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SUMMARY

Effective continuity of care (CoC) for patients requires a coordinated and collaborative approach. But when the principles of CoC are not followed, the results can be traumatic for patients and families. In this clinical insight, the author shares a personal story of CoC gone awry.

Key Words

Continuity of care, advanced care directive, patient experience

INTRODUCTION

The World Health Organization (WHO) found that in order for continuity of care (CofC) to work in practice, entities involved must share values that are conducive to a coordinated and collaborative approach to patient care.¹ Common themes evident in effective CofC are a personal relationship between patients and care providers plus communication and cooperation between care providers.² CofC should bring together fragmented healthcare systems to deliver better care and thus improved health outcomes.^{3,4}

In essence, best practice CofC is about collective management of patient care in a supportive, collegiate environment, without ego or individual ownership, that aims to deliver appropriate and effective patient care. It should also allow patients the opportunity to make informed choices about their own health care.

SUMMARY

My brother, aged 56 years, has complex healthcare needs. In mid-2019, he was admitted to a public hospital intensive care unit (ICU) following eight episodes of hypotensive shock and hepatic encephalopathy within a six-week period. Physicians thought the continued rupturing of intestinal varies from long-term chronic liver disease was due to complications from insulin-dependent diabetes, which he has had since childhood. He remained in the ICU for 22 weeks after which time we were told he was expected to pass away in the next few hours. He had a do-not-resuscitate order (DNR) and an advanced care directive, and the time had come to support his wishes of no further medical intervention given the many years he had bravely fought the intense pain and disability associated with his medical status. In his words “He had had enough”. Imagine our surprise the next morning to find him awake and functioning but in extreme pain. The ICU staff called it a miracle and were congratulating themselves on their care. Our family was stunned. Not only did he not get the dignified passing he wanted after many years of incessant

pain, someone had intervened medically and “brought him back to life”. I was furious. What right did that person have to override my brother’s decision that had been so hard for him to make. I looked at him lying in his hospital bed. His eyes said it all. He now knew what lay ahead. He was no longer his old confident self. He was frightened.

He was once again on the medical treadmill. Still in hospital, with multiple healthcare professionals (n=9) representing the following specialities: endocrinology, gastroenterology, cardiology, nephrology, critical care, and palliative care. All very vying to “cure him” or at least solve his problem and get him out of the hospital. Sounds great in principle—a clinical team coming up with a cooperative care directive to manage my brother’s health care and get him home. Our family had one simple request at a face-to-face meeting with all the specialists involved. Please assign one clinical lead that all treatment is approved through, which is the essence of continuity of care. A clinical lead was duly assigned, all records were duly noted, and all clinicians were on board. Notably, within two hours, a consulting team altered my brother’s advanced care directive without further collaboration with all the teams involved or discussion with the clinical lead overseeing my brother’s care. Unfortunately, this was not an isolated case.^{5,6} This is a typical example. One morning one specialist changed my brother’s medication regime without consulting the team. That same afternoon, his medication had again been changed by another specialist, again without consultation. By that evening he was once again critical. Our family met with the clinical lead who was very apologetic and assured us this would not happen again. Within 24 hours, one clinician had talked my brother into an experimental treatment—a transjugular intrahepatic portosystemic shunt—that was going to “solve all his problems”, while two hours later another clinician told him that the procedure had many complications and a very low success rate, therefore, he should not have the operation and should consider palliative care.

It is now 2020 and after seven months in hospital, my brother has been home for several months. He has had five very painful procedures since leaving hospital, he attends outpatient services at least three times per week, and he has haemodialysis via an arteriovenous fistula three times per week. The last experimental treatment he had was partially successful but requires monthly revisions. In essence, he has become an old man at 56 years of age. He is no longer the joker who can see something positive in every situation and is less confident in his own council. He has been well informed about future prospects in the coming year or two. However, he no longer has an individualised, integrated care plan that provides continuity of care, yet he is still under the medical care of the individual specialist teams who collaborated on his advanced care directive while in hospital.

LESSONS LEARNED

The irony of this situation is that I work in continuity of care in primary health care and understand well the complexities associated with its implementation in practice. This experience has highlighted to me that the theory of CofC does not always match practice in large public hospitals. It does not mean that individual health professionals are not committed to providing the best care to their patients. In fact, I think the opposite is true. However, in our experience, many changes were made to shared care plans by individual clinicians without consultation with the clinical lead, other team members, the family, or the patient. These changes resulted in a

near-fatal episode and poorer health outcomes for the patient. This experience has also taught me that having a patient advocate is not enough, particularly if the patients are unable to, or have trouble, making their own decisions. My brother had a family member with him at least 6 hours of every day he was hospital with at least two people contactable 24 hours a day, yet changes were made to his care without due process or adherence to his advanced care directive.

CofC has been linked to improved patient outcomes, increased adherence to treatment, and more effective use of health resources; however, its implementation requires a fundamental change in culture and practice. Perhaps it needs to be incentivised or systems need to change to better support shared care initiatives. We won't always get it right, but we need to strive to do better.

CLINICIAN INSIGHT

Our healthcare system is not perfect. Each specialist team aims to put the patient first and strives to provide the most beneficial outcome possible, whether this be for a minor surgery or an end-of-life discussion. However, the current system is designed to have consultations by numerous experts in their field to assist in the decision-making of a patient, often taking place without the home team present. Information—be it medical or patient wishes—can be missed or poorly communicated to each unit, thereby leading to incorrect advice being provided.

The author has experienced firsthand an example of poor communication between individualised treating teams and family wishes. This is inexcusable and an area of medicine all members need to improve on. Patients not only desire the best medical knowledge, they strive to be listened to, communicated with, and expect a collaborative approach on their medical options. Multidisciplinary meetings and other collaborative information sharing methods are assisting with these communication barriers, however, the day-to-day ward round still requires improvements on effective communication between teams.

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