Care of Chronically Mentally III Patients in a Managed Care Environment

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Lany managed care programs are poorly designed to provide care for chronically mentally ill patients (1). Traditional managed care systems too often focus solely on limiting the cost of each discrete episode of care, thereby failing to adopt the longitudinal perspective so important to the care of people with chronic mental illness. Capitated managed care systems often encourage caregivers to restrict medical care to the minimum necessary to eliminate overt symptoms, all too often condemning people with chronic mental illness to medical starvation rations.

I would like to tell the story of a child with a serious, pervasive, and chronic mental illness and then use her story as a springboard for a discussion of the issues involved in caring for such people in our current managed care environment. I offer no miraculous answers but hope that the discussion of this experience may be of some use.

CASE PRESENTATION

Elena's past history initially seemed surprisingly benign. Her mother had smoked during the first few months of Elena's gestation and had taken a few acetominophen, but nothing more untoward had occurred. Elena's delivery was likewise unremarkable. Elena had suffered no head trauma or any other defined neurological insult. At the

time of Elena's birth, Elena's mother was 19, a high school graduate, and a single mother with significant economic problems. The family history was remarkable only for a cousin with "seizures." Elena's mother described Elena as "a normal baby who didn't cry much"-in retrospect, a worrisome comment. It was not until Elena was 2 years old that her mother clearly realized that Elena was not normal. Elena's motor milestones were delayed, she did not relate to others, and she spoke only a few single words. Her attention span was quite limited, and she often threw tantrums for no apparent reason.

When Elena was 35 months old, her mother requested an outpatient evaluation. The results of this evaluation included a score of 20 months on the Bayley Scales of Infant Development, an overall score of 15 months on the Vineland Adaptive Behavior Scales, a score of 12 months on the Pre-School Language Scale, and motor skill scores at the 5th percentile. Her play was at the level of 17-19 months. She displayed no hand preference. Her speech was unintelligible. Elena received a diagnosis of autistic disorder. Elena's mother received guidance in parenting and behavioral interventions, and Elena was enrolled in a special educational program in the public schools.

Elena was not quite 4 years old when she was first admitted to the hospital. During the preceding 2 years Elena had become increasingly demanding and aggressive. Her tantrums had become more frequent and severe, including screaming, hitting, kicking, biting, and throwing heavy objects. She also ran into walls, licked electric outlets, and pounded her head on hard objects. Immediately before her admission evaluation, Elena had attempted to crawl into a lit oven, badly burning

her arm. She was sleeping less, and her minimal social and verbal skills had deteriorated even further. Other than echolalic repetition of her mother's speech, Elena's language was limited to a few words. She seemed relatively indifferent to pain or pleasure. Elena's mother, while clearly devoted to her daughter, was overwhelmed. Her job was in jeopardy, her family lived in another state, and her friends had been driven away by her daughter's behavior. Something had to be done. Given Elena's danger to herself and to other children and the failure of outpatient interventions, we chose to admit Elena to the hospital and were able to justify the admission to managed care reviewers.

One of our first efforts was to attempt to refine and clarify Elena's diagnosis. Elena's failure to develop normal language, her relative indifference to socialization, her echolalia, her preference for sameness, and her repetitive play all suggested a pervasive developmental disorder, rather than simple mental retardation. She was, however, too socially responsive and too socially aware to be considered truly autistic. The presence of language deficits argued against a diagnosis of Asperger's disorder, while the presence of primary social problems and the presence of protolinguistic behavior, such as babbling, spoke against a primary language disorder. Our final primary diagnosis was pervasive developmental disorder not otherwise specified. We also made a diagnosis of attention deficit hyperactivity disorder (ADHD). Were it not for the exemption from her diagnosis of pervasive developmental disorder, Elena would also have qualified for a diagnosis of expressive language disorder. The results of an initial pediatric examination, a pediatric neurological examination, an EEG, and routine screening chemistries were nor-

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mal. Karyotyping for fragile X syndrome was negative. Magnetic resonance imaging was considered but not felt to be sufficiently important to warrant the required anesthesia. Obviously, this diagnostic assessment was neither simple nor brief. The patient's managed care system, however, required that we specify a diagnosis at the time of initial authorization of admission, and it questioned the extent of our subsequent assessment. As I will discuss, however, the treatment team believed that thorough and accurate diagnosis was fundamental to effective treatment.

A strong multidisciplinary, multimodal treatment team guided Elena's treatment. The entire team worked together to develop and implement a focused treatment plan. The attending child psychiatrist directed her workup, conducted a psychopharmacologic assessment, and guided her medication management. A psychologist administered psychological testing and provided psychological consultation. A child psychiatry fellow met regularly with Elena's mother and with Elena. A social worker bolstered support services for Elena and her mother. A special education teacher and aide conducted an educational assessment and integrated treatment interventions into Elena's educational program, first in the hospital school and later in her home school. A speech and language therapist performed a thorough assessment and provided the treatment team with explicit, concrete interventions to enhance Elena's communication skills. The cottage's mental health workers provided a consistent, predictable milieu, modeled specific behavioral interventions for Elena's mother, helped her emulate Elena's treatment program at home, and integrated the multitude of interventions and recommendations into a coherent whole. The team's behavioral and environmental interventions brought about a substantial reduction in Elena's aggressive and selfinjurious behaviors. Her impulsiveness responded to low-dose clonidine. Her language began to develop. At this point, her objective behavioral symptoms had been reduced to the point that managed care approval for continued hospitalization was becoming increasingly difficult to achieve, despite the potential long-term gains. With the expectation that we might see her again, Elena was discharged to outpatient services and back to her home and school.

Elena indeed returned to the hospital 9 months later. In the interim, and unbeknownst to her hospital treatment team, Elena had been placed in treatment foster care. After several months in treatment foster care, however, Elena began openly masturbating, engaged in sexualized behaviors with stuffed animals, and voiced various sexual phrases in an echolalic manner. Strongly suspecting sexual abuse, Elena's mother removed her from treatment foster care and returned her to the hospital.

At the time of readmission, Elena had substantially regressed from her status at discharge. A pediatric examination revealed an anal human papilloma virus wart. Concerned by Elena's regression, the team again met to revise Elena's treatment plan and to begin its implementation.

The child psychiatrist conducted several medication trials during Elena's hospitalization. Elena's inpatient status allowed for accelerated (but safe) pacing of her medication trials. The team determined that buspirone dramatically reduced Elena's agitation and enhanced her response to educational and speech/language interventions. A trial of valproate—prompted by Elena's agitation, aggression, and affective lability—was somewhat helpful, but ultimately a combination of buspirone and low-dose risperidone was judged most effective.

The team decided to focus on bolstering basic educational and communication skills. Guided by the treatment plan, the team made a coordinated effort to develop and solidify such fundamental but vital abilities as staying seated, staying on task, following directions, and asking for help. The speech/language therapist provided ongoing consultation on how to help Elena develop her language skills. During this hospitalization, Elena's mother revealed that she herself had been abused as a child and continued to suffer from depression. The team arranged for appropriate treatment.

By this point Elena's objective behavioral symptoms had again improved to the point that managed care utilization review would no longer authorize continued hospitalization. Reflecting on the failure of preceding outpatient interventions, the inpatient team realized that they must either plan for recurrent admissions, as Elena slowly lost the gains achieved during each preceding admission, or must try to gain approval of longer-term residential treatment that would allow for more permanent gains. The team was successful in negotiating with utilization review to transfer Elena to residential treatment. From there she returned home, where she currently attends a school-based partial hospital program during the day. Her outpatient program is bolstered by wraparound services including behavior management specialist services, case management, and respite care. The treatment team has regularly modified Elena's treatment plan to fit her developing situation. This plan includes defined targets for each intervention, as well as measurable short-term and long-term goals, and forms the basis for discussions with managed care reviewers.

By the time of Elena's second discharge from the hospital, she had become a person: she was using complete sentences ("I want bubble gum"), she was initiating timeouts, she was accepting her mother's care, and she was able to stay in school. A small personal example of her progress was her behavior during meetings with me: Elena moved from her initial persistent repetition of "Go 'way" to acceptance of a small toy and her choice of it as a plaything in my presence-no "thanks," minimal eye contact, but an acceptance of my presence and a sense of human exchange.

But wait—two inpatient stays, multiple professionals, a diverse treatment team—how was this possible under managed care? It was, and how this was achieved is the topic of what follows.

DISCUSSION

I wish to make the following 14 recommendations.

1) Educate managed care entities about chronic mental illness and the consequences of a short-term approach

When Elena was first hospitalized, she was insured by a traditional, episode-of-care-oriented managed care program. The primary management tool was utilization review, consisting mostly of telephone conversations and medical record reviews. During the utilization review sessions, we discussed not only Elena's immediate behavior and symptoms but also the long-term implications of being allowed (or not being allowed) to carry out our treatment plan. In essence, we were encouraging the managed care system to take a longitudinal view for its own sake, as well as for Elena's. For example, we explained how and why her behavior in the acute-care cottage was a poor indicator of her viability out in the world. With Elena receiving intensive, 24-hour, 7-day attention from a highly skilled and experienced multidisciplinary staff, while living in a carefully crafted therapeutic milieu, we expected nothing less than rapid behavioral improvement. We were not, however, fooled into thinking that this behavioral improvement would be sustained outside of the hospital (2) unless Elena was permitted sufficient time to change and until we could work with Elena's mother to establish similar programs at home and at school. We explained to the reviewers how a short-term hospitalization would not allow Elena to acquire the basic protosocial and protoeducational abilities that she would need to keep her out of long-term institutional care or to enable her to benefit from wraparound services and special education. We explained how repeated deteriorations, and repeated hospitalizations, would demoralize Elena, her family, and her social supports, leading them to the false belief that her chronic mental illness was hopelessly untreatable. At times the reviewers understood and agreed; at times they didn't.

At the time of Elena's second hospitalization, she had made the transition to a capitated managed care system. Here the advantages of a long-term orientation were much clearer to the managed care entity. In our discussions with utilization review, we emphasized how short-term investments in the present were likely to pay substantial long-term dividends in the future (3) (the financial language was not accidental). For example, we explained that by being able to work intensively with Elena to develop necessary protoeducational abilities-such as sustained focus, sequencing, and planning-we would increase the likelihood that she would learn to communicate, thereby radically increasing her chances for sustained independent or semi-independent living (i.e., outside of an insurance-financed treatment setting).

Similarly, it is often worthwhile to explain to managed care entities that providing social skills training to a mentally retarded adolescent or enhancing the vocational skills of a person with schizophrenia can significantly increase that person's chances of avoiding institutionalization. Please note that these examples highlight the patient's transition from insurancefunded institutional care to community-based systems of care—a desired outcome both for managed care entities and for patients and their families.

It is also worth remembering that many mental health utilization reviewers are not mental health caregivers and therefore have a limited knowledge of psychiatric issues. At times, educating them about the long-term consequences of specific untreated symptoms or behaviors enables them to make more informed decisions. For example, explaining how improved communication ability can enhance social support and lead to increased compliance with medical treatments may lead reviewers to support speech and language therapy if they are initially inclined to dismiss it as nontraditional or inconsequential.

Finally, and especially in circumstances where first-level reviewers are required to base their decisions primarily on written standardized criteria, approval for more comprehensive treatment is sometimes more readily obtained on appeal. Appeal reviewers may be more knowledgeable about psychiatry and often have the authority to authorize more individualized treatments.

2) Diagnose thoroughly and carefully and attend to comorbid conditions

We can treat only what we diagnose. Poor diagnosis leads to ineffective, inefficient, even wasted treatment. Accurate, complete diagnosis is the foundation for precise, efficient, and effective care. While such statements may seem platitudinous, they bear repeating.

Note that during Elena's first hospitalization we made an additional diagnosis of ADHD. Only after we treated Elena's ADHD were we able to truly engage her in any sustained, focused, and enduring therapeutic efforts. Similarly, during Elena's second hospitalization we became aware of the extent of her anxiety, initiated treatment with buspirone, and thereby increased her overall ability to participate in treatment. These examples illustrate the basic psychiatric principle that comorbid disorders can dramatically influence the course and severity of a patient's primary difficulties. Treating comorbid depression in patients with chronic schizophrenia, or comorbid posttraumatic stress disorder in patients with borderline personality disorder, can significantly improve the primary disorder's response to treatment and thereby improve the managed care entity's bottom line (with the concomitant benefit of substantially improving the patient's life). In contrast, ineffective treatment resulting from inaccurate or incomplete diagnosis can lead managed care reviewers to doubt the soundness of the clinician's judgments and the wisdom of paying for his or her care.

Managed care systems often complicate the basic task of diagnosis. As was the case with Elena, all too often managed care systems require specification of a diagnosis before they will grant initial preauthorization. Stamping a patient with a diagnosis before actually conducting a complete assessment is clearly not in the patient's best interests, but then neither is the denial of care that may result from refusal to do so. Faced with this dilemma, physicians often choose to prediagnosecertainly understandable but exemplifying the frequent ethical and practical compromises required by the current managed health care system. Similarly, managed care systems all too often expect a diagnostic assessment to be essentially complete by the end of the initial encounter. Such expectations may at times be less the result of a corrupt system and more the result of an uninformed or undeveloped system (4), providing clinicians with clear opportunities for education and advocacy.

Managed care reviewers are often trained in specialties other than psychiatry and may not be familiar with the specifics of psychiatric assessment and diagnosis. In such circumstances, it is up to us to educate reviewers about the indications for specific assessments, their concrete benefits, and the potential negative consequences (clinical, legal, and financial) if they are not authorized. Nonpsychiatric reviewers are usually more familiar and comfortable with the assessment of nonpsychiatric medical disorders. In such circumstances, it is often useful to draw analogies to medical situations, such as the workups for myocardial infarction or diabetes. For these conditions, as with psychiatric disorders, a provisional diagnosis may be initially made but more extensive assessment is clearly warranted, and failure to pursue such assessment may lead to disastrous mistreatment.

Finally, it is important to further educate managed care reviewers about the importance of diagnosis by taking advantage of opportunities during subsequent reviews to demonstrate how assessment and diagnosis have made treatment more precise, effective, and enduring.

3) Integrate

This principle is obvious but important. In a restricted managed care setting, our patients cannot afford the inefficiencies of duplicated or uncoordinated care. Had Elena's pediatrician not been a part of the treatment team, we might not have learned of her anal human papilloma virus wart, with its implication of sexual abuse. This knowledge significantly influenced the direction of Elena's treatment. Likewise, we were able to dramatically enhance Elena's basic social skills only because everyone-cottage staff, teachers, therapists, nurses, doctorssupported and encouraged those skills and implemented the same techniques and strategies.

Such integration has financial advantages as well, which can and should be made explicit to managed care systems. We were able to make our multidisciplinary treatment team affordable because of our integrated approach. Each member of the team had explicit and limited responsibilities, thereby avoiding duplications of effort. Some members, such as the speech/language therapist, were used primarily as consultants, conducting an initial assessment and using it as the basis for recommendations to the rest of the treatment team. Other team members, such as educators, were advantageous because of their ability to integrate noncapitated services into the long-term treatment plan. We have found that managed care systems are sometimes more accepting of such an approach if the contracts specify an inclusive service rate, which ameliorates their fear of being overwhelmed by multiple individual charges.

4) Time interventions to patient's capabilities

As already described, Elena's language abilities blossomed during her second hospitalization. While this can be attributed to many factors, the treatment team believes that this occurred because Elena was at that point in time developmentally primed to respond to their efforts. It was also during Elena's second hospitalization that her mother became more open about her own difficulties and was more receptive to her own treatment.

Such timing of interventions is relevant to many patients, not just to children. For example, a chronically ill schizophrenic patient who is just recovering from a psychotic episode and who is heavily medicated may not at that moment be capable of benefiting from vocational training, while such training may be very helpful a month or two later.

Timing of interventions is important in a managed care environment because timed interventions are the most likely to be effective, whereas ill-timed interventions may well be wasted. Effective treatment is cost-effective treatment.

5) Attend to preparatory skills

The treatment team put a great deal of effort into developing Elena's basic skills and abilities. Illustrative of this is one treatment team meeting during which we discussed how to respond to Elena's requests for help. Once we knew she had acquired basic language ability, we decided to encourage her to verbalize requests for help, rather than (as we had initially done) guessing her needs from her nonverbal behavior. A child who can ask for help will find school (and life) much easier and much more rewarding. Such skills are prerequisites for being able to benefit from more traditional interventions, such as education, vocational training, support groups, and psychotherapies. This is as true for adult patients as it is for children. Such basic skills as reading, writing, planning, organizing, prioritizing, and monitoring one's own internal state are particularly important for the stability, employability, and viability of chronically mentally ill patients. In a managed care environment, where interventions are often tightly limited, we should do everything we can to enhance the efficacy of whatever care our patients are granted.

6) Take care of the family

For the chronically mentally ill person fortunate enough to have an involved and supportive family, the family can be a tremendous asset (5). While it is perhaps more obvious that children depend on their families for their survival, this is often equally true for chronically ill adults. The greater the patient's reliance on the family, the more important it is that we maintain the well-being of the family. At times, this means direct treatment of psychiatric conditions, as with Elena's mother's depression. At other times, we should help families establish respite care, refer them to a financial

counselor, or meet with the family's pastor or rabbi.

7) Include nonmedical care

Care by nonmedical organizations, such as schools, churches, social groups, and social service agencies, is usually not part of insurance benefits, and for this reason it is free from managed care constrictions. These activities are also out in our patients' communities and part of their everyday world, thereby providing a quality of support and involvement unavailable within the purely psychiatric domain. On occasion, however, managed care entities can be persuaded to pay for indirect supportive care if it is explained to them that it will help establish social survival systems for the patient that will likely reduce the frequency of more expensive (and disruptive) interventions, such as hospitalization (6).

8) Provide multimodal, multidisciplinary treatment and explain its importance to managed care companies

Managed care at times looks at multimodal, multidisciplinary treatment as excessive use of specialists or unnecessary multiplication of services. As clinicians, however, we know how important such treatment can be. We must, therefore, design and provide multidisciplinary treatment that is coordinated, efficient, and effective; then, and only then, can we realistically justify such care to managed care entities. For example, we did not send the entire treatment team out to meet with Elena's school to develop an individualized educational plan, and we certainly could not have justified billing for the entire team's presence. Instead, we designed our cottage treatment teams to include the teacher as a valued and integral member of the team. The teacher knew Elena's treatment plan and capably represented the team's position. Thus, we did not have to attempt to justify a clinician's participation in the school meeting to managed care utilization review, and our clinicians were able devote their time to more readily reimbursed activities. Such a multimodal, multidisciplinary approach is clinically more effective (7), and it is financially more acceptable for both the hospital and the managed care entity.

9) Work through levels of care; step down

Because we were able to successfully persuade the managed care entities of

the importance of granting Elena sufficient treatment time to internalize basic preparatory abilities, we were able to help her successfully make the transition to less restrictive levels of care, and she was able to benefit from that care. For patients with lifetime monetary caps on mental health benefits, using less expensive, but still effective, levels of care can extend the available benefits.

As well, it is worth remembering that all patients with chronic mental illness are at risk of institutionalization. We should obviously work hard to avoid this, not only because it is expensive, but also because it constricts our patients' lives.

10) Strive to keep chronic mental illness psychiatric

We were able to develop and implement a complex treatment plan for Elena only because we knew what we were doing. We had learned how to do it, and we were practiced. I am aware of at least one managed care entity that has declared that pervasive developmental disorders are not psychiatric disorders but are instead medical disorders. While debating the clinical implications of the mind-body problem can be edifying, the pragmatic fact is that child psychiatrists are trained and experienced in the care of children with pervasive developmental disorders much more than are pediatricians or family physicians. Care of the chronically mentally ill is, as a rule, a subtle and complex craft requiring specialized skill. We must appropriately advocate care provided by psychiatrists when such care is obviously needed. On the other hand, advocating that a psychiatrist see every patient with an adjustment disorder or an uncomplicated major depressive episode only weakens our credibility. Ultimately, the truth will win out.

11) Provide stability; attend to transitions; anticipate stresses; look for precipitants

Had we known about Elena's transitions into and out of treatment foster care, we would have anticipated that they would be stressful, and we would have been able to enhance her supports and stability in other areas. While we cannot be certain, it is likely that we would thereby have been able to prevent her second hospitalization, or at least to abbreviate it. As noted earlier, we subsequently assigned a case manager to Elena, in part to increase our awareness of such events. Continuity of care is especially important with chronically mentally ill patients, in part because it allows us to be proactive about transitions and stress and because it allows us and our patients to learn what is especially stressful or supportive for them.

12) Develop a focused treatment plan; use it

A good treatment plan can be the foundation for integrated, consistent, effective care. It can also be the foundation for focused, reasoned, consistent, and persuasive discussions with managed care entities. Too often, treatment plans are regarded as clinically irrelevant or as simply another form to be completed. As illustrated by Nurcombe (8) and Harper (9), however, a focused treatment plan can be an effective clinical tool. The repeated mention of the utility of treatment planning in the preceding case presentation was not accidental.

13) Establish a track record of appealing denials

Caregivers are often reticent to pursue appeals, because of the (nonreimbursed) effort involved and because appeals are seen as fruitless repetition of previous utilization review. I wish, however, to suggest that appealing denials is an important part of patient advocacy and can have long-term, cumulative positive effects, as well as more immediate ones. Appeals are often reviewed by personnel with more mental health experience and with more flexibility and authority, so the appeals process can be far from a repetition of previous reviews. Furthermore, appeals are often monitored by government oversight agencies or by accreditation bodies, who sometimes give appeals a negative connotation.

Appeals may consume caregiver resources, but they also consume managed care resources. Establishing a track record of appealing denials, especially if denials are reversed with some frequency, can provide the caregiver with more credibility in first-level appeals and may lead reviewers to decide in favor of patient care on the basis of costs and benefits.

14) Broaden the playing field

Especially at the time of appeals, it is important to broaden discussions from a narrow medical focus to include political, pragmatic, social, advocacy, and legal concerns. This is certainly fair, since patients and caregivers must deal with the entire situation and do not have the luxury of limiting their efforts to a strict medical perspective. It may be particularly persuasive to put such concerns in writing and to ask managed care entities to respond in writing. For example, going on the record about potential liability consequences if your patient does not receive what you judge to be necessary treatment and specifying that this treatment will be financially outside of the patient's capabilities if it is not authorized by the managed care entity, may be persuasive. While managed care entities often state that they are making decisions only about the funding of treatment, it is manifest that they are in fact substantially influencing treatment by doing so (10, 11), and this fact should be made explicit whenever necessary. Similarly, patient or caregiver contact with legislators, oversight agencies, or advocacy groups may bring additional attention to serious differences of opinion between caregivers and managed care entities. Such steps should not be taken casually, but they are particularly important with chronically mentally ill patients, whose entire lives may be at issue.

CONCLUSIONS

When I was beginning to learn about psychotherapy, I used to attempt to hurry through the discussion of appointments, payment, cancellations, and such so we could get on with the therapy. Of course, I quickly learned that these discussions are very much the stuff of therapy. These days, working with managed care entities often seems like an annoying prerequisite preventing us from accomplishing our real work. We must accept, however, that this work is for the sake of our patients, that it is part of our responsibility as physicians, and that we are therefore obliged to give it our best.

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