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(In)dependence in Palliative Care

Foreword

This past summer, with support from the Columbia Centre for the Study of Science and Religion (CSSR), I was able to participate in a 10-week internship during which I would investigate Palliative Care and how it is being provided at Terrance Cardinal Cooke Health Care Centre (TCC). In this final paper, I make an attempt at encapsulating the multidimensional and non-linear learning experience that I have had during this period. However, that being said, the provision of Palliative Care is an effort involving several different variables and disciplines, and to endeavor to touch upon them all would be too ambitious a feat. Inevitably, I will be unable to translate some of what I have seen and learned onto this paper, but it is only so that I may better organize the narrative of this experience.

The Mission of Medicine

It is unsurprising that many people are unsure of what exactly Palliative Care entails, given the relatively recent nature of the field. A Public Opinion Strategies national survey showed that only 3% of individuals felt knowledgeable about Palliative Care, with 70% feeling 'Not at all knowledgeable.'² In fact, the same study claims that even some physicians misinterpret the definition of Palliative Care, equating it with "hospice" and "end-of-life" care. These terms fall under the domain of Palliative Care, but do not holistically illustrate the scope of Palliative medicine, which is, according to the Center to Advance Palliative Medicine,

"specialized medical care for people with serious illnesses. This type of care is focused on providing patients with *relief from symptoms, pain, and stress* of a serious illness"² (emphasis own)

Contrary to many people's assumptions, Palliative care can and should be provided jointly with curative treatments. One study reported in the New England

Journal of Medicine shows that patients who received early palliative care, actually ended up with less aggressive care towards the end of their life but also survived longer.¹⁰ Despite these results, there appears to be this underlying belief in the physician community and in society that providing palliative care means that the healthcare system is 'giving up' on the patient or 'letting them die.' Mitigating the suffering of a patient seems to acquire importance only after the patient is beyond saving. Dr. Meier and Dr. Morrison attribute this questionable philosophy to the fact that medical care has traditionally dichotomized its purpose as either "to cure disease and prolong life or to provide comfort care."⁷ Moreover, they posit that the current mission of medicine is heavily dominated by a focus on "curing illness and prolonging life, rather than on improving the quality of life and relieving suffering."⁷ The implications of this statement can be easily interpreted to mean that our idea of good medicine has tunneled in too much on saving people, and that we have jeopardized patients' quality of life in the process.

There may come a point in a patient's life where sustained chemotherapy might no longer improve their condition. For a frail person dying of chronic disease, CPR might cause them intense physical and emotional pain that is in their eyes not worth the slim odds for positive outcomes. These cases don't mean to say that we should abandon research for cures and stop treating individuals, because in many instances curative treatment may indeed improve the patient's quality of life. Rather, what Meier and Morrison are advocating for is a shift in emphasis back onto the patient, rather than the disease. This means paying attention to patient quality of life and using greater discretion with regards to balancing patient suffering and the possible benefits of treatment. As one of the Palliative Fellows from Mt. Sinai Hospital that we worked with at TCC puts it, "the mission of medicine should not simply be to indiscriminately treat, but instead it should be to understand the goals of the patient and to use medicine *as a tool to achieve those goals.*"

Death with 'Dignity'

'Dignity' is a term that frequently makes its appearance in discussions around palliative care. Specifically in cases involving End-of-Life (EOL) care, there is constant mention of the cliché phrase of allowing someone to 'die with dignity.' However, this begs the question, what does 'dignity' exactly mean and moreover, what does it look like when someone 'dies with dignity.' The Oxford Dictionary defines dignity as:

“1. The state or quality of being worthy of honor or respect

1.2 A sense of pride in oneself; self-respect”³

From this we can consider two aspects of 'dignity,' the first relying on the judgment of others, and the second depending on our own values and how we perceive ourselves as falling in line with those values. The dual nature of 'dignity' is identified elsewhere as one that honors “particular values held by a specific individual” and also “recognizes the common worth of all people, ‘which is uniquely expressed by their life stories.’”¹ This means to say that there is a 'dignity' that comes from living in a way that is coherent with our values and beliefs, allowing us to consider ourselves with self-respect, but also a 'dignity' that we are all *meant* to hold by virtue of being human and individual. The way these two types of 'dignity' have manifested themselves during my time at TCC has been as follows.

Patient Choice and Agency – Internal Dignity

Ronald Dworkin, professor of Law and Philosophy at New York University, writes in his book on physician assisted death that “requiring someone to die in a way in which others approve but the patient believes is a horrifying contradiction of his life is a devastating, odious form of tyranny.”⁴ The nature of not only one's death but of one's medical treatment in general is “deeply personal since it reflects specific experiences, values, relationships, meanings, and spiritual beliefs.”¹ Dying with dignity is in other words is whatever the patient thinks it is. The belief that has crystalized during my time at TCC is that we as healthcare providers should do everything in our power to ensure that patients can decide as much of their care as

is possible. Unfortunately, I have met several patients at TCC who feel as though their agency is compromised because of institutional inefficiencies and disorganization. In order to better understand the instances where the patient's choice was not actualized and why, I investigated the cases of three individual patients, all whom had a very specific wish that was not being followed for one reason or another.

Case 1 – Mrs. A

Discharge is a topic that I commonly encountered during the course of my visits to patients. “I want to go home” was a response I frequently received when I asked if there was anything I could do to help. Many patients do eventually end up getting discharged back home, but there is also a significant portion that do not. I recall one patient who I got to know over the course of my internship, Mrs. A, who wanted nothing more than to die back at her home. She had lived in her apartment in downtown Manhattan for over sixty years and felt an incredibly strong attachment to that place. This neighborhood was one where she had raised six children, where she had lost her eldest son, and also where she had become a deeply religious person. This woman had struggled through most of her life alone, tasked with being a single parent, and abandoned by the rest of her children when her eldest became homicidal. Her home, more than anything, was the one constant she had in her life. One could absolutely make the argument that Mrs. A's place was one full of spirituality and “meaning” for her.

It was a great misfortune that she had been seriously injured by falls twice before her admission to TCC and was consequently at a high risk of falling. This compounded with her history of padlocking her apartment door (the Fire Department had to break her door down twice before) made New York City Housing wary of allowing her to return home without the medically recommended 24-hour supervision. The Home Care Association agreed to provide her with a 12-hour home aide to assist her at home, but that meant they still needed someone to stay with her at night for the remaining 12 hours. In an ideal situation, a relative would offer to

stay overnight at her place, but none of her children near New York were willing to sign off agreeing to stay with her. The social worker reported that s/he was able to get NYC Housing to agree to accept Mrs. A with just 12-hour supervision, but they reached another stumbling block when they tried to find an emergency contact for the Home Care Association. If the home aide was for some reason unable to assist Mrs. A that day, an emergency contact needed to accept the responsibility and liability for supervising Mrs. A that day. However, none of the children were willing to sign as emergency contact because they feared that her neighborhood was not safe for her and preferred that she transferred to another nursing home if she did not want to stay at TCC.

In our conversations with this lady, she would often tell me, “I’ve lived there my entire life, why can’t they just let me die there.” It was apparent how disenfranchised this woman felt, given how significant a piece her home was in her life narrative. She was a woman who had full decision-making capacity, but was being precluded from returning home. There was the potential for her to sign out against medical advice (AMA), but the social worker explained that she was hesitant to assist Mrs. A with that option because the family had fought very hard to get her to stay at another nursing home. It seems as though fear of resulting litigation, rather than the family disagreement itself is responsible for deterring the social worker from proceeding with the discharge. Even if Mrs. A’s wishes to return home despite potential consequences were well documented, the threat of litigation is taxing on the hospital’s resources regardless of whether the hospital wins the case or not. In any case, it was disappointing to see how Mrs. A lacked the familial support to live out the rest of her days in the home of her choosing.

Ethics Consultations for Families in Disagreement

In Mrs. A’s situation, reluctance to discharge her back home resulted from lack of family support and fear of litigation. Several strategies have been mentioned for managing family-patient disagreements, including patient support, facilitation of

communication, and ethics consultations.⁵ The goal of the first item is to validate the patient, who may feel vulnerable because of their dependence on others, while the other two items aim to encourage open dialogue between the family members. I know that for Mrs. A, the first and second options were explored, but I doubt that an ethicist was brought in to facilitate a family discussion. Some believe this option is useful because ethicists “are in a neutral position and [...] are able to identify the value conflict that exists within the group and focus on the goals of care.”⁵ In future cases of patient-family disagreement, this may be an option that care providers can consider in order to ensure patients can access treatment consistent with *their* values, not their family’s. As for the issue of medical litigation, it is unclear how we can ameliorate these issues. Perhaps this is a topic for cities and states to tackle.

Case 2- Mr. B

It goes without saying that some things will be out of the facility’s control. The onset of dementia cannot be indefinitely delayed, certain diseases have no known cures, and some organ damage cannot be reversed. For Mr. B, the decline of his motor functions, specifically his ability to walk, had been expected since his initial diagnosis. Mr. B is a patient with Huntington’s disease, a neurodegenerative disease that affects the mind, the body, and the emotions.⁹ The symptoms do vary from patient to patient and will usually worsen as the disease progresses. In Mr. B’s case, he was already in the ‘late stage,’ entirely dependent on others for his care and incapable of speaking and walking. A case conference was convened at the request of Mrs. B, the patient’s mother and health care proxy (HCP) to address the recent complaints she had about the care being given to her son.

In the days leading up to the case conference, Mrs. B noticed several things about her son’s case that she felt were not being adequately looked after. First, she noticed that her son was trembling more than usual and looked to be in pain. She had the impression that TCC was not taking appropriate action. Secondly, she brought up her son’s recent consult with the pacemaker specialist because she felt

like her son did not need a pacemaker yet and was worried the staff was taking premature action. Finally, the last issue she raised was with physical therapy and why they had discontinued services for assisted walking. In her words, TCC was “putting him in a chair too early.” Mrs. B even went so far as to say that she wanted to hospitalize her son and believed that another facility might do a better job of addressing his needs.

What Mrs. B did not understand at first was that the medical team at TCC was already providing the best possible care that Mr. B could receive. All the workups and tests that they might do at the hospital to investigate the trembling and pain were already being done at TCC. Moreover, Mr. B was able to have these tests done without leaving his home at TCC, avoiding hospitalization that can put patients under a lot of stress with new environments and unfamiliar caregivers. The failure of the institution was not in providing medically sound care, but rather its lack of transparency and mismanaged communication. Her son’s medical orders reflected a decline in physical function – physical therapy had determined it was unsafe for him to walk and the cardiologist had scheduled a pacemaker consult for his worsening heart – but no one had reassured her that this is normal for a patient with her son’s condition.

This was a woman who was intensely involved in her son’s case, more so than anyone I’ve ever met. During the meeting she pulled out his old medical records that she has kept from 5-6 years ago and waved them in the doctor’s face. She scrutinizes every item on the medication list and inspects every medical order on his chart. Her frustration during the meeting was clear in the quiver of her voice and the way she roughly shoved her folders back into her bag. I can entirely understand how some might view her as difficult and uncooperative, but that is not how I see it. This is a woman who was fiercely protective of her child and who had, unintentionally or not, been marginalized and discounted, made to feel as if her opinion was not important enough. All she wanted to do was ensure that her son was getting the best care that he deserved and that meant she would not be at ease

until all the doubts and queries she had in her mind had been covered. She manifested a common unwillingness to accept that her loved one was getting worse. However, despite her strong feelings, she could still be convinced otherwise and I was in fact able to witness it at this meeting. It took patience and an empathetic tone, but she eventually came to terms with his condition.

Open Communication Promotes Agency

While Mr. B's case does not necessarily focus on the choice of the patient, families too are a great consideration in Palliative care. The takeaway remains the same, regardless of whether Mrs. B was the family or the patient. Mr. B's case study highlights specifically the importance of open communication between healthcare providers, patients and their families. There will always be aspects of life beyond one's control, but the feeling of being wronged is only present when that loss of agency is felt to be preventable. In describing the indignity suffered by one of his patients, Dr. Rajagopal writes:

“these apparently *minor* things actually seemed to matter to her more than the cancer because while the cancer was inevitable this other suffering was unnecessary and hence unacceptable.”⁸

In an ideal situation there would be constant reassurance on the health care team's part that they are providing the best care that they can, with updates and explanations for patients and their families about changes in their care. It seems as though clarifying the situation to Mrs. B and then including her in the decision-making process by inviting her to Care Planning Meetings automatically improved her sense of control and gave her peace of mind, knowing that everything was indeed being done for her son. Ultimately, no one likes being kept in the dark, especially when it comes to our or our loved ones' health. However, open communication is incredibly time-intensive and given the staffing problems it is easy to understand why many situations fall short of the ideal.

Nevertheless, things could always be done better, and I've noticed two social work specific barriers to open communication with the residents that could be

attended to. The first being that many residents, on the discrete units and potentially in other units, mention feeling intimidated by their social worker and uncomfortable bringing up their concerns at the Care Planning meetings. This seems like an obvious problem and might have to do with the number of people at these meetings, sometimes it can go up to 6 if you include all the disciplines. However, it might also be due to the tone of voice and language that the health care team might decide to use when talking to these residents. For all intensive purposes, punitive language should not be used at all, but there have been occasions where I have heard the healthcare team wording things this way. It would be interesting to see if the punitive language affects the resident's level of intimidation, this could be an avenue for future studies.

The second obstacle I've encountered is that many residents, particularly in the geriatric and sub-acute unit cannot speak to their social worker when they need to. The Social Work department has instituted a type of 'office hours' for many of the social workers, where they spend time in their office and are open to residents coming to meet them in their office if they have concerns, in an effort to promote accessibility. The problem however, is that this does not accommodate bedbound patients, a large percentage of TCC's total patient population. What I recommended was creating a type of social work referral form, with the top 10 reasons why a patient might want to contact their social worker, and also including an 'other' option so that all concerns can be addressed. The form could be filled out with assistance from and passed onto the social worker by the Certified Nursing Assistant (CNA), and would allow the social workers to have a record of who wanted to see them and address each case whenever they had the time.

Case 3 – Ms. C

This final case study focuses on the issue of capacity as it applies to patient decision-making. Ms. C was an elderly woman, bedbound, generally debilitated, and suffering from a growing sacral ulcer. The ulcer was not at all painful when she lied

still, but only when they turned her over to treat the wound. She was perfectly comfortable staying in bed, not getting cleaned or treated. She began refusing care, claiming that she would leave it “in the hands of Jesus.” When the nurses made attempts at caring for her wound, she would scream and call the police to prevent further treatment. It was within this context that an ethics committee was called to discuss the potential option of withholding treatment for Ms. C.

The dilemma at hand was that Ms. C wanted to refuse treatment, but if untreated, her wound could end up mutilating her body, unacceptable in the eyes of the Catholic clergy, and causing her a lot of pain. The committee meeting had a lot of back and forth but there were ultimately two main points of contention that remained unresolved, the first being whether or not Ms. C had the capacity to fully understand the consequences of her decision. The concern of her court-appointed guardian was that Ms. C did not understand the full extent of the pain she will have to endure should the wound become more serious, and that if she did understand, she would opt to have it treated. In her words, Ms. C “thinks Jesus will take her before any pain befalls her.” The physician in attendance however, was of the opinion that Ms. C was indeed aware of the consequences. He reminded everyone that she indeed had the capacity to refuse treatment, highlighting the decision-specific nature of capacity. He argued that her diagnosis of dementia did not contradict her capacity to make this decision. Moreover, should it ever come to the point where her wound does worsen, they also have plenty of ‘ammunition’ to treat her pain if need be.

The second point of contention was with regards to whether or not Ms. C was ‘actively’ dying. In other words, was Ms. C going to die regardless of the wound, or would she be able to live much longer if she had the wound treated? The belief of the guardian and catholic minister there was that she was not actively dying, and that she had many more years ahead of her. The physician on the other hand claimed that Ms. C likely had less than 6 months to live, as suggested by some of her other symptoms including her dementia. His belief was that she was already dying,

and that allowing her to remain untouched would speed her demise but would do so on her own terms. This was a lady who was already prepared for death. Whenever I visited her, I would always hear her say without exception first, “the greatest gift I’ve ever gotten is Jesus the son of God,” and then, “I’m an 99 year old bat. Go save the children.” In the end, it was agreed to that the minister would try to remind her of her catholic duty to care for her physical body in order to persuade her to accept treatment. A few days later, she conceded to accepting a Fentanyl patch to help with the pain of moving her around and reluctantly allowed others to take care of her wound.

Decision Making Capacity – Who Does It Protect?

What is frustrating about this case is that Ms. C’s idea of ‘dignity’ – being comfortable, being left alone – was superseded by someone else’s notion of ‘dignity’ – sanctity of the body. I attribute much of what precluded Ms. C’s agency to incorrect assumptions about the nature of capacity. As the Veteran’s Health Administration (VHA) stated in a report on myths about capacity, “whereas decision-making capacity refers to the patient’s ability to make a particular health care decision, cognitive ability encompasses a broad range of processes including attention, memory, and problem solving.”¹¹ At Ms. C’s ethics meeting, I had the impression that her history of paranoia and diagnosis of dementia led some people to err on the side of caution and assume she did not have capacity, a dangerous logic jump that could prematurely disqualify patients.

According to the VHA, sound-decision making requires the following:

- “1. Capacity to communicate choices;
2. Capacity to understand relevant information;
3. Capacity to appreciate the situation and its consequences;
4. Capacity to manipulate information rationally.”¹¹

In Ms. C’s case, the psychologist had already determined that she met these four criteria and thus had the capacity and legal right to refuse treatment. However, counterarguments were made to argue that she was not fully aware of the potential

pain and so did not completely satisfy the third requirement for capacity. This contention is not unexpected, “in fact, in complex cases, experts may disagree in their capacity assessments of the same patient.”¹¹ The task of capacity evaluation is made especially difficult by the subjective nature of the judgments being made, which allows both of these evaluations of Ms. C to be valid.

People will inevitably have differing interpretations on a patient’s capacity, that is something we cannot change. What can be done, however, is to ensure that the staff and health care team have a correct understanding of capacity, so that we do not mistakenly disenfranchise the patients. I found two of the VHA’s ten ‘myths’ on capacity to be incredibly relevant. The first being that capacity does not equate to cognitive function, which has already been discussed, and the second being that capacity is not an “all or nothing”¹¹ phenomenon, but instead it is decision specific. Oftentimes I hear staff simplifying the patient’s capacity status, saying point blank, “they don’t have capacity.” Even on the electronic medical record, at the end of the physician’s admission note there is a “yes/no” evaluation of the patient’s capacity. This dichotomization of capacity can influence the way workers interact with the patients. It may cause them to marginalize the patient and take their choices less seriously. Further study should be done in order to ascertain whether or not staff education about capacity is lacking and should be addressed if found to be so.

Self-Reflection – External Dignity

“We are lonesome animals. We spend all our life trying to be less lonesome. One of our ancient methods is to tell a story begging the listener to say – and to feel – Yes, that’s the way it is, or at least that’s the way I feel it. You’re not as alone as you thought.”

– John Steinbeck⁶

I have talked a lot about patient autonomy and its importance to palliative care in this paper, but I’d also like to raise how, in an oddly paradoxical fashion, I have come to believe that we are never, in our whole lifetime, truly independent from one another. At the bedside of the terminally ill, confronted with the ephemerality of life, the question that creeps into my head is: ‘what is the point of it

all?' What does it matter whether we walked this Earth or not? What difference does it make that we existed? The answer doesn't seem to be money or prestige. After all, when we approach the end of our lives, we find our health deserting our bodies, our wealth turning to ash. Rather, what outlasts all else is the memory of us. And it will be different for each person, some identifying as war veterans, others as parents. Regardless, memories of us are how we live on even after we are dead, in the minds and hearts of others. However, to have others remember us is by nature, something that we cannot accomplish by ourselves. Ironically, in the incredibly isolating process of death, we as social creatures end up looking outwards, to others, in order to affirm our existence. Perhaps that is why amongst the residents there seems to be this unwavering willingness to share their life stories, to talk for hours on end about what they have done, where they have lived, and who they have met.

Interestingly enough, what I have enjoyed most about this internship was the process of getting to know the patients. It is an extremely gratifying and surprisingly symbiotic experience to spend time with patients, to be present at their bedside, to listen to their stories and to hold their hand. In a way, we remind them that they matter, that they exist and that they will be remembered. In doing so we validate these patients, but also receive a validation of our own, since we live on as much in their memories as they do in ours. Though we can improve on family counseling, open communication, and education regarding capacity, there is no substitute for the one's time and presence, and perhaps it is better this way.

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