

Lessons for Person-Centered Diabetes Services from Mental Health

2015

It may seem ironic that diabetes services would look to mental health to improve their effectiveness and person-centered services since for years mental health has been inspired to pursue more illness-centered services by diabetes. A whole generation of psychiatrists urged mental health patients to take their medications because they needed them to correct a chemical imbalance in their brains just like diabetics need insulin. The turnaround is not just because of the inevitable shifts up and back of the pendulum, but because the illnesses themselves have changed over time.

Thirty years ago, when I was in medical school and residency, Type 1 diabetes – juvenile onset, insulin dependent diabetes – attracted all of our attention. It had life threatening complications like Diabetic Ketoacidosis, hypoglycemic shock, and hyperglycemic related failures of multiple organs including heart, kidneys, liver, strokes, blindness, impotence, peripheral nerve damage and amputations. There were a few people who had the much less serious Type 2 diabetes – adult onset, non-insulin dependent diabetes – who we took far less seriously and advised diet or oral hypoglycemic medications.

Similarly, thirty years ago Manic Depression was a very serious, stereotypic condition with extreme hyperactivity, pressured speech, insomnia, euphoria, irritability, often complicated by delusions and/or aggression. Brought in by police, manic patients filled the hospital wards and were aggressively treated with Lithium and antipsychotics. Less commonly, there were milder related conditions of cyclothymia and later on Bipolar 2.

Today we have an epidemic of diabetes spreading across the world, fueled by changing diets and sedentary lifestyles, with massive morbidity and mortality, despite using upwards of 40% of our entire health budget. Today we also have an epidemic of Bipolar disorder, fueled by trauma, drugs, and changing social supports, with massive disability and social disruption, despite ever growing biological mental health services.

Although neither condition looks like their focused diagnostic predecessors, the approach to both epidemics has been strikingly illness-centered. Urged forwards by direct to consumer advertising, prescriptions treating diabetes and bipolar disorder have exploded. (For example, a study in the New England Journal of Medicine reported that between 1995 and 2005 the number of 12-18 year olds in the US diagnosed with Bipolar disorder and treated with mood stabilizers and antipsychotics increased from 20,000 to 400,000 people.) Doctors, and increasingly other prescribers, are being organized to more efficiently medicate more and more people. Pharmacies have developed systems to refill meds with more and more limited input

and oversight from doctors. Nonetheless, both health and mental health systems are crumbling under the ever increasing demand for lifelong medications.

And it's unclear how effective this response has really been. While we continue to focus on ways to increase our "productivity" the numbers of effected people and their impairments continues to grow. (It's unclear to me what's actually being "produced" besides medical billing and revenue. Neither system is good at collecting either symptom relief or quality of life, patient outcomes.)

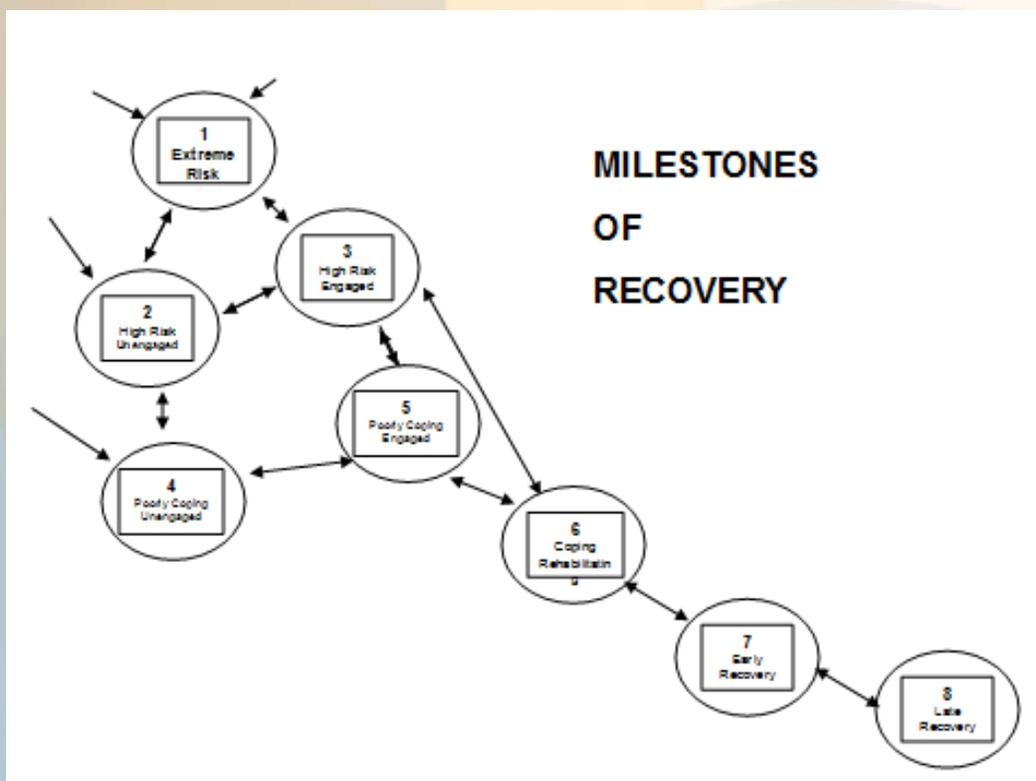
Over time, the patients themselves and their wide variety of "noncompliant" behaviors, have emerged as major obstacles to all this medical efficiency (including low motivation and engagement in treatment, limited ability to make behavioral changes, poor "social determinants of health", unhealthy behaviors, unstable lives including homelessness, indigence, and food insecurity, cultural and spiritual factors, poor self-coordination of health care, limited self-help, coping, and self-reliance, poor follow through with directions, denial of conditions, hiding information, shame, discouragement, and depression, learned helplessness, dependency, and "secondary gain", etc.) Person-centered approaches have emerged to try deal with this array of obstacles to illness-centered treatments including harm reduction, motivational interviewing, supported housing, consumer self-help groups, and case management.

Mental health has made two important discoveries while pursuing person-centered services: 1) A progression in overcoming these numerous obstacles can be described as a personal "recovery process" or even a "journey of recovery". By creating a "map" of this recovery process, we can more 'efficiently" match the person-centered intervention with the problematic personal barrier. 2) Especially for illnesses with substantial personal and social contributions, like the current epidemics of diabetes and Bipolar disorder, helping people "recover" can not only remove the barriers to treatment, they can even make people so healthy they're not ill anymore and no longer need illness-centered services. Pursuing personal recovery directly for many people can be a more effective path to health than pursuing relief from illnesses.

Facilitated by a CASRA (California Association of Social Rehabilitation Agencies) work group, Mark Ragins, MD and David Pilon, PhD from MHA-LA (Mental Health America of Los Angeles) created the MORS (Milestones of Recovery Scale) consisting of 8 milestones of recovery based on people's risks, skills and supports, and engagement.

1. Extreme Risk
2. High Risk / Not Engaged
3. High Risk / Engaged
4. Poorly Coping / Not Engaged
5. Poorly Coping / Engaged
6. Coping / Rehabilitating
7. Early Recovery
8. Advanced Recovery

The actual “map” looks more like this:



There are multiple possible “entry points” to services and people move in highly individualized patterns both forwards and backwards over time. The 8 milestones in this map can be used to facilitate three treatment needs:

- 1) It can define where a person is in the recovery process, what personal barriers they are likely to have, and what services should be best matched to their needs. (In managed care terms, it can be used to triage to and authorize specific service packages.)
- 2) It can be used to define specific goals of services - both moving forwards “recovery goals” and avoiding moving backwards “care taking goals”

- 3) It can be used to track “outcomes” and service effectiveness as people move forwards and backwards

Here is an overview of how these milestones could be applied specifically to diabetes services:

Milestone 1: Extreme Risk

These are people who are at immediate risk of death or severe complications from their diabetes. They need aggressive, rapid, and effective medical care usually beyond the capability of community clinics (or at least they'd be very disruptive and resource consuming for the clinic distracting from the rest of their services). These services should generally be provided in Emergency Rooms and acute hospitals. The over-riding goal is to avoid irreversible damage or death. At this milestone services are primarily done to people, even without their consent if not forthcoming, and there is little need for patient collaboration or self-help. It is often crucial to help people move on from this milestone as rapidly as possible. At the same time if we can avoid being too traumatizing for patients it may help engage them down the road. For many people hospitals and ERs are where they receive their first diagnosis and are introduced into the system.

Milestone 2: High Risk, unengaged

These people are at high short and medium term risk of severe complications from their diabetes, but not immediately. If they don't get better control, they are heading towards organ failures, blindness, impotence, amputations, strokes, etc. Oftentimes, they have already experienced some of these complications and are heading for more. In addition, they are not engaged with or complying with clinic based treatments. Although they too are often seen in ERs and hospitals, they wouldn't need to if there were sufficient community services and they were sufficiently engaged with them. They often present for “crisis” services and little else, frustrating the staff as they revolve in and out. The goals of this level are twofold: harm reduction and engagement. Harm reduction consists of both reducing medical risk, even with intermittent, interrupted treatment and building protective factors to increase their ability to manage the risks and increase resilience.

Frustrated staff and systems often want to impose treatment and structure, on this group of people. The patients usually resist the massive loss of freedom and lifestyle living in a structured treatment facility entails. Diabetics are not often treated in nursing homes, convalescent homes, rehabilitation programs, etc. at least not until other complications or aging or mental illness has been added to their problems. Conservatorships aren't often used for involuntary institutional care of diabetics. On the other hand, unnecessary hospital care can be avoided in the community with IHSS, home health, and nursing care like home hospice care uses. Initially visualized as a “hospital without wall” to decrease institutionalized populations, mental health developed this approach into Assertive Community Treatment (ACT) teams and

Full Service Partnerships (FSPs). These programs can incorporate significant outreach and engagement as well as peer outreach staff to help people become engaged. They also include intensive case management to coordinate care. These programs are expensive (though not as expensive as institutionalization or revolving door hospitalization) so it is often administratively difficult to divert enough resources into these programs to be effective and to control the enrollment to make sure they're targeted to expensive high risk people. Creating "flow" so they move on to lower levels of care opening up capacity for new people is also difficult.

Milestone 3: High risk, engaged

These people are also at high risk, but they are willing to work with clinic services. Treatment, however is difficult either because the illness is difficult to control, or because they are not using the treatment effectively. They may come and get prescriptions, but not take the pills as directed. They may not be able to monitor their sugars well enough to titrate their insulin dosages themselves. They may try diets and exercise but fail repeatedly. The goals of this milestone are harm reduction, continuing and increasing engagement, and building skills and supports for improved self-coordination. Lack of protective factors (like housing, money, transportation, family, community connections, etc.) can also interfere with the ability to effectively use treatment and can be addressed directly by social service staff attached to clinics. These people need integrated services that include accessibility and welcoming, intense clinical treatment, service coordination / case management, illness education and training, and social / poverty services. Busy clinics often don't have enough time to give the support needed to achieve these goals and these people too end up in ERs and hospitals as a result. ACT teams are also a strategy to coordinate the intensive, integrated services these people need.

Milestone 4: Poorly coping, unengaged

These people are not at high risk of serious complications from their diabetes over the short or medium term, though there is likely long term risk because they aren't doing anything much to control their diabetes to avoid developing long term complications or have healthy behaviors or communities. They are not engaged with services and not likely to be receiving any substantial services since they don't have "crisis" like MORS 2 and 3 do. They may occasionally try to engage with clinic services, but are drift away and disengage. The health care system is already overwhelmed with the needs of the people they're serving and unlikely to make significant efforts to serve these "hidden" people. Therefore, they are most likely to benefit from public health services – putting calorie counts on menus to improve food choices, changing food availability in their community, public education and screening campaigns, community exercise support, etc. The goal is to prevent the emergence of risk either through self-help, healthier lifestyles, and healthier communities without ever needing health care services or through

engagement in effective health care treatment. Using primary care doctors' "annual check-up" visits or behavioral health screening and referrals can be helpful.

Milestone 5: Poorly coping, engaged

Like the MORS 3 people they want to work with clinic services, but they are not using services effectively. Unlike the MORS 3 people they are not at high short or medium term risk. They need someone to help coordinate the services and to help them build the skills and supports to control their diabetes. Services that are integrated, accessible, and easily coordinated are easier for MORS 5 people to use. Motivation to actually follow through with long term health promotion efforts without the pressure of high risk may require specific health promotion and motivational enhancement efforts. These tend to be effective only with strong relationships between the patient and staff. Peer staff can be very effective. Since most people are more motivated to pursue their own goals than other people's goals, staff need to emphasize more empowering, client-driven, shared decision making, and collaborative approaches. The commonly used, brief, infrequent follow-up appointments featuring "doctor's orders" to follow tend to be ineffective for this group.

Milestone 6: Coping, rehabilitating

These people are making active efforts to control their diabetes and be healthier and they have enough skills and supports they can make substantial strides with substantial support from staff and others, but not on their own. They need assistance in formulating treatment goals and developing strategies to achieve their goals, but they're not going to be able to do it on their own. They need personal support. The goal of this stage is to help people move from being a passive patient to one who can actively use treatment. Staff can effectively use rehabilitation and active chronic illness management strategies with these people. In our usual system people at MORS 6 may look like MORS 5 if they never get the support they need to make any progress. Also they won't "flow" forwards opening up room for new patients earlier in recovery.

Milestone 7: Early Recovery

These people are largely self-coordinating and self-reliant. They can make treatment goals and successfully achieve them. The goal is either to successfully control the illness to minimize its negative impacts, living a full, meaningful life with it, or to eliminate it entirely. They can benefit from a variety of self-help strategies including peer run, health promotion, and technology based approaches. If educated, empowered, and given opportunities and resources to help themselves, they can care for themselves with minimal ongoing staff attention. Community based approaches can be helpful and these people may well give back to others.

Milestone 8: Late Recovery

These people no longer have diabetes, though they may be at risk of it returning. The goals here are to avoid diabetes returning and to be healthy. Health, however, is more than the absence of illness and sustaining health requires active healthy behaviors. Support can be connected to primary care while they monitor for the illness returning and/ or to public health services as with MORS 4 people. It is best if staff are actively promoting health as well as the absence of illness. Given their past history of diabetes, these people may have a greater stake and motivation to be healthy than those who never had diabetes. Over the course of their recovery they may have developed skills and supports that keep them healthier than if they never had diabetes.

A comprehensive system design can be created out of these 8 stages to match people with the services they need and to allocate resources to do the best we can with what we have. Here is an example:

MORS 1 Extreme risk	MORS 2 High risk, unengaged	MORS 3 High risk, engaged	MORS 4 Poorly coping, unengaged	MORS 5 Poorly coping, engaged	MORS 6 Coping, rehabilitating	MORS 7 Early recovery	MORS 8 Late recovery
Harm reduction	Harm reduction, Engagement, Protective factors	Harm reduction, Build skills and supports, and self-coordination, Protective factors	Screening, Prevent emergence of risk, Engagement, Self-help, Healthy behaviors and communities	Activate and empower patient, Build skills and supports and self-coordination	Learn to define and achieve goals, Build skills and supports, self-coordination, and self-reliance	Live well with illness or eliminate it, Self-help, Healthy behaviors and communities	Keep illness from returning, Health is more than not being ill – healthy behaviors and communities
Hospitals ERs	Hospitals ERs Structured treatment facilities, ACT / FSP	Integrated Service Agencies ACT/ FSP	Public and community health, Primary care	Community clinic	Community clinic	Community clinic, wellness center, Public and community health	Public and community health, Primary care, Wellness Center

Even if we create an entire person-centered recovery based system like this, everyone will not recover, or even progress towards recovery, but everyone will be given the services they need to have a true opportunity to recover. Services that directly address people's barriers rather than ones that directly respond to funding structures are what we mean by "do whatever it takes." If services are restructured to "meet people where they are at" it can also be clearer when people are not recovering because our services are mismatched to their needs and what programs and staff skills are missing. Recovery based services are not necessarily cheaper or more expensive than illness based services. But they do set different priorities to "do the best we can with what we have." Services like welcoming, motivational interviewing, supportive housing, shared decision making, peer support, self-help, illness education, and wellness promotion that have a low priority in our present system – nice additions if extra funding and staffing is available – become essential core services.

When I was a resident I had several supervisors who urged me to find "good psychotherapy patients" so I could learn how to do effective psychotherapy. I was told to look for people who would come to appointments reliably, not drunk or high, be verbal, psychologically minded, willing to look at themselves, and motivated to make changes. My sarcastic response was, "Can't you teach me any psychotherapy that would help the patients I'm actually seeing?"

Reconceptualizing the abundant barriers to treatment as behaviors we expect and are prepared for, as normal milestones along the way to recovery, reduces staff frustration and helps build alliances. Instead of harshly judging, blaming, and even rejecting them for being who they are we can be compassionate and accepting. When I was struggling to run a group therapy and complained about all the self-destructive ways the patients were acting, an older, wiser, but also sarcastic, supervisor responded to me, "You know, these patients would be so much easier to treat if they didn't have what's wrong with them, but that's what we're here for." Engaging proactively with their barriers is likely not only to be more effective, but it is also likely to help our staff build emotional comfort.

Although it is possible to build an entire person-centered recovery based system like this around the illness of diabetes, many people, especially the most costly and challenging ones, will have multiple conditions – including mental health and substance abuse conditions. If programs and staff are focused on their responsibilities for treating a certain illness, like diabetes, they can become resentful when people's other conditions intrude. The most common strategy used then is to refer to other programs or specialists. Unfortunately, only people at high MORS levels can effectively use referrals and coordinate fragmented, multi-specialist care. The lower levels, including the most difficult and costly people will likely fail with this approach. They need to have multiple specialists, including mental health and substance abuse care integrated into their care setting. That means there has to be integrated hospitals, ERs, structured treatment facilities, ACT /FSP, primary care, and community clinics. The person-centered system described above opens up the possibility of treating people with

multiple conditions, including mental health and substance abuse, at every level of recovery. The same triage system applies regardless of diagnosis.

Not only are programs and staff likely to feel unskilled at dealing with other conditions, but they may also lack compassion for and acceptance of other conditions. They may not be emotionally drawn to serving people with other conditions besides their target illness. They may even be overtly hostile or rejecting towards other conditions, especially socially stigmatized ones. Even if relevant specialists are integrated into the program and relationships built between the colocated staff so they can work as a team, there still remains the challenge of creating a “counter culture of acceptance” that includes all the people being served even with their diversity of conditions.

Since recovery is a universal personal process regardless of diagnosis, a recovery based system has a better chance of overcoming the divisions and intolerances that separate us than a multi-specialist, illness-centered system has. But it likely won't come easily.