Family Presence in Hospitals and Long-Term Care: Learning from COVID-19 Experiences

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1 – 2:15 pm ET

Presented by…
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Helpful tips
❖ All participants will be muted upon entering.
❖ Please post questions and comments in the chat box.
❖ A recording of this webinar will posted to IPFCC’s website.
❖ Experiencing technical issues with Zoom? Please chat with Matt D’Silva.

In our time together…
❖ Review IPFCC’s commitment to family presence & participation
❖ Learn about two PCORI-funded projects related to COVID-19
❖ Share themes and topics common to the two projects
❖ Discuss how the project findings can help prepare for future public health crises

PCORI
PCORI helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community. www.pcori.org

Both projects were funded through a Patient-Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award
IPFCC’s Commitment to Family Presence and Participation

1992 The Institute for Family-Centered Care is founded with a commitment to families being viewed as partners in all care settings.

2003 Changing the Concept of Families as Visitors: Supporting Family Presence and Participation

2010 Pandemic Planning and Patient- and Family-Centered Care

2014 Better Together: Partnering with Families Campaign and Toolkit

2020… IPFCC initiated several projects focused on family presence.

“When COVID was hitting initially, nobody knew anything... You didn’t really know what it did or how to not get it and so it was just this awful kind of cloudy experience.”

— Hospital Physician

Learning from Experience: Exploring the Impact of Approaches to Family Presence in Hospitals During COVID-19

Project Goals

❖ Prepare three health systems to engage in future patient-centered outcomes research about family presence.
❖ Prepare patients and families to share experiences of hospitalization during COVID-19 and the impact of different approaches to family presence.
❖ Identify and prioritize themes, topics, and questions to inform future PCOR/CER on the impact of different approaches to family presence.
❖ Identify strategies for engaging stakeholders, especially patients and families, in future patient-centered outcomes research.

Key Activities

❖ Establishing a Multidisciplinary Care Team at each site in collaboration with the IPFCC project team across all project sites, and co-developing an initial planning meeting with each team.
❖ Gathering findings about themes/topics/questions for pilot projects and strategies for engagement with members of the three Care Teams.
❖ Establishing key virtual meeting with the respective teams to discuss all key issues and project goals.
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Partner Core Teams

- Johns Hopkins Bayview Medical Center
- Intermountain Health
- University of South Carolina Patient Engagement Studio

Core Teams: Clinician, frontline staff member, researcher, coordinator of patient and family advisory program or staff member from the diversity/inclusion department, and two patient and family partners

Each Core Team:
- Recruited and supported 5 additional patients and family members to participate—the Augmented Team
- Co-facilitated meetings
- Collaborated in developing resources

Process for Developing Themes/Topics
- Recorded all meetings
- Transcribed all recordings
- Analyzed transcriptions
- Coded for themes and topics
- Summarized and shared with teams for feedback

New Resources

Building Capacity for Long-Term Care Stakeholders in COVID-Related Patient-Centered Outcomes Research

Patient
- I had the shakes really bad from the drug. I couldn’t text or type, that was really hard. I couldn’t communicate and there was nobody there to help communicate with my words.

Family
- My sister was hospitalized. I never did get to see her before she passed. They had a quota. It just wasn’t in the pecking order for me to be able to see her. It was very difficult not to be able to say good-bye.

Staff & Clinicians
- It was just so hard to be the kind of physician you wanted to be. And I felt so bad for all of our patients. And, you know, it was an awful time.
Explore the experiences of social isolation and loneliness in long-term care that resulted in an adverse impact on mental health and well-being of residents and families during the COVID-19 pandemic.

Build a foundation for collaboration among residents, families, other stakeholders, and researchers in planning for Patient-Centered Outcomes Research/Comparative Effectiveness Research (PCOR/CER).

Project Objectives

❖ Develop partnerships among residents, families, staff in long-term care communities, researchers, and other stakeholders related to planning and conducting PCOR/CER.

❖ With residents, families, and other stakeholders, identify and prioritize the root causes of social isolation and loneliness during the COVID-19 pandemic.

❖ Develop topics and themes appropriate for future PCOR/CER from the prioritized list of root causes of social isolation and loneliness.

❖ Engage all key stakeholders in dissemination of project findings.

**Project Goals**

**Project Objectives**

Key Project Activities

Small Group Conversations with Residents and Families

Written Summary and Key Themes

A fishbone diagram was used to illustrate the Root Cause Analysis.
Across the Two Projects: Themes and Learnings

- Different stakeholders; different settings of care—hospitals and long-term care
- Many common themes
- Impact on care, communication, decision-making
- Impact on well-being of patients, residents, families, staff, clinicians, and leaders
- Emerging evidence about harm due to family presence restrictions

Restrictions Impacted Care

- Families could not advocate for their loved ones.
- Decisions about care were more difficult to make and even delayed.
- Families could not provide direct care and support activities of daily living, e.g., feeding, dressing.
- Families could not provide comfort, support, and companionship.
You could definitely see there was a physical change in the man not having human touch...that can provide that voice, the familiarity wasn’t there for him...he had a significant decline.”
— Family member of resident

“I think if my Mom had been there, she would have noticed the change in my mental state sooner. I would have been able to get that medical attention sooner.”
— Patient

Information about patient prior use of or problems with medications were not known.
Without families being present, vital information important to decision-making may be missed.
Lack of information contributed to depression and fear of death.

“I was allergic to a lot of medication. Because of the lack of communication, they had given me medications that I was allergic to. My husband kept trying to get numbers to fax them the medications and stuff.”
— Patient

“Well of Patients/Residents and Families
❖ For patients/residents, it was frightening to be isolated, separated from family and friends.
❖ Families could not advocate for patients/residents effectively.
❖ Families felt powerless because there was so little they could do.
❖ Changes in staffing or not being able to recognize staff in PPE was difficult.
“The isolation almost did her in. She was way too quiet. She wasn’t smiling...It has left a lasting effect on her and her level of depression.” — Family member of resident

“I’m an introvert anyway. And I just felt so alone. I had to really try hard to not be depressed. Most of the time I go up and down, up and down.” — Resident

Well-Being of Staff and Clinicians

❖ Staff missed the essential roles that families play.
❖ Staff found it difficult to limit access to families.
❖ Staff were distressed that they could not provide the quality of care they had before.
❖ Staff could not provide clinical care, support for daily living, and emotional support typically provided by families.

Limitations of Use of Technology

❖ Virtual calls not the same as physical presence
❖ Challenging for those who lack experience using technology
❖ Often not helpful for those who have limited English proficiency
❖ Not useful for those who are very sick or have visual, hearing, and/or cognitive impairments
❖ Devices and internet not accessible to everyone

Benefits of Sharing Experiences

❖ Transcends other differences
❖ Provides an opportunity to hear different perspectives—patients/residents, families, staff, and clinicians
❖ Highlights the commonality in lived experiences across the continuum of care
❖ Leads to mutual understanding and respect
“Even though our experiences are different, they are the same. It just feels good to openly discuss what you went through. Because everybody doesn’t understand.” — Family member of hospital patient

“The information gathered in this project is so important. The meetings were sometimes emotional, but so therapeutic, it gave people the opportunity to finally express themselves, let out all their pent-up grief, frustration, and if they had any, anxieties.” — Long-term care staff

“Residents and families enjoyed participating. One resident...shared with his social worker that he was invited to be a part of the committee that talked about the pandemic...he expressed pride in being part of the group and it gave him a sense of purpose in sharing his thoughts. I saw the resident in a different light. I saw his strengths instead of his places of need which we most often focus on in skilled nursing.” — Staff person in long-term care

Experiences Partnering with Patients, Residents, and Families in Research Planning

❖ Participating hospitals had experience and structures in place to collaborate with patients and families.
❖ The long-term care communities had not built the infrastructure and had less experience in partnering in quality improvement and research planning.
❖ Providing support for effective partnering with patients, residents, and families contributes positively to research and new understanding for health professionals.

“I learned that people really do have a story to share if you offer a listening ear, if they are given time to share their story. In terms of research, even if the story is not formulated in a way that this is our path to research, having them tell their story can lead to a direction for change...” — Staff person in long-term care

For more information, visit www.ipfcc.org

Join us on April 25th!

PFCC.Connect Informal Conversation:
Family Presence in Hospitals: Where Do We Go From Here?
April 25, 2023
12 – 1 pm ET
Register today at www.ipfcc.org
Discussion

We want your feedback!
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