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Personal Reflection

Person- and Family-Centered Approach Offers Healing in Long-Term Care during the COVID-19 Crisis

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Mr. Watson, a coronavirus disease 2019 (COVID-19) positive octogenarian in a nursing home, had little fear about his own death.

In his own words ''death is the last thing I fear.'' He had neared death on multiple occasions in the past year due to complications of chronic obstructive pulmonary disease (COPD) and aspiration pneumonia. His family had peace about this. What they struggled with, which became apparent after goals of care and serious illness conversations involving the patient and his family, was, understandably so, the uncertainty around his quality-of-life due to the pandemic circumstances. The isolation and concerning media reporting of long term care (LTC) conditions during the pandemic provoked a state of fear, doubt, guilt, and anxiety with families of residents in LTC. For example, a family member of Mr. Watson said during one of our conversations, ''I feel that by advocating for my dad, I am advocating for other residents who might not have a family member speaking up on their behalf.'' The pandemic crisis revealed much to us about LTC needs, but the value of having early and frequent goals of care conversations is probably one of the most important lessons learned, yet underemphasized in public dialogues about LTC reform. The issues raised by Mr. Watson's family were explored and a plan was created to alleviate associated suffering of uncertainty and fear for the entire family. We devised a schedule to revisit these goals and updated the family on weekly basis of dad's overall health and well-being status.

It is critical to emphasize that this was an interdisciplinary goals of care approach. Meaning that nurses and allied health were part of the conversations and communications with the family. This is important as goals of care conversations are often thought to be a responsibility of the physician only. Although the physician's expertise is needed, perhaps more so initially, for prognostication and treatment plan discussions, eliciting patient values and goals is a trainable skill for nurses, social workers, and other members of the team. Furthermore, a sensitive goals-centered approach to communicate with families is also a learned skill. Through values-centered conversations and shared decision making, most families can have peace and acceptance when supported to be part of the journey, as challenging as it might be, through shared decision making.

Mr. Watson's family verbally expressed relief and satisfaction after the second goals of care follow-up conversation during the outbreak. We also noticed reduction in number of emails and calls made to the administration of the nursing home by the family, previously expressing panic, frustration, and anger. Instead, the family felt aligned with the staff and the facility in their goals and hopes for their father's care.

I'm left convinced that among the things we need to do more of moving forward is talk more about end of life goals of care and talk about them earlier. In fact, a policy to implement goals of care conversations on admission to LTC and with care conferences would be ideal. A training policy for frontline staff to engage in these dialogues is also critical for sustainable reform. These conversations give permission to engage in the narrative of the person's life story, their fears and hopes, and this can be healing for patients and their families.[1] Indeed, this is part of what is known as dignity therapy, which is part of an effective palliative approach to care.[2] Training both clinicians and allied health members of the team to take part in these conversations in a consistent and regular manner is of tremendous value in general, but in particular, at times of crisis. Although the initial time and planning invested in these conversations might be significant, the future time and cost saving to overworked staff and underfunded LTC homes are invaluable.[3] The serious illness conversation guide with substitute decision makers was used in this case.[4]

To our pleasant surprise, Mr. Watson survived COVID-19 infection! He never returned to his baseline functioning but he recovered well enough to be independently operating his own wheelchair and having in person visit with his family once the outbreak was declared over at the LTC facility. Seeing him wheel himself around the nursing home nowadays offers a sense of victory and hope amid this ongoing crisis after many challenging weeks and efforts to contain the outbreak in this LTC home.

Despite the chaos of COVID-19 outbreaks in nursing homes, it is possible, through early, consistent, and frequent values-centered interdisciplinary planning and conversations, to deliver high-quality end-of-life care. Not only does this deliver high standard of care but also lessens the burden of the process on families and the LTC facility. Parallel to providing LTC homes with adequate resources, one hopes to see increased systematic efforts and policies to offer

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goals of care and serious illness conversations with residents and families in LTC.

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