

Central Line Dissent and Fatal Dialysis Fear: The Story of Florence

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This case study focuses on an incapable patient requiring life-saving medical intervention to which she does not assent and the ethical challenges that stem from this refusal. This article discusses the law's limitations in managing such situations as well as the difficulties for substitute decision makers (SDMs) and the clinical team when SDMs consent to treatment that cannot proceed without patient cooperation. The moral distress that befalls the clinical team and caregivers in these unique situations lead one to conclude that resources should be made available to support families who are suffering when loved ones deny needed therapies. From an ethics point of view, one can conclude that organizational support should be available to clinical teams to effectively manage these challenging cases.

INTRODUCTION

I watched her walk into the clinic with her mother. She looked undisturbed, almost complacent, which contrasted heavily with the butterflies in my stomach. Given the fact that she was my patient and I was her social worker, I wondered why she made me feel so nervous. Then it hit me: It was the fact that I owe her a duty, the duty of care that scares me. Of all these years in practice, I have never met someone so adamant in refusing care.

Florence is middle-aged, well groomed, neat in appearance and lives with her mother. On a superficial level, she is articulate and actively able to engage in conversations. However, after a vaguely described cognitive insult 30 years ago, she has remained cognitively limited. Both Florence and her family were unable to give a good history of what happened to cause her to be limited. According to her mother, Florence left for a vacation away from home and came back "different." It was initially reported to us that she suffered a head injury, but the cause and further medical history following the injury is unknown. All health care team members were concerned about possible psychiatric illness. Consequently, a psychiatric assessment was requested and completed. The assessment found that her judgement, insight and reality testing were nonexistent. She was further found to be incapable of consenting to treatment and required a substitute decision maker (SDM). Underlying her psychiatric problems was a schizophrenic disorder for which she agreed to take antipsychotic medications. As with the rest of the team, she refused dialysis when the idea was brought forward by a psychiatrist.

Physically, Florence has chronic renal failure and is urgently in need of dialysis. Prognosis without dialysis is less than 6 months. She refused the central line procedure, emphasizing that she does not want dialysis. "Pricking my neck with a sharp object will damage me," she said, referring to the insertion of a neck line. The procedure and its implications have been explained to her repeatedly, as well as her impending death if she does not quickly accept dialysis. Even with the risk of death, she refuses dialysis. For the team, her refusal to accept dialysis seems irrational as the its benefits outweigh the risks, notably the risk of death.

LEGAL PRINCIPLES AND PROCESSES

Health care legislation across jurisdictions is precise about the process of obtaining consent for treatment. There are several key principles to which one must legally and ethically adhere when seeking consent for treatment. The first principle is that the clinician proposing treatment must start the process from the presumption of capacity (Health Care Consent Act [HCCA], 1996, section 4.2). Capacity is roughly defined as a person's ability to understand information provided in order to make a decision and appreciate the consequences of giving or refusing consent (HCCA, 1996, section 4). With this in mind, every person who has decisional capacity has the right to give or refuse consent on any grounds, including moral or religious grounds, even if the refusal will result in death. Integral to this right is that all information a reasonable person would need to make an informed decision is offered and consent to a proposed treatment must be given voluntarily, not by fraud, misrepresentation or coercion (HCCA, 1996, section 11.1).

After being informed about her condition, Florence said, "My kidneys are fine. I will likely live for another 20 years without hemodialysis. Herbal teas and laxatives are all I need." Here is a person who is given correct information and asks appropriate questions, yet fails to appreciate this information within her own context. Thus, she was deemed incapable to make this health care decision for herself. Her mother was determined to be the SDM. She wanted her daughter to have dialysis but recognized the need for daughter's cooperation for the procedure. Making a scissoring motion with her fingers she stated, "If we force her to have it, she will cut the line."

As a health care team, our hands are shackled. It is a tricky situation. Here is a patient who needs life-saving therapy and who has a substitute decision maker (SDM) whom everyone on the team believes is willing to act in the patient's best interest. However, the insertion of the central line and provision of dialysis requires the patient's cooperation. If she does not assent, our ethical motivation of doing good and avoiding harm cannot be achieved. Unlike a surgical procedure for which the SDM might have given consent and the team treated the person, dialysis would be impossible in

an outpatient situation because her cooperation to attend is imperative to its success. In this situation, use of restraints would likely increase her resistance, not to mention being an attack on her dignity. In a case of emergency, a health care provider can intervene without consent or involve the person's SDM. Although care may be provided without a person's consent if it is determined that the person needs care and is incapable of giving or refusing consent, the incapable individual's assent is often required to undertake invasive procedures. In this case, dialysis requires invasive preparative and maintenance procedures to which the patient does not agree. Even with the best intentions, this lack of consent places the patient, her family and the health care team in a challenging moral dilemma: Knowing an effective treatment exists but being unable to provide it.

If a person is a risk to themselves or others, he or she can be admitted involuntarily to a hospital for psychiatric assessment. With her lab values reflective of being very seriously ill and therefore a harm to herself, Florence was admitted to a hospital by the pre-dialysis clinic physician for psychiatric assessments to determine whether there were any treatable reasons for her not accepting a beneficial therapy. The assessment confirmed her psychiatric illness and incapacity to make treatment decisions but cannot offer any methods to break through the impenetrable barrier to gain her participation in a proven therapy that can help her precarious physical well-being. As such, she was at risk of self-harm through non-acceptance of therapy. However, the nature of dialysis, which is not a single event but a life-long therapy, negates the legal provisions that allow for treatment to proceed in an emergency.

Florence's dignity and how our therapies would affect her quality of life were on my mind. She was prescribed more than 10 daily medications. "I throw the medicines that stink," she told me. "It's like eating chalk." A restrictive diet lacking salt, proteins and fats was prescribed to her. In addition, she was instructed to restrict her fluid intake and watch her urine output. These commonly prescribed lifestyle changes, drugs and therapies have profound effects on patients' daily lives in ways the health care team often can barely imagine. Adding another layer, introducing her to dialysis, which requires Florence to come to the dialysis unit thrice weekly for extended hours and be connected to a machine, may have further pushed her away from the decision to have dialysis.

I engaged her in multiple discussions in an effort to persuade her to accept dialysis. As part of the medical team, it is expected that each member encourage the patient to follow the proposed prescribed treatments. The medical team is expected to save the patient's life, not watch the patient die. Florence has been seen by psychiatrists, dialysis nurses and bioethicists. After what many have described as "way above doing our due diligence," she still refused treatment. Treatment could not proceed without her cooperation. The team discharged her back home to

be followed up in the renal clinic. "Prayers will save me," were her parting words.

This clinical encounter leaves the dialysis team emotionally paralyzed. "She is too young to be allowed to have a death that could have been prevented," her nephrologist said. For the team, the moral distress is enduring. As her social worker, I find myself wondering regularly whether I have done everything in my power to help her help herself. It is my role to advocate for my patient. The nagging feeling that I let her go without life-saving treatment haunts me.

THE ROLE OF THE SOCIAL WORKER

My role as a social worker in the pre-dialysis phase and as part of the multi-disciplinary team is to educate patients and families about kidney disease and treatment options so the patient can make an informed decision. Very often the patient is overwhelmed with the information presented to them and feels lost in the process; therefore, one of the social worker's key roles is to advocate for the patient.

There are many definitions of advocacy. For this article, I have chosen the definition from Hepworth, Rooney, Dewberry Rooney, Strom-Gottfried and Larsen that defines advocacy as "one who pleads the cause of another" (2006, p. 431). Furthermore, advocacy is embodied in the values and ethics of the social work profession, "... social work profession has embraced ... dignity and worth, self determination and giving voice to the powerless" (Hepworth et al., 2006, p. 431)." Bateman pointed out that the earliest origins of social work as a profession involved the advocate role. He described social workers as "possessing skills and resources to ensure the individuals who may not have a voice, who may not have the power or who are considered socially marginalized, that their interests are not overlooked or overridden" (Bateman, 2000, p. 33). Advocacy is seen as a fundamental component of social work that is written in the code of ethics, whereby the goal is to "empower and protect people who are vulnerable, poor and/or disempowered" (Bateman, 2000, p. 33).

Different types of advocacy exist. In a hospital setting, clinical advocacy refers to the social worker's skill needed in "response to patient deficits that have clear clinical relevance to the patient's health problem" (Dhooper, 1997, p. 196). To advocate for Florence is to ensure that her wishes are heard and considered, especially if her decision does not concur with the medical team. Literature dictates that advocacy involves strategies to assist the patient by way of educating, persuading, negotiating and bargaining. These strategies are either "alliance, neutral or adversarial" (Dhooper, 1997, p. 196). Literature points out that whatever style or strategy used by the advocate, one needs to remember to "ensure that the patient's autonomy and sense of mastery is not undermined" (Dhooper, 1997, p. 196). Literature is quick to point out that sometimes advocacy can produce, "a certain amount of strain and tensions: moreover a positive outcome cannot be assured" (Hepworth et al., 2006,

p. 430). Consequently, advocacy can produce conflict. The conflict is between ensuring the patient's needs are heard as well as "the needs of the institution and other health providers" (Davidson & Clarke, 1990, p. 326). Returning back to Florence's case, a conflict existed between Florence's right for self-determination and freedom of choice and her best interests as assessed by the medical team, which includes social work. This conflict created moral distress for this social worker.

Moral distress is incoherence between what one sincerely believes to be right, what one actually does and what eventually transpires (Webster & Baylis, 2000). A dilemma can arise if the advocate is expected to maintain and encourage the team's recommendation to the patient, simultaneously ensuring that the patient's wishes are taken into account. The moral distress is further complicated if the patient has been found to be incapable of making treatment decisions for his or her health care. Does the social worker's role change because Florence was found incapable? This circumstance puts further onus on the advocacy role, as the patient is not able to champion her cause.

Hemodialysis (HD) is typically performed in areas that are visible to staff and other patients. It would be very difficult for staff to treat a patient who actively resists being dialyzed and for patients to witness another patient being "forced" to be on dialysis. Doing so would likely affect the unit's morale and the daily functioning of the staff.

These issues raise social workers' moral distress. Yet, the issue that draws the most amount of moral distress is in allocation of scarce resources, in this case the social worker's limited work time. In an ideal world, a social worker would not have to restrict the time and effort spent with one patient to assist another. Sadly, this does not reflect reality. Every extra minute spent with Florence saps time and energy out of my other consultations. How much time and resource is adequate to say that the team has done its "due diligence"? Other ethical questions to which I have still not found the answers:

- Is allowing her to die infinitely worse than restraining her thrice weekly for dialysis?
- What is the *good* we are trying to achieve?
- Can life sometimes be worse than death, in all its finality?

CONCLUSION

Writing this article was a way to provide a closure for my wanting to linger back to the encounter, playing it in my mind over and over again and checking her clinical chart to make sure I have not missed anything important to add to the story. The discharge notes read: "End Stage Renal Disease. Failure to consent to HD." Does this tell her story or mine?

If I were to reflect, what made this particular case different? I would honestly have to admit that my interaction

with Florence made me stop and think. We get preoccupied, rightfully so, with the instrumental items, such as ensuring that patients have the benefits they need and the information they require about housing, their illness and their treatments. In the end, it can become mechanical or routine. Florence had housing, financial benefits, medication coverage and a family that was supportive, yet she refused dialysis. Florence was consistent; she was determined to follow whatever she felt was best for her even though she was told repeatedly that she was going against medical advice.

What did I learn from working with Florence? I would have to say this case reminded me of what I was taught: The first principle of social work is to respect and value the patient. This case reinforced my social work values and ethics, including the right of self-determination and Florence's intrinsic value. With this in mind, I was able to continue working on Florence's behalf, to make certain that her wishes were heard even though it meant going against the rest of the medical team. The apprehension and hesitation about working with Florence is gone.

The process to reach this stage involved several consultations with fellow renal social workers, some renal team members, the hospital bioethicist who has a social work background and a clinical ethics fellow. Another form of consultation involved participating in a case presentation at the Joint Centre for Bioethics, University of Toronto. Membership of the group consulted included bioethicists with from diverse backgrounds, including social workers, physicians, philosophers and a lawyer. The presentation provided me with the opportunity to gain a collective perspective from different disciplines on Florence's case. I am cognizant that it is not the norm to have the chance to consult with such a wide range of professions. Consultations in general and this one in particular provided me with valuable peer support, guidance and a "sounding board" for ideas about how to work with patients/clients.

The other component to the process, which is unique to social work, is self-reflection, a soul searching. Early in the education to become a social worker, one is taught to be objective and neutral when working with patients/clients. However, it is also important to be aware of one's biases and values, and how these biases and values can influence the working relationship with the patient/client. Social workers are fully aware that they will encounter patients who may make decisions with which they may not agree. These decisions can be a struggle within the social worker, but it is important to remember that there is no right or wrong answer when dealing with people's lives. To work through this struggle, I remind myself that I am here for the patient. I understand that as a member of the medical team my job is to persuade the patient to follow the proposed treatment plans. However, the priority should be the patient, especially if the patient's wishes were not being heard. My priority needs to be Florence. She needs to be provided with support, not judgment, and a voice when others may not have

given her one. Once I came to this realization that my role as Florence's social worker is to make certain that her voice is heard loud and clear, the ethical dilemma subsided.

EPILOGUE

A few months after the conclusion of this case study, I met with Florence on admission to the emergency unit after a bout of severe symptomatic uraemia. She finally agreed to a trial of HD. She is currently on hemodialysis and attending clinic for her care. There is no clear plan for her future medical care but to take each hemodialysis session at a time. Will she continue to come in for her life-sustaining treatments? Of one thing I am certain, Florence continues to be my patient and I continue to be her social worker, her advocate. Thus, Florence's story continues.

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