Published in final edited form as:
Community Ment Health J. 2010 October ; 46(5): 486–493. doi:10.1007/s10597-010-9326-0.

Case Managers Discovering What Recovery Means Through an HIV Prevention Intervention

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Abstract

Following a randomized trial of case manager delivered HIV prevention intervention to persons with severe mental illness (SMI), this study sought to document changes within the service environment and with case managers themselves as a result of their experience and skills training. Utilizing qualitative methods, researchers conducted focus groups and in-depth interviews with 22 case managers and 3 administrators at an urban community mental health center. Beyond confirming previously established barriers to case manager delivery of HIV prevention interventions for persons with SMI, most noteworthy was the finding that case managers were generally unskilled in conducting assessments and tended to focus on "spoiled identity" and illness parts of their consumers. Experimental case managers revealed that they had been transformed by the training experience in a manner permitting them to both understand and work from a recovery model. Implications and directions for further study are discussed.

Keywords

Recovery; HIV prevention; SMI; Case managers; Clinical skill

Introduction

Since HIV disproportionately infects persons with severe mental illnesses (SMI), researchers have diligently worked toward making empirical strides in identifying this population's constellation of unique risk behaviors in order to design effective prevention interventions. However, researchers have ignored making the proportional and requisite effort to gauge the skill capacity of the very mental health providers who not only deliver the lion's share of services to persons with SMI, but who have long been considered the likeliest choice to be their HIV prevention interventionists, the case managers. This oversight has served to stymie further progress for effective HIV prevention for persons with SMI.

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"Are you protecting yourself?" This question, taken from an in-depth interview with a case manager in the "field" for 14 years, exemplifies the manner and extent to which case managers, typically inexpert at assessing risk behaviors and delivering HIV prevention intervention messages, speak with their SMI clients about safer sex. Subsumed within the question itself are latent impediments to the potential delivery of evidence based HIV prevention intervention in community mental health settings. These include problems with cloudy terminology, lack of clinical skills, reluctance to probe for risks, and differential power dynamics.

In this paper, we present findings from focus groups and in depth interviews with case managers following an HIV prevention clinical trial that took place at the agency where they worked. We sought to learn about experimental case manager's experience of having been trained to deliver Preventing AIDS Through Health (PATH), to their SMI clients. PATH is a hybrid of the Center for Disease Control's Project RESPECT, the first HIV prevention program to show that one-on-one counseling can reduce risky sexual behavior (CDC 1996); and CBOM, the National Institute on Drug Abuse's Community-Based Outreach Model (NIDA 2000), which showed that community based out-reach is an effective strategy for reducing HIV risk in substance using populations. Our aim in this aspect of the study was to append an earlier qualitative assessment conducted prior to implementing this randomized trial (Solomon et al. 2007), and to document the changes that may have occurred both within the service environment and with case managers themselves as a result of their experience and skills training with the PATH intervention. We also sought to determine the extent to which control case managers were impacted by this intervention and whether spill-over of PATH had occurred. We report on the results of these assessments in this paper.

Background and Significance

Prevalence rates of HIV in persons with SMI are as high as 23% when co-occurring drug use and homelessness are concomitantly present (Cournos and McKinnon 1997; Blank et al. 2002; Meade and Sikkema 2005; Satriano et al. 2007; Walkup et al. 2008) and researchers continue to amass a growing list of barriers that impede case manager led HIV interventions for SMI adults. These barriers include case manager's concerns regarding confidentiality (Sullivan et al. 1999), antiquated beliefs that many SMI persons are asexual, lack of knowledge and skills related to HIV interventions, discomfort with discussions of sexuality, lack of designated funding and lower prioritization of HIV prevention activities as compared to other case management work (Arruffo et al. 1996; Brunette et al. 2000; Carmen and Brady 1990; Grassi 1996; Knox 1989; Sullivan et al. 1999; McKinnon et al. 1999; Shernoff 1988; Solomon et al. 2007) along with institutional cultures that discourage the systematic addressing of sexual behavior, sexual health, or HIV sexual risk for persons with SMI (Wainberg et al. 2007; Blank et al. 2008). Case managers often lack the recovery orientation which would allow them to overcome these barriers as outlined by the early leaders of the consumer recovery movement (Deegan 1988; Fisher 1994; Davidson and Strauss 1992; Ridgeway 2001) and more contemporarily promoted by the Substance Abuse and Mental Health Services Administration's (SAMHSA) 2006 consensus statement on mental health recovery. SAMHSA outlines that recovery for persons with SMI encompasses all aspects of an individual's life and that providers and provider systems play key roles in creating and maintaining meaningful opportunities for consumer access to these holistic supports.

Recently, Solomon et al. (2007) confirmed Encandela et al.'s (2003) findings that formalized training of case managers in the delivery of HIV prevention is extremely rare. Further, Solomon et al. found an attitudinal disconnect between SMI consumers and their case managers regarding willingness to discuss sexual health issues. Consumers were quite open to and interested in addressing issues of sexuality and risk behavior while case managers displayed great discomfort and did not agree that HIV prevention work be part of their role

responsibilities. Finally, case managers were concerned about blurring professional boundaries and worried that relationships cultivated with consumers might not withstand the stress of introducing topics on safer sex.

These mounting concerns and pockets of resistance must be understood before we make a final turn of attention away from utilizing case managers as providers of HIV prevention for persons with SMI. Gordon et al. (1999) had earlier emphasized the underutilization of qualitative methods in HIV research despite recommendations from the Office on AIDS at the National Institute of Mental Health to attend to contextualized factors for traditionally underserved populations (Pequegnat et al. 1993).

Therefore, as a book end to our earlier qualitative study that assessed to what extent prevention services and materials already existed prior to the implementation of the PATH RCT, we again use these qualitative methods to uncover any changes in case manager attitudes and skills at the conclusion of the HIV prevention RCT. We additionally examined the extent to which leakage of the intervention occurred. Since community-based RCTs do not function in isolation but are imbedded within larger social contexts that play a major role in effectiveness of the experimental intervention (Orwin 2000), monitoring interaction between control and experimental providers is important. Focus groups are a sound method used to assess the fidelity of the intervention, as well as to determine these spill-over effects (Solomon 1997).

Methods

Setting

The locale for this study was a community mental health center (CMHC) situated within an urban hospital network. This CMHC provides services to center and southern parts of a large east coast city and proffers an array of child and adult services to economically disadvantaged neighborhoods. Though 82% of residents within the catchment area are Caucasian, most clients served at the CMHC are African American. The service area has over 50% of all homeless shelter beds as well as a large number of residential programs for persons who are homeless with cooccurring mental illness. This CMHC is also attached to one of five psychiatric Crisis Response Centers (CRCs) which serves all parts of the city. The agency serves 350 clients per day and 3,800 adults a year. Over three-quarters of the clients have severe mental illnesses, and two-thirds are dually diagnosed with substance abuse disorders.

The agency has three different case management programs. Resource Coordination (RC) is a combined broker-direct service case management program averaging 30 consumers per case manager. There is an Intensive Case Management (ICM) program for consumers assessed as having greater support needs where caseloads hover around 17 persons. Finally, ACCESS case management targets individuals with extensive homeless experiences and multiple other needs in addition to SMI, and these caseloads contain far fewer individuals at around 8–9. All three case management programs were involved in the present study.

Participants

Researchers obtained IRB approval to recruit this convenience sample of key informants for focus groups and in-depth interviews. We then sent a general description of our intent to conduct focus groups and interviews with both experimental and control case managers to a supervisory intermediary who shared this information at staff meetings. In order to make the focus groups convenient to attend, we advertised that we would be providing refreshments and would chose time slots well in advance and during a period where few case managers had scheduled vacations. Research assistants followed up with individual phone calls to confirm attendance with those who had volunteered.

We conducted two morning focus groups on different dates. Each of the groups lasted approximately two and a half hours and was held in a large private conference room within the CMHC. The first focus group was comprised of case managers that had been trained to deliver PATH and consisted of 10 individuals (5 African American females, 3 African American males and 2 Caucasian females). The second focus group included case managers that operated as controls and consisted of 5 individuals (1 African American male, 1 African American female, 1 Caucasian male, 1 Asian female and 1 Latino male). In depth interviews were conducted with 3 experimental case managers (2 African American males and 1 Caucasian female), 3 control case managers (1 African American male and 2 African American females), and 3 agency administrators (2 Caucasian females and 1 Caucasian male). For case managers, tenure within the agency averaged seven and a half years and most had worked in their case manager capacity in excess of 5 years.

Interview Procedures and Qualitative Data Analysis

Interviewers were trained and experienced in conducting research interviews. The facilitator of the focus groups and first author of this paper had extensive experience in conducting not only focus groups with this workforce type, but also possessed professional work experience as both a provider and administrator in other CMHC settings.

Focus group scripts were developed and structured to probe about the experience of either providing PATH or conducting case management work as usual while the study was going on. Experimental case managers were asked questions such as “What has it been like to deliver PATH to members of your caseload?; How has introducing topics of safer sexual behavior and condom use impacted relationships with your clients?; How do you feel about having case managers deliver this type of intervention?” For control case managers we included another domain of questions on leakage of the intervention. Some examples of these questions include “Have you gotten access to any of the materials associated with the PATH study?; How did you get these items and from whom?; How about condoms?; Have you seen or read the PATH intervention manual?; What parts have you used with your clients?; How have you changed your work with clients based on the PATH study?”

Focus groups were double audio-taped by two research assistants and later transcribed verbatim. Individual interviews were also audio-taped and transcribed verbatim. Transcripts were initially coded line by line by research assistants within the first 2 weeks of data collection. These transcripts were then analyzed by the research assistants and first author for implicit and explicit themes. Next, we used focused coding to synthesize and group together themes (Charmaz 2006; Glaser 1978) and corresponding excerpts from participant remarks. Finally, the second author of this paper reviewed coded transcripts and confirmed or amended the arrived at themes. In the section that follows, we describe the most universal and significant themes derived. We also present a few disconfirming cases that indicate some variation within our sample.

Results

Revelations: Experimental Focus Group Results

For the experimental case managers, there were several significant themes that drew consensus. Before sharing this detail, it is noteworthy that many of these case managers had working relationships with consumers that had lasted in excess of 4 years. Naturally, in those instances, case managers believed that they had developed an expertise of understanding those consumers and “knew” them well. Further, an essential element in training these case managers to deliver PATH related to developing their clinical skills of conducting risk assessment. In particular, they were told that they could assume nothing about their consumer's sexual behavior and were

coached intensively to ask open-ended questions and to avoid closed ended questions despite previously held assumptions about sexual behavior of these longstanding consumers.

The case managers were astounded to learn that many more of their clients were sexually active than they had previously thought. Furthermore, our study confirmed previous findings that case managers of persons with SMI are often unaware that some consumers are parents and may need support services related to parenting (Nicholson et al. 1993, 2007; Mowbray et al. 2001). There were also consumers whose sexual orientation came as a surprise to their case managers. Finally, many of the consumers shared with their case managers that they were not using condoms when engaging in sexual activity and some had previously been treated for a sexually transmitted infection.

However, the most stirring finding from this group was their high agreement that, rather than levy damage to relationships they had developed with consumers over the years, this intervention was at least neutral in its effect and at most, enhanced their relationships, but did not have a negative impact as previously thought. In fact, case managers shared that some consumers felt that they were being treated as "whole" persons in being asked these questions and this same view was reflected in case manager comments. One case manager shared, "I did not think she had a sex life. She kept that separate because she felt it was not expected of her ... that she was mentally ill." Another case manager described her consumer's reaction, "Ok, I have a mental illness, but you are treating me like I can learn, like I can be educated ... they appreciated us coming to them." Case managers reported that consumers were taken aback in some respects due to the alteration of expected routines with their case managers. One case manager reported that his client said, "Why are you asking about my sex life? What do you care? It has nothing to do with my medication."

Not surprisingly, experimental case managers also concurred that learning to deliver PATH enhanced their overall skills as case managers. Many said that this experience helped to make consumers comfortable, helped forge stronger relationships with consumers and made it easier to talk with them about all sorts of topics, not just safer sex and safer drug and alcohol use behaviors. "It {introduction of the topics of safer sexual behavior and condom use} opened up a lot of consumers from whom I would normally just get one word answers from ... it allowed them to talk about anything."

The case managers did believe that discussions of safer sex were better held between same gender case manager/consumer dyads. Many had made arrangements with an opposite gender case manager for delivery of the PATH intervention to an opposite gender consumer during the course of the study. However, they still believed that case managers were not necessarily the best provider to be delivering HIV prevention despite the fact that they all wanted the PATH program to continue (Table 1).

Are You Protecting Yourself?: Control Focus Group Results

Findings from the control focus group and control case manager in-depth interviews reinforced earlier empirical conclusions about the barriers to case manager delivered HIV prevention interventions. Case managers assume that clients are not sexually active and, if they address safer sex behaviors, it is mostly directed at clients they view as "promiscuous." As one case manager stated, the conversation goes something like, "It seems you're having sex with someone ... have you had protected sex?" In response to a question about whether safer sex practices or proper condom use is discussed with consumers, another case manager stated, "Safer sex, yes ... condom use, no." However, without including condom use, there is, of course, no full discussion about safer sex practices taking place.

The control case managers expressed concerns about bringing up such sensitive material with consumers who are gay, psychotic, are detoxing or who have a history of sexual abuse. Though they agree that HIV prevention is important, they believe that therapists, “clinicians” and psychiatrists should be the ones to provide safer sex education to their SMI consumers. They did report being more aware of sexual issues with their clients while the PATH study was being carried out, though none of the control case managers reported having had access to any study materials such as intervention manuals, condoms or educational pamphlets.

On being randomly chosen to be a control case manager, one woman said, “I was kind of relieved, cause there were just certain clients that I just could not imagine, clients where there were already certain boundary issues and I could just not, could not see me having this discussion with them without making them think that this was a, you know, come on, or that this would be a very difficult discussion.” She further articulated a worry about having to disclose aspects about her own personal life and habits and an inability to negotiate professional boundaries, “I think that the disadvantage would be that feeling that they now have free reign to ask me about my ... so I guess the disadvantage would be my clients telling me how you look—oh you've gained weight (laughs), it blurs that boundary.” It was as if she felt that a quid pro quo was required due to the informal nature of the relationships and settings where interactions take place, “And, like I said, clients asking what about your life and trying to keep your personal still personal while really being all in this person's life.”

Finally, another control case manager reflected that, “It definitely helps you to look at a person as a whole. You think of them more than just their disease, you also think of them as a person. That does get left out.” This statement underscores that while case managers want the best services for their clients and want to be good at their jobs, they, nevertheless, have developed a customary approach to truncating the lives of their SMI consumers into a few salient, albeit stigmatizing characteristics that are associated only with their disease (Table 2).

Discussion

We observed a remarkable process unfold with the case managers who had learned to deliver PATH to their consumers. First, due to lengthy relationships, many assumed there was nothing of import in the lives of consumers to which they were not already privy. Second, resistant at the start, once case managers began to incorporate the clinical skills they were taught, such as asking open-ended questions, they were faced with the growing recognition that they had indeed seen consumers as their illnesses. Many case managers had viewed consumers as not having a self apart from their diagnosis and consumers had responded to their vision in kind. The mere notion that a consumer thought she was not “expected” to have a sex life or of another being jarred by being asked about something other than medication reveals the diminishment of the sense of self these individuals had experienced in relationship with their case managers. We were amazed that a case manager could have a relationship with a consumer for many years and not know she had children, or a sexual partner or any of a myriad of life experiences that constitute our humanness.

Also noteworthy, despite earlier case manager protestations, instead of hurting formerly established case manager/consumer relationships, discussing safer sex and safer drug and alcohol use in the context of the HIV prevention intervention was more often a vehicle that enhanced general clinical interactions with SMI consumers. Furthermore, while case managers marveled at the impact of the intervention as having been facilitative of generally stronger relationships with their consumers, “opened up consumers I would normally just get one word answers from ... allowed them to talk about anything,” they did not seem to grasp that it was the simple addition of a new clinical skill set that yielded improved working alliances. In fact, within this study, we had measured alliance using the HIV Risk Alliance Scale (HRAS) and

determined that when the consumer felt comfortable talking to his/her case manager about sensitive issues such as personal sexual behavior, they were actually more likely to use condoms. We would assert that the feeling of comfort on the part of the consumer in discussing these topics among others is likely a response to a more engaging and clinically skilled case manager. Thus, it is important that the case manager is seen by the consumer as being interested, open, non-judgmental, and closely listening to the responses that the consumer provides to questions. We found that in teaching how to conduct the HIV risk assessments for PATH we had to carry out extensive trainings with case managers that included role plays, specifically working with them on skills of engagement designed to elicit more expansive responses to questions about sexual and drug and alcohol use behavior. None of the case managers were equipped to work with clients in this way prior to our trainings. Through this training we heightened awareness of the case manager's tendency to ask closed ended questions and their propensity to tell clients what to do. We insisted, despite case manager opposition based on what they thought they knew about their consumers, that case managers ask open ended questions about sexuality and drug and alcohol use rather than closed ended questions that would invite single word responses. As a consequence of this PATH training, the case managers developed stronger recovery oriented clinical skill sets.

In essence, though centered around assessing for risk of sexual, drug and alcohol use behavior and ultimately collaborating on an individually tailored safer goal plan that the consumer is genuinely willing to try, the clinical skills taught within PATH were facilitative of the adoption of a recovery orientation for the practitioner that used it. The recovery movement has been about addressing the “whole” person and not compartmentalized pieces of individuals with mental illnesses, thus embracing a posture of respect, collaborative power sharing and methods of open communication. Without awareness, these case managers had begun to learn to work from this recovery framework.

Additionally, ironically, the unusual situation of having working relationships with consumers, often for more than 5 years, did not necessarily serve to make case managers more expert at knowing their consumers and allocating appropriate services. In fact, it may have served to obscure varying features of their consumers since case managers had such confidence that, most likely from assessments or intakes conducted long ago, their consumers were the persons they imagined them to be. Ultimately, these case managers communicated, through their actions and words, the notion that consumers were simple and fixed and thus, different. The case managers consequently focused on the “spoiled identity” (Goffman 1963; Link and Phelan 2006) and illness parts of their consumers they felt competent to work with.

Wright et al. (2000) have discussed this concept in relationship to HIV prevention in persons with SMI and have stated that the sense of being “different” may contribute to increased feelings of self-depreciation among adults with SMI which may in turn decrease their ability to negotiate and insist on condom use. Wainberg et al. (2007) have also drawn attention to effects of mental illness stigma on sexual risk behavior, a relatively unexplored area of HIV risk among people with SMI, and highlighted the need for further study.

We determined that there were three main findings from this qualitative study with the control case managers. First, findings reinforced earlier studies that revealed case managers untrained in HIV prevention would assume most consumers were sexually inactive, target overtly “promiscuous” consumers for any discussions on HIV risk, express discomfort with the prospect of discussing topics related to sexual behavior, and worry about boundaries and the prospect of being misunderstood.

Second, though control case managers had not been trained to deliver the PATH intervention, the vicarious exposure to a training taking place in their agency that focused on consumer safer

sex and negotiating intimate relationships, forced these control case managers to consider what meaning may arise for consumers and for themselves as a result. They realized that they needed to view consumers as whole people rather than their diseases. Control case managers had not obtained any of the materials from the study but had developed a heightened awareness of sexual issues for consumers.

Operating from a framework of recovery requires clinical skills rarely in the possession of case managers who work with persons with SMI. More than extending our understanding of the factors interfering or facilitative of case manager delivery of HIV prevention interventions to their consumers with SMI, through this study, we discovered a profound deficit in clinical skills that would not allow for most types of assessments, let alone HIV risk assessments. We uncovered why we cannot consider case managers being solely accountable for the delivery of HIV prevention to persons with SMI given their current skill level. The untrained case manager's typical foray into a discussion of safer sex, speaks volumes about lost opportunities for HIV prevention interventions for persons with SMI and the lack of public sector attention to HIV in persons with SMI makes it difficult to explicate how HIV training could be made available given the condition of current resources. If we are going to make case managers responsible, they must be given the proper tools to carry out such an important task. In fact, without suitable and appropriate training, the case manager/consumer relationship dynamic may form a social determinant of HIV risk in persons with SMI in contributing to the destructive effects of mental illness stigma. Case managers themselves often do not believe that they are the best provider type to deliver these interventions, perhaps because they recognize their lack of clinical skills and do not feel competent to do so.

This study has some limitations, including that the experimental focus group was twice the size of the control group and all case managers had unusually lengthy tenures at the agency, making generalizability a concern. One of the researchers functioned dually as both a focus group facilitator and trainer of experimental case managers at the start of the study. However, throughout several years of study implementation, research assistants were paired with case managers to provide technical assistance during which the researcher in question did not play a prominent advisory role to case managers, thereby reducing the likelihood of social desirability in responses. These items notwithstanding, the study raises important issues regarding more complex barriers to case manager delivery of HIV prevention for persons with SMI. Further, if we are going to seriously address this longstanding public health problem for SMI individuals, all constituents, including advocates, researchers, providers and policy makers will have to more concertedly stress the urgency and importance of demanding recovery orientations from providers of services to persons with SMI. Case managers are often provided with facts and education on issues such as HIV when trained in their agencies, but seldom are they taught techniques to intervene. Extensive clinical skills training for how case managers can integrate issues of healthy sexuality in their routine practice should be mandatory and not discretionary. Further, these trainings must go beyond sharing statistics and information and include skill development components. Developing successful HIV prevention strategies for persons with SMI requires that we assess them as “whole” human beings and consequently equip providers with the necessary clinical training to do so.

Acknowledgments

This research was supported by funding from National Institutes on Drug Abuse (NIDA) for *HIV Prevention Among Substance Abusing Seriously Mentally Ill Adults, R01-DAO15627.*

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Table 1

Themes and excerpts from experimental participants

Revelations following PATH delivery	Consumers are sexual. Some have had children. Some are not heterosexual. Some consumers have experienced sexually transmitted infections. Consumers are not using condoms. Broaching subject of sexual behavior did not negatively impact case manager/consumer relationship. In some cases, clinical skills taught tended to improve communication in other domains. Clients appreciated being thought of as "whole." One case manager shared prevention materials and intervention with her family members. Generally all agreed it had been a positive experience for them and for their consumers
A new skill set	Case managers grateful to have learned a new skill (HIV prevention)
Gender matching	Belief that discussions of safer sex worked better with gender matched dyads
Case managers appropriate to intervene?	Should be optional for case managers to provide HIV prevention. Still think that therapists and psychologists or even peer providers would be better choices to deliver the HIV prevention intervention
Continuing availability of safer sex resources within agency	Wanted to have program continue into the future and to have a stock of condoms and pamphlets on HIV prevention available

Table 2

Themes and excerpts from control participants

Assumptions about clients w/severe mental illnesses	"Many people are not sexually active"—Reinforce earlier findings Promiscuous clients are the SMI individuals who could use HIV training
Discomfort with topic	"He was gay and quite flamboyant and I was uncomfortable ..."
Clinical Skill of case manager	"Seems like you are having sex with someone ... are you having protected sex?"
Perceived barriers to discussing safer sex and drug use behavior	Discomfort with gay clients, worry about upsetting persons who are psychotic or detoxing or known to have been victims of previous sexual abuse
Gender matching	Would only discuss topics related to safer sex with consumers of the same gender
Boundaries	Concern about consumer perception that this is a "come on." Worry about how to respond when consumer asks about case manager's sexual behavior
Case managers appropriate to intervene?	Not case managers, but therapists, "clinicians," psychiatrists should be the ones to discuss this topic
Leakage of intervention	Due to the presence of research assistants interviewing clients, are more aware of sexual issues. Did not get access to materials (condoms, pamphlets etc...)