

Beginning A Journey To Embrace Patient-Centered Outcomes Research:

Do academic nurses practice what they preach by assisting patient-centered outcomes research?

Ming (Huey-Ming) Tzeng, PhD, RN, FAAN
Professor, School of Nursing

The University of Texas Medical Branch at Galveston, Texas
<https://nursing.utmb.edu/About/Faculty/Biography/hutzeng>

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Disclaimer

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Introduction

- ***When people's stories are recognized, it does something: It creates a possibility.*** (JOHN A. POWELL, Professor of Law and Professor of African American Studies and Ethnic Studies at the University of California, Berkeley School of Law, is an internationally recognized expert in the areas of civil rights, civil liberties, structural racism, poverty, and democracy)
- My mantra: Love is an action verb.
- My vision: Embrace holistic health through aging research.

Research Topic & Why Important

- Research Topic: This presentation intends to answer the question:
 - **Do academic nurses practice what they preach by assisting patient-centered outcomes research (PCOR) and researchers through their engagement with patients, caregivers, and other community stakeholder partners in nursing research?**
- Why important?
 - Limited literature has documented how academic nurses have integrated patient-centered outcomes research into any academic activity involving a research infrastructure
 - Got to learn from patient/caregiver partners!

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- **Patient-centered outcomes research (PCOR) aims to make the voices of patients and their caregivers heard** when assessing the value of their healthcare options and assisting them in communicating and making informed healthcare decisions.
 - **Who:** PCOR can include the patients, caregivers, and other stakeholder partners (e.g., clinicians, policymakers).
 - **Where:** PCOR can occur in diverse settings and include participants from across the care continuum (e.g., community settings, health care providers from primary care, secondary or tertiary settings).

(Patient-Centered Outcomes Research Institute, 2012
<https://www.pcori.org/research-results/about-our-research/patient-centered-outcomes-research>; <https://www.pcori.org/assets/PCOR-Definition-Revised-Draft-and-Responses-to-Input.pdf>)

Methodology

- A communication paper
 - An overview of how academic nurses began to embrace patient-centered outcomes research in the University of Texas Medical Branch at Galveston, School of Nursing (UTMB-SON), Texas, USA
 - Using the strategic plan of UTMB-SON to demonstrate a systematic approach to embracing patient-centered outcomes research and supporting a researcher's journey to fulfill her patient-centered outcomes research goal.
 - The process of developing the community-engagement infrastructure.

Table 1 Summary of the related activities by dates at the University of Texas Medical Branch (UTMB) at Galveston School of Nursing

Date	Activities
2019 - 2025	<p>The UTMB SON developed the strategic plan titled “Vision 2025,” which emphasized the importance of engagement by expanding professional networks and community interactions to generate opportunities for students, faculty, and alumni to promote long-term beneficial collaborations.</p> <p>The UTMB SON has begun implementing a systematic approach to support patient-centered outcomes research.</p>
2020 - 2021	<p>The UTMB SON Research Innovation and Scientific Excellence (RISE) Center developed its strategic plan, which emphasizes the importance of community engagement and interdisciplinary collaborations.</p>

Table 1 Summary of the related activities by dates at the University of Texas Medical Branch (UTMB) at Galveston School of Nursing (Cont.)

Date	Activities
August 2019 - January 2021	<p>The first author received the University of Texas System Rising Science and Technology Acquisition and Retention (STARs) Award for equipment, repair, and renovations funded from Permanent University Fund bond proceeds in August 2019.</p> <p>These funds were used to renovate the space to be used for a new Community Space for Health and Well-Being within the UTMB SON RISE Center. The refurbishment of this facility was completed in January 2021.</p>















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Family isn't always blood. It's the people in your life who **want you** in theirs; the ones who **accept** you for who you are. The ones who would do anything to see you smile & who **LOVE YOU** no matter what.

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Table 1 Summary of the related activities by dates at the University of Texas Medical Branch (UTMB) at Galveston School of Nursing (cont.)

Date	Activities
October 2019	<p>The Community Space Design Advisory Committee was formed.</p> <p>The committee members have been actively engaged in grant proposal development since the committee was formed.</p>

- *Maribel's experience*

- *(Nurse/Caregiver Partners) (recording)*



- Patient-Centered Outcomes Research virtual training, 8 hours, in August 2020: co-learning among researchers, patients and stakeholder partners

- better engage older African Americans (AAs) to participate in health research
- discussing the purposes of research, the basic research concepts, and processes

- Well-received: This training could well increase confidence in communicating health research with AAs and reduce the current mistrust among older AAs.

- The training is available to AA and other communities.

The Community Space's mission, vision, etc.

- **Mission:** guided by patients, caregivers, and the larger healthcare community—supports and encourages patient-centered outcomes through research, education, and community participation
- **Vision:** fully integrated into the community through conducting innovative research and education
- Initial strategic priorities (Nov. 2020) centered on fall prevention among community-dwelling older individual
 - based on the Community Space Design Advisory Committee members' interests and their perceived needs of Galveston County, Texas



Table 1 Summary of the related activities by dates at the University of Texas Medical Branch (UTMB) at Galveston School of Nursing (cont.)

Date	Activities
May 2020 - April 2021	In May 2020, during the COVID-19 pandemic, the UTMB School of Nursing Community Space Design Advisory Committee received the National Network of Libraries of Medicine South Central Region’s Technology Enhancement Award to fund a project titled “Development and Evaluation of a Technology Education for Community and Home Program for Older Adults and Their Family Members and Caregivers to Support Independence.”

Learning **from and with** community-dwelling older adults about how to introduce MedlinePlus and innovative devices to their peers (1)

- The goal: to raise awareness of MedlinePlus (<https://medlineplus.gov/>) and market-available devices that improve health and well-being.
- Co-implemented the project using PCOR methods
 - Team of 5 patients/caregivers, researchers, and 3 community stakeholders
 - Sealy Center on Aging
 - Osher Lifelong Learning Institute



Learning **from and with** community-dwelling older adults about how to introduce MedlinePlus and innovative devices to their peers (2)

- Associated with multiple priorities of the Community Space (i.e., b. training, d. communication and awareness).
 - topics:
 - Stay Active (leisure, exercise, and mobility),
 - Care for Your Body (nutrition and medication),
 - Fear Not (safety and security, e.g., fall prevention),
 - Stay Sharp (memory and learning), and
 - Everyday Tools (communications and activities of daily living)



A medical reference librarian at UTMB shared her personal story and discussed her belief in and commitment to patient-centered outcomes research:

Due to my connective tissue autoimmune disease, I have had many orthopedic surgeries and joint replacements.

However, the ability to walk without assistance has never been taken for granted.

During my outreach activities, I have been passionate about helping older adults learn how to use medical information and assistive devices to tackle their physical obstacles.



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- During the COVID-19 pandemic (2020-2021)...
 - A proposal-writing group co-developed three grant proposals for patient-centered outcomes research with local community organizations.
 - e.g., the International Nurses Unit of the Church of God in Christ, Inc., Galveston Baptist Association
 - In 2021, the writing group published one peer-reviewed journal article.
 - With gratitude



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Working Together to Work Wonders

A female caregiver of her mother-in-law and a nurse of the Catholic faith (one of the co-authors) shared her experience with the patient-centered outcomes research training provided by the Community Space for Health and Well-Being:

I have been a family caregiver for my mother-in-law, who lives with me, and a virtual family caregiver for my mother, who has lived in southern Asia with one of my sisters, for over 20 years. My mother-in-law is a Muslim.

Understanding her belief and cultural practice related to self-care, such as preventing falls at home, is important for me to be an effective family caregiver. As a nurse for more than 30 years, I have been passionate about helping older adults stay independent and stay in their own homes as long as they are able and want to.

The August 2020 patient-centered outcomes research training was very informative, and I learned a lot. I believe that researchers, clinicians, patients, caregivers, and stakeholders need to have shared knowledge about patient-centered outcomes research. We must collaborate with our patient partners, especially older adults, on developing solutions that will meet their learning styles and help them perform their activities of daily living. We need to hear their voices and learn about their values through listening, focusing on their beliefs and preferences, and soliciting active participation, thereby building trust.

Summary and Conclusions

- UTMB School of Nursing has taken several steps to intentionally engage community stakeholders in all research phases.
 - Developed the mission and vision statements with communities.
 - Established a community advisory board for the community space to build trust and provide opportunities for community members to have representation in research activities.
 - Provided training and workshops to community members.
 - Promoted research relevance among community stakeholders.
 - Continuously sought community stakeholder feedback on research or project procedures.

Thank You!



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Question & Answer