

Moving Beyond the Illness: Factors Contributing to Gaining and Maintaining Employment

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The work presented here, exploratory in nature, uses a comparative and qualitative approach to understand the factors associated with the ability of individuals with severe and persistent mental illness to successfully gain and maintain employment. Based on open-ended interviews with individuals in an Assertive Community Treatment (ACT) program, we compare the experiences of those who have been successful gaining and maintaining employment, with those who have been successful gaining but not maintaining work, and those who have been unsuccessful gaining employment. The three groups seemed to differ in three significant ways: (1) in the ways the individuals talked about their illness, (2) in the ways the individuals talked about work, and (3) in the strategies they described for coping with bad days. In each of these areas individuals' awareness of and attitude toward their illness was significant. The findings have clear implications for agencies working to help people with severe and persistent mental illness obtain and maintain employment.

KEY WORDS: employment; strength-based research; community-based treatment; recovery; assertive community treatment.

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The benefits of employment in the recovery process of individuals with severe and persistent mental illness have been well documented. There are increasing numbers of vocational programs within mental health services, and state and federal human service policies are beginning to reflect a growing emphasis on work. However, at any given point less than 15% of people with psychiatric disabilities are employed (Anthony & Blanch, 1987). As mental health professionals continue to develop programs and strategies for increasing this percentage, it is wise to pay attention to the experiences of those who have been successful at gaining employment.

Our research, based on in-depth, open-ended interviews with clients of an Assertive Community Treatment (ACT) program is the result of such a process. We listened to and probed the perspectives of successfully employed clients, comparing their experiences with less successful clients. What we learned, and present here, has significant implications for community-based treatment programs geared toward helping clients with psychiatric disabilities become functioning and productive members of their communities.

Literature Review

The last few years have seen increased attention in the literature to the significance of work for people with serious and persistent mental illness. Much of this research has focused on examining the outcomes of successful employment. Mueser *et al.* (1997), for example, found that individuals who had been employed for at least six months tended to have lower symptoms and higher self-esteem than when they first began working. Similarly, Van Dongen (1996), in a comparison of workers and nonworkers, found significantly higher levels of self-esteem in addition to a perceived better quality of life among workers (see also Perese, 1997). The psychological, economic, and even attitudinal benefits of work (McCrohan, Mowbray, Bybee, and Harris, 1994) have, by now, been well documented.

Given the demonstrated benefits of successful employment, several studies have assessed the outcomes of various kinds of employment programs. These programs range from consumer cooperatives (Clark, 1995) to in-home programs (Kates, Nikolaou, Baillie, & Hess, 1997) to programs following the Individual Placement and Support model (Drake *et al.*, 1996; Bond, Dietzen, McGrew, & Miller, 1995; Xie, Dain, Becker, & Drake, 1997; Drake, Becker, Biesanz, & Wyzik, 1996). Others (e.g., Marrone, Balzell, & Gold, 1995) have focused more generally on programmatic elements that seem to be key to the success of any employment program.

With the exception of a focus on symptoms, however, which has pro-

duced mixed results (see, e.g., Anthony, Rogers, Cohen, & Davies, 1995; Bell & Lysaker, 1995), scant attention has been given to *individual* factors, such as worldview, perceptions of work, and perceptions of one's illness, that may be associated with employment success (see Braitman *et al.*, 1995; Scheid & Anderson, 1995; Mowbray, Bybee, Harris, & McCrohan, 1995). An understanding of these factors is especially important given that it is often difficult to know if the higher self-esteem we see when comparing workers to nonworkers is a product of the employment or was there at the outset (Van Dongen, 1996). Our research, exploratory in nature, contributes to filling this gap.

Our work also contributes to the expansion of the descriptive, ethnographic literature on consumers' experiences and expectations, a project begun largely by Estroff (1981), with recent contributions in the area of work by, among others, McCrohan *et al.* (1994) and Kirsh (1996). Guiding our work is the assumption that, by listening to the experiences and perceptions of individuals who have been successful in employment, we can identify attitudes and strategies that could be helpful for those who have been less successful in this area.

Using qualitative research methods, particularly in-depth, semistructured interviews, we compared the experiences and perspectives of three groups of people: those who have been successful obtaining and maintaining employment; those who have been successful obtaining, but not maintaining, employment; and those who have not been successful obtaining employment. The individuals interviewed were all clients in an Assertive Community Treatment (ACT) program at the time of their participation.

The Assertive Community Treatment (ACT) Model

Assertive Community Treatment (ACT) is an approach developed in the early 1970s by Stein and Test in Madison, Wisconsin, to serve adults with severe and persistent mental illness. The original experimental program was known as Training in Community Living (TCL). Compared to treatment as usual clients, the TCL group required less hospitalization, spent more time employed, had better living situations, had more positive peer relationships, and were more satisfied with their lives. The key elements of ACT include a multidisciplinary team approach, *in vivo* treatment, instruction and assistance in teaching basic living skills, 24-hr availability of staff, integration of community resources, and an assertive approach to minimize client dropout (Stein & Test, 1980). The ACT model of treatment has been widely disseminated throughout the country. Currently, there are 397 teams in 14 states (Meisler, 1997).

The ACT model is gaining recognition for its treatment outcomes. Baronet and Gerber (1998) provided a critical review of four major rehabilitation programs including assertive community treatment. The review of the research indicates that assertive community treatment is effective in decreasing both recidivism and the use of emergency mental health services. They also found that the treatment improves medication adherence and involvement in treatment but has mixed results when it comes to community adjustment outcomes including vocational functioning. With this in mind, we were interested in finding out why some clients were more successful than others in the employment arena.

ACT of Kalamazoo, Inc.

ACT of Kalamazoo, Inc., is a private nonprofit agency that provides ACT services to 275 adults with severe and persistent mental illness. ACT has six multidisciplinary treatment teams, each comprised of social workers, psychologists, psychiatrists, registered nurses, and occupational therapists. The client-to-staff ratio is about 8:1. Agency staff work within the community seeing consumers in apartments, coffee shops, and jobs. The program is available 24 hours per day, 7 days per week. Instead of individual case manager responsibility, the staff function collectively as a team. The treatment revolves around teaching necessary coping skills. Staff members assist consumers with shopping, cooking, laundry, budgeting, and the use of transportation. Staff provide counseling, medication monitoring, and access to medical health care. No predetermined date for discharge is set, although annually, about 5% of the agency's consumers no longer require services and the cases are closed. The agency also employs a Vocational Coordinator. The Coordinator assists clients in prevocational counseling, assisting consumers in obtaining jobs, and providing a limited level of job coaching to help sustain employment. Clients referred to ACT have generally not been successfully treated by other treatment modalities and have typically experienced numerous psychiatric hospitalizations prior to ACT involvement.

Clients range in age from 17 to 66, with a median age of 40. The median amount of time clients spend with the agency is 54 months, ranging from 1 week to 10 years. Fifty-six percent of the clients served are male and 44% are female. Seventy-two percent are Caucasian, 25% are African-American, 1% are Asian-American, 1% are Hispanic, and 1% are Native American.

Sixty-six percent of the clients enrolled have a diagnosis of a thought disorder (primarily schizophrenia), 13% have a diagnosis of a mood disorder

der, 16% have a diagnosis of personality disorder, and 5% some type of other disorder, either organic or developmental. Many agency clients have more than one diagnosis: 60% have a current or historical substance abuse problem, and 20% have a secondary developmental disability diagnosis. ACT clients averaged 96 hospital days per client for the year prior to starting ACT services and 15 days per client last year (1996). Nineteen percent of the Agency's clients are employed a minimum of 5 hr per week. Fifty percent of employed clients have sustained employment for 6 months or longer.

METHODOLOGY

Sample

Clients that were selected for this study had been receiving ACT services for a minimum of 1 year and were not over 40 years old. The age limitation was imposed to include only clients who had not experienced extended psychiatric hospitalizations (admissions lasting longer than 1 year). As people are less and less likely to come into mental health programs today with long hospitalization histories, it made sense to exclude those whose hospitalization experiences were dramatically different.

Seventeen clients were selected using a stratified, purposive sampling technique. To compare the experiences of individuals with varying degrees of success in gaining and maintaining employment, clients were chosen on the basis of their recent employment history. Clients in Group 1 were employed at the time of the study and had been in their current job for at least 6 months, clients in Group 2 have been able to obtain work but unable to maintain employment for longer than 4 months, and clients in Group 3 have been unsuccessful at obtaining employment. (We included in "unsuccessful at obtaining employment" clients who may have been hired for a job in the past but did not last even the first week.) The jobs held by individuals in the sample are all minimum- to moderate-wage jobs and include the food service, industrial, custodial, and domestic sectors. The median age of the sample is 27, and the range of time as agency clients is 1 to 8 years. Table I provides age and employment information, length of time with ACT, and average Brief Psychiatric Rating Scale (BPRS) scores (see Overall & Gorham, 1962), for each group. As the BPRS scores indicate, there are no significant differences in symptom severity among the three groups.

Given that we selected clients in a certain age bracket, our sample is not representative of ACT clients as a whole. We did, however, try to

Table I. Comparative Data for the Three Groups^a

	Group 1 (<i>n</i> = 6)	Group 2 (<i>n</i> = 5)	Group 3 (<i>n</i> = 6)
Age			
Range	22–40	22–33	20–30
Median	26.5	27	25.5
Length of time as agency client			
Range (months)	12–60	24–90	18–72
Median	36	48	24
Employment information			
Current No. of hours employed (mean)	18.5	15.6	0
Length of time jobs held in months (range)	6–36	2–4	0
Psychiatric information			
BPRS (mean)	61.8	59.2	65.6
BPRS Positive Symptom Cluster (mean)	15	14.2	18.2
BPRS Negative Symptom Cluster (mean)	11.2	11	13.5

^aGroup 1—those who have been successful in gaining and maintaining employment; Group 2—those who have been successful in gaining, but not maintaining, employment; Group 3—those who have not been successful in gaining employment.

ensure that our sample included diversity on the basis of gender, ethnicity, and diagnosis in proportions similar to the wider client population. Twelve are male and five are female. Twelve are European Americans, three are African Americans, one is Hispanic, and one is Asian American. Twelve have a primary diagnosis of a thought disorder, two have a diagnosis of impulse control disorder, two have a primary diagnosis of a personality disorder, and one has a diagnosis of a mood disorder. The 17 clients averaged 90 hospital days per client for the year prior to receiving ACT services and less than 1 day per client during the year prior to the study.

Interviewing Process

Information on the experiences of individuals in each of the three groups was obtained through open-ended, semi-structured interviews. Each individual in the sample was given a letter from the researchers describing the research and asking if she/he would be willing to participate. They were informed that the interviews would be strictly confidential and that the interviewers would be students from Kalamazoo College who had no official connection with ACT. If the individuals agreed to be interviewed, they signed a consent form and were subsequently contacted by an interviewer. Both interviewers had extensive training in and experience with ethnographic interviewing. The interviews, lasting from 30 minutes to an hour, were conducted at the interviewees' convenience, at a place of their

choosing. All of the interviews were tape recorded (with the interviewee's permission) and were subsequently transcribed verbatim by the interviewers. Of the 17 individuals in the original sample, 2 did not consent to the interview, and 5 were unable to be contacted; they were replaced with others.

The interview itself consisted of a series of open-ended questions, grouped under four main topic areas: employment issues, illness management, interpersonal relationships, and ideas of the future. We were interested in asking questions that elicited responses related to how the individuals viewed their illness, how they viewed the illness in relationship to work, how they felt about their relationships with friends, family members, co-workers, etc., and what role they saw work playing in their future. A total of 56 questions was included on the interview guide. Consistent with this kind of interviewing, we were more concerned that the issues were all addressed, than that every question was asked.

After all the interviews were completed and transcribed, they were coded topically for ease of information retrieval. The topics coded for included those we specifically asked questions about in the interviews (e.g., "relationships with family members") as well as unanticipated themes in the interviews (e.g., "spirituality"). The list of topics was developed through a process of reading through all of the interviews, noting the common themes as we went. This process was done collectively. The interviews were then coded according to the list of topics, with the two interviewers separately coding all of the interviews. Because the topics were fairly unambiguous, there were no disagreements between the coders.

The analysis was primarily interpretive in that we were interested in identifying themes running through the interviews. We would ask ourselves, for example, when we compare the statements clients make about the topic "perceptions of role of their illness in their life," are there ways that these perceptions vary among the three groups? Similarly, how do clients in the three groups differ in "attitudes toward work"? By retrieving segments of the interviews related to certain topics, we were able to compare clients' perspectives on those topics.

FINDINGS AND ANALYSIS

The three groups seemed to differ in three significant ways: (1) the ways the individuals talked about their illness, (2) the ways the individuals talked about work, and (3) the strategies they described for coping with bad days. We discuss each of these below, using pseudonyms to refer to the interviewees.

Descriptions of the Illness

The difference among the three groups in terms of how they spoke about their illness seemed, in large part, a difference in attitude. Individuals in Group 1, the individuals who had been successful gaining and maintaining employment, tended to be able to see their illness as just one piece of who they are. Chad, for example, stated,

I used to worry about schizophrenia but actually the people around [work] have helped me to allay my fears. They're like, 'No, you're normal. Don't worry about it. . . .' So what I've really done is overcome a lot. . . . And I just happen to be at a place where I had a mental health problem, but that was only a certain percentage of my problem. The rest I could fix up so that I could still improve myself as a person.

One individual in Group 2, those who had been successful obtaining but not maintaining employment, expressed something similar:

There's days when you feel bad, and days when you don't. It's like any other day—you have to take the bad with the good. Whenever you have a sculpture, and this little piece doesn't fit, you can tear it away. And you have this little piece of clay that you can make something out of, and that's just part of your life. . . .

This ability to see oneself as having an illness, as opposed to being an illness, and understanding that, as Chad says, "the rest I could fix up," contrasts sharply with the attitudes of individuals in Group 3, those who had been unsuccessful obtaining employment.

Two of the six people in Group 3 did not describe their illness as affecting their lives at all. For example, one person said, "Nope. I don't do that. I don't get depressed or none of that." The four others described their illnesses in varying ways, from one man describing his illness as "being stressed out a lot" to Joan's more poignant explanation:

I don't know yet myself what I have to offer to the world. . . . I get really lonely. I just have this deep lonely side. . . . I am always having to feed it every day. And it keeps me from functioning in society. . . . I don't know where I fit in yet. It's a struggle for me.

The differences, particularly between Group 1 and Group 3, in the attitudes toward and awareness of the illness were striking to us as we read through the interviews. Individuals in Group 1 were far more able to see their illness as one part of their lives, a part that needed to be managed but that need not be the center of their lives. Those in Group 3 tended either to deny that they had an illness or, like Joan, to be consumed by it.

Descriptions of Work

Another area where differences between the groups emerged was in people's discussions of why they do or do not work. Again, the difference

is largely one of attitude. Although all of the individuals in Group 1 spoke about their jobs in a generally positive manner, they did not feel more positively about work than those in the less successful groups. Rather, people in Group 1 tended to see work as a necessary activity which could increase their own self-regard and even offer some control. As one person said, "It is something to do instead of sitting around here all day. . . . I can pay the bills, and I make more than they would have given me." Another framed his motivation for work in slightly different terms: "I honestly think that if you can work, it's good to work . . . it makes me feel good about myself. . . . I know I am being productive and trying." Chad described his job in a factory as "something that I have to do, not something that I want to do." He said that he always works on a good station because he does a good job there and that "I've finally reached a plateau where I can just be myself, and everyday that goes by just gets better and better."

All of the individuals in Group 2 mentioned receiving wages as a primary motivation for working. Three of the six people also mentioned that they need to keep busy and have structure. Steve, who works in an automobile related job, linked his motivation to work to his mental illness:

I started coming up with the skills to adapt to the working world. I heard a lot of people talk about how they can use their mental illness as part of their leisure, and work as part of their structured environment. . . .

The individuals in Group 3 talked more about the barriers to successful employment they experience. Two people mentioned communication with co-workers as difficult, and a third mentioned "acting crazy." The other three people said that they became bored with the work and so they started sleeping in and not showing up. Joan's frustration with her inability to move beyond the illness is apparent in her explanation for not working:

It's just that I want to be able to do more eventually. . . . I have this ever estranged side that is loud and free and just wants to be free from all these chains in society. But yet I still need time to figure out what's going on with myself and where I fit in. I am so afraid of making mistakes. . . . It seems like there is no right answer.

While the differences in the attitudes toward work are stark between people in Groups 1 and 3, one can also see differences between Group 1 and Group 2 in this area. People in Group 1 seem more able to see the role that work plays in their recovery from mental illness. Those in Group 2 also see work as important in their lives but do not seem to be as clear about the role of work in their recovery process. This same pattern is evident in individual's descriptions of how they deal with especially bad days.

Strategies for Coping with Bad Days

Five of the six people in Group 1, when discussing strategies they use for coping with particularly bad days, mentioned the necessity of “mindsets,” or taking things as they come, day by day. For example, one person said that he would “try to compose [himself] and say hey—it’s gonna be over. Every day it always hits six o’clock!” Another said he always remembers that “[t]he sun will come up tomorrow. There is always tomorrow.” Three of the six people in Group 1 also mentioned relaxation as very important in controlling their symptoms and dealing with bad days in the workplace. Chad uses a particularly innovative strategy for dealing with bad days by combining the sound of the machinery with the voices he hears to entertain himself:

I have thoughts which entertain me. It’s hard to do a job with any kind of restrictions without getting bored or going to sleep. It’s like a magical environment in there because of all the positivity I have created for myself. . . . I try to fix things up to make it a place I want to be.

The individuals in Group 2 mentioned various ways to cope with their illness and work. Two people mentioned taking deep breaths and counting to 10. Another isolates himself and watches TV. And two people talked about the importance of focusing on the task at hand. Steve explained it this way:

When I am at work, I can’t think about outside forces. I can’t think about what I am going to do tomorrow. I can’t think about what I did yesterday. . . . I am happy doing what I am doing at the moment.

While people in Group 1 tended to deal with bad days by reminding themselves that things will get better, demonstrating once again an ability to see beyond the illness, people in Group 2 were more likely to talk about focusing on the moment. Their descriptions tended to reflect an awareness of the illness and a clarity about what to do during bad days, but they did not refer to the transitory nature of the problem.

While individuals in Group 3 could not talk about coping with bad days at work, they did offer a variety of strategies for coping with the illness itself. These strategies included using caffeine, listening to a Walkman, conversing with the voices in her room, relying on emotions, trying to think of other things, smoking and drinking, and developing ESP to use against those who “talk” to you. Clearly, these strategies are very different from those described by people in Groups 1 and 2. Unlike the latter, people in Group 3 used strategies that, for the most part, covered up the problem with another substance or tried to push it away.

In sum, in comparing the three groups a clear pattern emerges in terms of their awareness of and attitude toward their illness. Those individuals who

are most successful at gaining and maintaining employment tend to have a clear perspective on their illness and the place of the illness in their lives more generally. Those in the middle group have a clear perspective on their illness and a solid set of strategies for managing it, but express less of a sense of the illness as only one piece of who they are. Those in the least successful group have a more muddy perspective on their illness and describe illness management strategies that tend either to cover up the illness or to push it aside.

DISCUSSION

The differences in attitude and illness awareness that emerged from our research have significant implications for agencies working to help people with severe and persistent mental illness obtain and maintain employment. It may be that the attitude we saw among the individuals in Group 1 was at least partially responsible for their being successful with work. This is consistent with Mowbray and co-workers' (1995) finding of work attitude as a predictor of current work status.

Overall, the majority of the people interviewed were aware of the pressures of work and the need for management of their illness. However, those who were more successful at continuous employment have specific strategies in managing their illness that they have found successful. Similar to what Sullivan (1994, p. 25) found to be characteristic of those further along the road to recovery, "[T]hey make choices that are consistent with their desires and goals while remaining cognizant of what is needed in the management of a serious illness." For the more successful individuals, this meant increasing the number of work hours gradually or not at all. As one person said, "You know, my mental illness can hold me back if I put too much stress on me, like when I asked them to put me on full-time. . . . I'd flip out, you know, and end up back in the hospital."

In addition, these strategies are combined with a view of their illness as something that does not take over the totality of their being. This allows the individuals to work in spite of their symptoms because their symptoms are just another part of daily living instead of all that they are. Not viewing their illness as the totality of their existence leaves room for people to view themselves as workers who have something to contribute to the world. This finding is congruent with Bebout and Harris' (1995, p. 401) suggestion that "perhaps the business of getting to work is less about finding something to do and more about recovering or discovering something to be."

Sullivan (1994), in his evaluation of his own and Estroff's (1989) work, suggests that there is no clear evidence whether it is better to accept an

illness as synonymous with the self or to view oneself as a person with an illness. However, Scheid and Anderson (1995, p. 170) state that, as Estroff (1989, p. 193) mentioned, "Coping with chronic mental illness involves a fundamental redefinition of self and identity" which also affects employment considerations. The present study suggests that it is indeed better (in terms of continuous employment) to view oneself as a person with an illness rather than the illness being the person. After all, if the person is the illness, where is there room to be a worker?

One has to ask, however, whether it is the work itself that leads the people in Group 1 to have the attitude that they do. We would agree that being successful in gaining and maintaining employment may well improve the attitude they have toward their illness, which would, in turn, lead to being even more successful in work, etc. However, the experiences of those in Group 2 suggests that simply gaining employment will not lead to the kind of attitude we see among people in Group 1. After all, Group 2 people did gain employment, but that in itself did not lead to developing a perspective like those in Group 1; rather they either quit or were fired. Thus, having a clear perspective on their illness, a characteristic of Groups 1 and 2, seemed to be a significant factor in being able to gain employment. But seeing the illness as only a piece of who they are emerged as a significant factor in maintaining employment. While additional research with a larger, more diverse sample and longer time frame is needed to answer this chicken-and-egg question more definitively, there are some immediate implications for policy and practice stemming from our research.

Much of the substance of treatment programs for individuals with serious and persistent mental illness involves helping people develop coping strategies. Our research suggests that strategies that help people manage their life are more useful, at least in the area of employment, than those focused on helping people manage their illness. Comparing the experiences of the people in the three groups seems to suggest that how one manages one's illness is less significant than how one manages one's life having an illness. Emphasizing the development of strategies that help individuals gain the kind of perspective on their illness that we saw in individuals in Group 1 might be more effective than focusing on controlling the level of symptom acuity. Moreover, helping people acquire this perspective *before* working could go a long way toward helping them successfully secure and maintain employment.

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