

## Fragmentation of Care: A Case for Care Coordination — Dr Mariana G Hewson

Mariana G Hewson PhD,  
Associate Researcher  
Dept of Medicine and Paediatrics  
Clinical Sciences Center  
600 Highland Avenue  
Madison Wisconsin 53792, USA

### Curriculum vitae

Dr Mariana Hewson is a medical educator in the departments of medicine and pediatrics at the University Hospital and Clinics, University of Wisconsin, Madison, USA. She has a PhD in education from the University of the Witwatersrand. For the past six years she has specialized in hospital-based, clinical medical education. She is particularly involved in helping clinical teachers become better educators of residents, medical students, and patients.

### Summary

*With increased medical knowledge and skills, complex medical histories are more common than ever before. With the increase of such patients there is also an increased need for medical care to be coordinated. Care coordination is commonly thought of as the role of the primary care doctor, yet there are occasions when this may not be easy or possible. At these times, other care givers (ranging from medical specialists to allied health care providers) who are involved with a patient, may need to take on this role. The family (or sometimes friends) of patients with complex, medical conditions need to act as advocates for their loved ones by ensuring that care is adequately coordinated in order to prevent fragmentation resulting in unnecessary complications; or even death!*

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### KEYWORDS:

Patient Care Team; Patient Advocacy; Physician, family; Consultation; Interprofessional Relations.

In complex, medical histories, communications can break down, leading to confusion and delayed medical intervention. The large number of personnel involved in a complicated history, and the maintenance of the history over a long period of time, tend to confuse any situation. I will describe the case of my mother, a patient scheduled for heart surgery. The question arising from this patient concerns the need for care givers to coordinate the facts of particularly complex patients prior

to medical decisions being made, and the role of family members to advocate for the patient, and ensure that this is done where needed.

The patient, a 74-year-old woman living in South Africa, was diagnosed as having aortic valve disease. She had a complex medical history and had been extensively examined. For approximately 10 years she had suffered from intermittent fevers and night sweats for which no cause had been found. Her history also revealed that she had been diagnosed as having malaria about 15 years previously, but no organism had been identified. Over the last two years she had gradually become short of breath and needed to rest after mild effort, and had recently been in pulmonary oedema. The current findings were that her sedimentation rate remained elevated, she had a positive antinuclear factor, hepatomegaly, and a liver biopsy showed lymphocytic infiltrate, the implications of which remained unclear. On the basis of these findings, a collagen vascular disorder had recently been diagnosed, and she had been on steroids for two months. Furthermore, she had a recent gastrointestinal bleed for which no cause was found. She had a small abdominal aortic aneurysm, possible bronchiectasis, and an intermittent productive cough requiring antibiotics.

The cardiology report recommended aortic valve replacement and a graft into the right coronary artery and circumflex. But until some of the above-mentioned complicating factors could be better understood, this surgery had been delayed. The patient had been admitted to three different hospitals during the most recent investigative phase, and had been in two others in the recent past.

## ... Fragmentation of Care

She had recently been seen by six different medical doctors: her primary care doctor, two specialist physicians, a gastrointestinal specialist, a cardiologist, and the cardiac surgeon.

Two of the patient's adult children had lived with their mother's illnesses for so long that they had become dulled to the urgency of the situation. The complexity of the history, the many physicians involved, and the frequent postponements of surgery caused them to feel overwhelmed. I live in the United States, and decided to make an urgent visit to South Africa. From my experiences as a medical educator, I recognized that the complexity of this patient could make it difficult for the surgeon to take action, and that he might be unlikely to proceed, jeopardizing the chances for survival for my mother. It could become one of those cases that "fall through the cracks."

Upon arrival in South Africa, I tried to establish the history of my mother's current illness, her prognosis, and the proposed treatment plan. She was now

Long illness, many physicians, and frequent postponements of surgery made the family feel overwhelmed

hospitalized in a city about 200 kilometres from her home village. Having been in various hospitals for three or four weeks, she was upset, somewhat disoriented, and confused. The repeated questioning about her extensive medical history led to less than accurate accounts, yet the

cardiologists and cardiac surgeon seemed to be relying on *her* to give them chronologies of past illnesses and drug treatments. Her medical records from earlier unrelated surgery (a hip replacement), and hospital investigations of the unidentified fevers had not been assembled. At this point, the cardiologist who recommended the aortic valve replacement and graft

Specialists relied on a rather confused, ill patient to give them chronologies of past illnesses and drug treatment

into the right artery and circumflex, went on holiday, turning her care over to the cardiac surgeon. He, however, was not prepared to operate on a patient with apparently serious, compromising medical problems. He told the family that if they wanted the operation, they would need to find another surgeon. The family was, at this point, becoming convinced of the futility of surgery. It was clear that a stalemate had developed.

Because the primary care doctor was far away, and had not been providing recent care for my mother, I urged the cardiac surgeon to have her medical records assembled from all the different hospitals and clinics, to communicate with all physicians involved with her over the previous ten to fifteen years, and then to meet with family members. This he graciously consented to do.

The family met with the surgeon, who arrived with a daunting pile of medical records. He carefully went through the data, explaining their

relevance and implications. The family asked questions about the past and present history of the various medical problems, the fevers, the gastrointestinal bleed, the effect of cortisone treatment on post-operative recuperation and so on. They asked what the risks of the operation were, compared with the prognosis if no surgery was attempted. The surgeon's answer was: "Six months without the operation and about 80% success rate with the operation." He also enquired about their views on proceeding with the surgery. The collection of all the records, the conferences with other physicians (including one who had been involved with the patient ten years previously), and the act of explaining to the family apparently clarified the situation for him. For example, it became clear that the unidentified fever had not had an adverse effect on the earlier hip replacement procedure. At the end of the meeting, it was mutually decided to proceed with surgery. The eight-

A concerned family member can also initiate care coordination

hour operation was conducted successfully, and within two weeks the patient was home without complications.

My role in this case was to advocate for my mother through insisting on the assembling of all past medical records, and contacting the past care givers. For a brief, but crucial time I promoted care coordination through my need to know what was happening, and why. In this case, the cardiac surgeon was the person who

## ... Fragmentation of Care

coordinated the care (a role to which he admitted he was unaccustomed).

A care coordinator is a care giver who is able to communicate effectively, and help compile and coordinate relevant information in complex medical histories.<sup>1</sup> Communication skills include being able to talk with other health care professionals (primary care doctors, specialists, nurses and allied health care providers), administrators, insurance representatives, and, most importantly, the patient and family members. He or she must have medical training to understand a diagnosis, and to explore medical options, encourage and empower families or patients to make independent decisions (self advocacy),

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### Care coordination is normally the task of the GP

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have the capacity to look at situations objectively, and be vigilant regarding standards and procedures for quality assurance. Not all patients need a care coordinator, but those that are particularly complex, involving multiple care givers and a lengthy history of illness, need a person in this role.

While care coordination would normally be the responsibility of the primary care doctor, this task can also be accomplished by other care givers involved with the patient (nurses, social workers, physiotherapists etc). In the history described here, a family member persuaded a specialist to serve as a care coordinator in a case involving a complex medical history, multiple care givers, and a primary

care doctor in a distant village. The patient's primary care doctor could have coordinated the care, but he did not have all her medical records, and was not closely involved with her recent medical developments. In this case, a family member facilitated a process in which a specialist surgeon became clear in his own thinking about a particularly complex situation through coordinating the lengthy medical history of the patient, and ensured that the patient did not fall through the cracks.

### References

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