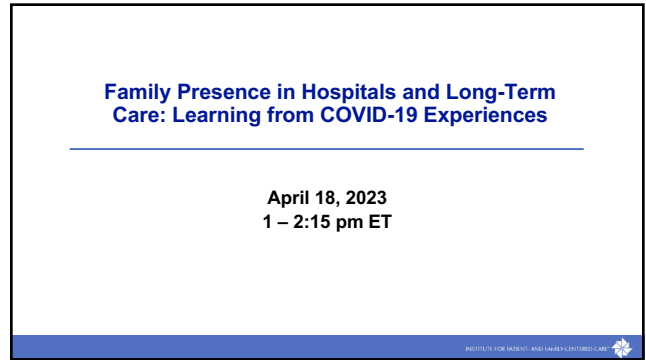




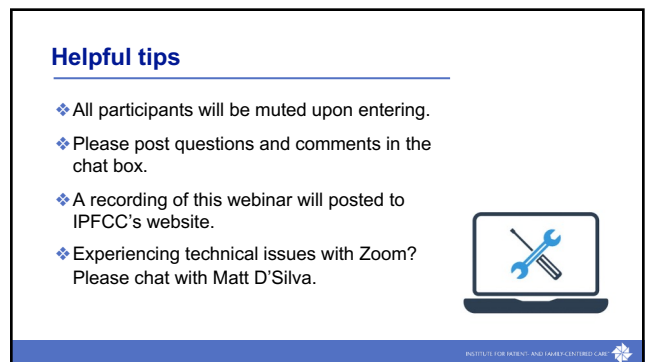
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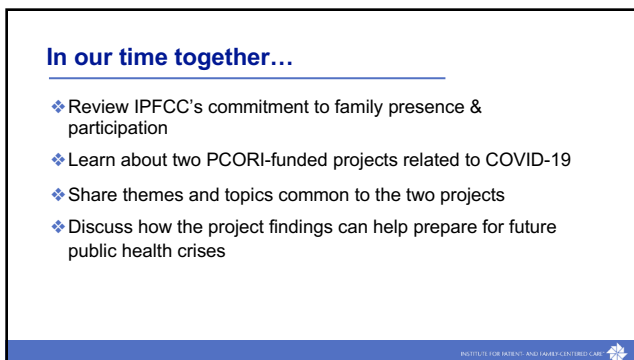
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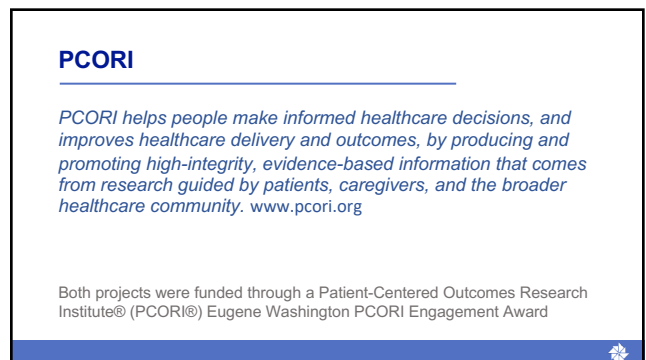
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6


IPFCC's Commitment to Family Presence and Participation



7

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	<i>Changing the Concept of Families as Visitors: Supporting Family Presence and Participation</i>
2010	<i>Pandemic Planning and Patient- and Family-Centered Care</i>
2014	<i>Better Together: Partnering with Families Campaign and Toolkit</i>
2020...	IPFCC initiated several projects focused on family presence.



8


"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



9


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



10

Project Goals

<ul style="list-style-type: none"> ❖ 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. 	<ul style="list-style-type: none"> ❖ 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.
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Key Activities

Establishing a multidisciplinary Core Team at each site to inform and collaborate with the IPFCC project team across all project tasks; and conducting an initial planning meeting with each team	Augmenting the Core Teams with additional patient/family partners; and conducting three site specific virtual meetings with the Augmented Team at each of the sites
Summarizing findings about themes/topics/questions for future research as well as strategies for engagement, with review from leaders of the three Core Teams	Conducting two virtual meetings with Augmented Teams in which all three sites participated

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Partner Core Teams

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

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Partner Core Teams

- 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



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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

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New Resources



16



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**.*

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

18

Project Goals

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).

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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.

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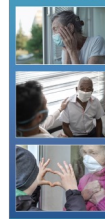


IPFCC is partnering with four long-term care communities to learn how changes made during the COVID-19 pandemic have impacted quality of life as a first step for future research.



21

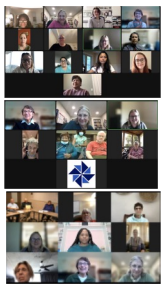
Residents & Families Needed!



Key Project Activities



22

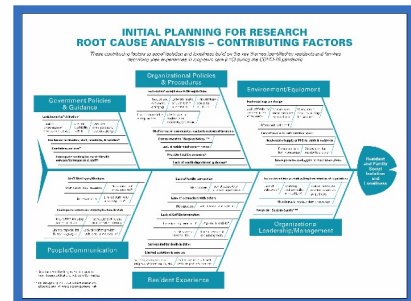


Small Group Conversations with Residents and Families

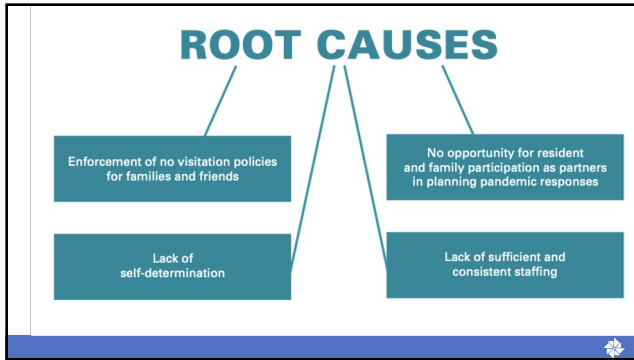
Written Summary and Key Themes

23

A fishbone diagram was used to illustrate the Root Cause Analysis.



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New Long-Term Care Resources

RESEARCH TOPICS & THEMES
FOR LONG-TERM CARE DEVELOPED IN
PARTNERSHIP WITH RESIDENTS AND FAMILIES

A GUIDE FOR PROMISING PRACTICES
IN ENGAGING LONG-TERM CARE COMMUNITIES
IN PLANNING FOR FUTURE RESEARCH

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Across the Two Projects: Themes and Learnings

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Affirmation of Family Presence

- ❖ 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

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“So most of his [difficulty] coping had to do with why I couldn’t come there. ‘You are my wife, I’m your husband...’”

— Family member of a resident

“Looking back...I definitely wish I would have had every single family member there for every patient. I hated having to see them go through this thing alone.”

— Hospital nurse

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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.

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"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

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Impact on Communication and Information-Sharing

- ❖ 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.



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"I wasn't allowed to have anybody come in with me [ER]. It was not having somebody in the room able to communicate what I had been dealing with over the past months."
— Patient

"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

"When I went to the hospital, I understood when they said that there's no beds, no rooms, but also they had no interpreters."
— Spanish-speaking patient

33

"All of a sudden, people have gone and disappeared."
— Resident

"I think that they shared with us what they could, or what they were allowed to...but we all knew that it was really bad, and no one was talking about how bad it really was..."
— Resident

"I lived in isolation throughout the pandemic and didn't know what was going on."
— Resident

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Well-Being 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.

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"It was devastating...because I could not be there for my mom. There was not one time that she had been sick that I was not by her side. So to have to trust these professionals to take care of her the way that I had was very, very hard."
— Family member

"I was depressed. I questioned myself for going to the hospital at all."
— Patient

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"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

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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.



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"Watching residents suffer, being separated from their families, was what was most impactful during the pandemic."
 — An All-Staff Debriefing from a Long-Term Care Community

"It was really, really hard to stand there as people would pass away or people would get sicker...you're standing with this iPad, showing this person their family member and they're just devastated...absolutely nothing I can do."
 — Hospital nurse

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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



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"Communication was via telephone, which could be difficult in a unit that was locked down with fans blowing to create the negative pressure environment. It was really hard to talk to families over the phone."
 — Hospital nurse

"My grandmother would hit the mute button and wouldn't unmute herself. No one would come and notice that she was muted until that the whole hour was over."
 — Family member of resident

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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



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"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

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"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

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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.

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"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

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For more information, visit www.ipfcc.org

www.ipfcc.org/bestpractices/supporting-family-presence/index.html

www.ipfcc.org/bestpractices/long-term-care-partnerships/index.html

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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

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