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# Adherence Training Key to Improved Coordination of Care, Use of Specialty Drugs

By Joel Zive, BS, PharmD, Adjunct Clinical Faculty at the University of Florida College of Pharmacy | October 1, 2013

I have been fortunate enough in my career to do humanitarian work in East Africa, and I have witnessed incredible health care service performed despite a paucity of resources. Conversely, one of the many health care tragedies in that part of the world is the downward therapeutic outcome spiral due to unattended simple maladies. An untreated toe could turn into a raging skin infection or worse. A simple break of a person's leg improperly set could leave that person crippled for life.

In the United States, we have a different set of complex issues affecting our health care system. But there is a beacon of hope with some of the most vexing health care issues:  specialty drugs. Yes, they have annual costs that approach the length of phone numbers, but research and development costs must be taken into consideration.

Yet when one evaluates the pain and suffering these compounds alleviate – sometimes also saving money for our health care system in the areas of solid organ transplant rejection, HIV, Multiple Sclerosis and Cancer for example – real value emerges.

Despite their high expense, there are organizations, including the HealthWell Foundation, that help patients pay for access to these medications. And do not forget social workers, case managers and an army of master insurance billers in doctor's offices and pharmacies across the country.

Yet these drugs carry with them a promise and a peril: A promise if their regimens, with high pill burden, are adhered to and the side-effects are understood. And a peril to the patient and unnecessary high cost to our health care system.

What person who deals in specialty drugs has not been brought to the brink of tears due to the frustration of non-adherence? Of a transplant patient who never told their pharmacist or transplant coordinator that he stopped taking their immunosuppressive medications and lost their transplanted organ? The efforts of the pharmacists, nurses, prescribers, surgeons, transplant coordinators, social workers that were wasted along with precious time and money are horrifying.

On the other hand, you have a patient newly transplanted or newly diagnosed with a complex disease. Frightened, scared — even angry — wondering whether they can afford medications to stave off dialysis or stay alive. In my career, I have seen first-hand examples of turnarounds in patients' attitudes and quality of life due to these medications and adherence training:

- A kidney transplant patient who was on dialysis for years who saw other patients go into dialysis walking, then in a wheelchair, then on a gurney before expiring.
- Another patient at the dialysis center who announced one day, "I give up." This individual had sufficient motivation but still needed guidance and assurance he would get his medications in a timely manner. Now, this person is rebuilding a life for himself and his family.
- A woman tired, frail and scared lying in a hospital bed post-transplant wondering how she will live the rest of her life. With encouragement and adherence training she is now flying cross-country to see her relatives.
- Another patient was diagnosed with relapsing remitting Multiple Sclerosis in the prime of his life. Yes, he had difficulty dealing with his insurance company and their specialty pharmacy. But he had help and encouragement from an outside specialty pharmacy. And with patience and persistence from others he is now in graduate school.

What do these examples underscore? That although the United States enjoys an abundance of health care resources compared to Africa, what we're missing is the coordination of care. Sometimes this is due to the health care system and sometimes this is because of the patient.

There are a couple of strategies providers can employ to improve this situation:

- This scenario I saw first-hand in Rwanda. If a pharmacist senses there is something not right mentally with the patient, he can contact a social worker in the clinic for further workup.

- Another approach includes an agreement among the multidisciplinary team about what the adherence goals should be. If the goals seem to be remiss, then the pharmacist could be notified, and he could handle the issue or direct it to the appropriate provider.

In both cases, there is feedback among the health care team. In the area of specialty drugs, adherence training can fill and highlight these gaps to the patient's benefit. As my colleagues in East Africa have told me, "We admire your health care system."

We have many issues to be worked out and negotiated in the weeks, months and years ahead. But let's use adherence training to give my colleagues overseas something they can aspire toward and emulate.

What other strategies can providers employ to improve coordination of care? How can hospitals, government and health care industry stakeholders coordinate to become part of the solution when it comes to more effective adherence training?

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