Understanding the Difficulty

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 Safely administering infusional therapies is my primary role as an oncology nurse working in the outpatient setting. Included in this function are many supportive measures to ensure that each patient has the optimal chance not only to benefit from this encounter, but to experience the least harm. Last September, a 69-year-old retired men’s clothing designer named A.C., who had metastatic colon cancer diagnosed in 2006, was scheduled in my clinic to receive IV hydration. This was necessitated by intractable diarrhea presumed to be a result of previous chemotherapy drugs, which had since been discontinued. He reported emptying his colostomy of two to three liters of liquid stool per day and had recently been discharged from a four-week inpatient stay for the same reason. He was still receiving single-agent IV immunotherapy every two weeks, which, as indicated on computed tomography scan, had kept his disease stable; however, A.C. suffered daily with the effects of prolonged, unrelenting diarrhea. Of note, A.C. was a Medicare recipient derived) and, instead, was taken by wheelchair to the lobby to get his taxi home.

At times A.C. seemed genuinely appreciative of our nursing care, thanking us for answering his multitude of questions or for arranging his session to be done in his favorite room. Although his calling us “sweetheart” was not taken by all the nurses as an affectionate gesture, it seemed better than the times he cursed at us for not increasing the infusion rate so he would be finished sooner. Despite explanations why the latter request could not be granted, A.C. would not hesitate to use his cell phone while in our clinic to contact the POAs or call the pharmacy directly to argue whether this truly was valid. Another dilemma we encountered at times was his refusal to empty his colostomy in the toilet, rather than the sink. When asked repeatedly not to do so for hygienic reasons, he would reply, “Don’t tell me what to do, just turn on my TV.”

Although his calling us “sweetheart” was not taken by all the nurses as an affectionate gesture, it seemed better than the times he cursed at us for not increasing the infusion rate. The weeks we continuously hydrated A.C. on a daily basis soon became two months. Questions began to arise among staff as to just how long this would continue. We expected at first for it to be a temporary measure, but realized it now seemed to be the very treatment that sustained his life. Without this massive hydration and replacement of electrolytes, A.C. would surely not survive. He was able to eat and drink and did so on a limited basis, but with the continued diarrhea, along with intermittent vomiting, there was no way for him to maintain an adequate fluid status.

Team Effort

Because I cared for A.C. on more days than any other nurse, declaring myself his primary nurse gave me the responsibility to sort out all of the concerns and comments about this patient to re-evaluate our plan of care for him. Foremost, I knew this must be a collaborative effort, and I began by discussing A.C.’s case with his attending physician. Dr. S revealed that, ideally, this patient should be receiving home total parental nutrition (TPN) to better meet his nutritional needs. He had also tried several oral hydration supplements and had been unable to tolerate them. The abdominal pain and nausea the patient experienced were so severe that it was impractical to use oral hydration.

The attending physician and I decided to proceed with a temporary nasogastric tube placed with barium to confirm the diagnosis of a pseudo-obstruction in the colon. The patient tolerated it well and since then has tolerated oral intake. However, he continues to have some diarrhea and we are trying to balance this with continued IV hydration and electrolyte replacement. The patient has now received three infusions of 1 mg/kg of loperamide, which has been proven to be effective in treating chronic diarrhea.

As the days of hospitalization accumulated, the patient’s primary nurse began to feel that this was an unusual case. Although we had been caring for patients with chemotherapy-induced diarrhea, this was the first time we had seen such a prolonged and severe case. The patient’s desire to maintain dignity and comfort was a constant challenge. Because of the patient’s condition, we found it necessary to limit the number of visitors to one at a time and to have the patient wear the hospital gown for as long as possible. We also found it necessary to provide continuous monitoring of the patient’s vital signs and to anticipate potential complications. The patient’s family was always present and was very supportive. They helped to maintain the patient’s dignity and comfort and were always willing to offer support and encouragement.

The patient’s case also highlighted the importance of communication among all members of the healthcare team. The patient’s primary nurse worked closely with the attending physician, the pharmacist, and the nurses to ensure that the patient received the best possible care. We also found it necessary to coordinate the patient’s care with the oncology team and the home care team to ensure that the patient received the best possible care. The patient’s case also underscored the importance of patient education. The patient and family were provided with education about the patient’s condition and the importance of hydration and electrolyte replacement. The patient was also provided with education about the importance of maintaining a healthy diet and avoiding foods that could cause diarrhea. The patient and family were also provided with education about the importance of maintaining a healthy diet and avoiding foods that could cause diarrhea.

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infinite fluid and electrolyte needs. That medical recommendation was echoed by his colleague, the head of the nutrition service; however, the patient refused this offer repeatedly, citing a previous mediport infection from a prior course of TPN while inpatient. Dr. S also shared his questioning as to whether or not daily hydration was proper use of our institution’s facilities, and expressed his frustration regarding the patient not heeding medical advice to receive home TPN. Given the amount of time we had been providing A.C. with daily care, Dr. S was appreciative to hear that I wanted to call a roundtable to discuss this case with all its myriad issues. My goal was to have all involved actively participate to come to understand what it must be like for this patient to endure this way of life essential to his survival, to share in the experience both with him and together in hopes we could be better equipped to address the nuances of A.C.’s situation as caring nurses.

Invited to our roundtable were physicians, POAs, a pharmacist, a patient representative, and nurses who held various roles, including the office practice nurse, treating nurses from each clinic, and the nurse case manager. A special request also was submitted to have a member of the ethics committee join us. The latter was instrumental in guidance concerning not only how to handle difficult situations encountered with A.C., but also in terms of educating and engaging the group to examine guiding moral principles we are expected to accept as caregivers. The chair of the ethics committee (M.M.), a master’s prepared nurse, chose to join us. She spoke directly to our nursing role, sensitive to the esthetic experience both with him and together in hopes we could be better equipped to address the nuances of A.C.’s situation as caring nurses.

Finding Solutions

Perhaps the most contentious question raised was how long we were going to continue to provide hydration when, medically, he truly required TPN. According to the nurse case manager, Medicare was paying for these daily hydration sessions in the outpatient clinic, whereas they would not pay for them to be administered at home. A.C. was well aware of this as his right to be treated, no matter how unconventional. Medicare also would pay for home TPN, which he knew but repeatedly refused. We also wondered whether coming to us daily was an “outing” for him, considering his wife was tended to by her own HHA in their apartment, and because of his inability to socialize in ways that he used to.

M.M. reviewed with us that, although we may disagree with this seemingly never-ending cycle of fluid and electrolyte repletion, as nurses we were obligated to care for each and every patient equally and fairly, including those with character traits we may dislike. However, this ethical component of nursing does not prohibit us from reaching out for help that may be valuable to alleviate suffering (Carper, 1978). We realized that calling upon the social worker might be helpful to diffuse some of A.C.’s angry behavior and give him more opportunities to share his experience with a professional not directly involved in his day-to-day care. The patient representative reiterated her availability and guidelines on how to deal with unacceptable behavior from this patient, such as directly telling A.C. he would be limited to two phone calls a week and suggesting he keep a list of questions ready. Expanding the collaborative effort aided the nurses with feedback, giving us better insights into A.C.’s feelings, and thus giving us more tools to continue to care for him following the patterns of knowing.

The physician continued to confer with other specialists, even outside of the cancer center. Dr. S proactively placed orders for laboratory work with parameters for IV hydration and electrolyte replacement. With those standing orders, we could draw laboratory tests and view results without a delay in the preparation and administration of A.C.’s daily IV solutions. The nurse case manager was in weekly phone contact with A.C.’s wife and visited with him as well. In addition, she sent weekly e-mail updates to the rest of the roundtable participants. The true benefit to A.C. was our coming together in an interprofessional collaborative effort, because just us doing so was a shared experience.

Each of us gained a better appreciation of this patient’s suffering and it seemed to somehow put in perspective that our difficulties with him could not compare to the impact this situation had on his life.

Recognizing I was involved with a very unique patient situation set me into motion to reach out and bring varied staff members together. Emotions ran high at times as we expressed frustration, disgust, and then guilt as we acknowledged how awful this situation must be for A.C. Helping clarify the empirical evidence as well as extract the aesthetic experience of providing nursing care to this patient was a therapeutic and learning experience for all of us.

Reference