

Singling out members with less-prevalent diseases is no longer a rarity for plans

Effective rare-disease management programs promise plans cost-effective care, better quality of life for patients

BY TRACEY WALKER



ARTVILLE / PHOTODISC

ASIDE FROM MEETING a basic need, food fuses powerful associations of image, taste, texture, comfort and pleasure. But for 36-year-old Lisa Bowling, sitting down to a meal could mean the difference between life and death.

Bowling, a public relations director in Virginia, is believed to have systemic mastocytosis, a little-known, orphan disease that manifests itself like an allergy. When in a masto “attack,” she suffers from anaphylactic episodes. Food, odors—even stress—can trigger a potentially fatal mast cell attack.

“The most disconcerting issue—other than the possibility that I could lose my life through an unexpected anaphylactic episode—is that I have not

found a single doctor who is prepared to deal with the big-picture of a rare disease,” Bowling says.

Furthermore, countless dollars have been spent in diagnostic procedures and chasing leads on the symptoms.

“I am not interested in endless tests,” she says. “Instead of letting my health deteriorate, I want to be set on a course of treatment. I just want information on how to control this disease—before it completely controls me.”

Until recently, patients who have a rare disease were not always having their needs met. Their care was routinely disregarded because health plans did not view programs to help manage their care as cost-effective.

Fortunately for both the patient and the provider, that prognosis is changing. While many plans have disease management programs for more common chronic diseases such as diabetes or asthma, some are now opting to include programs that deal with these rare and sometimes fatal diseases—including sickle cell anemia, Lou Gehrig’s disease, Parkinson’s disease, rheumatoid arthritis, hepatitis C, cystic fibrosis, multiple sclerosis (MS), hemophilia and lupus, to name a few.

“Health plans in the future will have DM programs that are aimed at managing rare diseases, because that’s where the expense is,” says Jeffrey Levin-Scherz, MD, FACP, senior consultant at Reden & Anders Ltd., an Ingenix Company.

Rarely do numbers present such a compelling reason to take action. Consider these facts: Patients with rare diseases consume the most hospital, physician and pharmacy dollars of any one group of healthcare users and their ag-

gregate annual healthcare bills are sky-high.

"We've looked at data from a lot of different commercial health plans," Dr. Levin-Scherz says. "About 1% of patients represent about 30% of all the dollars spent. About 0.5% represents about 20% of all the dollars spent, so it makes sense to develop a medical management program aimed at those people who expend a lot of resources."

MHE Advisor Al Lewis, executive director of the Disease Management Purchasing Consortium & Advisory Council LLC, Wellesley, Mass., says plans should

consider management of rare diseases as part of a complete DM program. "You can't cure these, obviously, or even extend the life span in some cases, but you can make patients as comfortable and as self-reliant as possible. These are patients who otherwise would fall through the cracks," Lewis says. "The ROI is consistently 2:1 or better. It's easy analytically and inexpensive to manage rare diseases, and there are hardly ever provider-relations issues."

Steven K. Schelhammer, president of Accordant Health Services, an AdvancePCS Company, shares a similar view-

point. "As these conditions have a low total prevalence, member and provider intrusiveness is minor, and the number of providers impacted is small compared with DM programs with high prevalence," Schelhammer says.

DRUGS COST MORE

Typically, the rarer the disease, the more expensive the pharmaceuticals used to treat it. This leaves some managed care executives wondering how a 2:1 return is possible.

"Drug spending is on average only about 30% of total expenditures in these

CASE STUDY

One-of-a-kind calling

AS A MISSION-ORIENTED healthcare company focused on caring for the poor and disadvantaged, AmeriHealth Mercy also was obligated to develop effective programs for its members with rare diseases, as well as common conditions that get a bit more attention, such as hypertension, diabetes and asthma.

When AmeriHealth did an analysis of those patients that chronically used the most hospital, physician and pharmacy dollars, it was noted that a condition common to a large number of these members was hemophilia.

"The attractiveness of our network to Medicaid recipients with this rare condition provided us with a unique opportunity to manage nearly all the patients with hemophilia in southeastern Pennsylvania," says AmeriHealth Mercy Vice President of Pharmacy Services Mesfin Tegenu. "While some MCOs would call this adverse selection, we consider it our obligation. We also have been able to support our mission by reducing costs for our members with hemophilia by \$2 million per year."

Ideally, an effective DM program has an easily identifiable and manageable patient population with a treatable, chronic condition, each using a significant amount of healthcare resources, according to Tegenu.



Using this definition, AmeriHealth Mercy believes hemophilia is a perfect fit for the creation of a DM program.

"While the treatment costs of other conditions ... have an aggregate annual bill greater than hemophilia, the amount consumed by any one individual typically is not significantly greater than any number of other chronic debilitating diseases," Tegenu says.

"The health plan must reach out and touch thousands of members with these particular conditions to get the same reduction in healthcare resource utilization as can be realized, in our case, by effectively managing our 65 members diagnosed with hemophilia," he says.

SMALL AND FOCUSED

The small number of members with hemophilia means that AmeriHealth Mercy could focus its efforts on 100% of members with this disease, work closely with the small number of specialty providers who care for them, and deliver all the

usual DM and case management services at the high intensity required of these patients, according to Tegenu.

"Because the number is relatively small, the resources required also are low compared with other DM programs," he says.

However, this is not to suggest that AmeriHealth Mercy determines whether or not to provide programs for these other conditions based on their ROI, which might not be as high as programs focusing on conditions such as hemophilia.

"What is critical to understand," Tegenu explains, "is that for those health plans that do not have the manpower or resources necessary to implement the larger programs needed to deal with conditions such as diabetes, asthma and hypertension, focusing on diseases like hemophilia, end-stage renal disease, etc., can have a significant impact on both the members' quality of life and the health plan's ability to redirect financial resources to these other areas of concern."

AmeriHealth Mercy is confident that its approach can work in other markets, and has begun offering its care management programs, PerformRx and PerformMED, to state Medicaid programs to manage these high-cost recipients in their fee-for-service populations.

— Tracey Walker

conditions,” Schelhammer says. “The greatest single cost component is inpatient care, at about 35% to 40% of total expenditures, and in these conditions, there are many predictable and preventable complications. So there are great DM opportunities, which together yield the 100% plus net ROI we have seen time and time again. This said, drug management and initiatives to provide lowest net drug costs through pricing, appropriateness and other techniques are valuable and add to the ROI guarantee.”

The cost of Factor VII, which is used to treat a bleeding episode in a patient with hemophilia, can cost as much as \$100,000 per bleeding incident, according to AmeriHealth Mercy Vice President of Pharmacy Services Mesfin Tegenu. “It doesn’t take a DM program that prevents even one accidental

bleeding incident per-member, per-year, to show a remarkable reduction in resource utilization,” Tegenu says.

Brian Reagan, vice president of business development for Chronimed, describes this specialty pharmacy’s response to a hemophiliac patient’s emergency medical event: “The young patient fell on a Thursday night and was rushed to the hospital where there was no blood factor available at the hospital or any local pharmacies to treat the patient,” Reagan says. “Chronimed was called and delivered the blood factor to the hospital in time to save the patient’s life and provide the best possible health outcomes for the patient and payer. Our pharmacists play a major role in an individual’s care, often in collaboration with physicians, nurse practitioners and other caregivers.”

In most cases, Tegenu says, because the cost of the drugs is so high, by effectively controlling or managing a chronic rare condition there is an opportunity to reap

the benefit of improved quality of life for the member and reduced financial burden to the health plan. “For a number of conditions, a key component of the DM program is to improve members’ compliance with their prescribed medications,” Tegenu says. “This actually increases pharmacy costs, but reduces overall healthcare costs by reducing doctor visits, emergency room and hospital visits.”

Identifying members with rare diseases can be relatively simple, Dr. Levin-Scherz says. “Generally, health plans have good reporting tools for pharmacy and for high-cost cases,” he says. “There’s a big

pharmacy component for members with Gaucher disease or hemophilia, for example. It’s often easy to identify these people through pharmacy claims.”

Many plans would like to internally develop the administrative and management capabilities

for the common conditions and keep that skill-set as part of their own core competency, and in many situations, it makes sense for them to do so, according to Warwick A. Charlton, MD, senior vice president of product development and management, Accordant Health Services.

“However, internal development for these complex, less-prevalent conditions does not fit these requirements, as the developmental effort, staffing and expertise required for such niche conditions is not practical or often feasible,” Dr. Charlton says. Therefore, to manage members with rare diseases, health plans must either consider an independent DM company or a drug delivery company.

“DM is an extremely resource-intensive undertaking,” Tegenu says. “Drug distribution companies are primarily set up to distribute product, and with price competition as keen as it is, it is difficult for them to factor the cost of effective DM programs into their contracted prod-

uct pricing. Effective DM encompasses more than just compliance with medications, and vendors interested in providing DM services need to have the tools to effect change in multiple dimensions of the healthcare delivery system.”

Schelhammer believes that the business models of the traditional home care and distribution companies are fundamentally misaligned with the goals of health plans. “The principal business of the traditional home care and distribution companies is to provide more drugs and to maintain the best margins on drug pricing they can, as these two factors drive their business model,” Schelhammer says. “Health plans, on the other hand, are principally concerned with the total cost of care at the end of the day.”

The AccordantCare program is patient-centric and operated efficiently, thus “the impact on the health plan’s administrative functions and the cost to implement the program are low, and the speed to start the program and achieve benefits is high,” Dr. Charlton says. “In fact, these factors stacked up make a more compelling total business case for a complex, chronic DM program than common-condition DM programs.”

Among its complex regional payer customer base, MEDecision Chairman and CEO David St. Clair is observing a trend in collaborative DM with rare diseases, as well as with common diseases. “There’s a trend toward not completely outsourcing DM services, but rather centralizing control of that disease within the walls of a payer’s own organization, or creating joint control situations, which isn’t a common model in DM today,” says St. Clair.

For example, since most rare diseases are serious and sometimes fatal, many patients fall victim to depression. “A care manager specializing in MS might not have any idea how to deal with that patient’s depression,” St. Clair says. “Having that integrated information is imperative to good quality care.” MHE

“Home care and distribution companies’ business models are misaligned with those of plans.”



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