



INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

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KEY THEMES FROM THE SUMMARY OF SMALL GROUP CONVERSATIONS WITH RESIDENTS AND FAMILIES — August 30, 2022

INTRODUCTION

Resident and Family Small Group Conversations were conducted between April 22-May 6, 2022. This document lists the key themes drawn from these conversations. A separate document describes the summary of resident and family perceptions and experience during the COVID-19 pandemic. The key themes and summary have been developed to create a better understanding of the root causes of social isolation and loneliness during the pandemic that led to an adverse impact on mental health and well-being. They will be used in the September stakeholder meetings to generate topics and themes for future research.

KEY THEMES

- **LOSS OF FAMILY CONNECTIONS AND SUPPORT:** Both residents and families conveyed that the loss of family connections was amongst the hardest part of the pandemic experience. Although the modifications to in-person time with families and use of technology helped to ameliorate the sense of loneliness and social isolation for some elders, it had adverse consequences for others.
- **LACK OF SELF-DETERMINATION:** The loss of self-determination due to pandemic restrictions was a dramatic change for the everyday lives of residents, often with negative consequences. There appeared to be no opportunities for residents and families to serve as true partners in pandemic planning over the last 2 ½ years. There were almost no structures in place to support these effective partnerships.
- **LIVING ARRANGEMENTS:** Isolation in a room with or without roommate(s) and moving to new floors contributed significantly to feelings of loneliness, depression, loss of connection with staff and friends, and the lack of self-determination.
- **ACTIVITIES, MEALTIMES, AND LOSS OF CONNECTIONS WITHIN THE COMMUNITY:** Residents stated that interesting activities, some mealtime interactions, and informal connections and communication with friends and staff in the long-term care community contributed to their quality of life during the pandemic.
- **INTERACTIONS WITH STAFF:** Both residents and families praised staff and recognized the difficult working conditions created by the pandemic. However, staff shortages contributed to limited activities, ineffective communication, and impacted residents who now did not know their caregivers as they had previously. Similarly, these new caregivers were unfamiliar with residents and families.

- **COMMUNICATIONS/APPROACHES TO SHARING INFORMATION ABOUT COVID:** Residents described various ways their organization communicated information about COVID with themselves and their families, including a newsletter, the PA system, and emails. However, even with these strategies in place, residents and families expressed concern and frustration about lack of communication. As examples, they reported phone messages going unanswered, policy changes not being communicated, and lack of information about COVID cases within their long-term care community.
- **DEATH AND/OR CONCERNS OF DYING AND CONTRACTING COVID:** Living in an environment with death and dying so prevalent was a powerful reminder of residents' vulnerability and contributed to high level of anxiety.
- **ADVERSE IMPACT:** The adverse impact of COVID restrictions on physical, emotional, and cognitive well-being as described by residents is integrated throughout the summary. Families reported that social isolation and loneliness had a profound impact on their loved ones.
- **RECOMMENDATIONS FOR THE FUTURE:** At the end of the conversations, residents and families contributed further ideas for improvement in the future. A resident recommended: "The minute you hear on the news, it's coming over from wherever, you get your vaccines ready. And then if you have to, hate to say this, lock down everything." Other residents recommended the following to reduce the spread of infection:
 - Have masks and protective equipment more readily available.
 - Limit larger gatherings, including eating in the cafeteria.
 - Have vaccines ready to be distributed.
 - Set up places where you can have an outdoor visit using clear screens to separate residents from families.

Families recommended approaches to limit isolation but still preserve protections to prevent transmission of infection:

- Provide small group activities if residents have tested negative and wear masks.
- Offer group activities for small clusters of room.
- Improve the use of technology so that residents can be seen on the screen, cannot unintentionally hang up or mute themselves during calls, and provide adequate support for the hearing impaired.
- Consider use of a tele-conference type cart with a screen or a computer/television so the resident does not have to hold the phone.
- Bring evidence of negative rapid COVID tests before visiting.
- Use of a dashboard to communicate the breakdown of people sick with Covid by residents, nursing staff, and other staff, etc.

A family member also offered a suggestion to minimize the feelings of social isolation and loneliness for those separated by language and culture: *"If there could be like that one person that someone can click with, and...even if it's like a weekly*

visit from that person...I think it makes a huge difference, especially if there's a language barrier...just to see someone like that...for my dad, that would be huge.” Another family member suggested that if the long-term care community did not have personnel who spoke the residents’ native languages, they could partner with another organization that had personnel with these language skills. *“Speaking in your home language, particularly under stressful circumstances, can also reduce stress and give a person the feeling of being understood.”*

A resident had a suggestion for maintaining normal activities while still providing isolation: *“I wish we had another little building that...if you get the COVID, they put you in there until you get better. ... then they don't stop all the activities ...here it goes from one floor to the next floor. When you get well you come back, everything is fine. And then they don't stop all the activities.*

A family member made this recommendation: *Couldn't an exposure index be calculated? The amount of time you spend out in the community surely contributes to your exposure to an infection. An exposure index could help to ensure that certain family members residing in independent living could visit their loved ones in skilled nursing or other care areas safely. It could be calculated by determining the level of risk of transmitting the virus to residents based on the amount of time spent with others both within and outside of the long-term care community, e.g. staff vs. residents in independent living.*

Residents also offered these thoughts:

- “Praying to God. It helps a lot if you pray. It helped me.”
- “[Staff] made a stand and had pictures of everybody that passed away so we could see them again.”
- “Keep your spirits up. Don't get too depressed...just do positive things...Stay positive.”
- “Think about the other person.”