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A Traumatic Tale in Texas: A Mute Patient and a Muted Lone Caregiver

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A Traumatic Tale in Texas: A Mute Patient and a Muted Lone Caregiver

During non-pandemic times, the role of the caregiver for transplant patients is extremely difficult. This is especially true for the caregivers of patients experiencing post-transplant delirium in extensive intensive care unit (ICU) stays. This essay will begin to explore how and why caregiver support of ICU patients is especially problematic in a healthcare system under stress during a pandemic. The recently published theoretical work on “caregiver types” found in Wittenberg, Goldsmith, Ragan, and Parnell’s (2021) *Caring for the Family Caregiver: Palliative Care Communication and Health Literacy* will be applied to attempt to analyze the experience of caring for a loved one during a “no visitor” policy time period in an ICU in the Texas Medical Center (TMC) during the Coronavirus pandemic. While new communication technologies like FaceTime and texting were used by the caregiver in an effort to help the patient (her spouse), they were generally unsuccessful even though the healthcare providers worked hard to support both the patient and the caregiver under such difficult circumstances. Consequently, more theoretical work needs to be done to account for situations in which communication is made difficult, or impossible.

To begin with, the nature of post-transplant delirium in the ICU must be understood. Many factors contribute to the development of a patient’s delirium:

[The] ICU...is a stress-generating area in which patients may experience both psychological and physical discomfort...In addition, an ICU is a nonfriendly environment for patients...as they have no frame of reference and may frequently be exposed to moments of sensory and psychological overload...Finally, they may suffer from altered sensory perceptions and hallucinations as a result of their critical illness or the administered drugs.

(Biancofiore et al., 2005, p. 967)

A patient who enters into this altered mental state may become hyperactive or hypoactive. Hyperactive patients have increased motor activity, restlessness, and communication agitation. Hypoactive patients, on the other hand, have decreased motor activity, lethargy, and communication withdrawal. In both cases, insomnia usually occurs. It is very difficult for healthcare providers to know what care to provide for these unique medical conditions. Often, they can only rely on drugs like

melatonin and the adjustment of environmental factors in an effort to get the patient to sleep. Caregivers, however, can often provide additional personalized help for the patient. Since they have a shared history with the patient, they can tap in to common experiences in order to make the patient feel safe so that they can begin to move and communicate more normally. Consequently, in-person communication in the caregiver-patient relationship during post-transplant ICU care is crucial, even though hospital pandemic policy establishes an environment of patient isolation for pathogen containment purposes. This normally difficult health situation, then, is made even more difficult in the context of the Coronavirus pandemic.

The Coronavirus Pandemic in Texas

For many in Texas the world came to a screeching halt on March 11, 2020. On that day, the Houston Livestock Show and Rodeo was shut down due to community spread of the COVID-19 virus. It was the first time in history that the large event had ever been canceled. Shortly thereafter Harris County Judge Lina Hidalgo issued a “stay-home order”. As a result, all bars and restaurants were closed except for takeout and churches, schools, and workplaces went into remote mode. Hospitals throughout the county adopted a “no-visitor” policy and even suspended elective surgeries. By late May COVID-19 cases had begun to decrease and these restrictions were amended to allow the public to move more freely with the use of mandatory masks; and in the case of hospitals, allow for one visitor who had completed additional health screenings to enter to support patients.

In late June of 2020, my spouse was diagnosed as needing an urgent solid organ transplant after only one month of testing and hospitalizations. Because his condition deteriorated so rapidly, communication between the primary caregiver (me) and the healthcare providers happened quickly and without much time for outside research and consultation with other family members. Subsequently, my spouse became so ill that he was unable to participate effectively in discussions about his condition in the pre-transplant period. Thankfully, the overall transplant went extremely well. After the transplant, however, my spouse experienced a severe case of post-transplant delirium in the ICU. The delirium then continued on the regular transplant caregiving floor where he was moved for what should have been routine post-transplant care and discharge from the hospital.

During my spouse's pre-transplant and post-transplant period, the Coronavirus pandemic had its "second wave" of increasing infections, hospitalizations, and deaths in Texas. To cope with the additional patients and minimize the spread of the disease, the TMC again went into shutdown mode. This meant that the previous visitor protocols of "1 screened visitor per patient per day" were changed to "No in-person visitors". This also meant that effective in-person caregiver support of my spouse was made almost unattainable. To try to understand the frustration that I felt with this hospitalization experience, I found the new theoretical work on "caregiver types" by Wittenberg et al. (2021) beneficial. As Oliver (2021) notes in the Foreword, "...the book provides methods to assess family caregiver needs and more effectively address them" (p. vii). It was, in short, a way to at least begin to deconstruct the complex communication web created by the TMC.

Caregiver Types

Wittenberg et al. (2021) identify four caregiver types: the Manager caregiver (one who manages and leads family members in decision making), the Carrier caregiver (one who is supported by other family members, but protects them from the burden of caregiving), the Partner caregiver (one who shares the role of caregiving with other family members), and the Lone caregiver (one whose family is absent or provides no support). They argue that it is important to understand each type of caregiver's communication and health literacy needs so as to positively influence patient outcomes based on the particular caregiver-patient relationship that is present. This is because "A caregiver's information and health literacy needs have a direct impact on patient care...[and] Family communication about chronic illness (or lack of communication about chronic illness) influences the caregiver's ability to communicate with the care recipient and providers" (Wittenberg et al., 2021, p. 95). After identifying myself as a "Lone caregiver" using the typology presented in the book, I now better understand why the communication situation I found myself in with my spouse was so traumatic.

The Lone Caregiver

As a Lone caregiver whose family was either absent or provided no support when in attendance, the lack of communication (that would normally be present) with my spouse during this pandemic hospitalization experience was problematic. The "no visitor" policy

established by the TMC negatively impacted the family communication patterns, family behaviors in the illness process, family expectations and roles for caregiving, family decision-making and uncertainty, and palliative care communication and health literacy considerations identified by Wittenberg et al. (2021) significantly.

It is useful to start with a general description of a Lone caregiver. According to Wittenberg et al. (2021),

The patient relies on a Lone caregiver for information, care, and emotional support – in short, everything. As a result, the caregiver has many concerns because the patient has many needs....The Lone caregiver explicitly notes high uncertainty and seeks support and guidance from ongoing relationships with providers....Decision-making is primarily undertaken between the caregiver and staff; and the patient and caregiver are often tightly partnered in the management and navigation of care". (pp. 93-94)

Lone caregivers and their patients form this strong partnership primarily through their communication interactions during the course of the illness.

Family Communication Patterns

Lone caregivers do not communicate or interact much with family members except for the patient, even if they live close by. Wittenberg et al. (2021) describe the Lone caregiver "...as a person who is in a constellation of family but is not receiving regular or engaged caregiving support from the family" (p. 177). This was certainly the case in our situation. My spouse and I live alone and have no children. Although several of his out-of-state family members quarantined and then drove to Houston, they were not available for much consultation prior to the transplant because of the "1 screened visitor per patient per day" policy. During the post-transplant delirium phase, the "No in-person visitors" policy meant all family members were unable to see my spouse in person.

As a result of a lack of family communication, the Lone caregiver is able to do all of the medical care decision-making efficiently as the need for consultation and coordination with other family members is not necessary. Consequently, Lone caregivers have the space and time for "navigation, orientation, and execution...[of] medical support from systems and providers for the care recipient's illness(es)" (Wittenberg et al., 2021, p. 178). Again, this was certainly true for our situation. As the Lone caregiver, all decision-making prior to, and after, the transplant was ultimately left to me. Fortunately, I had the time necessary for researching

post-transplant delirium sufficiently and uncovering possible treatments for it.

Family Behaviors in the Illness Process

Without family communication and support, and armed with extensive research, the Lone caregiver is able to focus their efforts on the best possible care for the patient. "Making care choices is the goal, but not just for the sake of having a plan. It has to be a plan that will be the most effective" (Wittenberg et al., 2021, p. 179). Because my spouse was experiencing hypoactive delirium, I focused my research efforts on helping him to feel safe and secure enough to move and communicate.

Once a plan is established by a Lone caregiver, it must also be enacted. "Because of their need to create a network of support outside the family structure, the Lone caregiver and the recipient have the unique burden of figuring everything out and dealing with it" (Wittenberg et al., 2021, p. 181). As a result of my online delirium research, my plan was based on information from the Memorial Sloan Kettering Cancer Center (2019) and included talking about current events or things inside or outside of the room, reading books and newspapers aloud, playing calming music, and bringing familiar items from home. Obviously, I was not allowed to do this in person because of the pandemic visitation protocols. Ultimately, I tried to use texting, voice calls, and FaceTime to communicate with my spouse. While he was fortunate enough to have his own smartphone and iPad, he was unable to use these devices on his own. I had to rely on healthcare provider support to set up and encourage his use of these devices. This support was affected by the current patient load on the floor and the healthcare providers' experience with the technology. Sometimes everything worked, and sometimes it did not.

Family Expectations and Roles for Caregiving

Because Lone caregivers do not have much communication or interaction with other family members, there is little to no extended family expectation for caregiving. Any expectations that exist come from outside the family system. "Having low family support requires the Lone caregiver to seek support networks to cope throughout the caregiving experience" (Wittenberg et al., p. 184). While my spouse's family members were physically present at times, they were not comfortable discussing his medical condition with me or taking part in lengthy FaceTime conversations with him. Consequently, I turned to close

neighbors and work friends for socially-distanced moral support through the use of new communication technologies.

Most importantly, the Lone caregiver has a great deal of communication and interaction with the patient. While the two discuss almost everything, there are times when concealment occurs. "Concealment behaviors mask distressing information directly or indirectly related to a care receiver's medical condition" (Wittenberg et al., 2021, p. 187). In this case, the communication between the Lone caregiver and the patient was effectively halted due to hypoactive delirium and the inability of the two to meet in person. While the concealment was due to environmental and medical factors, it was still quite stressful for me to receive very little information from the one-way communication with my spouse via new communication technologies. Even his nonverbal communication behavior was difficult to assess at times because of the limited video access.

Family Decision-making and Uncertainty

When it comes to family decision-making about patient care and dealing with all of the uncertainties related to the patient's illness, the primary decision-makers are the Lone caregiver and the patient (if that is possible). "The main player who serves to bring dimension and multiple perspectives to care decisions is the care recipient" (Wittenberg et al., 2021, p. 189). In the bulk of the time leading up to the transplant, the Lone caregiver and the patient made all of the decisions. Once my spouse became too ill to communicate right before the transplant, all decisions were made by me with little to no consultation with other family members. Again, all decisions were made by the Lone caregiver after the transplant during the time of hypoactive delirium. This led to a significant feeling of uncertainty on the Lone caregiver's part because the patient was not able to communicate his thoughts and wishes at all.

Obviously, the nature of the decision-making communication between the caregiver and the care recipient depends on their relationship. "Conversations between the caregiver and care recipient can vary over time in terms of openness, topics discussed, and specific details shared and is dependent on the dyad's relationship (Goldsmith & Miller, 2014)" (Wittenberg et al., 2021, p. 80). What began with a very open relationship between us, became an almost nonexistent relationship because of the onset of hypoactive delirium. The one-way communication with my spouse via new communication technologies was unable to re-

establish the closeness of our relationship. Consequently, both the caregiver and the patient were basically rendered mute. This is one area where more theoretical work on the Lone caregiver type is necessary.

Palliative Care Communication and Health Literacy Considerations

As seen previously, the Lone caregiver engages in a great deal of research in preparation for decision-making with the patient. This can result in tension with the healthcare providers because “The Lone caregiver may challenge providers as a result of their own ardent research and careful investigations. In fact, a care provider may misinterpret the caregiver’s tenacity and direction resulting from careful planning and investigation as obstinacy” (Wittenberg et al., 2021, p. 191). Throughout the “no visitor” policy healthcare providers worked hard to support both the Lone caregiver and the patient by assisting the patient with the electronic devices. However, I felt they were not able to do enough and pleaded with them to allow an exception for visitation because my spouse had “a disability or other medical condition” and needed assistance communicating with the healthcare providers. In-person visitation was not granted until two weeks after the transplant, and then it was only granted under the rationale that the Lone caregiver was there for post-transplant caregiver training.

Because they have such an extensive knowledge base, the Lone caregiver *is*, however, the best lay advocate for the patient. According to Wittenberg et al. (2021), the Lone caregiver actually has the “...highest functioning knowledge of the system...[and] a high level of health literacy” (Wittenberg et al., 2021, p. 191). Once I was allowed to visit my spouse in person, the plan to include familiar items from home like aromatherapy, blankets, photographs, and other personal items was put in place. This, along with my actual presence, resulted in my spouse quickly moving from a hypoactive state to a hyperactive state and then ultimately, to a more normalized state where hospital discharge was possible.

New Communication Technologies Were Not a Panacea

New communication technologies like FaceTime and texting were used in an attempt to reach out to the patient, but they were generally unsuccessful even though the healthcare providers worked hard to support both the patient and the Lone caregiver under the difficult circumstances of the Coronavirus pandemic. Unfortunately, other families may have to endure similar traumatic experiences. On December

3, 2020, the visitor policy put in place in hospitals in the TMC during the “third wave” of the Coronavirus again relies on new communication technologies completely:

Memorial Hermann facilities are no longer permitting in-person visitors. Recognizing the important role loved ones play in the healing process, Memorial Hermann encourages the use of mobile and personal devices for virtual visits with patients. iPads are provided to patients without a mobile or personal device.

(Memorial Hermann, 2021)

While this pandemic visitation policy positively deals with the issue of lack of access for patients without electronic devices, it still eliminates the in-person communication that the patients of Lone caregivers may require. In these types of relationships, the patient and the Lone caregiver are inextricably bound by their ability to communicate with each other.

It is the hope of this author, that the administrators of hospitals in the TMC will reconsider their policies in light of this new communication theoretical framework on the different types of caregivers for patients. For each type, the role of communication in the caregiver-patient relationship is very different. As we have seen, for the Lone caregiver it is the heart of this relationship. No matter the caregiver type, the TMC ultimately has the power to negatively affect patient outcomes by controlling in-person access to patients in the ICU.

Conclusion

In conclusion, this essay was a preliminary attempt to understand the importance of communication in one caregiver-patient relationship during the patient’s medical crisis while in a locked down healthcare facility in the TMC during the Coronavirus pandemic. The recent theoretical work on “caregiver types” by Wittenberg, et al. (2021) was applied to this unique communicative situation. While the framework did help to explain the frustration felt by the Lone caregiver in this case, it was not able to provide insight into a situation where the patient is rendered completely mute by both the medical situation and pandemic circumstances. Although an attempt was made to utilize new communication technologies in the absence of in-person communication, it did not solve the various communication problems for the Lone caregiver and the patient in all instances. Ultimately, the visitation policies put in place by the hospital administration resulted in a muted caregiver for a mute patient in his greatest time of need. Therefore, more

work needs to be done to extend the analysis of the role of communication in the Lone caregiver-patient relationship, especially during pandemic ICU hospitalization situations.

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