

Powerful Choices: Peer Support and Individualized Medication Self-Determination

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Introduction

I am a certified peer specialist. I have helped homeless people and people with mental illnesses reclaim their lives by sharing my story of recovery from both homelessness and mental illness. I use many tools and creative talents each day at work: poetry, PowerPoint presentations, personal conversations, recovery research, and extensive social networking. I believe that the mental health system can change to provide recovery for every single person with mental illness. I think that 2 of the important science-to-service gaps in real-world schizophrenia treatment are the ability to inspire people to make changes in their own lives and to help people decide to take responsibility for important choices that will affect their recovery. As a peer specialist, I tackle both issues. I think that we need both more peer support and more medication self-determination and individualization of treatment.

My message is a story of hope that all people with mental illness can take control of their lives on the other side of a diagnosis. We can regain a productive and fulfilling membership in the community. By combining my life passions, my recovery story, my dreams, and my joys, I am able to create novel presentations and workshops. I perform these for day programs, support groups, consumer-run organizations, and staff trainings at community mental health centers. These are active and participatory learning experiences that incorporate performance or spoken word poetry, PowerPoint slides, and cutting edge research that challenge how the current mental health system is being funded and operated. I am a storyteller, and I tell a tale of change: taking the power back to help oneself, taking risks, and finding new

dreams. I create short or long workshops where people can become inspired by both giving and receiving peer support in order to learn the importance that mutual relationships can have. I believe that peer support is the future of the mental health system, and we will be some of the most powerful forces in transforming the mental health system to a “recovery-oriented community of hope.”¹

My recovery involved finding a way to maximize my strengths and move beyond my weaknesses, and active transportation, including walking, running, and bicycling, is an important element in my daily routine. Patricia Deegan, PhD, a psychologist who has also recovered from schizophrenia, has come up with a term called “personal medicine,” which is what we do for ourselves. Pill medicine is what we take, and personal medicine is what we do, both how we stay well and the reasons we find for wanting to stay well.² I have incorporated my art, my work, and my life, in a way where many of the things I do will enhance my recovery. I ride a bicycle everywhere I go and advocate for the 8.3% of Missouri households that have no access to an automobile.³ I use exercise as a positive coping tool for stress, I am out and involved in the community, and I have made a great group of friends and supporters who enjoy my personality with or without mental illness. My plan, my power, and my way is to do what I can to be a positive, inspirational person who has immense potential to make the world a better place.

Reclaiming Dreams

A few years ago, when I was more ill, I read somewhere that when an initial diagnosis of mental illness is made, what should happen is that the doctor should give the diagnosis and give some basic information about the illness and the treatment. Then the doctor should walk out of the room, and a person with that diagnosis should walk in and say, “I have this illness, and I have a life. I have some really good things going for me on the other side of this diagnosis.”

When I first read that, I thought, “I’d like to be that person.” Now I am. I am a certified peer specialist working for Mental Health America of the Heartland, an information and advocacy organization in Kansas City. My last peer support assignment was at a local homeless shelter, where I gave my peers information on recovery,

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helped them look for jobs, helped advocate for their residential needs, taught people how to prepare an agenda for their medication appointments, assisted with transportation planning, and served as an example that recovery is possible. I also co-coordinate a warmline, a consumer-operated alternative to a crisis line where people with mental illnesses can call and just talk to someone else who is experiencing the process of recovery. Our warmline is all volunteer staffed with about 28 consumers who answer about 350 calls a month while learning employment skills, recovery information, assertiveness, and how to build their own personal peer support networks. My job is to help people rebuild their lives. What I try to communicate as a peer specialist is that it is worth digging a mile through stone. I try to give people the tiny hope of a baby dream that they can recover; however, they need to hear it. I try to help people connect and to learn to help themselves. My story, along with my joys and passions, is part of the peer support movement that is transforming the mental health system.⁴ I advocate for clients' larger possibilities in staff meetings, I challenge stigmatizing statements made in the back rooms, I share updated information about recovery, and I bring in creative client-centered solutions to my coworkers. Most importantly, I provide an example of productivity and recovery for every staff member with whom I interact. This ability to change attitudes and perceptions for both clients and other staff is unique to the peer support role.

Spoken word poetry is one of the most powerful tools in my arsenal. This is a dense art form that can communicate emotion, ideas, and my ambitious personality in a brief amount of time using intonation, gestures, and choreography. I have a 7½-minute poem about being a member of the 1996 Olympic Judo team that contains the same important images, skills, character, and a lot more emotion than the original 60-minute PowerPoint presentation. After hearing this poem, people have said, "That is the most inspirational thing I have heard in a long time," and "I was so hopeful that it brought tears to my eyes." One of my poems was selected for publication in *Mind Matters Monthly*, a newsletter for people inside Osawatimie State Hospital, the biggest inpatient institution in the state of Kansas. A peer specialist who works in the hospital said, "When people read the poem, and saw all that you had accomplished, the light bulb went off for them. They just realized, 'Yeah, I can do this'. It was really powerful and amazing to watch."

Peer Support as an Evidence-Based Practice

Peer support is qualitatively different than other mental health staff interactions. A client at the homeless shelter where I worked told the other peer support worker and me, "I really like working with you two because it seems like you understand where I am coming from. You two are the best part of this facility." Paulson et al⁵ compared

practice patterns of consumer and nonconsumer providers of mental health services and found a much greater qualitative than quantitative difference. "While the activity log analyses showed that both teams had similar patterns in *what* they did, that is the type and distribution of time spent doing case manager activities, there were observable differences in *how* the teams carried out these same activities. In other words, there were differences in the practice 'cultures' operating in the two teams [italics and quote original]." The kind of differences included boundary issues such as a greater willingness to self-disclose, less expressions of fear of the clients, and less rigid issues of personal space like a friendly "good-bye" hug. The consumer team had less emphasis on adherence to rules and seemed to work more cooperatively rather than imposing sanctions. Perhaps, the most important difference observed was a more relaxed pace "where the case manager seemed to 'be there' for the client, where it was not the task but rather the relationship and being fully present with the consumer which was considered paramount in the recovery process."⁵

Sells et al⁶ found that "... clients with peer providers perceive that their providers' communications are more validating compared with clients with traditional providers. Moreover, peer providers' invalidating communication appeared to be linked to clients' subsequent improvements in social relationships and health, whereas no corresponding associations were found for clients of traditional providers." Often when I have had to disagree with a client, I have been able to bring in first hand experience. I remember one particular conversation discussing the merits of hospitalization with a person who was not really suicidal or a danger to others. I was able to bring in my own experience of multiple hospitalizations that not only kept me safe but also somewhat delayed me in the process of finding solutions to my primary problems of a job, friends, and housing.

Peer support was designated as an evidence-based practice by the Centers for Medicare and Medicaid Services (CMS) in August 15, 2007, letter to State Medicaid Directors that said, "CMS recognizes that the experiences of peer support providers, as consumers of mental health and substance use services, can be an important component in a State's delivery of effective treatment." The letter emphasized that plans and goals must be individualized and person centered.⁷

Report of Eiken and Campbell⁸ on Medicaid coverage concluded that "1) when provided in addition to other mental health services, a majority of studies suggest peer support helps participants improve psychological outcomes and reduce hospitalization; and 2) a majority of studies suggest peer providers perform as well as non-peers when peer-delivered services are an alternative to traditional mental health services." Gates and Akabas⁹ found that barriers to integrating peer staff include attitudes toward recovery among nonpeer staff, role

conflict and confusion, lack of clarity around confidentiality, poorly defined peer jobs, and lack of opportunity for networking and support. The authors suggest workplace strategies to respond to each of these issues. The agency I work for, Mental Health America of the Heartland, employs 9 peer specialists who work in collaborating nonprofit agencies throughout our bistate metro Kansas City area. Although we are one of the largest groups of peer specialists in our region, we have barely scratched the surface of the demand. Many other states have yet to make the effort to create a certification process so that they can bill Medicaid for providing peer support. Increasing the amount of peer support would remedy an important science-to-service gap in the real-world treatment of schizophrenia.

The Importance of Choices

I think that the science-to-service gap can be summed up in one word: choices. In an ideal world, all people with schizophrenia would have access to available evidence-based treatments. The power of choices is summarized in Patricia Deegan's article "Recovery as a Journey of the Heart" that explains how those of us with psychiatric disabilities can choose to become helpless rather than hopeless when our efforts feel futile. Deegan explains that choices are essential to help someone come out of this place and says "... the staff must not fall into despair, feel like their efforts are futile, grow hard of heart, and stop caring themselves. If they do this, they are doing exactly what the person with the psychiatric disability is doing."¹⁰

Role modeling of hope is one of my most important jobs as a peer specialist. By sharing my recovery story, I can help staff avoid the trap of feeling that their efforts are wasted by pointing out that people do indeed recover. At the homeless shelter, I started a process of collecting success stories of clients so that they could be used to inspire other clients for grant writing, to reassure staff, and to reward the clients who were so recognized. One of the clients I approached said, "Well, I didn't really consider myself a success, but I guess I have made a lot of progress." I help both the clients and the other staff recognize small milestones. I learned in a support group that I helped to facilitate that recovery is best understood in hindsight—just as it is possible to travel most of the way from Miami to California without seeing a single sign for over 1500 miles that you are on your way to California.¹¹ I help both clients and staff to see the signs and keep hope alive. Fisher and Ahern¹² have described how the role modeling of hope works by providing hope, social connection, and a belief that people can regain control of their life.

When I was going through the certification training to become a peer specialist, Beth Filson, also a certified peer specialist and one of the trainers, told us, "In no other field could I take those ten years of my life that were so much misery and pure hell, and turn all that negativity

into something positive. All those experiences that were so terrible when I lived through them have now become valuable and have the potential to help someone else, and it's like, 'Wow, those years weren't wasted.'" Hearing people respond to my recovery story with a new sense of encouragement is incredibly powerful for both me and the person with whom I am working.

The Choice of Medication

Nowhere does the importance of choices have such a social and emotional impact as in the area of medication. Article of Roe and Swarbick¹³ on "A Recovery Oriented Approach to Psychiatric Medication" mentions that efforts to develop and integrate concepts such as shared decision making, self-determination, and informed consent are transforming the mental health system. The authors suggest that supporters can help by empowering consumers to ask questions, to help consumers prepare ahead of time for a meeting or to be present as an advocate, by role-playing aspects of the medication meeting, and by teaching consumers to ask for the drug prescribing information. As a peer support specialist, I have never once advocated medication discontinuance. Instead, I try to ask effective questions like, "How is that working for you?" or "What is your biggest barrier to reaching that goal?" or "Is there a way you can tell your doctor what you really need next time?"

Because I was first diagnosed with a psychotic illness relatively recently (2001), I was able to participate in a mental health system that allowed me some degree of choice. My initial symptoms of visual hallucinations were met with a prescription of an atypical antipsychotic, which worked for me. Later, a different doctor diagnosed me with a nonpsychotic mood disorder and abruptly took me off the antipsychotic with my consent. After about 2 months, I became floridly psychotic, with visual, tactile, and olfactory hallucinations. I remember vividly one time when I was trying to drive home and the hallucinations were so frequent that I was afraid to drive off the road or run into something that may or may not have been there. I finally pulled over and called a friend who is a mental health consumer. "Do you have any Thorazine?" I asked her. "I don't care if it's a bad drug, I'll take anything at this point." I was well aware at that time that atypicals were supposedly superior, although that assertion has come into dispute more recently.¹⁴ My friend did not have any meds for me but did talk to me about how to calm down and try to separate the real from the unreal enough to get myself home that evening. I got back on atypicals, and after a rough 2 or 3 more months including one more hospitalization, the psychotic symptoms were abated enough that I could live independently and work again. In fact, the job and the house I found to share were also very important steps as I learned to take responsibility for my own

life and to build a new life instead of trying to get back to the life I had before I was ill.

As a peer support specialist, I can use my personal experience with medication to reinforce both the benefits and the disadvantages to medications, and I can help the clients weigh their goals in order to make a more informed decision. This helps to create the individualized plan of care necessary for each person. I often have more time available than do my nonpeer clinicians, and I can try to work out the important values for the choice. I never tell people to discontinue medication, and in fact, when I do presentations, when people ask me about my medications, I tell them about Lance Armstrong, the cyclist. He is often asked about medications by people with the same kind of testicular cancer, and he tells them that medications and their effects are incredibly individual and have to be handled on a case-by-case basis, so what meds work for one person is irrelevant to another person's treatment.

Medication Issues, Peer Support, and Self-determination

There are people in the consumer movement who say, "I couldn't have recovered without my medications," and when I was more ill I was definitely in that category, although not so much anymore. Some people even advocate for a greater role of medication decisions made on behalf of consumers who may not see the need for medications.¹⁵ However, there are also people who say, "If I had stayed on my medication, I don't think there's any way my life would be as together as it is now."¹⁶ All these positions need to be recognized and validated. Bola and Mosher¹⁷ suggest that "An outright dismissal of antipsychotic medication use as well as an uncritical and universal prescription of these medications for all psychoses might be equally regarded as ideological positions."

Ignoring the fact that some people do well off medications might be another large science-to-service gap in the real-world treatment of schizophrenia.^{18,19} I am aware that many of the studies showing greater rates of relapse for people on placebo²⁰ are abrupt withdrawal studies, whereas gradual withdrawal, following sound pharmacological principles, has a much lower rate of relapse.²¹ I have found out that antipsychotics cause a discontinuation syndrome that can be confounded with relapse.²² This may be based on the fact that antipsychotics increase the density of dopamine receptors and convert dopamine D2 receptors from the low-affinity state to the high-affinity state that is implicated in psychosis.²³ These increased numbers of high-affinity dopamine D2 receptors are invariably associated with behavioral supersensitivity to the brain's dopamine, the release of which is increased by stress, street drugs, and other factors. In addition, combinations of different genes in different people can be associated with such dopamine supersensitivity. No single gene is sufficient to account for behavioral supersensitivity and psychotic symptoms. For example, the re-

moval or knockout of a particular gene will cause changes in the activity of other genes, which can converge to trigger dopamine supersensitivity and psychosis, so the race to find a single gene for schizophrenia is essentially futile.²⁴ This supersensitivity has been proposed to cause treatment failure over time²⁵ and has been suggested, along with side effects, as an important reason for the high rate of discontinuation during the Clinical Antipsychotic Trials Of Intervention Effectiveness (CATIE) trial.²⁶ It is possible that by medicating everyone, we are missing out on a group of people who are overrepresented in the best outcomes category.²⁷ More extreme detractors of medication have hypothesized that medications cause more harm than good and that lower use of medications explain the better outcomes found by the World Health Organization studies in the developing world.²⁸

Even though I understand these issues with medications, I still know from personal experience, from work observations, and from research data that medications do indeed have value. As a peer support worker, I have to try to avoid any dogmatic or judgmental characterization that would be unhelpful to my clients. I am very aware that although I am a trained professional, I am not a doctor. Instead of giving any specific medication advice, I teach clients self-advocacy skills, negotiation strategies, and problem-solving techniques to address their concerns with their doctor. I teach self-determination so that people can optimize their medication regimes for themselves. My job is to model hope, as Patricia Deegan said, to keep offering options and choices, and to help the staff I work with to keep from falling into despair. I know recovery is possible, and I help people to see how they still do have the ability to impact the world and make changes. I teach them to ask themselves questions like, "What is stopping me from working?" or "Was it really true when that doctor told me that taking the bus would be too stressful for me?" or "Who else can I find to talk to about this problem?"

I have helped other mental health consumers to apply for the peer specialist training after not working for long periods of their life. One of them said, "I still believe I have a lot to contribute to the world and I would like to make a difference for someone else the way other people have done for me." The choice of seeking employment is a powerful assist to recovery, yet a study on conformant care found that 52% of people had not been assessed for work potential. The same study found that 24% of people were undergoing polypharmacy with multiple antipsychotics, which the author defined as nonconformant to the Schizophrenia Patient Outcomes Research Team guidelines.²⁹ Because atypical antipsychotics cost \$300–\$600 a month, that could have bought quite a lot of peer support. In the wake of the CATIE trial results questioning the superiority of atypicals, Luchins³⁰ says, "The decision to reduce resources for other interventions while enormously expanding the

medication budget was not necessarily one that would have been supported by consumers, but it was a decision we made. In hindsight it was a mistake.”

As a peer supporter, my job is to challenge all the assumptions. The first assumptions I had to challenge were my own fears of never being able to work again at the same level and fears of not having friends or a family or a life worth living. I was very ill for a long time, and now I am not. I have a remarkable life with friends, passions, hobbies, and interesting and ever expanding opportunities. I have a practical and durable bicycle that gets me all over town while meeting amazing people and having interesting adventures along the way. Connecting with resources in the consumer movement helped me decide to keep trying after I had given up numerous times. Now it is my turn to keep asking questions, to help people to find what works the best for them, and to keep pushing their limits. My role is unique with the mental health system because I affect both clients and the other staff as they provide services. I help both groups see that there are many powerful choices available.

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