"Everything that I thought that they would be, they weren't:" Family systems as support and impediment to recovery

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ABSTRACT

Family help provision for adults diagnosed with co-occurring severe mental illness and substance dependence is understudied. This article draws on verbally-administered structured and semi-structured interviews with one group of 122 behavioral health care clients and one group of 54 client-nominated family members. In New Mexico, USA, these were collected as part of a larger, long-term study. We examine the latter's concerns and fears, relative desire to be involved with treatment, and difficulties connecting with professionals, as well as forms of assistance they gave to clients and intra-family communication. We found that family members' actions and communications often support client recovery through resource provision and other, intangible forms of help. However, their misunderstandings of and lack of knowledge about client experiences can also impede recovery. We also compare the two groups of interviewees' perspectives on assistance given to clients by family members. We give examples of family attempts to deliver help and their consequences. Last, we offer suggestions for providers and policymakers to better help family members achieve their goal of caring for clients in recovery.

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Introduction

Recent changes in behavioral health policy and philosophy emphasize the importance of including family in planning, delivering, and evaluating services, based on research concerning treatment effectiveness. Individuals with behavioral health difficulties whose families are involved in care, including but not limited to involvement in family therapy, adhere better to treatment regimens and experience more positive outcomes than those lacking such assistance (Biegel, Ishler, Katz, & Johnson, 2007; Brent & Giuliano, 2007; Nelson & Sullivan, 2007; Rotunda, O'Farrell, Murphy, & Babey, 2008). Yet lack of information, exclusion from treatment, and inability to contact providers are common complaints of family members who want to provide help. This is especially true in cases of adults diagnosed with co-occurring disorders (COD) of serious mental illness (SMI; e.g., schizophrenia or bipolar disorder) and substance dependence (SD; e.g., cocaine addiction) (Goodwin & Happell, 2006; Milliken, 2001). Exclusion from treatment is notable as it contrasts strongly with family inclusion in treatment for children and adolescents with behavioral health difficulties (Henggeler, 1999). Interpretations of confidentiality laws such as the Health Insurance Portability and Accountability Act (HIPAA) may be one reason why they are left out (c.f. Levine, 2006). However, despite being excluded or absent from formal treatment, family members can encourage recovery by providing informal care and assistance.

In this article, we focus on people who want to formally and/or informally "support" (i.e., provide help to) a family member with COD and avoid "enabling" behaviors that increase the likelihood of continued behavioral health problems. The purpose of this paper is to illustrate ways that the former both intentionally and unintentionally affect recovery, and how misinterpretations and lack of communication or information can lead to inadvertent interference with recovery. To do so, we compare descriptions and examples of "support" from family members and adults with COD who are receiving publicly-funded behavioral health care. Although family members did not always see their actions as specifically helpful, clients indicated that active and passive forms of care and encouragement provided scaffolding for their recovery. However, insufficient information about COD and learned mistrust toward clients sometimes led to misinterpretations and miscommunications that interfered with recovery. These misunderstandings

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illustrate the importance of actively involving families in treatment to increase their knowledge of the dilemmas clients face, and of when and how to provide effective assistance.

Overview of COD

SD and SMI commonly co-occur; having one increases risk for the other. Marshall (1998) found that having an SMI doubled the risk of alcohol dependence and quadrupled the risk of other drug dependencies. Prevalence estimates of COD in the United States range from 20% to over 80% of individuals with SMI, depending on the study's methods, definitions, and scope (Elam, Jaffe, & Segal, 2007). Data from the 2004 and 2005 National Surveys on Drug Use and Health indicate that 1.2% of adults − approximately 5.2 million people − were diagnosed with COD in the previous year. Roughly 41−53% received no treatment that year; only 8.5% received treatment for both disorders (SAMHSA, 2008).

Individuals with COD incur higher treatment costs, interact more frequently with medical and legal institutions (Gamm, Stone, & Pittman, 2003), are up to 60% more likely than those with SMI alone to be hospitalized, and are significantly less likely to adhere to medication regimens. A particularly high-risk behavior is "binging," when they are likely to stop taking prescribed medication while ingesting other psychoactive substances. This throws off their body's chemistry in two ways, and increases the risks just described (Comtois, Tisdall, Holdcraft, & Simpson, 2005).

People with COD face greater difficulties managing day-to-day situations than those with one condition. They are at higher risk for becoming homeless or incarcerated than their single-diagnosis peers (McNiel, Binder, & Robinson, 2005; Marshall, 1998) and for acquiring additional illnesses and disabilities (Comtois et al., 2005; Geppert & Minckoff, 2004; Klinkenberg & Sacks, 2004). They have difficulty gaining and holding jobs, and may not interact well enough with assistance agencies to maintain housing and food security (Gamm et al., 2003). They are at higher risk of trauma, suicide, domestic violence, and social withdrawal (Geppert & Minckoff, 2004). Family members, including those who might otherwise provide help, may reject or "disown" them due to overall family strain, a perceived history of untrustworthiness, or failure to attend critical social events (Hawkins & Abrams, 2007; Muslow, 2007).

Families: a brief overview of relevant research

Family support for individuals receiving behavioral health services is an understudied topic (Biegel et al., 2007). Research on caregivers for individuals with SMI has focused on "burden of care" and, to a lesser extent, rewards of caregiving. Researchers highlighted caregivers' fears for the client and feelings of shame; the lack of help and respite for caregivers; and stigmatization by professionals, community members, and media representations (Biegel, Katz-Saltzman, Tracy, & Townsend, 2006, Biegel et al., 2007; Corrigan & Miller, 2004; Doornbos, 1996; Larson & Corrigan, 2008; Peljert, 2001; Young, Bailey, & Rycroft, 2004). While noting that integrating clients into households through chores and family role fulfillment mitigated or eliminated feelings of burden and fostered positive family bonds, the literature largely neglects family dynamics that can marginalize individuals with COD.

Reports on the role of family in the case of people with SD largely ignore effects on family well-being and focus primarily on how relatives' providing help to clients impacts their recovery (Biegel et al., 2006; Nelson & Sullivan, 2007). Literature on "social support" for people with COD is sparser (Biegel et al., 2006; Tracy & Johnson, 2007). In their review of this topic, Tracy and Biegel (2006) found only seven articles that examine social networks and COD.

None compare perceptions of specific forms of assistance or directly examine intra-familial interactions, including behaviors or communications that can lead to aversive events or stress. Both significantly increase the risk of relapse (Ungless, Argilli, & Bonci, 2010). Low self-esteem or serenity, high impulsivity, and anger also increase relapse risk and are impacted by interpersonal relations (Pekala, Kumar, Maurer, Elliott-Carter, & Moon, 2009).

This article addresses these gaps in the literature by examining four understudied areas: First, little research explores specific fears of families with members diagnosed with COD. Second, research focusing on types and perceptions of assistance is scant. Guarnaccia and Parra's (1996) work on types of role-based care, instrumental versus socioemotional assistance, and ethnicity-related differences in care provision is a rare exception, but does not consider SD or COD. Third, we explore how families can impede recovery if members remain unaware of challenges to recovery. Last, although researchers highlight the value of family members' giving information to service providers (e.g., Muslow, 2007), the literature does not address interpretation of verbal and nonverbal communication.

Method

As part of a multi-method study of how behavioral health reform impacted access to and quality of care for low-income adults with SMI, SD, or COD in New Mexico, we undertook a qualitative investigation of help provided to clients by agencies, public services, and individuals. We also looked at how clients and their friends and families sought out and participated in treatment services. Participants were recruited from 14 behavioral health agencies, including community mental health centers, residential and outpatient treatment centers, and small group practices, located in six counties (three rural and three with large urban areas) between 2006 and 2007. More information about the policy reform and the broader study and its methods are available in separate articles (Kano, Willging, & Rylko-Bauer, 2009; Willging, 2008; Willging & Semansky, 2010; Willging, Waitzkin, & Lamphere, 2009). A limitation of the sampling method that is not addressed elsewhere concerns recruitment of client interviewees. The approach made it possible to recruit individuals who otherwise might not have participated. However, those with denser agency-related networks were more likely to be included than who were not well-known to providers.

Interview guides and informed consent protocols were approved by the Institutional Review Board of the Pacific Institute for Research and Evaluation. Candidates for client interviews were identified with help of agency personnel. We invited clients to take part in the study through presentations targeting treatment support groups and psychosocial rehabilitation programs at each agency. Eligible candidates included individuals with a diagnosis of SMI, SD, or both who (1) were under 200% of the Federal Poverty Level ("low-income"); (2) had accessed or attempted to access publicly-funded services in the preceding year; and (3) were age 18 or older. We recruited 325 clients to take part in semi-structured interviews with a verbally-administered demographic component. Clients were each asked to nominate an individual for a similar interview who had influenced their help-seeking activities or otherwise supported them in recovery; 217 such individuals were recruited. "Support" was defined for family members during the informed consent process before each interview.

Two complementary interview guides were created for clients and their nominated friends and family. An array of topics was addressed; those related to this paper include illness understandings, symptoms of concern, fears regarding illnesses and symptoms, treatment involvement, and help provision. Interviews took place in locations convenient to participants, e.g., agency settings, coffee

Table 1
Demographic characteristics of interviewed clients.

Race/Ethnicity:	Hispanic	38%
	White, non-Hispanic	36%
	Native American	19%
	Mixed Racial Heritage	5%
	African-American	2%
Sex:	Female	60.5%
	Male	39.5%
Age:	16—20	2%
	21—30	19%
	31—40	39.5%
	41—50	23.5%
	51—60	14%
	61—70	2%

shops, and homes. These digitally recorded interviews averaged 45 min.

For this analysis, we developed two datasets from the larger sample described above: (1) transcripts of clients with COD who self-described as having a COD or were enrolled in a specialized COD treatment program ($n = 122$); and (2) individuals they recommended for interviews ($n = 68$, 54 of whom were family, including people related by descent, marriage, or domestic partnership). Table 1 describes demographic characteristics of the client sub-sample.

Table 2 describes the demographic characteristics of the family sample. Slightly over half (52%) lived with the client, mostly in partnerships or mother/child relationships.

All interviews were professionally transcribed, imported into an electronic database, and analyzed through series of iterative readings. A systematic line-by-line categorization of data into codes using the qualitative software NVivo (version 8) allowed us to determine prominent issues in each dataset. We first pursued coding through development of a descriptive coding scheme from transcripts based on specific questions and broader domains of the interviews. Second, we engaged in "open coding" of all transcripts to determine new topics and themes and compiled detailed memos to describe the significance of each. Third, we used "focused coding" to determine which topics and themes were repeated often (e.g., lack of treatment involvement), and which represented unusual or individual concerns (Emerson, Fretz, & Shaw, 1996). Systematically combining NVivo features such as question-level coding, automatic source and reference counting, and hierarchical node structures made it possible to generate counts and percentages of specific types of information relevant to each theme (QSR, 2008). The results of this analytic process were vetted at research

Table 2
Demographic characteristics of interviewed family members.

Race/Ethnicity:	Hispanic	39%
	White, non-Hispanic	33%
	Native American	15%
	Mixed Racial Heritage	13%
	African-American	0%
Sex:	Female	87%
	Male	13%
Age:	16—20	7.6%
	21—30	27%
	31—40	19%
	41—50	13.4%
	51—60	5.7%
	61—70	0%
	71—80	7.7%
Relationship to Client:	Mothers	26%
	Partners	17%
	Siblings	11%
	Children	9%
	Other Family Members	37%

team meetings involving masters- and doctorate-level anthropologists involved in collecting and coding data for the broader study. Discrepancies in coding and analysis were identified and resolved during these meetings.

Findings

Key findings of this analysis concern family members' specific fears about a loved one's illnesses; their own involvement in treatment; types, manner, and effectiveness of provided assistance; and unintended impediments to recovery sometimes created by these attempts. Overall, family was rarely directly involved in treatment, although members often encouraged treatment use and adherence. Types of help that were given to clients varied broadly, including resource provision and passive and active forms of intangible support, defined below. Examples include "being available" for client contact (passive-intangible-support), providing transportation (active-resource-provision), and voicing encouragement (active-intangible-support). Critical unintentional barriers to recovery usually resulted from loss of trust and miscommunications that typically originated in lack of information. Examples illustrating commonly-shared experiences and quotations that underscore family members' and clients' perspectives are provided below to further illuminate such difficulties.

Fears and concerns about clients

Critical aspects of "caregiver burden" involve worries, fears, and concerns about clients. Family members were asked which of their loved ones' symptoms concerned them most, and what was their greatest fear about their clients' illnesses. Sixty-one percent reported that illness-related emotions and the behaviors they caused worried them most, especially depression/hopelessness (25%), anger/rage/violence (32%), and social withdrawal (28%).

When naming their greatest fear for the client, physical safety and health concerns predominated: death (42%), suicide or self-injury (29%), health difficulties (12%), and getting into dangerous situations (6%). Most family members feared deliberate suicide or self-harm, as when one described behavioral escalation:

He's told us that he's cut himself several times but not deep enough to where it would kill him. That's a cry for help when somebody is cutting themselves; they want you to do something and if you don't see that's a cry for help then he's gonna do something more drastic. Which is what I think he did this last time.

Some family members also feared the client might unintentionally cause self-injury or death. One worried that her sister might "hurt herself during a blackout" or that "somebody might hurt her." She added, "If she gets too drunk, she'll just walk out of the house, and I don't know where she goes. And that's what I worry about." Similarly, a father worried about potential consequences of a self-cutting mistake: "If she cuts in the wrong place and nobody's around to see her, she could bleed to death. I mean, if she cuts her leg, it'll heal, 'cause she's just cutting into muscle."

Other family members feared violence toward both self and others, especially from clients with histories of aggression. Nine percent of interviewed family members indicated concern that the client would "hurt" him or herself or a household member; an overlapping 10% worried that clients prone to anger outbursts would harm others but not themselves. One wife said her primary fears were her husband's "…threats of killing me, taking his life. Murder/suicide was the talk." Another stated, "What I'm really concerned about is that if he would keep on drinking, he would probably die because he has heart problems, and I wouldn't want

him to go out and kill anybody either." However, there were few reports of actual household violence.

Twenty-one percent of family members cited the client's prognosis as their greatest fear, expressing concerns that the person would "get worse" or "not get better." Long-term behavior patterns sometimes produced specific apprehensions. One husband feared his wife would "disappear again," unable to find her way home, and he would be unable to find her. Others worried about emotional or social problems the client might experience rather than physical danger. For example, some family members were concerned that the client would not learn interactional or self-care skills well enough to become socially integrated. One father said,

> She seems to be unhappy. I'm concerned about her having a good life. She's my child. She ticks me off sometimes, but she's my firstborn, and I love her. I want her to have a decent relationship where she can really go have fun with somebody, where she can feel like she belongs, where she can feel proud of her accomplishments, and where if she does have failures and she feels bad about it, that she feels bad about it in a normal, natural way, not like she's devastated and it's the end of the world. I would just like for her to be able to deal with reality and to be able to function in her world. I would love to see her actually really happy.

Treatment involvement

When directly asked, most family members (68%) said they were not included in treatment or treatment planning. Two others were "not sure" whether they were involved. One said the family "should" be more involved. Those who had participated in treatment were asked if they were satisfied with their level of involvement. Two wanted to be less involved; both were the only social resource for clients who had recently undergone serious crises. Three were satisfied; the remaining 10 wanted to be more engaged. Their most common reasons were to (1) be better advocates, (2) give information to providers, and (3) be better "able to help." Of those who had participated, only one regularly attended counseling sessions. Two others had sought services on the client's behalf; the rest had "encouraged" treatment.

Most had not received family psychoeducation (83%), information on "family support groups" (83% had not), or assistance with family difficulties. When asked if they had been invited to evaluate services, 96% said no. Family members were specifically asked how they coped with their loved one's illness. The most common answer (28.6%) was that they tried to communicate with the client; 21.4% said they created distance between themselves and the client; and 19.6% used prayer and/or meditation. Only three sought help from others: one from a counselor and two from other family members.

They were also asked whether they had participated in "support groups;" meetings of the National Alliance for Mental Illness (NAMI), Al-Anon, and Alateen were provided as examples when interviewees asked or seemed uncertain. No families used a fully-inclusive form of family therapy. Four family members reported attending Al-Anon in the past. Two found it helpful; the others said that transportation difficulties, lack of child care, and/or a feeling that the meetings were "bitch fests" or too "cliquey" dissuaded them from attending. No family members in this sub-sample participated in psychoeducation groups such as NAMI's "Family to Family" program. In most areas, there were no groups designed for family members of clients with COD. In some, existence of such groups was intermittent or focused on special events such as treatment program "graduations." Groups that re-formed did not consistently inform previous participants that the resource was again available.

Defining effective assistance: comparing family members' views with clients'

Although few family members participated in their treatment, some clients were amazed at and deeply gratified by help and encouragement they received while engaged in treatment. Past negative interactions with family had led many to believe they were "on their own" in recovery. The woman quoted in this paper's title explained, "I thought they would've been embarrassed by the fact that I was at a rehab, but everything that I thought that they would be, they weren't. In a lot of ways they are supportive." Another said, "My mother and wife are the main two that are really motivating me. I've got their support more than I was expecting." These new understandings enhanced clients' commitment to recovery and "starting over."

Interviewed clients were asked to describe help received from family and friends; relatives were asked to describe help they provided to clients. Follow-up questions specifically asked whether family members provided transportation, child care, housing, financial assistance, or help with treatment planning (Table 3). Two main, overlapping categories of assistance emerged from interviews: "resource provision" and "intangible support."

"Resource provision" is similar to the "instrumental help" described by Guarnaccia and Parra (1996): family members provided funds, commodities, and logistical assistance, such as transportation, to the client. According to clients, 59 (86%) of family members provided resources. Compared to clients, family members underreported resource provision to their loved ones. Most did not mention such help unless specifically asked. Some believed that helping with housing, childcare, or small, regular amounts of money was "just something family does." In contrast, clients typically considered these acts to be important, even essential to their recovery, simultaneously marking their status as an "included" family member and therefore an especially significant form of desired care.

We define "intangible support" as emotional, structural, moral, spiritual, or other interpersonal forms of encouragement, broadening Guarnaccia and Parra's (1996) category of "social and emotional support." Intangible support was provided actively or passively. "Active" intangible support was knowingly provided to clients by family. It included boundary setting and maintenance, vigilance for potential problems, determining client needs, and consciously refraining from acting. Reflecting their main worries, fears, and concerns for clients, some family members tried to create safe environments for their loved ones. For example, one aunt explained how she did so:

> We got rid of all of the drugs in our house: Cough syrups, cold medicines, everything — vanilla extract. I mean all the things that you think would do potential harm to somebody who's an alcoholic and a drug addict.

"Passive" intangible support was provided without conscious effort, sometimes described as "just being there" or as a lived assurance that the client was not alone. One woman described how she helped her nephew: "I'm not just gonna not be there and go away, because you're family. Family sticks together." Another form of passive intangible support occurred when family members served as a motivation for recovery; children and mothers most often provided such living incentives. One client stated, "My whole plan is to find myself, better myself. I want to be the mother that I was to my kids. I want to be the daughter to my parents. I want to be the sister to my brothers and my sister, and the auntie to my nephews and nieces that I once was."

In some cases, family members' acts combined resource provision and intangible support. One client said,

Table 3
Types of assistance provided by family members to clients. Multiple answers were sometimes given.

Type of Assistance	Client ($n = 82$)	Family ($n = 55$)
"Being There"	11/13.4%	0
Emotional or Moral Aid	54/65.9%	13/23.6%
Encouraging Social Activity	5/6.1%	0
Encouraging Treatment	81/98.8%	15/27.3%
Feedback on "How Client is Doing"	9/11%	0
Financial	77/93.9%	21/38.2%
General	82/100%	0
Going to Appointments	11/13.4%	0
Childcare	31/37.8%	6/10.9%
Housing	15/18.3%	11/20%
Listening	29/35.4%	13/23.6%
Making Appointments, Finding Services	10/8.2%	0
Reading/Writing, Math, Forms	5/6.1%	0
Family Socializing	15/18.3%	2/3.6%
Encouraging Self-Care	9/11%	0
Transportation	50/61%	8/14.5%
"Understanding"	18/22%	0
Other	11/13.4%	1/1.8%

[My siblings have] been real supportive so I think those two assets, positive assets, have really helped me to go on and not quit. For my birthday they brought me a present. They really listen to me and they really understand what I'm saying.

This celebratory gesture marked a significant restoration of "normal" relations for the client, as birthday gift exchange between family members is customary in mainstream U.S. culture.

Overall, clients interpreted more of family members' actions, environment creation, presence, and emotional responses as important forms of help in recovery than did family members. Acts of resource provision that family considered low-cost or culturally-expected behaviors were interpreted as important acts of generosity, trust, and/or inclusion by clients. Family members never described themselves or other relatives as living incentives, in contrast to how clients sometimes described them.

Unintended impediments to recovery

Some clients and family members reported that relatives had lost trust in clients, communicated with them in problematic ways, failed to maintain proper boundaries, or stigmatized them. Feelings of stress, isolation, depression, lowered self-esteem, anger, and "cravings" were linked to these reports. In some cases, family members' actions led to events that clients considered aversive (e.g., being exposed to substance use or having arguments with children). Lack of information about recovery stages, symptom management or exacerbation, relapse "triggers," medication side effects, and other aspects of clients' experiences sometimes led families to act on limited or mistaken understandings of relapse, recovery, and the impact of COD on clients' everyday lives. Ensuing difficulties commonly impeded recovery, despite their grounding in "good intentions."

Loss of trust

Interviewees in both groups regularly said that creating or restoring interpersonal trust was critical for recovery. Although clients were more likely to raise the topic, 28% of family members reported that the client had lost key family relationships due to loss of trust. One client described gradual losses of family and friends, saying, "I really do not have anyone to go to at all, you know? I'm at the end of my address book. Everyone's crossed out." Another reported,

My little sister doesn't really trust my mom now. And my little brother…We all still are kinda like apprehensive about trusting her. For a long time I didn't even want to talk to her, you know? And if I did, I couldn't trust anything she said or take anything seriously. But it's totally different now [that she has been sober long enough to regain trust].

Recovery was impeded when loss of trust continued long enough or was so intense that the client believed a desired relationship could never be healed. However, positive relationship recalibration sometimes occurred over time. This was typically a difficult, painful process. One client said, "It's a very slow process. Because you burn bridges and it's hard to build those bridges back up."

Interviewed clients and family members considered their efforts to be worthwhile when they had hope for repairing the relationship. One client said,

Actually, before I didn't have no trust with my parents or nothing, and now I've gained their trust and they're very supportive of me. I'd see them but they wouldn't really talk to me. And now it's like they're taking me to my meeting, to my [urine tests], to everything. I gained their trust. There's nothing like having your parents. My parents are the best.

Sometimes re-establishing trust required a joint effort. A woman in inpatient treatment described how she and her daughter cooperated, explaining, "I asked my daughter to write a list of items that she needs from me to regain trust. And I addressed these items and wrote them out. It's a plan to put in action when I'm released."

Mistrust and interpersonal distance sometimes led family to withdraw or form rigid, antidependent boundaries (Minuchin & Fishman, 1981) to "protect" themselves and others against being hurt or betrayed. Clients suggested that such boundaries led to feelings of stigmatization, isolation within social settings, lowered self-esteem, and stress, which increased the risks of relapse and symptom exacerbation. Family members typically did not discuss such boundaries or briefly spoke about maintaining interpersonal distance as protective.

Another type of mistrust reflected changes in family responsibilities. Some individuals responsible for childcare while the parent with COD was unable to perform this role continued acting as the "primary parent" rather than stepping out of the position upon the client's return. Clients reported difficulty regaining the parental role, stating that children who were used to "getting away with" misbehavior because the client had been "high" or absent resisted when the client disciplined them, or imposed or enforced rules. In contrast, they were well-behaved for the substitute caretaker. Some clients said their child had said he or she was not the "real" or authoritative parent, due to role abdication.

Some substitute caretakers were relieved to relinquish parental responsibility. In other cases, struggles over who was "in charge" led to family tension, violence, client uncertainty about parenting ability, or other negative repercussions that interfered with recovery. This was most often reported when the caretaker doubted the client's ability to be successful as a parent, disagreed about parenting style, or "naturally" took on the role. Conflict over who held authority began as soon as a client returned home or was delayed during a "honeymoon" period while family tried to adapt to the client's changed needs and behaviors.

Misunderstandings of treatment and recovery

Acting on misinterpretations of behaviors emerged as another way family inadvertently impeded recovery. One client said her family routinely interpreted her anger as "a symptom of mental

illness" or "flipping out," rather than as a situation-appropriate emotion. The resultant stress and interpersonal conflict made her feel like an outsider, which led to risk factors such as self-doubt and increased anxiety and anger. She had not discussed this with family, as she did not know how to do so without risking further "misunderstanding." Another client reported that a family member was

> …fond of using the infuriating, hot button statement of family of people with mental illness, blaming whatever they're upset by on mental illness. "I'm mad at you, but it's because of your mental illness." No, you're mad at me because I'm pissing you off. It's not my mental illness.

Her perception that any negatively-perceived emotional response was ascribed to "illness" rather than to "normal" family interaction made her feel "different," "misunderstood," and "angry" − sentiments she did not communicate for fear of rejection. Clients reporting this form of miscommunication said it sometimes led to their ending a specific interaction or decreasing communication overall, creating stress and isolation: known risk factors for relapse.

Family members who wanted to help but were uninformed about COD or *how* to help sometimes treated clients as though they were extremely emotionally fragile, making them feel negatively "singled out." One client described this as being "tip-toed around." Many family members admitted they did not know how to respond to specific behaviors, particularly "emotional highs and lows" and "hearing voices," and treated the client with extreme care rather than asking direct questions. Although rooted in desires to be respectful and helpful, clients generally interpreted "tip-toeing" as meaning they were "broken" or "damaged" and not fully-integrated family members.

However, family members also sometimes overestimated clients' recovery. Clients described engaging in internal processes they considered critical to recovery that were not obvious to others, such as avoiding situations, considering consequences, and "not using." Although some family members were aware of clients' hidden work, most were not. When family did not notice these efforts to remain "clean and sober" and treatment-adherent, they often believed the client had recovered more fully than was true. Without information about recovery processes, their ability to evaluate clients' level of recovery and negotiate difficult topics was limited. Some clients reported that unknowledgeable relatives, believing they were "ready," initiated conversations about problems or delegated responsibilities the client was not yet "able to handle." This perception that the person was "ready" was typically shaped by the belief that treatment or sobriety had "lasted long enough." These clients observed that such communications took place in informal settings, without trained facilitators or other experts, and often caused depression, anxiety, stress, and sometimes open conflict.

Setting appropriate boundaries was another important intangible support. Some clients expressly appreciated family who changed their practices to aid recovery. Others were unhappy at being "left out" of family events because some members would not change their "triggering" behaviors. For example, they would drink or use illicit drugs at social events, reminding the client of past experiences and creating a "craving:" a strong desire or perceived need to ingest the substance.

Another reported misinterpretation that impacted recovery stemmed from relatives' expectations that clients take part in all family activities even if the individual indicated a specific need for "alone time." Clients able to identify a "bad mental health day" reported withdrawing from social settings or rejecting invitations in order to take care of themselves and avoid imposing on others. Concerned family members who misunderstood this form of self-care sometimes misread such withdrawal in one of two ways, both problematic for recovery: (1) as an act of self-isolation or family rejection (hence a potentially serious sign of worsening SMI), or (2) as an opportunity for substance use. Either interpretation led family to take actions intended to protect the client and encourage social engagement, such as interrupting solitude.

Such responses were seen by clients and family members as well-intentioned, designed to help the person "snap out of it" or "protect them from themselves" by forestalling anticipated self-destructive acts. However, founded on a lack of knowledge about what constitutes "symptom" vs. "self-care," these behaviors inadvertently decreased clients' sense of autonomy and self-determination, created situations of conflict, and sent implicit messages that the client was not capable of reading internal cues and reacting appropriately. When clients and/or family members described conversations about withdrawal as illness management, one or both also stated that the family member now "gives space" for it.

At times, family norms included expectations of privacy such as avoiding discussing difficulties. Clients who described such family communication styles indicated that these norms were likely to be strictly enforced during and after treatment unless the family received information and help in changing. Clients typically interpreted these norms as indicating shame, decreasing their self-esteem and making them feel isolated. Family beliefs that the client was able to return to unchanged familial relations led to situations more conducive to relapse than recovery.

Family members sometimes tried to persuade clients to stop using prescribed medications, often due to concerns that the client might become "hooked" or "dependent" on them. Although many family members assisted clients with medication management, the majority expressed concern that the client would form an unhealthy reliance on medication. Some explicitly commented that they expected the client to "stop needing it." Others conflated the categories "medication," "drug," "illicit substance," and "street drug." One client stated,

> My father, when I have an appointment with a doctor, he argues about me with, "All you want is drugs. All you want is drugs." It's like, "No, I don't, Dad. It's just that these drugs help me, you know." He can't understand that.

Such messages run counter to what clients are typically told in treatment, but may be reinforced by friends, providers, or their own desire to be "well." In such cases, culturally-grounded semantics can increase the likelihood that family members will have misunderstandings related to psychiatric treatment for COD: The term "drug" is polysemic in U.S. culture, holding meanings related both to medication and to illicit substances with potential for abuse.

Disagreements about medication can impede recovery directly (e.g., if a client suddenly stops taking medication) or indirectly (e.g., by raising feelings of shame). Conversely, some clients reported that some family members saw the positive results of their medication adherence and, when the client exhibited behaviors that worried them, tried to convince the client that "more is better." This sent a dual message: the client and provider were unable to jointly evaluate and appropriately address the client's needs, and the client's behaviors reflected mental illness (only) and could be "medicated away."

In this study, family participation facilitated recovery by providing a sense of normality, acceptance, understanding, and tangible instrumental support. Family involvement with care was primarily described as increasing treatment regimen adherence and resulting in more positive outcomes (cf. Biegel et al., 2007). However, we also documented situations in which families acted primarily on misunderstandings and incomplete knowledge.

Family members and clients often stated that the former had insufficient information about the illnesses, symptoms and symptom management, medications, and recovery processes, They also said that family members' absence or exclusion from treatment and their being restricted from contacting providers kept them from learning potentially useful information. Misunderstandings and misinterpretations of client actions, and other miscommunications about recovery and client needs caused family members to act in ways that were unhelpful or actively detrimental to recovery.

Discussion

Clients routinely expressed appreciating assistance. Resources seen by families as "normal" resource sharing or gifting between relatives were reported more often and in more detail by clients than by family members. Similarly, a high percentage of clients reported appreciating the passive and active intangible support they received, but family members sometimes did not mention such care when describing help they provided, unless specifically asked about it. The disjuncture between interviewed clients' and family members' definitions of effective help most likely indicates that the latter do not recognize the level of assistance they provide nor its impact on those with COD, especially since no client reported being primed during treatment to notice such assistance. The unintentional nature of this care provision could actually amplify its power by tacitly informing clients they are accepted and positively valued. As many had previously felt negatively stigmatized by family, clients could experience this unstated acceptance as particularly powerful in mending family rifts and healing individuals.

Most unintended impediments to recovery in family settings were rooted in misinterpretations of action and inaction, misunderstandings and insufficient knowledge concerning the illnesses and recovery, and/or a lack of external resources. Family members who do not know a person is in recovery or who do not understand how environmental cues, adverse events, or stress can increase the risk of relapse might act in ways that increase risk without realizing it. For example, family members might have been unaware of the potential meanings and consequences of "having a drink at a party" because they had not been told about possible impacts or were not informed of clients' problems.

Direct service agencies and professional providers are well-situated to address these impediments by including families in therapeutic processes, psychoeducation, social support groups, and other recovery services. Interviewed family members said they are interested in such services, but often do not receive them. Logistical difficulties such as problems accessing reliable transportation and childcare, and lack of knowledge about programs were commonly-cited reasons why they did not more actively seek such services, rather than clients' reluctance to invite their participation. Some researchers, notably Rotondi (2010), have had success delivering web-based education on SMI. Such programs could serve as a basis for modules on COD that can be accessed in the home, reducing logistical barriers. Computer-literate families might also benefit from receiving electronic newsletters that provide information on COD, recovery, and online self-help groups.

Importantly, the family members we interviewed did not generally seek external help in coping with a loved one's COD. Without such help, they are at risk of "compassion fatigue," a depletion or exhaustion of physical, emotional, or spiritual resources that diminishes the ability to connect with or care for others. Compassion fatigue can lead to lessened care provision and contribute to behavioral health challenges faced by these family members (Conrad & Kellar-Guenther, 2006; Figley, 1995).

No client indicated that family therapy had been offered as an outpatient service. Clients who said that their service agencies offered family psychoeducation reported that the onus was placed on them for all outreach to their families, even when they asked for agency help. Caution concerning privacy law violation, particularly HIPAA, was typically cited as the reason given to them by their service agencies for the lack of outreach. However, no administrators or service providers in the larger study said during interviews that HIPAA was a barrier to family therapy. When asked about including families in treatment or treatment planning, they said they did not reach out to family members or suggest including them because they wanted to be "client-focused" rather than "family-focused." This disjuncture is worthy of further study.

By not reaching out to family in a systematic way after obtaining client consent, agencies were complicit in maintaining families' lack of knowledge. Unless this situation is changed, family ignorance is likely to remain institutionalized within service systems. Agency outreach based on permission from the client can play an instrumental role in better informing families. This can include relatively low-cost measures such as direct overtures from staff and mailing information to families about COD and/or any self-described support groups, organizations, and services that are or become locally available. Further research on agencies' communication with and information provision to motivated family members is warranted.

State policymakers can enhance families' knowledge and resources in a variety of ways. They can provide funding to further develop and implement interventions intended to promote family engagement. For example, systems-based interventions that identify families as clients are currently commonplace in treatment for children and adolescents but are not offered as freely to adults. Evidence-based interventions such as MultiSystemic Therapy help families adapt their communication and interactional styles to their loved one's stage of recovery (DeVore, 2011). Such measures are not included in all publicly-funded treatment options available to Medicaid-eligible adults with COD.

Increased availability of and access to evidence-based, integrated treatment programs that encourage family involvement would make it easier for people to find "a treatment that works." Although start-up costs might be high, funds saved by lowering relapse-associated costs (e.g., hospitalization, legal expenses, and other directly-measurable savings) could be shifted to fund such initiatives. Economic analyses are recommended to evaluate the feasibility of increasing family-inclusive services. Finally, instituting state-level public education positions that focus on behavioral health information provision and stigma reduction could facilitate the development of family and community contexts that aid rather than hinder recovery processes.

Conclusion

In this study, family members were not aware of the full range of the types of care they provided to clients, nor how important their assistance was considered. Interviewed clients rarely said they had discussed these aspects of their relationships with their families; thus they may not have communicated the gratitude they described to us. Horwitz, Reinhard, and Howell-White (1996) found that expressions of appreciation or affection are forms of symbolic exchange that foster mutual care that, in turn, makes relationships feel more reciprocal and less "burdensome." Recovery services should highlight the importance of such exchanges not only to promote client recovery, but also to enhance families' quality of life, help members sustain efforts to encourage recovery, and increase the feeling of success and interpersonal connectedness achieved through helping (Conrad & Kellar-Guenther, 2006).

Family members can surprise – even astonish – their diagnosed relatives with the levels and types of tangible and intangible supports they provide. Their assistance can be critical to helping individuals re-integrate into family, community, and society, and to recovering as much of their abilities and lives as possible. However, family members and systems must themselves be assisted and replenished. Further research should include assessments of what families need and want, including needs based on demographics, geographic regions, resource availability, and subtypes of COD. Moreover, changes at the level of the institution (such as outreach to families with clients' permission), and at the level of the state (such as publicly-funded coverage of systems-based therapy) will help provide families the information and resources they need to assist rather than impede their loved ones' recovery.

Acknowledgments

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