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Family-Directed Cognitive Adaptation Pilot: Teaching Cognitive Adaptation to Families of Individuals with Schizophrenia

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Abstract

Cognitive deficits are a major determinant of functional outcome in schizophrenia. A promising treatment involves teaching individuals to use cognitive adaptation strategies to minimize the functional impact of cognitive difficulties. We developed Family Directed Cognitive Adaptation (FCA) to train caregivers to help their relatives with schizophrenia use cognitive adaptations to improve living skills. The goal of this open pilot trial was to examine the feasibility of FCA. Ten adults with schizophrenia, each with at least one relative, participated in FCA and were evaluated at baseline, post-treatment, and 6-month follow-up. Domains assessed included adaptive functioning, psychiatric symptoms, school/work involvement, hospitalizations, family burden, and treatment satisfaction. Participants reported high levels of satisfaction with FCA, and all families completed the 16-session intervention. Relatives reported reduced burden at termination and follow-up. No participants were hospitalized during the treatment or follow-up period, and rates of work/school involvement increased from 30% at baseline to 50% at the end of treatment and follow-up. Individuals improved in negative symptoms and adaptive functioning over the course of treatment, but these gains were not maintained. This pilot provides preliminary support for the acceptability and feasibility of FCA, and points to the need to address the maintenance of treatment gains after termination.

Keywords

schizophrenia; cognitive adaptation; intervention; family psychoeducation

Schizophrenia is a serious illness that takes its toll on both the person who suffers from it and family members. Many individuals with schizophrenia live with family members

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(Lukens & Thorning, 1996), and even when they live apart, relatives are often very involved in providing practical, emotional, and financial support. A natural consequence of this role is that relatives often experience significant stress and distress (Kuipers et al., 2010), and report high levels of caregiving burden (Reinhard, Gubman, Horvitz, & Minsky, 1994; Kuipers, Onwumere, & Bebbington, 2010).

Family psychoeducation programs have been developed to teach families about schizophrenia, facilitate collaboration with the treatment team, and reduce family stress by improving communication skills and problem solving (Mueser and Glynn, 1995; McFarlane, 2002). Research has shown these programs reduce relapses and re-hospitalizations, and lower burden on family members (Pharoah, Mari, Rathbone, & Wong, 2010). However, individuals with schizophrenia often experience significant functional impairments that are unaffected by family psychoeducation and contribute to caregiver burden. One factor contributing to these difficulties is impaired cognitive functioning in areas such as attention, memory, organization, and processing speed. Some impairments in cognitive functioning occur in most individuals with schizophrenia, and are usually present across all phases of the illness (Fucetola, Seidman, Kremen, Faraone, Goldstein, & Tsuang, 2000). Reduced cognitive functioning is one of the strongest determinants of psychosocial functioning (Green, 1996; Harvey, 2013). Moreover, currently available medications have minimal effects on ameliorating cognitive dysfunctions (Green, 2007). To date, family programs have not focused directly on helping families cope with their relative's cognitive impairments to improve daily functioning.

Two promising psychosocial treatments targeting cognitive and functional outcomes include cognitive remediation and cognitive adaptation. *Cognitive remediation* involves behavioral training aimed at improving attention, memory, and other cognitive functions with the goal of improving psychosocial functioning (Cognitive Remediation Experts Workshop, Florence, Italy, April 2012 reported by McGurk et al., 2013). Cognitive remediation has been shown to improve cognitive functioning, and, when combined with psychosocial rehabilitation, functional outcomes (McGurk et al., 2007; Wykes, et al., 2011; McGurk & Mueser et al., 2013). However, the impact of cognitive remediation on cognition tends to be modest (e.g., $d=.45$; Wykes et al., 2011) compared to the degree of impairment, and most individuals continue to have cognitive impairments after completing such programs. These findings underscore the need for treatments to address the impact of cognitive deficits on everyday functioning.

Cognitive adaptation is another promising approach targeting cognition and functional outcomes. In contrast to cognitive remediation, which aims to directly improve cognition, cognitive adaptation focuses on reducing the impact of cognitive impairments through teaching or using strategies and environmental supports that can compensate for or bypass the effects of cognitive disabilities on functioning. This often involves modifying the person's environment through the use of signs, electronic devices, structure and organization of the person's home to cue and sequence adaptive behavior (see Table 3 for examples). Velligan and colleagues (2000) developed a home-based program, Cognitive Adaptive Therapy (CAT) for individuals with schizophrenia. This treatment involves the implementation of environmental modifications and self-management strategies by CAT

specialists (Bachelor's level psychology and social work trainees) who make weekly home visits over a nine month period (Velligan et al, 2000). Three randomized controlled trials of CAT showed that it improves global functioning and reduces symptoms and relapses compared to treatment as usual (Velligan et al., 2000, Velligan et al., 2008; Velligan et al., 2006; Velligan, Prihoda, Ritch, Maples, Bow-Thomas, & Dassori, 2002).

Despite the promising effects of cognitive adaptation approaches on improving daily functioning, most attention has focused on treatment delivery by CAT specialists, with little attention paid to the potential benefits of teaching family members how to provide such strategies. The need for long-term supports when implementing cognitive adaptation strategies suggests that the natural support provided by families could be harnessed by teaching them how to implement and sustain cognitive adaptive strategies, and in turn, foster recovery and improved psychosocial functioning. Such collaboration with families could be more economical than clinician-based cognitive adaptation and lead to more sustained improvements in functioning.

We developed Family Directed Cognitive Adaptation (FCA) to explore this treatment possibility. FCA is a clinic-based treatment that involves working with individuals with schizophrenia and family members to teach cognitive adaptation strategies to support and improve everyday functioning. FCA also strives to reduce burden on relatives by teaching them adaptive strategies to facilitate better functioning and require less prompting of their family member. The aim of this study was to evaluate the feasibility and preliminary outcomes of FCA within the framework of recommendations for the first step in the development of a new treatment (Rounsaville, Carrol, & Onken, 2001), which involves evaluating the feasibility and promise of an intervention.

Method

The Family Directed Cognitive Adaptation (FCA) program is a 16-session intervention, including both individuals with schizophrenia (referred to here as "clients") and relatives, aimed at improving daily functioning. An open clinical trial was conducted in which all participants received the FCA program, with assessments conducted at baseline, post-treatment, and 6-month follow-up.

Participants

Clients and at least one family member each were recruited from two academic medical centers in the Boston area. Inclusion criteria for participation were: 1) diagnosis of schizophrenia or schizoaffective disorder; 2) age ≥ 18 ; 3) no substance abuse/dependence in the past three months; 4) no dementia, neurodegenerative disease, pervasive developmental disorder, traumatic brain injury, or other neurological disorder that produces significant cognitive impairments; and 5) lives with at least one family member who was willing to participate. Eligible participants were referred to the study by their clinician, who met with the individual and family to describe the study. Interested participants and family members signed an informed consent. The institutional review boards at the Massachusetts Department of Mental Health and the Beth Israel Deaconess Medical Center approved the

study. Participants were paid for completing study assessments, but not for involvement in treatment.

Ten individuals with schizophrenia and 15 family members participated. For families in which more than one relative participated, a “primary caregiver” was designated as the member who spent the most time with the client, supporting daily living needs. The demographic and clinical characteristics of the study sample are summarized in Table 1. On average, clients showed significant impairments in cognitive functioning as measured by the MATRICS Consensus Cognitive Battery (MCCB; Nuechterlein et al., 2008) with a mean overall composite MATRICS *T* score of 33.9 (*SD*= 6.5, range 24–44), more than 1.5 standard deviations below average compared to an age- and gender-matched normative sample. All clients were engaged in treatment with an outpatient psychiatrist and were taking antipsychotic medication. Seven of 10 also received individual psychotherapy, and three were attending an early psychosis program that included two afternoons per week of specialized group programming, case management, and multi-family group support (Caplan et al., 2012).

Measures

Clients and participating family members were assessed at baseline (BL), end of treatment (ET), and 6-month follow-up (FU) by a trained clinical interviewer who was not involved in the intervention.

Client measures—Diagnosis was established at baseline with the Structured Clinical Interview for the DSM-IV (SCID; First, Spitzer, Gibbon, & Williams, 1996). Cognitive functioning was assessed at baseline using the MCCB (Nuechterlein et al., 2008).

Symptoms were evaluated with the expanded version of the Brief Psychiatric Rating Scale (BPRS; Lukoff, Nuechterlein, & Ventura, 1986) and the Scale for the Assessment of Negative Symptoms (SANS; Andreasen, 1981), both widely used interview-based measures for psychotic disorders. Adaptive living skills were assessed with the Social Adaptive Functions Evaluation (SAFE; Harvey, Davidson, Mueser, Parrella, White, & Powchik, 1997), a clinician-rated scale that assesses 19 areas of adaptive functioning over the past month on a five-point Likert scale, ranging from 0–4 with higher numbers indicating better functioning. Ratings were based on interviews with the client and family members. Participation in work or school in the past month, defined as paid work for at least five hours per week or taking at least one college course for credit, and history of hospitalizations were also assessed at BL, ET, and FU.

Family member measures—Family members completed the Burden Assessment Scale for Families of the Seriously Mentally Ill (BAS; Reinhard et al., 1994), a 19-item self-report measure of objective and subjective burden associated with caring for a relative with mental illness. Family members rated each item on a four-point Likert scale, with higher numbers indicating greater burden.

Satisfaction with FCA program—At the end of treatment, clients and family members reported their level of satisfaction with FCA using a modified version of the Client

Satisfaction Questionnaire (CSQ; Larsen, Attkisson, Hargreaves, & Nguyen, 1979). The CSQ is a self-report measure of general satisfaction with services that includes eight items, each rated on four-point Likert scales, with higher numbers indicating greater satisfaction (e.g., “To what extent has our program met your needs?”). For this study, one question was dropped, which was not applicable to the FCA program (“If you were to seek help again, would you come back to our program?”). In addition, participants were asked to rate how helpful they found specific aspects of the program to be (e.g., learning to use strategies to compensate for cognitive difficulties), to indicate how often they practiced skills learned in the program, and to make suggestions for improving the program. At the 6-month follow-up assessment, family members were asked how often they were using cognitive adaptation skills.

Family Directed Cognitive Adaptation (FCA) Program

FCA began with a cognitive and functional assessment that included: 1) a cognitive assessment (MCCB); 2) an assessment of adaptive living skills (e.g., time management, grooming, self-care) using the SAFE; and 3) a home assessment to identify barriers to adaptive functioning in the person’s home environment.

Following completion of the assessments, clients and their relatives participated in 16, 1-hour, single-family sessions conducted over a 5–6 month period. Components of the treatment included: 1) psychoeducation about schizophrenia and cognitive difficulties related to schizophrenia, 2) feedback about the client’s cognitive strengths and weaknesses and areas of functional difficulty, and 3) collaborative identification and implementation of cognitive adaptation strategies to target specific areas of difficulty. Additional details about the structure and content of FCA are described elsewhere (Friedman-Yakoobian, Mueser, Giuliano, Goff and Seidman, 2009). A general outline of treatment sessions and examples of behavioral targets and cognitive adaptation strategies are summarized in Tables 2 and 3. Most sessions were conducted at the clinic, with some sessions conducted at the client’s home to facilitate the implementation of the cognitive adaptation strategies. Clinicians providing FCA sessions maintained regular contact with the participant’s primary clinical team.

Data Analysis

We evaluated the acceptability and tolerability of FCA by examining rates of attendance and attrition, and total scores on the CSQ. Qualitative data from the CSQ were evaluated by summarizing specific comments made by participants about the FCA program, including likes, dislikes, and suggestions for improvement. To evaluate changes in adaptive living skills over the assessments, we computed paired *t*-tests to compare baseline SAFE scores to post-treatment and 6-month follow-up scores. Changes in symptoms were also evaluated with paired *t*-tests comparing baseline SANS and BPRS scores to post-treatment and 6-month follow up scores, as were changes in caregiver burden on the BAS. Statistical significance was set at $p < .05$.

Results

Twenty-five individuals with schizophrenia were referred to the program and 18 met eligibility criteria. Eleven families (61%) agreed to participate and signed consent. Of the seven other eligible families, three expressed interest but never followed up, three had family members who declined to participate, and one client decided not to participate despite family interest. Of the 11 families who consented, one dropped out prior to completing the initial assessments due to a schedule change limiting availability to participate. All of the remaining 10 families who began FCA completed the full 16-session program and at least one follow-up assessment.

On the Client Satisfaction Questionnaire, participants with schizophrenia and family members reported high rates of satisfaction with the FCA program. The mean score for the clients was 25 (out of 28 points; range 21–28), and for family members it was 26 (range 21–28). Aspects of the program rated as most helpful by family members included “learning about cognitive deficits related to schizophrenia” (93% rated “extremely helpful”) and “learning about specific cognitive strengths and difficulties of my family member,” (87% “extremely helpful,”). Clients reported that the most useful components of the program were “learning about my cognitive strengths and difficulties” (66% “extremely helpful,”) and “learning strategies for overcoming cognitive difficulties” (78% “extremely helpful”).

At the 6-month follow-up, seven of 10 family members completed the questionnaire pertaining to use of strategies taught in FCA. All seven reported that they continued to use the FCA strategies at least some of the time and that the FCA program had been “extremely helpful” ($n=6$) or “helpful” ($n=1$) with at least one area of functioning that was targeted by the program.

Participants with schizophrenia showed significant improvements in adaptive functioning on the SAFE and negative symptoms on the SANS at end of treatment ($t(8)=3.11, 2.35, p=.014, .046$, respectively), but these gains were not maintained at follow-up ($t(8)=-.41, -.58$, respectively, *NS*). Participants did not change significantly on overall symptoms on the BPRS over treatment or at follow-up.

Three of the 10 clients (30%) were involved in work or school at baseline, which increased to five (50%) at the end of treatment and at the 6-month follow-up. Sixty percent had been hospitalized in an inpatient unit in the year prior to participating in FCA, but none required hospitalization during the FCA program or the 6-month follow-up period.

The primary caregiver showed a significant reduction in burden on the BAS at the end of treatment ($t(8)=3.59, p=.007$), which was maintained at follow-up ($t(8)=2.97, p=.018$).

Discussion

This pilot study showed that the 16-week FCA program was feasible to implement. Among the 18 families who were eligible for the program, 11 (61%) agreed to participate, and 10 (55%) completed all 16 sessions. Among the seven families who did not participate, only one client and three family members explicitly stated they were not interested in the

program. Clients and family members both reported high levels of satisfaction with FCA, with the majority of each indicating they found learning about cognitive difficulties associated with schizophrenia to be the most useful part of the program. While family psychoeducation programs have proved difficult to implement and disseminate (Lehman & Steinwachs, 2003), these pilot findings suggest that clients and relatives perceive a need for help with improving daily functioning, and that at least some families can be readily engaged and retained in treatment targeting this outcome.

Clients showed significant improvement in adaptive living skills and negative symptoms at the end of the FCA program, suggesting that family members were able to learn how to provide cognitive adaptive supports. However, the gains in functioning were not maintained at 6-month follow-up. Velligan and colleagues (2007) also reported that functional improvements in therapist-implemented Cognitive Adaptive Therapy (CAT) were not maintained 6 months after treatment ended. It is possible that 16 sessions was insufficient for families to master the fundamentals of implementing cognitive adaptations on their own, or that families would have benefited from either gradually tapering the frequency of sessions or participating in booster sessions to facilitate the maintenance of gains in functioning.

Although improved functioning on the SAFE and lower negative symptoms on the SANS was not maintained at the follow-up, there were some improvements in role functioning. At baseline, three of the 10 (30%) participants were engaged in work or school, with this increasing to five out of 10 (50%) at both post-treatment and follow-up. Furthermore, these gains were observed despite stable levels of symptoms over time. While the sample size was too small to statistically analyze these results, they do suggest that FCA might facilitate engagement of clients in work or school.

Interestingly, family burden decreased from baseline to post-treatment and remained lower at follow-up, despite the lack of maintenance of functional improvements in clients. FCA may have helped relatives better understand the nature of cognitive challenges, which could have reduced feelings of irritation or blame. Relatives' attributions of responsibility for negative symptoms to clients have been shown to be related to stronger negative feelings about the relative and perceptions of burden (Barrowclough & Hooley, 2003; Scazufca & Kuipers, 1996). It is also possible that the maintenance of improvements in client role functioning over the follow-up period may have offset some of the increase in relatives' burden over this time related to the need for more assistance in daily living skills.

It is noteworthy that none of the FCA participants were hospitalized during the approximately one-year period they participated in the FCA program and follow-up assessments (compared to 60% requiring hospitalization in the year prior to engaging in FCA). These findings are consistent with longer family psychoeducation programs for schizophrenia (Pharoah et al., 2010). They also suggest that the improved clinical stability of the clients may have contributed to caregivers reporting lower levels of burden at end of treatment and over the follow-up periods.

Several limitations of this study should be noted. First, since this was an open trial with no control condition, it is not known whether improvements in adaptive functioning or

reductions in family burden can be attributed to the FCA program, rather than other treatments the client was receiving (e.g., medication, individual therapy). Second, the sample size was very small, and multiple comparisons were made to examine changes in participant and family member functioning, and thus the findings should be considered tentative. Third, the study included family members who were mostly non-Latino white (70%) and highly educated (60% with college degree), limiting the generalization of findings to other populations. Fourth, only limited data were obtained on involvement in work or school, an important outcome but one not directly targeted by FCA. However, despite these limitations, this study did show that it was feasible to engage and retain families in a program aimed at teaching strategies for reducing the effects of cognitive impairments on adaptive living skills, and suggested some benefits in terms of improved functioning and reduced family burden. More work is needed to capitalize on the natural, supportive role family members play in helping a member with schizophrenia gain more control over his or her life, and make progress towards important personal goals. While the current results are promising, further modifications to the FCA program may be needed in order to better retain treatment gains in client functioning after the end of the program, and controlled research is needed to more rigorously evaluate the effects of the overall program.

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Table 1

Participant Demographic Characteristics

	Individuals with schizophrenia (n=10)	Relatives (n=15)	Primary caregivers (n=10)
Age	<i>M</i> = 27.8 (19–40)	<i>M</i> = 57.5 (40–66)	<i>M</i> = 56 (40–66)
Gender	3 female, 7 male	9 mothers, 6 fathers	7 mothers, 3 fathers
Education	1 High school grad 5 Some college 4 Bachelor's degree	2 High school grad 2 Some college 7 Bachelor's degree 4 Advanced degree	2 High school grad 2 Some college 4 Bachelor's degree 2 Advanced degree
Race	1 Asian 2 African-American 6 White 1 Multi-Racial	2 Asian 2 African-American 11 White	1 Asian 2 African-American 7 White
Hospitalizations	<i>M</i> = 3 (0–5)	n/a	n/a
Years since first diagnosed/treated	2 - 1–2 years 4 - 2–5 years 4 - 5–10 years	n/a	n/a
Estimated premorbid IQ ¹	<i>M</i> = 105 (85–125)	Not assessed	Not assessed
MCCB ² Overall Composite <i>t</i> -score	<i>M</i> = 33.9 (24–44)	Not assessed	Not assessed

¹Wechsler Test of Adult Reading²MATRICES Consensus Cognitive Battery for Schizophrenia.

Table 2

Components of FCA

Sessions	Content
1–3	Psychoeducation about schizophrenia symptoms and treatment and cognitive difficulties related to schizophrenia. Introduction to cognitive adaptation.
3	Feedback provided about the participant's individualized cognitive strengths and difficulties (based on initial cognitive and clinical assessments). Participants are given a report summarizing recommendations.
4	Collaborative problem solving approach is used to discuss possible functional targets for FCA. One or two functional targets are agreed upon.
5–14	Family members and participants identify cognitive adaptation strategies to improve functioning in selected target area. Sessions focus on identifying barriers, selecting strategies and practicing cognitive adaptation strategies to improve target functioning. May involve some sessions (1–5) in the family's home or community to facilitate practicing cognitive adaptation in the participant's natural environment. (See Table 3 for examples of functional targets and cognitive adaptation strategies used)
15–16	Review of progress and plan for using cognitive adaptation after FCA ends.

Table 3**Example Functional Targets and Cognitive Adaptation Strategies**

Functional Target	Cognitive Adaptation Strategies
Wearing clean clothes every day	Clothing hamper provided with procedure developed for putting clothes directly in hamper after wearing once.
Brushing teeth twice a day	Adding a shelf in bathroom to keep toothbrush and toothpaste, 2-minute timer to ensure adequate brushing time, neon pink sign in kitchen with reminder "brush teeth immediately after breakfast and dinner" with "reasons to keep teeth clean" listed underneath (sign replaced with different color sign every 3 weeks to avoid habituation), participant practices routine of brushing teeth immediately after eating.
Taking medications as prescribed	Pill boxes with compartments for each day of week provided, procedures for filling box at same time each week practiced, reminder alarms set in phone, voice alarm reminders, medication taking paired with daily activities (e.g., putting on glasses in AM and taking them off at night).
Organizing a long term project at work	"Task Planning Form" used to identify 1) tasks needed to complete project, 2) steps involved in completing each task, 3) identifying when to complete each steps and resources needed.
Keeping up with work in college class	Introduce and practice using a to-do list and calendar and checking twice per day.
Organize room and keep track of belongings	Participant and family identify list of "benefits of having an organized room" and post them in a neon sign next to mirror. Family member and participant schedule 20 min per day to focus on organizing one part of room at a time, starting with removal of trash and dirty laundry. Shelves and bins with labels added to make clear where items are to be kept (e.g., wallet and keys, school books and assignments, shirts, pants, etc.).

Table 4

Patient and Family Member Outcomes

Outcome Measure	Baseline <i>M (SD)</i>	End of Treatment <i>M (SD)</i>	6 M ⁴ Follow-up <i>M (SD)</i>	BL vs ET <i>p, Cohen's d</i>	BL vs FU <i>p, Cohen's d</i>
Family Burden (n=9)	37.3 (8.4)	30.0 (5.0)	28.8 (6.3)	<i>p</i> =.007, <i>d</i> =.87	<i>p</i> =.018 <i>d</i> = 1.01
Client BPRS ¹ (n=9)	43.6 (12.6)	41.0 (11.0)	43.6 (12.6)	<i>p</i> =.542, <i>d</i> =.21	<i>p</i> =.159, <i>d</i> =.04
Client Adaptive Function (SAFE ²) (n=9)	14.0 (8.2)	9.3 (9.6)	14.8 (9.9)	<i>p</i> = .014, <i>d</i> =.57	<i>p</i> =.732, <i>d</i> =-.10
Client Negative Symptoms (SANS ³) (n=9)	27.3 (13.7)	20.7 (16.0)	30.2 (16.4)	<i>p</i> =.046 <i>d</i> =.48	<i>p</i> =.575 <i>d</i> =-.21
Client Working/School (n=10)	3 (30%)	5 (50%)	5 (50%)		
In Psychiatric Hospital in Past Year (n=10)	6 (60%)	0 (0%) ³	0 (0%)		

¹ Brief Psychiatric Rating Scale

² Social Adaptive Functions Evaluation

³ Scale for the Assessment of Negative Symptoms

⁴ One patient and one family member completed assessments at 3-month follow-up rather than 6-month follow up.