Missing the Boat?

by Mark Nelson
You would have to be a yak shepherd in Nepal or a roadie for the Grateful Dead to have not heard of consumer and patient engagement. Employers, insurers and health plan sponsors across the U.S. are constantly implementing programs designed to help people become clinical participants in order to take control of their health in the effort to reduce claim costs. The Safeway, Kaiser Permanente and Aetna stories are well known.

Similarly, hospital systems and physicians are always striving to enlist the patient as an engaged, or activated, member of his/her care team, rather than being a passive bystander, in order to improve the efficacy and cost effectiveness of the care provided. Mayo, Geisinger and Cleveland Clinic all have documented successes, to name just three.

A frequently quoted 2012 article in *Forbes Magazine* suggested that “Patient Engagement Is the Blockbuster Drug of the Century,” and 2013 was believed to be “The Year of Patient Engagement” according to some in the health care IT professional association, HIMSS.

The problem is, a lot of individuals still don’t seem to care. The National Institutes of Health has estimated that that 90% of Americans “may have problems with health literacy,” and that the average annual expense of a health illiterate person can be four times greater than that of a health literate person.

It is also estimated that $1 trillion of the U.S. $2.8 trillion in annual health care expenditures may be due to a lack of knowledge or responsibility on the part of the individual. The American Heart Association, as an example, has concluded that non-compliance with post-discharge care directives and medications cause 40% of hospital readmissions.

At the same time, medical science has continued to develop a financially crushing tsunami of new drugs, technologies and therapies that have made the last 50 years one of the most exciting periods in the history of medicine. Unfortunately, “excitement” is not a desired result of insurance industry underwriting and, as a result, payers don’t always view medical advancements with the same enthusiasm as providers.

The good news is positive clinical outcomes often translate into positive financial outcomes, which is a goal upon which both can agree.

**Why Examine Transplant Patient Engagement?**

Organ and bone marrow transplants continue to be leading edge, life-saving surgical procedures that still get a lot of attention - primarily because over half of all transplants cost $300,000 or more. But it is also interesting to note that transplant patient engagement could be one of the more highly evolved forms of patient participation models in use today and, as such, can serve as a reference point for payers and providers in assessing their own engagement efforts.

Why? A medical center really has to rely on the patient to be the caretaker and steward of the transplanted organ following discharge from the hospital, so there is a heightened urgency for patient literacy and compliance that may not be as well-established in other clinical disciplines.

Overall it’s a compelling engagement model to study because:

- Transplant candidates and recipients are a fairly engaged bunch - typically aware of their health issues, usually receptive to learning about transplant protocols, generally supported by family members and understandably focused on achieving the best possible clinical outcomes.
- They are also an easily defined group (you either had a transplant or you didn’t), and a statistically valid yet manageable sample size (about 48,000 each year when organ and HCT procedures are combined) with self-contained, accessible outcome data.
- And lastly, transplant nurse coordinators are a good source of information regarding patient attributes. They are often personally familiar with their patients and are tracking dozens of them at any given time, maybe hundreds over several years. In many cases a medical center will monitor a transplant patient for life.

**National Patient Engagement Survey**

To get a sense of current U.S. transplant patient activation strategies and the degree to which they might affect clinical outcomes a qualitative survey was conducted in 2013-2014 with the participation of 18 leading transplant centers representing 58 transplant programs that perform over 10,000 procedures a year.

The survey was simple: 20 questions...
1. In terms of basic transplant patient attributes the coordinators reported that:

- 25% of transplant patients have below average awareness of their underlying health issues, and
- 10% are not receptive to patient education.\(^5\)

2. Regarding patient compliance with post-discharge instructions and medications:

- 18% of transplant patients exhibit “low compliance,”\(^6\) and
- On average, 61% of post-discharge complications are believed to be caused primarily by patient non-compliance with either their medications or other discharge instructions. (Fig. 1) Three centers indicated that over 90% of post-discharge complications are believed to be caused primarily by patient non-compliance.

To be clear, many different factors can contribute to organ rejection episodes, infections or other complications. Some can be very expensive.\(^1\) Determining how often patient non-compliance may have been the primary factor giving rise to a complication was the focus here.

3. With respect to the degree of correlation that might exist between transplant patient engagement and clinical outcomes (Fig. 2), while trying to modestly account for case severity,\(^1\) the nurse coordinators reported that:

- Patient non-compliance with MEDICATIONS?: 38\% (3 centers > 60\%)
- Patient non-compliance with discharge instructions OTHER than medications?: 23\% (4 centers > 40\%)
- Factors unrelated to compliance: 39\%
Payers and providers have launched countless health, wellness and disease management programs in recent years designed to get people more involved in managing their own health to help reduce utilization and costs.

High compliance transplant patients
• 78% of the high compliance patients with good underlying health and a positive transplant procedure had above average clinical outcomes.
• 62% of such patients with poor underlying health and a complicated transplant had above average clinical outcomes.

Low compliance transplant patients
• 41% of the low compliance patients with good underlying health and a positive transplant procedure had above average clinical outcomes.
• 11% of such patients with poor underlying health and a complicated transplant had above average clinical outcomes.

Note: Academic researchers who use p-values and standard deviations should look into this.

4. The most effective patient engagement strategies cited were:
   • Requiring a caregiver (close family or friend) to work with the patient long term
   • Providing constant RN education for patient and his/her support team
   • Facilitating patient access to his/her EMR and providers
   • Coordinating with patient’s primary care physician, a key to long term compliance

5. In terms of the communication tools used to educate and engage transplant patients there was – curiously – a heavy reliance on printed text, which can be problematic for non-English speaking patients and their families. Additional tools included:
   • Anatomical graphics/visuals (44% of the surveyed transplant centers)
   • Narrated videos with graphics (40% of the centers)
   • Online tutorials/access to health library (29% of the centers)
   • Virtual education classes online (1 center)
   • 3D animated videos of the procedure (None)

The types of eHealth (electronic health) technologies being deployed are:
• Patient access to transplant information on center’s website (81% of the surveyed transplant centers)
• Patient access to their electronic medical record, e.g., MyChart (35% of the centers)
• Transplant educational videos on center’s website (27% of the centers)
• Patient access to their PHR personal health record (1 center)
• None of the above (3 centers)
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Only 39% of transplant patients were estimated to have used the eHealth tools offered by the medical center.

Regarding mHealth (mobile health) technologies being used:

• iPad/smart-phone educational programs (4 of the surveyed centers)
• Social media (1 center)
• Mobile access to patient’s own electronic medical record (1 center)
• None of the above (72% of the centers)
• Text messaging for patient communication (None)

So, apparently, nearly three quarters of the leading U.S. transplant centers do not have a mobile patient engagement strategy and none appear to be using text messaging.

6. Strategies and tools that the nurse coordinators felt could improve transplant patient activation at their center included:

• More patient internet access for online education
• Utilization of mobile apps
• Mobile phone text reminders for appointments and medications
• Improved transplant website coordination with outreach programs
• Using interpreters more effectively
• Establish a patient care contract or covenant to ensure patient compliance with post-transplant instructions

The National Perspective: Why Payers and Providers Have a Vested Interest in Transplant (and Specialty Care) Patient Engagement

The reality for most transplant centers is that transplantation is a mature market. Limited organ availability continues to be an issue.

In fact, the annual number of organ transplants has been flat for over a decade and 1-year to 5-year survival rates (the primary metrics of success or quality) have remained basically unchanged during the same time period. (Fig. 3 and Fig. 4)

It is, therefore, difficult for providers to deliver growth or value without further advancements in organ donation and immunosuppressant technology. Most transplant centers of excellence have essentially achieved “excellence” as defined within the current context. One of the few remaining cost / quality improvement strategies for transplant providers is to increase patient compliance and commitment to post-discharge success.

But many individuals, either by indifference or choice, privacy concerns or lack of self-confidence are still not on board, so it is sometimes difficult to assess the progress of such initiatives.

From the insurer perspective, transplant costs continue to rise. In terms of catastrophic claim experience (say, excess of $50,000 any one member in a contract year) the aggregated costs might represent 15% of a reinsurer’s overall loss history. Benefit design and the Affordable Care Act suggest that organ transplantation will be a significant ongoing claim exposure for the foreseeable future.

At the same time, most of the available contractual savings and the cost-efficiencies of RN case management are already represented in current transplant financial patterns. In terms of claims cost containment the one addressable area where ROI gains could still be made is patient activation that results in
better survival rates, fewer hospital readmissions and fewer re-transplants.\textsuperscript{18}

When it comes to insuring transplants and similar high cost medical treatments — in a broader, industrywide sense — favorable loss ratios may become increasingly dependent upon improved clinical outcomes vs. traditional underwriting strategies.

Takeaways: Perseverance, Precision Engagement and Privacy

A number of studies have examined the extent to which a patient's specific health risk factors and socioeconomic status can influence clinical outcomes.\textsuperscript{19} Their findings would obviously be helpful for this analysis of transplant patient engagement, but such a comprehensive discussion cannot be included here.

The transplant survey responses, although limited, from front line clinicians with considerable personal knowledge about a large, well-defined patient group with an evolved history of activation can, however, offer the following:

1. Problem Parameters
   - Non-compliance with medications and care directives cause roughly half of all complications and unnecessary readmissions to the hospital. The associated costs for even one individual can run into the hundreds of thousands of dollars.
   - High compliance patients might be two to six times more likely to experience above average clinical outcomes than low compliance patients with similar health profiles.
   - Conservatively speaking, about 25% of the population is not aware of the extent of their health issues.
   - Approximately 10% to 30% of the population is either “not receptive” to health education or compliant with medications and care directives. Medication side effects, depression and factors other than patient reticence may play a role in these responses.

2. Perseverance and Privacy
   - A caregiver/partner is key for establishing an individual’s long term compliance with care directives. Ideally, it would be a close, trusted friend or family member who is by definition supportive but who also implicitly represents privacy. (One might compare this to the AA “anonymous” model of individual sponsorship: one-on-one support for a frequently addressed life-long health condition that is carried out with unwavering respect for the individual’s privacy.)
   - Coordination with an individual’s primary care physician is also key for maintaining an individual’s ongoing engagement and compliance, again operating within the confidentiality of the patient-doctor relationship as an extension of the patient’s care team confidentiality at the transplant center.
   - Frequent follow ups, monitoring and ongoing education for the individual and his/her caregiver(s)

One highly visible patient group that can provide some insight into engagement strategies and their effectiveness is transplant recipients.

A recent national survey of 18 leading transplant centers demonstrates how.
are core components of effective engagement. There is a rededication to clinical goals that transplant patients, like many people managing chronic conditions, find useful for maintaining their personal commitment.

3. Precision Engagement
   • Technology, when appropriate, can be a cost effective engagement tool customized for each individual’s needs and delivered through a personal handheld device. (The 2013 HIMSS-commissioned book Engage: Transforming Healthcare Through Digital Patient Engagement leads the discussion in this regard.) Mobile diabetes management apps, online weight loss programs, WebMD symptom checking and remote heart monitoring technologies, for example, are achieving wider acceptance. Within the transplant field, unfortunately, certain technologies are probably not being used to their full advantage, but the discipline of addressing the specific needs of each patient has been honed by years of experience.
   • Language barriers can be an impediment to the communication needed for achieving effective engagement. Translation services obviously personalize the entire experience. (These barriers, however, can also pertain to knowing how to talk to insured members and consumers so the message does not come across as invasive or contains cumbersome clinical terminology.)

Observations
As it has often been pointed out, we are witnessing a major shift in health culture. Hundreds of health care start-ups, major hospital systems, integrated payer-provider networks, health industry associations, Federal Government agencies, venture funds, national and regional payers, managed care companies, telecommunication companies, app developers, IT vendors and health care consulting firms are all getting involved.

The engagement movement encompasses chronic health conditions, critical care, remote monitoring, electronic medical records, CDHPs, the quantified self, disease management programs, population health, CMS provider Meaningful Use requirements, patient and member website portals, dietary and nutritional sciences, patient relationship management, fitness and exercise, IT software development, accountable care organizations and telemedicine. It has generated thousands of health apps and websites plus an endless stream of industry analysis, white papers, academic
research, public policy debate, digital health strategy blogs and articles like this one. Moreover, it’s all interrelated and there’s a lot of cross-talk, so trying to cover the waterfront can be a challenging.

Maybe that’s part of the problem: engagement doesn’t speak with one voice.

Consumer apathy notwithstanding, if “advanced payers,” possibly with synced-up providers, can execute precision engagement strategies focused on the individual as an informed, active clinical participant while maintaining his/her privacy — similar to the strategies developed by transplant centers over the years — a dose of personally meaningful clarity and responsibility can be added to the claims cost equation.

For now, the widespread adoption of engagement principles and practice by consumers and patients might best be described as uneven, sometimes elusive. Payers and providers may need to constantly heed the advice that Jonathan Winters once offered when he said, “If your ship doesn’t come in, swim out it.”

Mark Nelson, MA, MBA, is managing partner of LOOK Alliance, LLC in Minneapolis, MN and Medical Avatar, LLC in New York, NY, specializing in best-practice precision engagement strategies for payers and providers seeking improved financial and clinical outcomes. He was previously an officer/AVP with Allianz Life Insurance Company, founded the LifeTrac Transplant Network and Protocol Networks. m.nelson@lookalliance.com

References
2“Engagement” in some contexts refers to initiatives like CDHPs and member/patient website portals. In this context it usually refers to the process of establishing the individual as an active clinical participant vs. an administrative participant and co-insurer.
4American Heart Association research and OptumRx study, May 2012.
5Protocol Networks and InterLink Health claims data 2005-2012.
6The immunosuppressant drug regimen is critical for the long term viability of the transplanted organ or tissue, and maintaining one’s overall health is necessary for optimal patient survival rates - which are reported annually to CMS, UNOS, FACT, and half a dozen centers of excellence networks.
8At any given time, according to one leading transplant center in the Midwest, a senior nurse coordinator can be managing 10 to 20 patients being evaluated as transplant candidates, 50 or more that are on the organ wait list, or two or three who are inpatient for the procedure and 20 or more who are being monitored post-discharge for medication management, testing, biopsies, etc.
9On the high end of the response range, five centers reported that 20% of their transplant patients were not receptive to patient education.
10Four centers reported that 30% of their transplant patients exhibited “low compliance.”
11Hospital readmissions overall are believed to cost the U.S. health care system $25 billion a year. American Journal of Transplantation, October 2012, and a re-transplant can cost 50% to 100% of the original procedure depending on the re-transplant payment provision of a COE contract.
12High-compliance patients are divided into Above Average, Average and Below Average in two categories: Good underlying health and a positive transplant experience, and poor underlying health with a complicated transplant. Low-compliance patients were categorized in the same manner. The coordinators were then asked to indicate what percentage of each group experienced an Above Average, Average or Below-Average clinical outcome in terms of post-discharge complications (readmissions, medication tolerance issues, infections and rejection episodes).
13Four centers reported that 30% of their transplant patients exhibited “low compliance.”
14Hematopoietic stem cell transplant (HCT) volume, growth and survival rates do not follow the same patterns as solid organ procedures, and should be analyzed separately.
16HIMSS - Healthcare Information and Management Systems Society, 2013, Engage! Transforming Healthcare Through Digital Patient Engagement, edited by Jon Oldenburg (Aetna), Kate Christiansen, MD (Kaiser), Brad Tride (HIMSS) and Dave Chase.