



Case Study

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Advocating for a Diagnosis

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Encounters: Advocating for a Diagnosis

From the day that we embark on this professional journey, we are taught to strive towards upholding the CanMEDS roles. The CanMEDS framework outlines 7 core roles of a competent physician, one of which is health advocate. In my pre-clerkship years, I recall hearing in numerous lectures about how to effect change for our patients and communities. I had often perceived advocacy efforts to be synonymous with intensive endeavors that direct change at a community or population level. However, it was not until I reached clerkship that I began to appreciate the dynamic integration of these core roles in clinical practice at different scales.

The Royal College describes health advocates as those who “contribute their expertise and influence as they work with communities or patient populations to improve health...to access appropriate resources in a timely manner... increase awareness... and support or lead the mobilization of resources on small or large scales” [1]. While the small scale for clinicians could be 1 patient interaction among the several dozen over the course of a month, for that 1 patient that small scale is in fact their entire world.

After 4 weeks on my General Internal Medicine (GIM) clerkship, there was 1 patient’s story that stood out among the rest, and her case had perplexed the team. DB, a previously independent 60-year-old female had been admitted under our service for close to 3 weeks. She lived just outside the city with her partner, loved to read and spend time with her grandkids. Initially, she was admitted for a new diagnosis of severe Ulcerative Colitis (UC). After a course of high dose steroids and receiving her first dose of biologic treatment, her symptoms had drastically improved. She was started on a prednisone taper and on day 9 of admission was close to being discharged from hospital. However, on day 10, she developed new, excruciating painful unilateral leg erythema and later wounds that began as hemorrhagic bullae. Unfortunately, as these new

leg wounds evolved and developed, she began to progressively deteriorate in terms of her physical conditioning and emotional wellbeing. She became completely bedbound due to the intense pain, no longer able to walk or toilet herself. Numerous investigations had been ordered, including ultrasound, CT, microbiology to help elucidate the diagnosis. A course of antibiotics was initiated for presumed cellulitis... to no avail. In the background, there were daily adjustments to the analgesic regimen to meet the patient’s increasing need for relief. While her markers of inflammation and white blood cells remained stable, the patient’s clinical picture told another story altogether. One of my undergraduate lecturers would always say “treat the patient, not the number.” Every day, I walked into that room, I felt a sense of helplessness, simply because I could not provide an answer as to the cause of the patient’s condition, and the agonizing pain she felt despite the bullae on her leg which appeared to be resolving. An answer, an explanation. The uncertainty seemed to compound her distress, as it likely would for anyone in that situation. This had taken its toll on her entire sense of wellbeing, it limited her appetite, energy and negatively affected her mood and outlook on her future. Thus, the diagnostic dilemma continued. In parallel, Infectious Diseases was consulted for this “non-resolving” cellulitis. A telephone consult ended with the conclusion that there was no active infection and therefore, no need for ongoing antibiotic treatment. Still, no explanation. Until pyoderma gangrenosum was put forward as a possibility. It was, after all, strongly associated with inflammatory bowel disease.

Day 25 of Admission

Dermatology was consulted and a workup was initiated, including biopsies. Notably, DB’s case was not reviewed at the bedside with staff. As the days passed, the patient grew increasingly anxious, as did our team as we too waited for answers. As expected, the eventual histopathologic diagnosis of neutrophilic dermatosis



was broad and left room for clinical interpretation. It begged the question, was this PG after all? Based on one set of diagnostic criteria, the initial consultant reported this was not truly in keeping with PG – she did not meet enough of the criteria. Pancreatic panniculitis? Another differential that was felt to be more favoured by the consultant, based on a nominally elevated lipase at 111 (U/L) (REF range <80 U/L)

Yet, there were no indicators of pancreatitis in this case... with the patient still in constant pain with little in the way of improvement and a foreseeable course in hospital, my preceptor was not satisfied with that response. DB was still bedbound, deconditioning, and conveyed that unfortunately, she was losing faith in the medical team. Again, the possibility of PG hung in the air. After all, our team noted the temporal association of the onset of lesions with the patient's steroid taper for her UC.

Day 32 of Admission

Our team continued to search for a diagnosis. After careful review of investigations and the clinical course, Dermatology was re-consulted for a second opinion with a firm request for in-person bedside assessment and follow-up communication with the primary team. The case was reviewed at the bedside by a new Dermatology staff and there was a real-time discussion between consultant and primary team to determine the best course of action. This time, PG was more strongly favoured. Consequently, high dose steroids were re-initiated as first-line treatment for PG. GI was involved to discuss re-initiating her biologic treatment, another treatment option for PG, which had previously been held amid concerns of infectious causes. A couple of days later, while seemingly miniscule changes, she expressed slight improvement in her pain and the wounds continued to evolve with meticulous wound care. This fortified a path towards recovery. She was noticeably in brighter spirits which, after many weeks of juggling uncertainty, was a welcome sign of progress. Soon after, DB was transferred to another internal medicine team. As I was approaching the end of my 8 week rotation, I dropped by to check on her progress.

As I entered, she warmly greeted me with a smile that lit up the room. She eagerly told me about the progress she had made in her mobility. Her appetite was improving, and she was finally able to enjoy her favorite home-made dishes. While she would likely need extensive rehabilitation after weeks of deconditioning, the small gains she made meant she was a step closer to her ultimate goal - returning home to her family. For that, she expressed her gratitude. At the time of this writing she was still in hospital (day

74), is receiving ongoing treatment with immunosuppressants, and is making progressive gains with the physical rehabilitation team

Being a health advocate can take many forms and to different degrees - this experience shed light on the complexities of patient advocacy on a small scale that expanded across multiple specialities and disciplines. In addition, it emphasized the irreplaceable value of bedside assessment. In our post-COVID world, virtual and telecommunication in the health sphere has skyrocketed. While it serves a place in medicine, some aspects of the patient's clinical status may be overlooked or altogether missed. Each day on rounds, our team and my staff bore witness to DB's pain, and the physical and emotional suffering. Just as outlined by the CanMEDS framework, resources were mobilized to facilitate a diagnosis and identify a course of treatment. This also involved reconsulting the dermatology team to review the case again in the context of a high degree of suspicion. When one avenue seemed to yield few answers, another was pursued, especially as things evolved. I would justify that any individual with the loved one in a similar situation would hope for the same.

So What is Advocacy?

As I move forward in my training, I have been fortunate to have this modeled by my staff in this instance. It means taking a stand for our patients, as we truly are the patient's voice at the interface of access to consultants and medical services. Not only does it shape patient care, but it also fosters trust in the patient-physician relationship and can change the trajectory of their illness experience. For me, this story is a distinct reminder of what advocacy can truly mean.

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Conflicts of Interest

None.

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None.

References

1. The Royal College of Physicians and Surgeons of Canada (2015) Health Advocate. Ottawa (CA): The Royal College of Physicians and Surgeons of Canada.