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Reimagining Dementia Family Caregiving Engagement for Post-Acute Care Transitions: Lessons Learned from Covid-19

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Keywords

Caregivers; Pandemics; Skilled Nursing Facilities; Adult Children; Inpatients; Patient Transfer; COVID-19; Dementia; Decision Making; Communication; Patient Care Team; Policy

Abstract

Family caregivers of persons with dementia (PwD) experience three-times more post-acute care transitions (PACT) to skilled nursing facilities than other caregivers. During Covid-19, visitation policies drastically changed, limiting family caregiver engagement. This was a widespread experience; yet, few studies have examined dementia family caregivers' perceptions of PACT engagement during Covid-19 restrictions. This qualitative study focused the findings and lessons learned about the meaning of engagement, barriers, facilitators, and support needs during Covid-19, using an interpretive descriptive approach. Participants (n=15) were mostly female (n=13), adult children (n=8), and the majority (n=9), had a PACT experience during the Covid-19 pandemic. Family caregivers reported improved engagement with the PwD and healthcare team in the inpatient acute care setting because hospital policies on Covid-19 allowed one visitor—allowing them be physically present and advocate for the PwD. However, the majority of family caregivers who had the PACT experience during COVID-19 reported no ability to engage with the PwD or the healthcare team after a PACT due to skilled nursing facility visitation restrictions, “only essential workers” policy. Lack of perceived support negatively affected family caregivers' ability to communicate, share knowledge, advocate, and participate in critical decision making. These Covid-19 challenges highlight the importance of being physically present as a necessary component to engagement which facilitates a form of communication compensation that improves outcomes for the PwD. Future practice policies should view family caregivers as essential to the healthcare team and develop innovative solutions to connect family caregivers to the PwD during Covid-19 or future pandemics.