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Clinician Narrative
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The case I am choosing to reflect on for the clinical recognition program is one in which my role as a social worker evolved over the course of my work with this patient, her son, and close family friend. Due to this patient's advanced dementia and inability to communicate, much of my work was with her son. My role resultantly took on many different shapes and forms as rapport was established and strengthened over the course of our work together. I think my ability to build rapport was based on the ability to listen, validate/sympathize and establish trust amid a life-changing crisis for this family.

Mrs. H was an 85-year-old European bilingual woman with a past medical history of advanced dementia, hypertension, hyperlipidemia, urinary incontinence, falls, depressive disorder and sigmoid colon cancer. Mrs. H lived with her son P in a two-bedroom apartment in Boston, MA. She was admitted to MGH from home following a fall that occurred earlier in the day. After several hours of failed attempts to lift Mrs. H off the floor, her son contacted a friend for advice on what to do. His friend encouraged him to call 911 for immediate assistance. Mrs. H was resultantly transported to the MGH ED where she was found to have altered mental status, poor hygiene, dehydration, malnutrition, low blood pressure, abrasions on her right elbow and right hip, a pressure ulcer on her backside, and sepsis. Fortunately, radiology imaging ruled out evidence of an acute fracture or dislocation as well as ruling out evidence of a brain hemorrhage, mass or infarction.

Mrs. H's son, who was her caretaker and pursuant HCP, reported that her nutritional intake had been poor for several days prior to admission. Her son also noted that her teeth had not been brushed in days, and that she often had bleeding from her gums. He further reported that Mrs. H is supposed to use a walker at home, but she often refuses and thus occasionally loses balance and has falls. Her son confided to ED staff that he was reluctant to call EMS because there is a "hoarding situation" at home and Elder Protective Services (EPS) is already involved. Mrs. H was admitted to a medical unit at MGH for further evaluation and treatment.

I was consulted by the respective unit based Social Worker regarding concerns around Mrs. H's son's inability to make medical decisions on her behalf. This was evidenced by verbal cues (perseveration, anguish of his mother's declining health and inability to make any decisions on her behalf) and nonverbal cues (inability to attend scheduled meetings even while living within the same neighborhood of MGH). Throughout her hospital admission there was close collaboration with EPS, Mrs. H's Primary Care Physician (PCP), and outpatient Social Worker at MGH Senior Health. The concluding recommendation was that Mrs. H was not safe to return to her home setting. Specifically, per reports from home visits by EPS and MGH Senior Health, the home is filled with belongings, trash, old food containers, cups ½ filled

with liquid (in the belief that the fruit fly infestation will land in the water and die), old soda/juice bottles, and bowls with cigarette butts and tissues. Son's active smoking in the cluttered home raised heightened safety concerns for fire.

The reports from EPS and Senior Health were quite detailed and painted a vivid portrayal of P's own mental health needs. For example, reports described that the apartment was overcome with hoarding, that there was only a narrow pathway leading from the front door to the bedroom(s). Their belongings were reportedly about waist high in the living room and rimmed the edge of the bedrooms. The kitchen counters were reported to be covered with items including both Mrs. H's and son's medications and meals on wheels food containers. The kitchen itself could not be entered because of large industrial garbage bags on the floor. The bathroom had a raised toilet seat which was covered with feces. The floors of the apartment were covered with ground in dirt/food.

Despite the concerning condition of their apartment and P's observable mental health issues, it was apparent Mrs. H's son was visibly devoted and concerned for his mother. He recognized that his own health care issues had been neglected because he could not bear to be away from his mother for any amount of time. Mrs. H's son was visibly struggling in maintaining the role as his mother's caregiver and decision maker (Health Care Proxy).

I first met with P following several family/team meetings aimed at educating him why his mother was unable to return home to a community setting and therefore required transfer to a skilled nursing facility for long-term care. In addition to consenting to this difficult decision, P would also have to work with Patient Financial Services in completing a Mass Health application to identify a payer source for this level of recommended care. When I first met P, it was evident he was in significant emotional distress. He was devastated by the news his mother could not return home and he endorsed a great deal of guilt around this. I quickly tried to alleviate him of this guilt and remind him that the care his mother presently required was more than any one person in the hospital was providing. I praised him for all the years of care giving he provided to his mother and highlighted how much he loves his mother and clearly wants what is best for his mother. I then attempted to guide P toward accepting his mother's increased care needs as a progression of her dementia vs. a reflection of his own shortcomings. P appeared to appreciate this perspective but continued to struggle with the burden of making the decision to place his mother in a nursing home setting.

As the conversation continued, it highlighted why P was unable to maintain the responsibility of making both medical and financial decisions for his mother. I shifted the conversation by informing P that in situations like his, it is not uncommon for guardians to be appointed through the court to assist in making medical decisions. I explained the role of a guardian (and conservator) and informed him this would grant him the opportunity to remain the loving son

without bearing the burden of making such difficult decisions on behalf of his mother. I sought to portray this information in the most compassionate, yet direct manner. In doing so, I made it evident that the plan to proceed with guardianship was a hospital decision, and therefore not a decision he needed to feel the burden to make. P appeared to feel relieved with news. He also demonstrated awareness of how “paralyzed” he is by his mother’s failing health. He apologized for appearing “difficult” and appeared to gravitate toward the support of social work. I validated the very difficult position he was in and attempted to explore his support system. P shared that his closest support is an old college friend whom he identified as someone who understands his complexities because she too is caring for her ill mother. P granted me permission to contact his friend, R.

As time continued, I grew to have many conversations with both P and R. I learned from R that P was once a bright, social and very capable man who R had often turned to through the years to help guide her through difficult times. R recognized that P had developed profound mental health issues over the course of the past year as his mother’s condition declined. R was so concerned about P that she was prepared to take a frontline role in becoming the guardian for Mrs. H. She felt confident her strongly founded relationship with P would allow her to intervene in a gentle, but proactive manner. R was also committed to guiding P toward receiving mental health counseling, including an admission to an inpatient psychiatric stabilization hospital.

Throughout the course of Mrs. H’s admission, P continued to embrace the support of social work as well as the support of R. P also allowed me to reach out to maternal family (cousins) in Pennsylvania to make them aware of his mother’s declining health. One cousin stepped forward and eventually became endorsed as Mrs. H’s conservator. Although P appreciated her assistance, he also struggled with her gaining access to such personal information about his mother’s assets. I played a strong role in validating his concerns while also helping to reassure him this was a positive next step.

Shortly after the hearing for Temporary Guardianship/Conservatorship, Mrs. H was transferred to a skilled nursing facility. Unfortunately, she was readmitted to MGH shortly thereafter with failure to thrive. P was inpatient at the time on a psychiatric stabilization unit at an outside hospital, but he quickly signed himself out upon learning the news of his mother’s readmission. P was informed it was the impression of his mother’s medical team (and palliative care) that she was in the process of dying. This was understandably extremely difficult information for P to process. He cast great doubt in the “opinion” of the medical team and shared his perspective on why he believed his mother was in “better health” than the team believed her to be. He also voiced a strong opinion that the medical team was “killing” his mother.

My role now was to support P by helping him to accept his mother was dying. It was advantageous that P and I had developed good rapport during his mother’s last

admission because he quickly embraced my involvement. He also appeared to value my input. I attended numerous Family Meetings with P so that I would be able to share my impression of the information the medical team was providing to him. I worked closely with the medical team during this time and made P aware of my collaboration with his mother's care team as it was important for him to know I was aligned with the team. I consistently attempted to remind P that like myself, his mother's care team is here to support both he and his mother during this difficult time.

I also tried to guide P in conducting a life review of his mother as an intervention for P to focus on his mother's life long accomplishments. P appeared to greatly appreciate the opportunity to reflect on his mother's life, including her having been a Holocaust Survivor and esteemed professor. The ability to conduct a life review proved to be a therapeutic intervention for P. He was so proud to share stories of his mother's courageous journey. I encouraged P to bring in pictures of his mother to share with us. P returned the next day with many pictures of his mother as a young woman. This was a marked achievement for P as he had struggled tremendously with completing tasks. As we reflected on his mother's many accomplishments, we spent much time highlighting the remarkable bond he and his mother shared. I validated how difficult it must have been over the past decade to watch his mother's health decline as her dementia advanced. I encouraged P to reflect on the decline in quality of life that his mother had over the past year in attempt to assist P in accepting this final chapter in her life. P was able in the moment to accept that his mother was dying but would quickly revert to concerns that the medical team was "killing" her.

Throughout the course of working with P, I learned that it was most difficult for him to accept his mother's pending death while he sat at her bedside. Therefore, P and I would take walks off the floor for a change of scenery. On some occasions, we walked outside around the hospital campus. Where this was also his home neighborhood, the outdoors seemed to help place him more at ease. It was during these discussions that I could obtain a glimpse into his baseline personality. He could joke and share various stories of his own personal life. But most importantly, he could talk about the future of his life once his mother was no longer in it. I viewed this as significant because it demonstrated to me that on some level P was able to understand not only that his mother was dying, but that his life could and would continue amidst this tremendous void.

Mrs. H was eventually transferred to a Hospice House where she passed away the following day. I kept in close contact with P during the initial days following his mother's death. P was able to choose a funeral home which was no easy feat. Approximately 3 weeks later, I received a call from both P and R. They were on the phone with one another and took a chance in trying to conference call me into their discussion. I was informed they were calling because Mrs. H's body was still at the funeral home and P was struggling with the decision of whether to conduct an autopsy. They informed me that the decision to call me was because P valued the

impression of both R and I greatly and would therefore appreciate my involvement in one of the final decisions he would need to make regarding his mother. I expressed how honored I was by his kind words. Together, we were able to explore P's "pro's and con's" around conducting an autopsy. The most distinguishable "con" was the idea of subjecting his mother to any further invasive testing. We were eventually able to guide P to share that although he does not expect an autopsy to reveal anything significant, he needed to have this verified as a sense of closure for him. He expressed that he would continue to feel unsettled if he did not opt for an autopsy. Both R and I recognized that what P needed from us, was to lift the burden of guilt he was feeling that the autopsy was for the purposes of his own needs vs. that of his mother's. R and I were able to support P's decision to proceed with the autopsy. P endorsed immediate relief when R and I confirmed the decision to move forward with this. The conversation continued for a while longer and by the conclusion, P appeared to sound more confident and prepared to move forward with the next steps. He also spoke of plans to write a detailed obituary for his mother highlighting the many accomplishments he had shared during the life review with me.

This case is a classic example of the work hospital social workers do every day. We patiently listen, support and guide. This case was especially meaningful for me because it highlights the profound impact we can have at the most difficult of times under the most challenging of circumstances. This case challenged me to draw on my skill sets by utilizing several interventions to help support a struggling family member through a most devastating time in a most patient focused manner.

SAMPLE QUESTIONS:

Clinician/Patient Relationship:

1. Can you give an example of a case that didn't go well?

Clinical Knowledge & Decision Making

1. With Mrs. H's son P, did you ever explore him getting his own treatment?
How far does your role extend to supporting him?

Teamwork & Collaboration:

1. What do you consider your influence on practice?