Turning Patients Into Research Partners With Patient-Generated Data

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October 20, 2017

Inviting patients to share their own health data can result in a better understanding of diseases and treatments beyond what can be learned from clinical data, according to a health data specialist who presented a session during the Academy of Managed Care Pharmacy 2017 Nexus meeting.

According to Maria M. Lowe, PharmD, BCPS, health data and drug information clinical specialist at PatientsLikeMe, in recent years the healthcare industry has begun to accept patients as partners, as evidenced by efforts like the FDA's Patient-Focused Drug Development Initiative. In this initiative, patients provide input on their day-to-day challenges and interests, which better informs the FDA's ability to evaluate the risk-benefit profile of new drugs.

Another frontier where patients are becoming partners is as a source of data. Patient-generated health data, according to Lowe, are unique compared with clinical data like those found in health records because they are originated and controlled by patients. This information "serves as a natural complement" to traditional clinical data because it fills in the gaps in data between clinic visits and indicates what really matters to patients.

Patient-generated health data can take a range of forms, Lowe explained. They can be structured (eg, biometric readings or answers collected through multiple-choice froms) or unstructured (eg, free-text journaling, qualitative notes, and images), and can be recorded actively in self-reported diaries or passively through devices like step trackers.

Regardless of the format, these data represent the output of "patient-powered research networks," in which patients can learn from their own data and from others. These networks often allow patients to connect with other participants, which helps form a sense of community. Lowe cited several examples, including MoodNetwork, which engages patients with mood disorders to provide longitudinal data on their health outcomes and to help guide the development of research studies.

Despite the promise of patient-generated data, there are some challenges. After collecting data, it can be difficult to standardize patients' responses, as they all describe their health in different ways. Analysis is a challenging step, as researchers must take a rich spectrum of experiences and distill it into numbers. It is also essential to build trust among participants that their sensitive health information will be handled securely. Finally, there are obstacles to utilizing this relatively new source of data that is not yet fully understood by all stakeholders.

Still, Lowe believed the benefits gained from using patient-originated data make these obstacles worth

overcoming. If the experiences of the audience members as patients or caregivers could be combined, "Imagine the things that you could avoid having to experience because you've been able to stand on the shoulders of those who came before you," she said. "Harnessing everything we have each learned as individuals and bringing it together on a high, aggregated level, we could be unstoppable."

In her work with PatientsLikeMe, a patient network platform, Lowe had gathered a number of lessons that she shared with the audience. She advised that the donation of health data is not a one-way street, and that patients should be able to track their progress over time and learn from the data that has been reported. Furthermore, each participant should have a shared understanding of the purposes of data collection, which can be achieved by providing a customized, "concierge-like experience" where patients are shown who the researchers are.

She highlighted a number of successful patient-generated data initiatives, including one that allowed for remote data collection alongside a clinical trial for patients with amyotrophic lateral sclerosis. By allowing them the flexibility of staying in the comfort of their home, this type of data makes the patients' lives easier while also enabling more to participate in research.

As the use of patient-generated health information progresses, Lowe spoke of the need to keep the momentum going in order to elevate it to the level of clinical evidence. For instance, this kind of data could be used in managed care to add context to utilization or cost trends. She also highlighted the importance of better integrating patient-reported data into practice at the point of care and in electronic health records.

By pairing patient-generated information with data from other sources like wearable devices or biologic test results, researchers and clinicians will begin to "learn more about what's going on inside while pairing it with what's going on in the world that the patient is interacting with every day," Lowe concluded.