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An Evaluation of the NAMI Basics Program

Teri Brister • Mary A. Cavaleri • S. Serene Olin • Sa Shen • Barbara J. Burns •

Kimberly E. Hoagwood

T. Brister

National Alliance on Mental Illness, Arlington, VA

M. A. Cavaleri ✉ • S. S. Olin • S. Shen • K. E. Hoagwood

New York State Psychiatric Institute, New York, NY

cavaleri@pi.cpmc.columbia.edu

B. J. Burns

Duke University School of Medicine, Durham, NC

Abstract

This brief report describes results from an evaluation of NAMI Basics, a peer-delivered family education program for family caregivers of children and adolescents with mental illness. Over six classes, family members are given information (e.g. education about mental illness and treatments), skills training (e.g. family communication skills) and advocacy support. We report data from 36 caregivers who completed pre and posttest instruments measuring self-care, empowerment, and family problem-solving and communication skills. Results showed significant improvements in self-care, empowerment, and “incendiary” family communication after participation in the program. Results suggest that NAMI Basics may improve both parental functioning and familial processes. Implications and future directions are discussed.

Introduction

Peer-delivered family education and support (FES) programs originated over 25 years ago to support family caregivers of children and adolescents with mental health difficulties (Hoagwood et al., 2010). Caregivers often report stress and strain managing their child's needs and accessing services, yet commonly experience stigma and social isolation from family, friends, and their community (Gyamfi et al., 2010). Peers, who are also parents of children with mental health needs, are often perceived as credible role models because of their personal experiences and can assist other parents by decreasing isolation and modeling active engagement in their child's treatment (Hoagwood et al., 2010).

Peer-delivered FES services are a major function of family-based organizations (Gyamfi et al., 2010); they have proliferated in recent years (Hoagwood et al., 2010). Components vary, but most include the following: skill-building (parenting skills), instrumental services (transportation, respite), advocacy (information about parental rights), emotional support, and education (see Hoagwood et al., 2010 for a fuller review). Peer-delivered family support differs from clinician-delivered support in key ways. A recent review by Hoagwood and colleagues (2010) of 50 family support programs delivered by clinicians, peers, or clinician/peer teams showed clinician-led programs tended to be grounded in behavioral and cognitive behavioral theories, and focused on parenting skill building to manage child symptoms. In contrast, peer programs emphasized the provision of advocacy and emotional support and to emphasize shared experiences. Additionally, peer-led programs were more likely to focus on caregiver satisfaction or caregiver perceived support as outcomes, in contrast to clinician-led programs, which aimed to reduce child symptoms, improve functioning, and decrease parents' levels of stress.

In 1991, the National Alliance on Mental Illness (NAMI) rolled out the Family-to-Family

Education Program for family caregivers of adult relatives with mental illnesses. Family-to-Family aims to a) decrease caregivers' strain due to caring for their relative and managing their own lives, b) empower them to advocate for their relative and c) increase caregivers' confidence in and endurance for their ongoing supportive role (NAMI, 2010).

Family-to-Family is currently available in 46 states, Puerto Rico, Canada, and Mexico, and is the most commonly used model of family education (Dixon et al., 2001; Lucksted, Stewart, & Forbes, 2008). In 2007, demand for a similar program for family caregivers of children and adolescents with mental illnesses resulted in Family-to-Family's progeny, NAMI Basics.

Developed by the first author (TB), NAMI Basics consists of six 2 ½ hour classes offered weekly for six weeks, or biweekly for three weeks. NAMI Basics classes are currently available in 29 states. Upcoming classes are posted on each state NAMI office's website; caregivers also become aware of classes through media advertisements, radio and television interviews, and through referrals from juvenile justice and other systems serving families of children with mental illnesses. In order to enroll, caregivers must either be a parent or primary family caregiver of a child who is 21 years or younger (caregivers of individuals 22 years of age or older are referred to the Family-to-Family class). In order to ensure that each participant has time for discussion and interaction, classes are limited to between six and 20 caregivers; on average, nine caregivers enroll in each course. Classes are led by a team of two teachers or facilitators who submit an application and complete approximately 22 hours of intense training delivered over one weekend by either the Executive Director of the NAMI Programs for Young Families, or a State Basics trainer trained by the Executive Director. Teachers must also have lived through the experience of having a young child with a mental illness; therefore, they must be the parent or primary

caregiver of a child who experienced mental health symptoms prior to the age of 13.

Similar to its predecessor, course content includes: a) information about normal reactions to mental illness, mental health disorders, and the most effective treatments available; b) skill-building (problem solving, communication skills); c) research about the biology of mental illness; d) information about the school and mental health system; e) planning for crises and how to locate appropriate community supports and services; and f) advocacy initiatives to improve and expand services, particularly personal advocates for the family (NAMI, 2010).

This brief report examines data from a subset of classes offered in Tennessee and Mississippi between October, 2008 and December, 2009. An earlier pre/post evaluation found participants displayed increased knowledge about mental illness, treatment, and advocacy (Deal, 2008). This brief report evaluates the program's impact upon additional caregiver and family factors targeted by the curriculum. We hypothesized participation would improve a) empowerment, b) family problem-solving and communication skills, c) parental stress, and d) self-care.

Methods

All caregivers enrolled in 12 NAMI Basics classes (seven in Mississippi and five in Tennessee) were eligible to participate. Two teachers introduced the study during the first class and distributed the consents, a demographic form, and four questionnaires: 1) the Family Empowerment Scale (FES) to measure caregivers' feelings of empowerment concerning family issues and their child's services (Koren, DeChillo, & Friesen, 1992), 2) the Self-Care Inventory (SCI) to measure whether caregivers take care of themselves physically, psychologically, and emotionally (Child Welfare Trauma Training Toolkit, 2008), 3) the Parent Stress Survey (PSS) to measure stress regarding parenting, familial matters, and their child's mental health needs

(Sisson & Fristad, 2001), and 4) the Family Problem Solving and Communication Scale (FSPC) to assess two types of communication: incendiary escalating conflict, such as yelling during disagreements, and affirming, including maintaining calm during conflicts and discussing disagreements until family members solve the issue (McCubbin, McCubbin, & Thompson, 1998).

Questionnaires were linked by an identification number. However, to protect participants' privacy, these data were not linked to the demographic form. Participants completed the outcome measures during the first class (pre-test), last class (posttest), and three-months following posttest by mail. Given the ongoing and long-term stress that caregivers often experience when managing their child's mental health needs, we expected changes in stress levels to occur gradually, and after more immediate improvements in skills and attitudes-both of which were directly targeted in the course curriculum. Therefore the PSS was only administered at pretest and follow-up. Participants were sent a \$10 Walmart gift card as incentive to complete the follow-up questionnaires. IRB approval was obtained.

Participants

Eighty-two caregivers completed the demographic form; 64 (81%) parents, eight (10%) grandparents, and seven (9%) stepparents or adoptive parents. The sample was 39 years old on average ($SD=11$) and predominantly female ($n=61$, 87%). Thirty-three (41%) were married, 29 (36%) were single, 14 (17%) were divorced, and five (6%) were separated or widowed. Two-thirds were Caucasian ($n=50$, 66%), one-third ($n=25$, 33%) African-American; only one was of Hispanic descent.

Caregivers also reported on the identified child. Youth were predominantly male ($n=60$, 78%); their mean age when first diagnosed was 5.5 years old ($SD=4.05$). Forty-five (55%) were

diagnosed with one disorder, and 19 (23%) were diagnosed with two disorders. The most common diagnoses were Attention Deficit Hyperactivity Disorder ($n=44$) and mood disorders ($n=25$). Forty-seven caregivers also reported on their child's current age, which was 10 years old on average ($SD=4$).

Data Analysis

Thirty-six caregivers completed the questionnaires at pre and posttest; only nine completed the questionnaires at all three time-points. We excluded follow-up data from the analysis because of the low rates of completion, which was due to several factors, including weaknesses in study procedure (e.g. teachers forgot to distribute the packets, gift cards were given before receipt of the completed follow-up forms), and several follow-up packets were returned as undeliverable. Further, caregivers were already overwhelmed with managing their child's needs and their own responsibilities; completing the forms added another burden to an already-stressed family. Because the PSS was administered only at pretest and follow-up, it was excluded from analysis. Because similar procedures were used to collect data across both sites, data were combined.

Time effect (pre vs. post) on each outcome was tested using repeated measures analysis with PROC GENMOD procedure in SAS. Time period was treated as a repeated measures factor with two categories: pre and post. Effect was assessed using Chi-square tests with a degree of freedom=1. Analysis controlled for the effect of state (Tennessee or Mississippi).

Results

Table 1 presents the main results, which showed statistically significant improvements in the SCI, both subscales of the FES, and the total score. Only the Incendiary subscale from the FPSC was significant. The total score approached significance.

Discussion

Participants reported improvements in self-care and empowerment. These findings suggest curriculum components including parenting strategies, information about resources, and coaching to advocate for themselves and their child may have enhanced caregivers' sense of empowerment in managing their family's needs, their child's services, and fostered attention to taking care of themselves.

Participants also experienced reductions in inflammatory communication, but not improvements in affirming communication. This seems counter-intuitive but intriguing. A major component of NAMI Basics is to discuss strategies to help parents remain in control when communicating with their child. This includes controlling anger, pre-empting the development of problems ("catch the positive") and being highly specific about expectations. Because of the considerable amount of material this is covered in a short time, less focus is given to affirmational communications within the family. Perhaps this is why we saw differences in "incendiary" communication but not affirmational. More attention to these communication distinctions may be helpful in future research. .

This study had several significant limitations, including small sample size, lack of randomization or even a comparison group, and inability to obtain adequate number of follow-up assessments. Because of IRB requirements, we were unable to link the demographic data to the outcome questionnaires. Consequently these results should be interpreted cautiously. These limitations prevent our drawing any causal relationships between the program and outcomes, and limit the generalizability of results. Nonetheless, this study offers preliminary support of ways in which peer-delivered family education may benefit families of children with mental health conditions.

Conclusions

These findings add to a growing knowledge base suggesting that peer-delivered family education programs are likely to be a valuable service for families. Results suggest that NAMI Basics may improve both parental functioning and familial processes

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Table 1

Outcome Measures

Measure	Pre	Post	Post vs Pre ¹	
	M(SD)	M(SD)	χ^2	<i>p</i>
SCI	3.47 (0.61)	3.70 (0.64)	10.81	0.001
FES Family	3.78 (0.56)	4.26 (0.50)	14.61	0.0001
FES Services	4.03 (0.78)	4.38 (0.68)	7.15	0.01
FES Total	3.90 (0.60)	4.31 (0.55)	13.21	0.001
FPSC Affirming	2.20 (0.62)	2.33 (0.52)	0.72	0.4
FPSC Incendiary	1.25 (0.66)	1.01 (0.49)	5.5	0.02
FPSC Total	1.98 (0.58)	2.16 (0.44)	2.87	0.09

Note: ¹adjusted for state