and abilities, connect meaningfully with residents, redirect challenging behaviors, reduce...
distress, and increase positive interactions. Quality Improvement (QIP) supports for participating providers include specially designed protocols for 60+ preference-based activities, instructional videos, tip sheets, and virtual coaching:

- Tip sheets:
  - Considerations Before the IPPI, https://www.preferencebasedliving.com/tip-sheets/considerations-before-the-ippi/
  - IPPI Resources
  - Considerations During the IPPI, https://www.preferencebasedliving.com/tip-sheets/considerations-during-the-ippi/
  - Ending the IPPI, https://www.preferencebasedliving.com/tip-sheets/ending-the-ippi/
- Documentation:
  - IPPI Resident Preferences Worksheet
- Videos:
- IPPI Guidebook for Providers

**Emotion-Focused Communication Training Professional Certificate**

Caring for a person living with dementia requires psychosocial skills such as active listening and recognizing emotions that require advanced emotion-focused communication competency training. The new Emotion-Focused Communication Professional Certificate training program helps caregivers better manage their own feelings as well as the emotions of residents living with dementia. Through self-paced virtual learning modules, caregivers learn to identify and manage their own feelings, decode residents’ feelings based on body posture and other nonverbal cues, and respond skillfully to residents’ emotions. The first group of graduates reported that the Emotion-Focused Communication training course significantly increased their knowledge and self-confidence related to implementing emotion-focused communication strategies. They reported high levels of satisfaction (96% are satisfied or very satisfied with the training).

General Tip Sheets
Family Engagement, Effective Communication, and Honoring Preferences During Covid-19 Pandemic

- Using the PELI to Advocate for Person-Centered Care, https://preferencebasedliving.com/?q=tip_sheets
- Top Preferences Across LTSS Settings, preferencebasedliving.com/?q=tip_sheets
- Do Resident Preferences Change Over Time?, https://preferencebasedliving.com/?q=tip_sheets
- Strategies to Improve Dining Satisfaction Using the PELI, https://preferencebasedliving.com/?q=tip_sheets
- Keys to Person-Centered Communication, https://www.preferencebasedliving.com/tip-sheets/keys-to-person-centered-communication/

Pragmatic Assessment Tools: Preferences for Everyday Living Inventory (PELI)

- PELI-PAL Card 8-Item MDS-Section F 3.0 Interview, https://www.preferencebasedliving.com/pal-cards/peli-pal-cards-8-item-mds-3-0-section-f-interview/
- PELI With Communication Icons (under development, testing 100+ images)
Webinars

**Family Engagement, Advocacy, Effective Communication While Wearing A Mask During Quarantine**


**Virtual Presentations to Provider and Professional Groups**

- Utilizing Care Preference Assessment of Satisfaction (ComPASS-16): A New, Interactive Tool to Facilitate Person-Centered Care, Ohio Association of Gerontology and Education Annual Conference, April 2021
- Better Together: Leveraging Partnerships to Realize Person-Centered Care, Ohio Association of Gerontology and Education Annual Conference, April 2021
- Engagement and Person Centered Care: Assessing Preferences for Everyday Living, Linked Senior, webinar, [https://www.youtube.com/watch?v=mr3t7VPRWls](https://www.youtube.com/watch?v=mr3t7VPRWls)

**Training Video**

**Engaging Family and Friends in Preference Assessment**


**Audit Trails and Tip Sheets for Quality Improvement**

- Sample Audit Trails Handbook (*under development*)
- Audit Trails and Quality Improvement Video (*under development*)
- Tip sheets:
Case Studies
Brief profiles highlight Ohio nursing homes’ successful efforts to enhance preference-based, person-centered care
• Preference-Based Living Case Studies: Four Communities. (2019), https://preferencebasedliving.com/?q=case-studies

Podcast
• Pioneer Network for a Listen, Learn, Explore podcast and virtual learning circle webinar, https://www.youtube.com/watch?v=fek3XZWhzDA

Web-Based Application
  • Currently, 63 provider accounts, 83 users have entered data on 339 residents
  • Webinar: Introduction to ComPASS-16
  • Monthly online demos for potential ComPASS-16 users