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BY HEATHER MANOLAS, DNP, RN





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When a loved one is admitted to the hospital, family caregivers expect to be involved in their care. But often, family caregivers perceive a lack of communication and feel they are being dismissed, ignored, or patronized by health-care professionals (HCPs)—like doctors, nurses, and nursing assistants. During the COVID-19 pandemic when family caregivers were often isolated from their loved one and the care team alike, many perceived a further breakdown in communication. Good communication matters: not only because family caregivers deserve empathy and an understanding of their loved one's care, but also because family caregiver

perceptions have an impact on patients, HCPs, and organizations. Positive family involvement improves patient outcomes like delirium, and it can boost HCPs' satisfaction along with financial reimbursement for the hospital. This article opens a discussion of how hospitals can explore and examine their policies and procedures to improve communication at the patient's bedside and address negative perceptions by the family caregiver. At the same time, hospitals must continue to mitigate the residual and ongoing physical and psychological impacts of the COVID-19 pandemic on the healthcare workers themselves.

Impact of Family Caregivers' Negative Perspectives on Facilities and Healthcare Professionals

More than 50 million people worldwide live with neurocognitive disorders such as Alzheimer's disease, and a fast-growing six million of those are here in the United States (Gilbert, 2019). The effects of the pandemic, including illness and isolation, have been shown to speed cognitive decline in older adults (Cagnin et al., 2020). All this means healthcare staff will be caring for more and more of these patients and their family caregivers in acute care settings. Patient/family/caregiver perceived satisfaction with the care provided in hospital acute care settings drives many policies and procedures and is closely tied to the hospitals' ratings and financial stability (HCAHPS, 2021). A positive relationship driven by good communication between HCPs and family caregivers has a greater chance of improving outcomes and satisfaction than does one where the family caregivers perceive they are not welcome to be involved in the patient's care (Schmitt et al., 2017).

Reported Family Caregivers' Perspectives

During implementation of an evidence-based project by this author, some anecdotal feedback from several family caregivers of those living with dementia exposed some of their negative perceptions during previous hospitalizations of their loved ones (Manolas, 2021). First, of note, was the need for caregiver education on the delirium commonly experienced during a hospitalization. Second was their strong desire to advocate

for their loved one and be involved in care during a hospitalization. Unfortunately, several expressed the perception that they did not feel as if they were free to ask questions and speak up. They feared the HCPs would retaliate against them and cite the COVID-19 staffing shortages as a rationale for not engaging in effective communication or delivering quality care to their loved one (Manolas, 2021). Without a relationship that fosters trust and communication between the two, effective collaboration, education, and good outcomes are at risk (Hart et al., 2020).

In one study, family caregivers expressed a feeling of being overwhelmed by the new onset of delirium and a sense that education and communication were lacking, and that HCPs were dismissive toward them during their attempts at communication (Julian, 2020). Family caregivers often reported feeling treated as if their knowledge was less than important, and that staff and doctors were often distracted or unavailable and focused on other tasks. This leads to an erosion of a trusting relationship (Day & Higgins, 2015).

One recent systematic review found 20 articles examining 1,993 caregivers' perspectives of health-care delivery on their loved one with dementia (Beardon et al., 2018). Although negative perspectives were not the majority, a significant number of similar themes emerged: that often caregivers felt a need for staff education on delirium and dementia, felt a lack of respect by HCPs, and reported a lack of communication and trust (Beardon et al., 2018). Other common themes included a perception of less than dignified treatment, that staff were overly focused on other tasks which impacted quality of care,



and that HCPs did not consider personal preferences of the patient or seek input from the family (Beardon et al., 2018).

In another study, while some family caregivers had positive experiences, only 8.7% of caregivers were approached by the HCPs to involve them in care and to communicate, despite the fact they already were aware their loved one was experiencing delirium (Day & Higgins, 2015). Of note are the family caregivers' hopes for good communication, involvement in care-planning, and an empathetic tone from HCPs, but often enough they did not receive it (Julian, 2020).

These studies and experiences occurred prior to the pandemic and its subsequent enormous strains on the healthcare system, HCPs, patients, and families.

Impact of the COVID-19 Pandemic on Patients and Family Caregivers

COVID-19 has placed a great deal of stress on individuals living with dementia and their caregivers. A recent study of almost 5,000 patients with dementia found rapid physical and cognitive decline in up to 60% attributable to isolation and confinement due to quarantine, illness, delays in medical care, the consequences of caregivers' loss of income, and changes in routines (Cagnin et al., 2020). Two-thirds of their caregivers experienced a significantly higher level of distress (Cagnin et al., 2020). The burden on family caregivers is partly due to social isolation, loss of income, closures of resources—adult day-centers, support groups, and churches—and the challenges of handling pandemic-related worsening of dementia in their loved one (Tsapanou et al., 2020). At the bedside level, this stress may, on the one hand, exacerbate family caregivers' negative perceptions of care delivery by HCPs. Or, on the other hand, seeing HCPs face dynamic challenges during the current crisis, family caregivers may now have a new sense of empathy for them, leading to fewer negative perceptions of the behavior they witness.

Impact of the COVID-19 Pandemic on HCPs

HCPs themselves are still dealing with an unimaginable crisis right now. Hospital staff lack resources during the pandemic and have increased stress levels, long hours, changing responsibilities at home, grief experienced from sick and dying patients, ethical dilemmas, and the demands of caring for an increasing number of seriously ill patients. All of these factors have emotional and physical consequences on those

heroes (Rao et al., 2021). There is also a fear of contracting COVID and spreading it to their loved ones, as well as the ever-present discomfort of wearing PPE all day and the challenges it poses to "connecting" with their patients and families (Wang et al., 2020). As the effects of the pandemic do not appear to be going away any time soon, these experiences by HCPs must be acknowledged, addressed, and mitigated to support conversation on addressing family caregiver perspectives. This will also lay solid groundwork for improved procedures at the bedside level when the pandemic is behind us.

Addressing the Family Caregiver's Concerns

Beyond the desire by hospitals to improve patient and family perception is the impact delirium has from an outcome and financial perspective. Delirium increases length of stay by at least twelve days, increases mortality and morbidity significantly, and increases the rate of falls and hip fractures by 70% (Goodman, 2015; Johansson, 2018). These harmful and serious events are sometimes called "never events" because they should never happen, and so a great deal of effort goes into preventing them from occurring. As such, costs related to these "never events" fall, not on Medicare, but on the hospital (Felhberg et al., 2017). Staff and caregiver education and communication are at the heart of addressing such outcomes.

From a nursing perspective, preventing delirium translates to reducing wandering and pulling out IVs and sensors, along with very frequent reorientation and behavior management. These strategies, combined with medications often used to manage delirium, delay the patient's recovery time and significantly increase the stress and workload of bedside staff (Julian, 2020). Involving the family as experts is crucial to the cause.

Staff Education

A recurring theme in the recent systematic review, from family caregivers' perspectives, was that HCPs did not fully understand dementia and delirium and were thus falling short of appropriate care (Beardon et al., 2018). Lending to this perception is the lack of standardized or required education on delirium and dementia for HCPs (Gilbert, 2019). Leadership presence and support will be crucial to educating staff on delirium identification and prevention, including these key points: knowing who is at risk, what the risk factors are, how to identify delirium, and what exact measures to take to prevent it. There is substantive evidence supporting a multi-component,

nonpharmacological approach to delirium prevention. These components include early identification, use of sensory enhancement devices like hearing aids and eyeglasses, validation orientation rather than reality orientation, adequate hydration and nutrition, and family involvement (Manolas, 2021). Some hospitals have found success in upskilling nurses and engaging “Cognition Champions” to spearhead such measures and serve as peer mentors on units where at-risk patients are admitted (Travers et al., 2018).

Hospitals may also find opportunities to promote and practice effective and empathetic communication as, many times, HCPs are unaware of how their verbal and nonverbal communication is received by patients and family caregivers, especially when HCPs are confronted with multiple stressors and burnout. Opportunities may come in the form of educational seminars, one-on-one role-play or coaching, and even bringing in outside experts to hold classes on customer service.

Using Technology to Promote and Enhance Communication

Family involvement in their loved one’s care is proven to reduce delirium, reduce length of hospital stays, and positively impact patient outcomes and family caregiver perspectives. Vital to family involvement is open, frequent, and effective communication between HCPs and caregivers (Ludolph et al., 2020). Good communication is especially important in the age of COVID-19 and during any other healthcare crisis. Crisis/pandemic-related restrictions and limitations on visitors exacerbate the consequences of lack of family presence and lack of family involvement in care-planning, and impedes regular communication (Manolas, 2021). Communication with family, especially now, is the most effective yet least utilized factor in delivering quality care (Negro et al., 2020).

In a proactive step to communicate with a patient’s family under COVID-19 restrictions, fewer hospital rounding teams are entering patient rooms, but they are still collaborating using video conferencing technology workstations on wheels. Using those virtual rounds to invite the families’ questions and seek their valuable expertise has been of great benefit (Rosenbluth et al., 2020). Many clinicians are using a checklist to facilitate the virtual conversation with the family. Some have even implemented a family liaison to schedule a time frame for the video call and prepare them for the visual impact of seeing their sick or confused loved one (Negro et al., 2020). One can imagine that the new use of technology to promote communication will continue to be used moving forward and seen for its benefit in delivery of quality care.

Addressing the Negative Psychological Impacts of the COVID-19 Pandemic on HCPs

Now more than ever, we are seeing evidence of HCPs’ sense of duty, altruism, benevolence, and dedication to being part of a unified front against a common enemy: COVID-19 (Rao et al., 2021). This enemy has also created countless needs for HCPs, as earlier described. The most effective means of determining the needs of our HCPs is for leaders to ask them, and we are seeing this happen in many ways. Leaders may survey their workforce to determine what stressors are at the forefront and how they are impacting their physical and mental health, then create ways to support them during this time. Much of this support is evidenced by ensuring no-cost care and maintenance of sick days during a COVID illness, providing pet and childcare and free meals, attending to the mental health of their HCPs, and even providing physical and mental health support for their children (AMA, 2021). Many leaders are frequently checking in on their HCPs, arranging moments of silence, supporting real-time needs, providing food and personal care items, and advocating for them as the need arises (AMA, 2021). The guiding principle in all efforts is “hear me, protect me, prepare me, support me, and care for me” (Shanafelt et al., 2020). Experiences by HCPs must be acknowledged, addressed, and mitigated to support conversation on addressing family caregiver perspectives and improving communication. This lays a solid groundwork for improved procedures at the bedside level.

As we come out the other end of this pandemic, we are learning many lessons and making changes that will continue to be part of the way we support each other in all things. The world has faced an unprecedented crisis that is highlighting the need for compassion and collaboration amongst all persons. Additionally, the already-struggling healthcare system is under further strain from the pandemic, yet the dedication to delivering and improving quality care remains at the center of focus. Interwoven into all these considerations are the experiences of HCPs, patients, families, and the communities where they serve and live. As we continue to move forward, perhaps this crisis will help us all to strengthen empathy and compassion, which will ultimately lead to better outcomes for us all. •CSA



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