

Discrete Unit Advanced Directives Study

CSSR-TCCHCC Summer 2012 Medical Internship

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Introduction:

Eileen Yung and I met SP the day he and his family made the decision to receive hospice care. SP's deterioration to that point had been swift and decisive. SP suffered from AIDS and was experiencing a host of infections. SP slept for most of that first day while we sat with him for hours. In the few moments that we spoke to him that between his hours of sleeping, he often anxiously asked if his computer was safe, if he'd missed his meeting with his grandma. When we inquired about the pictures on the wall—smiling moments with his friends and tender moments with his mother as a young child—he simply cried out in distress that he wasn't sure what they were, that they only confused him more. At one point he said in the midst of his frustration: "I can't remember my name!" But over the next few days SP had calmer moments when we learned that he had loved to dance before his illness—mostly modern and contemporary. When I commented on how graceful and beautiful his hands were he flourished one in the air and smiled at me. In the hours we spent with him SP floated in and out of sleep, in and out of worry, in and out of reminiscences of the past—but always with so much sweetness.

The last day we saw SP he was lying in his room with two friends and his niece. He had just had what his loyal friend Alan lovingly called "a bad day." His eye was swollen from edema and his breathing was slow and labored. He opened his eyes once or twice but never talked. So instead we all talked about him. His friends laughed about the way SP clung to his sense of humor—still rolling his eyes at ridiculous comments and scoffing at everyone thinking he couldn't hear them just because he had his eyes closed. They said he was still sharp—even remembered to ask his friend about her exam on the 27th. After a little while we took our leave.

The next morning we discovered that the nurses had been called just five minutes after our departure and he had been declared dead within the next hour. I found out weeks later that SP's decline had been the result of a broken heart. He had been recently jilted by a lover and refused to take his medications in response. In some ways, he had succumbed to his disease by choice.

Research Project:

SP's death led me to the issue that would be the focus of my months at Terence Cardinal Cooke Health Care Center, a Catholic skilled nursing facility in East Harlem. I decided to spend my two months at the facility studying the unique population of residents in the center who are diagnosed with AIDS, in recognition of the fact that their circumstances and character differed so much from the geriatrics and Huntington Disease residents on other units. These residents younger and more ambulatory on the whole, and in many ways much more socially complicated. By reputation most of the unit had a history of substance abuse and what some staff vaguely referred to as "colorful pasts". These vague references led me to question what the particular challenges these social histories presented to staff as they worked to provide effective palliative care including the designation of advanced directives.

In order to answer this question I chose a list of twelve specific residents who the social workers presented to me as prime examples of the particular challenges they frequently faced on the unit. I explored these cases from the perspectives of the doctors, the social workers, the nursing staff, and from my own interactions with them. In the process I conducted 17 interviews with staff about their experiences with this resident population. In my interviews with the three social workers and three physicians I focused my questions primarily on the challenges they faced in determining advanced directives. Additional interviews with the nursing staff, chaplains, psychologists, and recreational therapists, as well as my experiences working alongside the Substance Abuse Recovery Program contributed to my knowledge and impressions of the

resident population as a whole and offered me insight into how the quality of the care on the unit might be improved. In this paper I would like to present my findings about the barriers to advanced directives by presenting three complete resident narratives as case studies and then use these narratives to frame my conclusions, which will also be supported by other case examples and staff observations.

Case Studies:

SP is a 49-year-old female who suffers from paralysis from the waist down and AIDS. As a result of her paralysis she also has deep, infected wounds on her lower body. She has designated her parents as health care proxies and has no other advanced directives at this time. SP is non-compliant with her medications except for opiates. Although SP claims she has not used drugs for 3 months and that she does not have a drug problem, she has repeatedly tested positive for drug use while living in the facility, including in the past month. According to the story SP told me, she contracted HIV from her pimp who was also the father of her 11-year-old son. She also spoke to me about four years working as a beautician followed by a long career as a prostitute. She told me she would still work the streets today if she were not paralyzed.

SP is frequently verbally abusive to staff. I was witness to one of SP's outbursts in a care planning meeting when she threatened to do "whatever came to mind" if she were not granted a pass for the Fourth of July. In another instance when I was talking to her she said the care team had put her on restriction for threatening to burn down the facility. She confided to me that she had made the statement in a fit of anger and hadn't really meant what she said.

SP is a 49-year-old Hispanic male who suffers from HIV dementia. He has a sweet demeanor and speaks in an inaudible Spanish murmur. SP once offered me a bracelet he had made at a recreation activity and then pantomimed crying when I declined the gift. SP has a sister who is also his health care proxy. She used to visit often but her visits have decreased greatly in frequency over the years. She confided to the social worker that it is "just too hard." Rob, the social worker, facilitates contact between the siblings by calling the sister on the phone. While the sister once tearfully told Rob that she felt guilty about these phone calls, they are the highlight of SP's week. Even during the period of time when the sister was frequently visiting

still, however, she repeatedly cancelled appointments to deal with advanced directives or simply did not show up.

SP is a middle-aged total care resident suffering from progressive multifocal leukoencephalopathy (PML), a viral disease of the brain, who lacks capacity and is not verbal. He has a friend who has come to spend time with him, to bathe him, to shave him daily for seven years. The visitor claims to be the resident's father but his true relationship to the resident is unclear. SP's mother is the resident's health care proxy although none of the staff seems to have ever met her and I found no evidence that she visits at all. The physician and social worker once called the mother with a translator phone in order to explain SP's medical situation but the interaction was a "waste of time" according to the physician. The mother was just screaming and complaining about other things while the translator was trying to explain why doctors recommended DNR. According to the physician: "I don't think she understands the gravity of her son's illness"

Barriers to Determining Advanced Directives:

While each of the above cases presents challenges specific to that resident's circumstances, there are a few factors and patterns that present themselves consistently with the residents on this unit. While staff members rightly hesitate to make generalizations about the population, two long-time staff members made interesting characterizations of the resident population. One social worker said that the population is comprised of many easily narcissistically wounded people, both due to their backgrounds coming into the institution as well as their current state of displacement from their usual routines, contexts, and ways of functioning in the world. The psychologist made a similar observation, calling it instead the patient's "neediness" which she described as their loss of equilibrium due to their medical condition. While she commented that this neediness is a generalization that can be made of all patients, the chronic nature of these resident's illness makes this lack of equilibrium easy to

forget: their illness becomes a state of being. It is with these observations in mind, which are consistent with my own extensive interaction with the resident population that I would like to approach the challenges caregivers face when serving this population.

When I first asked the physicians on the unit what the biggest obstacle they encountered in determining advanced directives was, one physician immediately responded with incredulity and gusto: “They want to live!” This is the most basic and important obstacle in any population in having a conversation about end of life. I spoke to the psychologist about her impressions of this population with regards to this will to live. We discussed the possibility that perhaps it was the youth of the population, as one physician hypothesized, which led them to cling so fiercely to life. She said that although she could not give a fast answer to this issue she observed that she has seen aged populations cling equally desperately to life. All patients—all people—want to live. And in the case of health care proxies making decisions for their loved ones: they want their loved ones to live. I do not think that it is at all over-simplifying the issue to assume that this is the foundational principle in all barriers to establishing advanced directives.

In terms of the ways that this will to live can present itself as an obstacle, SP’s case, narrated above, presents many of the common challenges. When I asked SP’s physician Dr. Sterlin about her perceptions of the reasons for SP’s hostility and resistance to care, Dr. Sterlin responded that SP is in a state of denial about her condition. Rob, SP’s social worker at the time of her decision about advanced directives, recalled that this denial was consistent with his experience in discussing SP’s advanced directives. Although SP did designate her parents as health care proxies without issue, Rob commented that there was very little discussion around the other aspects of advanced directives. He observed at the same time that designating a health care proxy is by far the most comfortable of advanced directives. He said his experience with SP is consistent with his experiences in this area with many residents; he often finds that few people

are really willing to grapple with the gravity of the decision about advanced directives. He said that he has really only had one discussion with a resident when he felt that the importance and meaning of the decision was truly being considered. While this approach on the part of the residents may not necessarily present itself as an obstacle in making some determination of advanced directives, it certainly presents itself as a barrier to the resident being willing to truly consider the best possible kind of death for him or herself. Dr. Sterlin similarly noted that denial was a common problem, recalling one resident who had sunk into such denial that he left the facility insisting that he did not have AIDS and although he returned to the facility so sick he was nearly dead he continued to deny his condition. This example powerfully demonstrates the destructive power of denial in a condition that requires constant self-maintenance.

Denial presents itself in other less pernicious ways as well. One social worker commented that all of the residents believe that they can be discharged; that they can survive in the community. One hospice resident SP frequently informed me that he would be going out to find an apartment in the next few days. Perhaps this mindset could explain why according to one social worker many of the residents refer to the facility as a prison. When a patient is in denial about his or her need for medical care, it is easy to feel as though they are being held in the facility by force.

While denial and simple will to live were the obstacles emphasized by physicians, social workers on the unit tended to bemoan the lack of complete narratives from the resident. Many staff members told me that everyone has a different story from the residents, with the psychologist in particular receiving completely different information. As referenced above, SP tends to fall within this category of residents who give a different story to everyone. One social worker referred to the narratives residents provide as “bizarrely convoluted stories.” He said that this is sometimes the result of lack of communication among members of the team, which results

in each staff member having one small unique piece to the story that no one else has. Although he said that the team communicates in care planning meetings as well as on the chart and in morning meetings, this communication is not enough to overcome the confusion.

Withholding information from staff is, of course, a matter of the resident's privacy. However, in the case of one transgender resident who suffered from severe infections of her private areas due to her refusal to be cleaned by staff, this can also have negative health consequences for the resident. This particular resident lived at TCC for months before a urology consult was called and informed the shocked staff for the first time that the resident had had a sex change operation thirty years ago that was creating health complications. When I asked the psychologist about the possible motivation behind resident's giving a different story to everyone she asked me if I meant different or *deeper*. She felt that because psychology is such an ambiguous kind of discipline residents feel that a holistic and complete view of their lives is more relevant to the care that they will be receiving from her. She also commented that residents might be sensitive to what is expected of them from the staff and may also edit their stories based on what information they feel the staff person might require to provide care.

Both SP and SP's cases depict the challenge that I witnessed facility-wide with language barriers. I sat in on one care-planning meeting in which disciplinary actions had to be explained to two misbehaving residents through the translation of a nurse from another unit. I could not help but observe that the same resident who repeatedly struck out at staff was one who could not communicate with them with his words due to the language barrier. While I applaud the nurse's willingness to sit in as translator for these kinds of interactions, it is clear that a more permanent and consistent solution be brought about. Even incorporating these meetings into a staff worker's schedule so that the care planning meetings were guaranteed a Spanish speaking staff-person was present would assuage this problem. Dr. Sterlin account of the failed advanced

directive conversation through the translator phone is a clear indicator that the translator phone may not be adequate for many sensitive conversations.

The last complication that presented itself frequently as a barrier to having a good discussion about advanced directives was complicated family dynamics. As one social worker put it: “it’s like dealing with a family of patients”. I expected that lack of knowledge about HIV/AIDS would be primary to the family’s role as a complicating factor in this discussion. However, while there are instances of the health care proxy not knowing a patient’s HIV status and other similar situations, it seemed that in many cases the family is not even involved enough to be a barrier. One older patient SP who suffers from HIV dementia and has a history of alcohol abuse had no family connections according to the physician. However, the social worker’s version of the story was much less straightforward. The social worker struggled to find SP’s older brother at the resident’s urging. When he was finally able to call SP’s brother, he found that only the sister-in-law was available to speak to him since the brother had passed away years ago. The sister-in-law refused to have anything to do with the resident because he had been unavailable to them during the time of his brother’s death. Their third brother has not been heard from in years. The steps moving forward with advanced directives in the case of SP were fairly straightforward: Dr. Abebe determined that the patient did not have capacity and made a decision about the patient’s advanced directives himself in conjunction with another physician. But the struggle of finding family and dealing with these complicated family dynamics takes a toll on the social workers.

At times, even when the family members are willing to be involved there is simply avoidance on the part of the health care proxy to deal with the situation, as in the case of SP recounted in the case histories. However this issue is in no way particular to this unit. I took part in a number of discussions with family members from other units in which the health care proxy

was very hesitant and demonstrated a great amount of ambivalence towards the withholding of life sustaining treatments.

Current Method of Determining Advanced Directives:

As the method of conducting a discussion about advanced directives stands now, the social workers must labor to find the families and to piece together the messy situations that many of these residents find themselves in by the time they cross the threshold of TCC. One social worker said that many of these residents simply go through life leaving disasters in their wake. It is these disasters that the social workers must try to piece together in order to determine family members and other relevant parties who should be taking part in the discussion about the resident's care. The time spent looking for the answers to these questions does of necessity diminish the possibility for face time with the residents. One social worker confessed that he did not feel that he was able to provide the quality of care that his discipline demands as a result.

From the physician's perspective, the information about the family is handed to them and they make the necessary calls. The biggest struggle that Dr. Rinaldi recounted was determination of capacity. In the case of SP, a hospice resident with terminal cancer, he struggled to determine the resident's capacity and still expresses some doubts about whether or not he had made the correct call by calling in a psychiatrist to make the final determination of capacity.

Also notable in the physician's role in the advanced directive discussion is the personal approach of each of the physicians to the issue. The two physicians who made the most adamant claims about how the discussion should be approached, stated that they try to give information and respond to questions and ambiguities, but that they do not push or even advise about the decision one way or the other. Dr. Rinaldi was very forceful about the fact that his reasons for this approach are ethical and not related to the particular needs of the population. He felt that

people should be able to make decisions for themselves and that it is not his place to tell people what to do.

Barriers to Care:

The more time I spent on the unit the more I realized that the issues that were presenting as obstacles to determining advanced directives were also obstacles to other aspects of palliative care: they kept the residents from developing healing relationships with family, from receiving love from the staff at times when they were particularly combative. It also came to my attention that not only were the residents at times standing in the way of their own care but they were also putting the staff in danger. In care planning meetings I heard about multiple instances of abuse of staff particularly on 7C and 8C. I was led to wonder what kind of support the CNAs are receiving when these kinds of events occurred. From both the staff side and the resident side it seemed that the direct care staff were bearing the brunt of a lot of the bitterness and anger the residents hold towards the institution and towards their situation.

I similarly felt that the issues with communication were greatly affecting care. While the psychologist's claim that she received more complete narratives from patients due to the nature of her discipline I think is valid, in some ways I believe that the psychologist might have been short-selling her own skills and training as a communicator. While I believe that it is true that context has a great deal to do with what the resident is willing to divulge, according to the residents their response to staff has a great deal to do simply with the staff's manner of communication. I often heard residents say in substance abuse recovery meetings that they felt disrespected by staff, that they felt as though they were not being treated as people. This issue was also voiced in a resident council meeting in which the residents complained that staff was often cold with them and did not smile. One social worker observed that he does see the staff shut themselves off emotionally in order to protect themselves from the danger of abuse.

Possible Solutions:

As a solution to the issue of language barriers I concluded that even a simple system

	Spanish			French			Mandarin		
CCP	Name	Title	Unit	Name	Title	Unit	Name	Title	Unit
6A									
6C									
7A									
7C									
8A									
8C									

whereby a staff person

could be consistently

available for one meeting a

week if need-be would

make a significant

difference in the resident's feeling heard and to ensure that the residents understand the

instructions offered to them by the care planning team. A simple matrix like the one on the left

might save the team time in looking for a staff person who speaks a particular language and

might give the staff person a chance to anticipate the hour spent in the meeting translating.

Concerning the issue of the escalation of animosity between primary care staff and residents, I collected impressions from 8 members of the nursing staff as well as speaking to many of the members of other disciplines about the issue. When I conducted my 7 CNA interviews my initial question was "What is your interaction with or relationship with your residents?" While the opinions differed in how the CNAs dealt with the difficulty of the situation, there was a consensus that the CNAs are exposed to many abusive situations and that the nurses are usually called in to deal with the situation. According to Ms. Cummings the brunt of this abusive behavior falls to her: "There is no support for staff; I have to sit them on my couch." She recalled one specific instance when a resident made a nurse cry because she told her she was fat. Ms. Cummings also said that there used to be a system in place for a support group for the staff. The recreation staff and the psychologist recalled the meeting as well. While there were differing responses to relationships with the residents, staff members consistently said that the staff needs more support to deal with this population. One CNA commented that when she

faces abuse she simply keeps her head down and stays quiet because she is afraid that if she says anything she will be fired. She observed: "The customer is always right." One staff member commented that he could understand why CNAs feel unsupported since if there is any complaint about a CNA they are immediately dismissed until further investigation has taken place. The nurse manager similarly stated that the nursing staff has an attitude that they should simply take it. The accounts were not all negative, however. One CNA told me about a situation when she had been spit on by a resident when she called him for dinner. She said that the directors all came and the resident was sent out immediately. She repeatedly told me she was very happy with the way the situation had been dealt with and had felt very supported.

The psychologist did comment that she is available for staff to talk to on a casual basis however she noted that they no longer had a consistent weekly meeting. She agreed that it would help staff to have an opportunity to express themselves, saying that everyone needs an outlet and that it is important to help staff identify steps they can take before they allow things to become personal. She recalled, however, that in many of the old counseling meetings the nursing staff brought up issues of re-admission of certain residents and other administrative questions she could not answer.

In light of these comments I discussed the possibility of a group session led by Loren Mask in which the nursing staff had an opportunity to simply talk about the resistance and abuse that they face. Loren told me that if I could gather adequate evidence that the staff wants this kind of group she would be willing to take steps to put something of that nature in place. Of eleven staff members with whom I discussed the issue, only two felt that there was no need for that kind of meeting. Particularly the leadership felt very strongly that there should be something of that nature in place.

I also feel that a system of re-admission of abusive residents that incorporates accountability to staff about why a patient who has physically abused a staff member should be allowed back in the facility is absolutely essential. Even the social workers were unclear on the process behind re-admission. It also behooves the administration to carefully consider their motivations behind accepting back a resident who has hit a CNA while releasing a resident who has hit a doctor, which I was informed occurred 3 times in the past. I believe that by not making a policy on staff abuse that is consistent regardless of the discipline of staff, TCC may unwittingly contribute to the societal structures that devalue lower-wage workers, people of lower education, and women of color. I feel that the administration ought to be drawing the line for residents saying what is acceptable and what is unacceptable in a manner that places equal significance on the safety of all staff.

Reflections:

I found in this project that I could have spent the entire two months finding the right questions to ask. Every new interview led to insights that challenged the assumptions I had entered into the project with. I found myself challenging the idea that all death is bad, that an older death is in some way less tragic than a younger death. I found myself pulled between sympathies with the staff, with the residents, with the administration. At times I felt that perhaps there is nothing more we can do with such a damaged and needy population.

My visit to Calvary Hospital eight weeks into the internship, however, was a turning point for me in my perspective. Although the hospital is far from perfect and has different challenges than TCC as an acute care facility rather than a long-term care facility, Calvary was a vision for me. The unit was quiet and peaceful and the nurses and doctors I spoke to were touchingly sympathetic with the struggles of the residents. One story from the visit was particularly moving to me: the psychiatrist recounted the story of a homeless woman with a

history of drug abuse who had recently attempted suicide. He recalled how he had immediately gone to the woman's bedside to welcome her and tell her about the care she would be receiving at Calvary. Her eyes remained trained blankly on the ceiling above her head and he felt uncomfortable speaking to her, as if he were babbling at a brick wall. At the conclusion of his awkward introduction the nurse prompted him: "Doctor, tell her what else we're going to give her." So he looked down at the unresponsive woman with dirty matted hair and said to her: "We're going to give you love here." At these words the woman sat up and embraced the psychiatrist, saying: "I've been waiting my entire life to hear someone say that." This narrative challenged me to think of how many of the cold and occasionally violent residents around me had thought that very thought.

During this internship I also carried out a number of audits of residents with end of life care plans in place. There was also an audit of the uncompleted MOLST forms. This audit work came to a head when the state came and completed a survey of the care the facility provides. In preparation for the survey all of the staff performed ambassador-rounds in which we evaluated the residents' room cleanliness, the staff nametags and the wristbands. This experience gave me great insight into the kinds of standards the facility is held to and the number of details that must be kept in place in order to even stay open. This experience provided me with a window into the administration's mindset and priorities.

In hindsight, the breadth of my exposure to different aspects of the nursing home care astounds me. Through the flexibility of this program I was privileged to work alongside members of the administration, the pastoral care team, the substance abuse recovery team, and the medical team. I am overwhelmed with gratitude at all of the staff's openness to my inquiries about their work and their patience with my clumsy attempts at providing assistance. I am also unspeakably indebted to Dr. Anthony Lechich who has modeled for me how a physician can

truly love and care about his patients. I am inspired by his example and most of all inspired by the sweet old souls on the third floor of TCC whose smiles and kisses will stay with me forever.