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Care through Communication: From Defining to Defying the Gaps

Introduction:

What happens when healthy is no longer an option? Spending time at Terence Cardinal Cooke, an acute care facility in Manhattan, provided answers to this question in terms of end of life medicine and palliative care. While these terms are often inclusive, palliative care, including comfort care and the treatment of pain, can occur at any point in a disease. Though palliative and end of life care plans aim to improve the quality of life for patients, challenges often coincide with these forms of medicine. I decided to look into challenges associated with staff communication and how the spiritual pain of residents is noted. Palliative care involves alleviating both physical and spiritual pain, issues whose proper detection directly tie into the quality of life a patient has in centers such as TCC. When systems within a facility work smoothly, quality of care and life, as well as working environment, can improve.

Contrary to common conception, medicine does not always equal an aggressive curative measure. As medicine is often associated with prolonging life, placing a patient on end of life care can be difficult. In addition to being a challenging care plan for families to acknowledge, sometimes getting across the benefits of DNI/ DHR/ DNH¹ can be tough. Prognostication can also be a road block; it is often difficult to gauge how much time a particular patient has especially considering the ups, downs, and plateaus a

¹ Do Not Intubate / Do Not Resuscitate/ Do Not Hospitalize

particular illness may have. Screening for patients in decline or noting the trajectory of patients can also prove taxing. If communication between staff members and with medical records is not up to par, a patient may fall through the gap. For example, Hospice, a strictly end of life care program which requires two doctors to agree a patient has less than 6 months and that curative treatment is stopping, is often started later than would be most beneficial to a patient.ⁱ

I found the challenges of this area of medicine particularly striking when one of my own patients passed away. Mrs.SG had a long life, living into her mid 80s and battling cancer for 10yrs. Yet, by the time I met her, she had stopped dialysis and was becoming sadder as her independence declined. Mrs.SG died suddenly and unexpectedly one morning after breakfast. Though she chose not to be resuscitated (DNR) and seemed to pass peacefully, it was a bit disturbing that she was not on an end of life protocol. Was she really as comfortable as possible? Did she understand that by coming to TCC, though she came after a fall, there was a possibility that she may not leave? Would she have wanted hospice? Did her daughter truly understand how ill her mother was?

This occurrence and the questions it raises points to just how important communication and end of life discussions are. Though families, and even staff, may be hesitant to put a patient on an end of life care plan it is important to remember that it is not necessarily an active choice, but a “choice” made by their bodies that resembles fact. There should not be debates about saying yes to an end of life plan; to the best of their ability practitioners should use their knowledge of medicine and the human body to recognize when the end of a patient’s life may be approaching. Still, the term “End of Life care plan”, may seem a tough pill to swallow. During my internship it was suggested

that swapping the name “End of Life” for “Advanced palliative care” or something like it may ease the reluctance of patients, practitioners, and families, and make the table clearer for practitioners to explain a prognosis and promote the use of palliative care or hospice from there on in.

In the eighth week of the internship, I had the opportunity to visit Calvary Hospital, a place for terminal patients where both “End of Life care” and palliation was an acknowledged reality. There was an atmosphere of peace at Calvary, and it seemed to provide a clear example of what palliative care should be. It was bright, clean, calm, and even had a wonderful scent wafting from the air fresheners around each floor. The doctor we shadowed there embodied how palliative care is medicine, but goes beyond the administration of medication to ensure comfort.

Dr. C was like a character you would read about in a novel. Her expression, gestures, words of wisdom, and even how she carefully and lovingly touched her dying patients was a vision of what a physician embracing palliative care should be. One of Dr.C’s patients in particular stuck out to me. There was a woman with brain cancer who was frustrated about not being able to walk to the bathroom anymore. Instead of ignoring this frustration, attributing it to an inevitable decline, or reminding the patient that she would most likely never be able to walk out of the doors of Calvary, Dr.C. whispered “I know it’s frustrating”, and went out to write a physical therapy request as soon as she left her patient’s room. It struck me that Calvary aims to view their patients as living rather than dying; a statement dangerous regarding conversations on advanced directives but profound in regard to the aim of palliative care toward improving quality of life, regardless of whether life is drawing to a close.

The multidisciplinary nature of palliative care became notable the more time I spent at TCC. In addition to physical pain of patients, emotional and spiritual pain are attempted to be alleviated as well. TCC has pastoral, psychological, and therapeutic recreation departments that help assist with generating a balanced atmosphere of palliation. Soon I was able to see such forces at work with a simple trip to the park for residents. Being able to go outside into the fresh air, something we often take for granted, visibly lifted the spirits of the residents that went on the outing.

As the internship continued, I picked up certain patients and followed them throughout my internship. The physical pain of most of the patients I visited was handled well, but their emotional pain often became a heavy burden as they lay in bed or roamed the hallways of TCC.

I remember one patient, LS, remarking about her time at TCC. She was generally unhappy and mentioned that she feels “trapped” by her illness. She conveyed how both the frustrations of a failing body and family difficulties stick with her as she lies in bed; causing the pain she experiences daily to be “more emotional”.

Another instance with one of my patients, Mr. LA, pointed to the emotional or spiritual pain that often accompanies illness. Generally Mr.LA appeared in a dour mood, but was normally willing to converse a bit with me. One day, soon after we met, I became a bit concerned about how he might be feeling on the inside. I asked him if he was ok. When Mr.LA said no, and I asked him what was wrong. His expression became angry and he yelled, “I can’t even go to the bathroom by myself!” The frustration he revealed in that moment made me consider how much more might still be inside of him. How does he cope? How would I cope in a similar position?

Ms B., a CNA in the 6 Cohen discrete unit of TCC, seemed to especially understand situations like that of Mr.LA. She mentioned how she treats one of her patients who is depressed about their current condition and disgruntled that they might not be able to return home soon if ever. While explaining why that resident is angry or difficult at times, Ms. B relented, “He’s depressed, he’s sad that he’s here. Most people forget that patients here were out in the community two months ago. I understand that, I try to make him happy and give him what he wants.”

Project:

How emotional health of patients is recorded, staff communication, and the role of CNAs

Such cases led me to question the role of autonomy as the body weakens. Through noting the experiences of patients such as those mentioned above, it struck me how institutional life could be marked by depression. It is in places like TCC, a hospital, long term, or nursing home setting, that most Americans spend their last days.ⁱⁱ Is there a way to stave off spiritual pain along with physical pain in such settings? According to Kenneth Miya’s article “Autonomy and Depression”:

Reactive depressions are seen to evolve from a multiplicity of causal factors. One frequently observed theme among persons who manifest clinical depression is their seeming inability to behave autonomously, to assert themselves. Such difficulty results in a sense of oppression, a gradual loss of self-esteem, and other symptomology which is descriptive of the depressive syndrome.ⁱⁱⁱ

Additionally in a study done by the University of Texas’ School of Social Work it was found that with residents:

The major themes related to the causes of their depression were loss of independence, freedom and continuity with their past life; feelings of social isolation and loneliness; lack of privacy and frustration at the inconvenience of having a roommate and sharing a bathroom; loss of autonomy due to the

institutional regimen and regulations; ambivalence toward cognitively impaired residents; ever-present death and grief; staff turnover and shortage; and stale programming and lack of meaningful in-house activities. Self-reported coping mechanisms included religion and stoicism, a sense of reality, positive attitude and family support. In regard to depression treatment, the interviewees appeared to prefer nursing home programs that reduce their isolation over group or individual psychotherapy.^{iv}

Such sentiments, including the concern over isolation and staff turnover, as well as the knowledgeable reflections of Ms.B about her patient, made me consider the role of CNAs in a patient's emotional health. They are the care providers that are closest to residents, often know them the best and have the most consistent relationship.

A research project done by Melissa Brown for the University of North Carolina evidences just how connected CNAs are to the quality of care of patients:

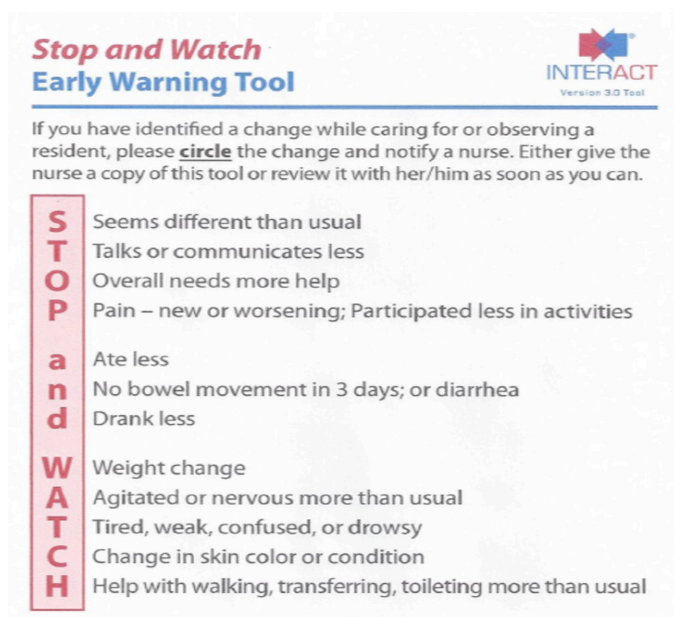
It is the CNA's job performance that is likely to have the greatest influence on the residents' quality of care (Burgio, Fisher, Fairchild, Scilley & Hardin, 2004). Anderson, Corazzini and McDaniel (2004) reports when CNAs hours per resident day are higher, CNAs are more likely to feel greater satisfaction in being able to take time to do a good job and to spend time with residents. Chou et al.s' (2002) found that enhancing residents' satisfaction with the staff's care, can increase all aspects of residents' satisfaction.

Promoting job satisfaction among nursing assistants results in greater continuity in the relationships between residents and those who care for them (Noelker & Harel, 2001). Staff can be better trained to communicate with residents without increasing the amount of time of direct care (Burgio, Allen-Burge, Roth, Bourgeois, Dijkstra, Gerstle, Jackson & Bankester, 2001) ...Interaction is necessary to structure staff resident social interactions during care to positively affect resident quality of life (Burgio et al., 2001). It is obvious, as older adults are entering nursing homes, it is important to educate CNAs about the importance of preserving the autonomy so they are better prepared to care for older adults.^v

Thinking about how the CNAs know their patients, and have such a key role in their quality of care led me to consider a system that theoretically functions as a voice for the CNA, the Stop and Watch.

Defining the Stop and Watch:

The Stop and Watch is a booklet created by the Interact system, a health care plan that attempts to reduce hospitalizations and improve quality of care. On one side, as seen below, it lists differences in a patient that CNAs, housekeepers, etc. should take note of. The other side depicts a figure of a person that should be circled in the region that a difference in a patient is noted. It is ideally kept in the pockets of CNAs, filled out when needed, and presented to a nurse on duty when “differences” in a patient appear.



Stop and Watch
Early Warning Tool

INTERACT
Version 3.0 Tool

If you have identified a change while caring for or observing a resident, please **circle** the change and notify a nurse. Either give the nurse a copy of this tool or review it with her/him as soon as you can.

S	Seems different than usual
T	Talks or communicates less
O	Overall needs more help
P	Pain – new or worsening; Participated less in activities
a	Ate less
n	No bowel movement in 3 days; or diarrhea
d	Drank less
W	Weight change
A	Agitated or nervous more than usual
T	Tired, weak, confused, or drowsy
C	Change in skin color or condition
H	Help with walking, transferring, toileting more than usual

I was curious about if the “STOP” part of the Stop and Watch worked well as a red flag for spiritual or emotional pain in TCC, if a different “Emotional Stop and Watch” was necessary and if the stop and watch system was currently effective in TCC. Furthermore I was interested in some of the challenges that CNAs face, thinking that if they feel stressed or less listened to tools such as the stop and watch would get used less often. As effective communication from CNA to CNA, CNA to RN, and RN to CNA is

key to improving quality of care, I also wanted to gather CNAs' opinions on where this was currently lacking and could use improvement.

In order to study the effectiveness of the Stop and Watch, I interviewed several CNAs from three general areas of care: geriatrics, subacute, and discrete. I asked them around 5 questions that were generally open ended to gather feedback on what CNAs thought about the stop and watch, how emotional needs of patients were picked up, and if they felt like part of a team.

Examples of some of the questions asked are:

- Do you find the stop and watch useful? How?
- When do you use it and how often?
- Where do they go after you write them
- Do you feel like the other staff listens to you?
- What clues you into how a patient is feeling?
- Do you feel like knowledge about patients is transferred well between shifts and floaters? What do you think would help?

I interviewed 12 CNAs total: 3 from floor 3 Hospital (a subacute and geriatric floor), 2 from 4 Hospital (a subacute floor), 3 from 6 Cohen (a HIV/AIDS floor), 1 from 8 Cohen (a HIV/AIDS floor), and 3 from 6 Hospital (a geriatric floor).

About 9 of the interviewed CNAs (75%) responded that the Stop and Watch was useful with 6 (50%) saying that it is useful to “protect yourself” in case a nurse forgets an issue that a CNA reports. On the other hand, two CNAs said that it is not really useful and may need to be modified.

All of the CNAs interviewed mentioned that if there is an issue they are more likely to verbally report it to the nurse, with only 2 CNAs responding that they often fill out a stop and watch along with reporting. Most CNAs said that they rarely use the Stop and Watch, with one CNA on 6 Cohen responding that she uses it, “once or twice a

month if ever.” CNAs relayed that if the stop and watch is used they would use the “WATCH” part indicating physical changes (and most likely the differences noted would be major changes). The “WATCH” part of the Stop and Watch corresponds to weight change, agitation, tiredness or confusion, color change, and more help needed in movement. For instance, reporting bruises or skin tears was the most common example given for implementation of the Stop and Watch.

When I asked if the Stop and Watch was utilized for emotional distress or changes, most CNAs responded that it was not used for this purpose. Two CNAs responded that it could be used for emotional purposes, with only one actually using it as a tool for marking emotional health changes. One CNA responded that the Stop and Watch, “Is for physical [changes] and not for emotions, at least for me.” Thus the “STOP” portion of the Stop and Watch is often ignored or its function is not understood. STOP stands for “Seems different than usual”, “Talks or communicated less than usual”, “Overall needs more help than usual”, and “Participated in activities less than usual”; possible clues into the emotional health of a patient and differences that could signal an oncoming mood swing or possibly a descent into depression, an illness that one study found existed in 44.2% of nursing home patients.^{vi}

Interestingly, that same study found that only 37%-45% of cases of depression were recognized. Though that study was not conducted at TCC, its data implicates that many residents of TCC may be suffering from undiagnosed depression, a condition that the “STOP” part of the Stop and Watch may be able to filter out if correctly used. For example, if a CNA notices emotional differences in a patient and fills out the STOP portion of a Stop and Watch, once it is handed off to the nurse a referral could be made to

psychology or volunteer services. Hence a patient experiencing emotional difficulties may be able to talk it over with a professional, or gain a friend and listening ear through the company of a volunteer. Additional training or a staff in service may help with increasing use of the Stop in Watch, both for general use, and for picking up on patients' emotional health.

Other Suggestions:

While Stop and Watch forms find their homes in a unit binder after being presented to a nurse, I think that a tab should be added to Sigma in order to electronically record differences CNAs have noted. This would allow for a patient's trajectory to be noted more clearly, make for better assessments, prevent loss of information and allow earlier interventions to be made.

One possible roadblock for the use of the Stop and Watch is in communication and teamwork between staff. Though 7 CNAs (58%) said they feel like they are part of a team most of the time, several mentioned that there are sometimes communication difficulties or tension between them and the nurses. One CNA from 6 Cohen sticks out to me in particular. When I asked what she thought about the stop and watch she responded, "I think it should be fixed...Sometimes it's hard to get it signed." Nurses are required to sign a stop and watch from a CNA, and refusing to sign it indicates they do not want to be held responsible for or acknowledge an issue that is happening with a patient. In addition, several CNAs indicated that there is not adequate follow up on the part of nurses after reporting a problem or submitting a Stop and Watch. A few CNAs mentioned they are not certain what happens to a Stop and Watch after they hand it to a nurse. On

one day in July, such miscommunication with the Stop and Watch came up during the daily morning report. When an administrator told the nurse managers that the stop and watch should be used and asked where nurses put the stop and watch forms, no one was able to give a straight answer. An in-service day on staff feedback and how the Stop and Watch should function may be able to help with some of these issues.

In addition to problems with implementing the Stop and Watch, CNAs expressed that issues with staffing, communication and tension with coworkers made their job challenging. Two CNAs mentioned tension arising with older CNAs after starting to work at TCC. One new CNA from 3 Hospital relented, “It’s like they think I’m here to take their job or something.” Several CNAs also mentioned that they do not always feel respected by other staff members. For instance, a CNA on 6 Hospital verbalized that, “Sometimes people look down on us because of education...but we’re the ones who know the patients best.” Though there are people with many different levels of education contributing to health care at TCC, all are valuable and their teamwork is essential to the quality of care available at TCC. In my opinion if the CNAs, those that work closest with patients, are pleased and less stressed with their jobs, they would be better equipped to serve their patients well.

Staff Appreciation:

An example of something that could promote feelings of job appreciation and improve work environment is a compliment box at nurses’ stations. At Calvary hospital each nurses’ station had such a box clearly visible. If someone was excelling in their job, there was a clear way to recognize their effort. Additionally, I remember teamwork

having a strong place at Calvary. Before going into a patient's room, Dr.C. asked both the CNA and the nurse taking care of the patient about what was going on with them. In-services with nurse managers or flyers encouraging teamwork could help foster cohesion and respect. Encouraging teamwork and making compliment boxes available on each unit may contribute to both quality of work environment and quality of care.

Increased Shift-to-Shift Communication:

Another issue acknowledged by several CNAs was communication during the changing of shifts. On 4 Hospital, a subacute unit, one CNA relayed that she wishes nurses let CNAs know more about the events of a day and what was going on with patients. She gave one instance where the nurse on duty did not inform her about a patient's fall till the end of her shift at 11PM. Similarly, a CNA on 3H mentioned that he wished, "They [nurses] told more details," during the changing of shift. On the whole CNAs would like more information on what is going on with their patients and the resolution of issues they report.

During the CNA falls meeting on Wednesday afternoons a similar sentiment was exchanged. When talking about possible ways to eliminate falls, it came up that CNAs were often not told about what happened to their patients during earlier shifts. They attributed some of this lack of communication to "floaters" who are not always on the same unit, or CNAs who do not remember what is going on with their patients. Issues during changing of shift, and the fact that CNAs cannot always view what happened with their patients in sigma, were also mentioned. For example, a CNA relented, "How are we supposed to prevent falls when we are not even told when a patient [goes to the

bathroom].” Such miscommunication directly connects to patients’ wellbeing. For instance, if a patient is constipated, understandably they may try to get up to use the restroom out of urgency or discomfort and then fall. Hence it seems that an in-service on how change of shift should be conducted would be beneficial. If possible, nurses should give more information on what is going on with patients and what to look out for and CNAs should pass on information such as bathroom use to those that will be following them. Adjusting sigma so that CNAs can see what CNAs on previous shifts have recorded would also be useful. In addition, and if stop and watch forms increase in use, I think that CNAs should flip through the stop and watch binder on their units before starting their shift.

Increased TCC Training:

In addition to training with the Stop and Watch tool, further in-services and staff screening may help improve quality of care. One CNA on 4 Hospital mentioned that in-services on introductory psychology and end of life care would be useful in serving patients that may be approaching death. She remarked that she was trained in end of life care upon beginning her career as a CNA, but “A refresher would be good.” Furthermore, screening for new employees who really seem to care about people can help improve quality of work environment and care. Three of the CNAs that I interviewed, including the one from 4 hospital, mentioned how their position was more than just a job, they loved serving people. There is a difference in “taking care of” and “caring for” patients.

Helping Patients Understand Trajectory

My time at TCC has illuminated issues that may come up in palliative and end of life care as well as solutions that may be applicable through CNAs. Along with communication, the difficulty of prognostication struck me. Dr. Lechich, a wonderful physician and the medical director at TCC, mentioned early in my internship that physicians are often wary of prognostication and timelines for end of life patients; their trajectories often turn around or plateau. It also struck me that people often have a difficulty grasping just how sick they are. One of my patients, Mr.JP exemplified this notion of misunderstanding trajectory. Though dealing with prostate cancer that had metastasized to his shoulder and a failing liver, he believed that leaving TCC would not equal going on Hospice and life drawing to a close, but would allow him to get stronger, return to his teaching job, and direct a play he was writing. Though Dr.Lechich had spoken to JP and his family, they believed Mr.JP's extraordinary optimism and revoked the DNR order that had briefly been put in place.

In conversations with the critically ill, sick people should be viewed more as people who are sick. The person inside the weakened body is often fighting to reclaim ownership of their previous life; a striving that though in some situations may be illogical can exist nonetheless. Understanding this can help in approaching people who are ill, reinforce the need to treat them as an autonomous person in conversation, and underline how important end of life conversations can be. During several care plan meetings I attended, multiple residents did not understand how serious their illnesses were and that they may need to remain in TCC indefinitely. Listening to Dr.Lechich talk to a family in one of these situations illuminated how conducting end of life conversations is like an art. As one of my colleagues, Steve Kwon, studied, doctors need to learn how to ask more

catered questions while gently but accurately laying down the facts of an individual's disease. In order to provide the best care, and put a patient on the correct care plans, honest conversations should be held with patients and their families to help them understand the reality of their trajectory.

Suggestions for Volunteers:

This internship has also opened my eyes to future research ventures and extensions of the volunteer program that may be beneficial. Looking further into communication, building teamwork, and how quality of work environment translates to care could be useful for future studies. In terms of extending the At Your Service volunteer program, it would be great if volunteers could be able to take residents with pass privileges outside to the park. Several of my patients mentioned how they miss being able to go outside and would love to get some fresh air. Training in areas such as nail cutting, aromatherapy, grooming, etc. could also help enrich the lives of residents. Additionally, I think that volunteers should take on more than one long term companion if possible. One of their companions could be higher functioning and the other could be an end of life patient or someone who is non-verbal (residents who would probably benefit from having someone simply sit next to them for awhile). Additionally, a reflection session where volunteers could bounce around their ideas, findings, and issues could also benefit the At Your Service program and help volunteers gain a richer experience while navigating the best ways to serve TCC. As also addressed by my colleagues Bryana Williams and Michael Jiang, it would be great if volunteers complete a checklist recording how their patients are doing on a week to week basis. This would

allow trajectories of care to be recorded and the volunteers to function as both advocates and liaisons to care providers; a path to ensure patients' needs are known and are being addressed.

Conclusion:

Coming into this internship as an At Your Service has reinforced some of my experiences, but spending a summer at TCC has taught me so much more. It was great to learn about what palliative care means, how it is implemented, challenges that come with end of life care, and how much goes into keeping places like TCC running. Palliative care, when done to the upmost, is like an art form. The mediums of several levels of health care providers, as well as recreation and pastoral care, should come together to cater care to a patient and enrich their quality of life as much as possible, providing a picture of comfort both inside and out. It takes skill to communicate effectively with patients and their families while simultaneously peeling back the layers of what they want, what they think they want, and why. I feel truly blessed to have had an opportunity to gain a base in palliative care, a part of medicine I hope to bring in to my future career, regardless of specialty. This internship has also reinforced how important it is to keep the human side of medicine in mind. People are not just bodies; their spirits and the lives they have lived are tied to them as well. Keeping this in mind, in terms of treating both emotional and physical pain as well as in having conversations with patients, can reinforce a holistic view of medicine and ensure that palliation remains connected to care.

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