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Outcomes of a Family Peer Education Program for Families of Youth and Adults with Mental Illness

Jason Schiffman¹, Gloria M. Reeves², Emily Kline^{1,*}, Deborah R. Medoff², Alicia Lucksted², Kimberly Hoagwood³, Li Juan Fang², and Lisa B. Dixon⁴

¹Department of Psychology, University of Maryland, Baltimore County, Maryland, USA

²Department of Psychiatry, University of Maryland School of Medicine, Baltimore, Maryland, USA

³Department of Child and Adolescent Psychiatry, New York University, New York, USA

⁴Columbia University Medical Center, New York, USA

Abstract

Family members of consumers with mental illness often play important roles in initiating and supporting treatment. Self-help programs such as the National Alliance on Mental Illness (NAMI) Family-to-Family Education Program (FTF) have been shown to provide a variety of benefits for family members. Despite recognizing the benefits of FTF, little is known about who may benefit most, and in what ways they might benefit. One group of interest is family members of younger consumers, a group shown to report more negative caregiving experiences and more depression and anxiety than caregivers of older consumers. The current study assesses whether relatives of youth (ages 8–18) differ in their response to FTF as opposed to relatives of adults (19 years and older). Results suggest that all members benefit from FTF. Family members of youth in FTF, however, reported gains more pronounced on their depressive symptoms, and negative perceptions and experiences, relative to family members of adults. The importance of peer support programs is discussed, as well as the specific usefulness of these programs to effectively address concerns of relatives of youth with serious mental health concerns.

Keywords

family-to-family; NAMI; family members; youth peer education; depressive symptoms; mental illness

INTRODUCTION

Family members of individuals with mental illness are often involved in initiating, advocating for, and supporting their relative's mental health care [1–3]. The importance of family involvement and family psychoeducation is recognized by best-practice guidelines for the treatment of individuals with serious mental health concerns [2, 4–5]. Surveys of

Address correspondence to Jason Schiffman, Department of Psychology, University of Maryland, Baltimore County (UMBC), 1000 Hilltop Circle, Baltimore, MD 21250, USA; schiffma@umbc.edu.

*Current affiliation: Department of Psychiatry, Harvard Medical School, Beth Israel Deaconess Medical Center, Boston, Massachusetts, USA

relatives of individuals with serious mental illness suggest that family members desire information and inclusion regarding their relatives' care [6–7]. Despite these recommendations, providers of mental health services report inconsistent engagement of families, and there is low uptake by mental health providers worldwide [4, 8–10]. Perhaps in part as a result of this disconnect, families commonly describe frustration and unmet needs with regard to their interactions with mental health care systems [6, 11–13].

Self-help programs oriented toward family members' experience of mental illness offer a promising approach for relatives who have unmet needs associated with their loved one's mental health concerns and care. The National Alliance on Mental Illness (NAMI) sponsors the most widely used self-help platform for family members of individuals with mental illness, the Family-to-Family education program (FTF). This program provides a peer-led, twelve-week structured curriculum developed and conducted by trained participants in which family members learn about mental illnesses, treatment options, self-care, communication skills, advocacy skills, and problem-solving strategies. By attending weekly two- to three-hour sessions, family members also have the opportunity to give and receive emotional support, and to develop insight into their own feelings about mental illness.

A randomized controlled trial of FTF was recently conducted to assess the effectiveness of the program. A total of 318 consenting participants across a demographically diverse state in the United States were randomly assigned to FTF or a three-month or longer wait-list. Participants were interviewed at enrollment and at three months (termination for the FTF group) regarding a variety of factors FTF is designed to influence (e.g., coping skills, burden, distress). Assessors underwent strict blinding procedures to prevent knowledge of participant study condition. Fidelity to the FTF program was monitored, with experienced FTF teachers rating one session of each course based on a structured rating form formatted by the creator of FTF. Fidelity based on the form was at 90 percent. Results of the study suggested that compared to the wait-list control group, participants in FTF benefited on a variety of outcomes, including improved coping, problem-solving, empowerment, reduced anxiety and depression [14]. The demonstrated effectiveness of FTF, along with the documented benefits of family involvement, positions the program as an important service option in the treatment of people with mental illness.

The FTF program is nonspecific in that it targets all family members whose relatives may be struggling with mental health concerns [15]. The inclusiveness of FTF groups may constitute a strength of the program in that participants can offer unique and varied perspectives regarding their experiences with mental illness, and the participants' characteristics (e.g., relation to person with mental illness, cultural background, socioeconomic status) and experiences may be quite diverse. Thus the effectiveness of FTF may vary for individuals depending on key participant characteristics. Understanding the effects of FTF on specific subgroups within the program could shed light on who might most benefit from FTF, and in what ways.

One potentially important characteristic of FTF participants is the age of their family member with mental illness. Although FTF is not generally targeted toward family members of young children, all family members are welcome and many relatives of younger people

attend. Family members of youth appear to play specific, developmentally driven roles in supporting their children's recovery from mental health problems, and may constitute one subgroup with unique concerns within the broader pool of FTF participants. The challenges of typical development for young people (e.g., school, learning to function independently, navigating complex social relationships) can be magnified for both youth and family members when mental illness is also a concern [16]. Coordination of care for youth often involves multiple systems, including, for example, schools, pediatrics, juvenile justice, and child welfare. Thus, obtaining developmentally appropriate and well-coordinated care for youth may be particularly challenging in contrast to finding care for adults [17–18].

As a result of these divergent experiences, family members supporting youth with mental illnesses are likely to have different reactions and needs surrounding their relatives' mental illness as compared to family members supporting adults with mental illness [19–20]. Within a large sample of prospective FTF participants at entry to the program, parents of youth (18 years and younger) with mental illness reported more problems with their child's difficult behaviors, greater concern with youth's dependency on parents to coordinate care and support daily living, greater concern with the effect of mental illness on their families, and higher levels of stigma, anxiety, and depression relative to parents of adults (19 years and older) with mental illness [21]. Caregiving obligations, perceptions of burden, and fragmentation of youth service systems for family members of youth with mental illness may leave them more vulnerable to mental and physical health concerns of their own, and less equipped to play an optimally supportive role in their children's treatment and recovery [22–25].

These findings, suggesting that relatives of youth and adult consumers enter FTF with divergent experiences and concerns, raise the possibility that FTF might have different effects for these groups. Given baseline differences in relatives' responsibilities, attitudes, and distress, aspects of the FTF program may be differentially beneficial for family members of youth as compared to family members of adults. Understanding the potentially different effects of FTF for relatives of adults and youth might facilitate refinement of interventions to best suit the needs of specific family subgroups, guide providers on effectively engaging family members of particular patient populations, offer evidence to support the intervention in subgroups of parents, and possibly support new program development and improved services across the developmental span of people with mental illness.

The current study explores whether age moderates the effectiveness of FTF for relatives of youth as compared to relatives of adults. Participants in the current study include randomized control trial (RCT) study participants who attended at least one FTF class. Participants also included individuals who declined participation in the RCT, but participated in FTF and completed observational baseline and follow-up assessments. The observational arm was in response to concern for possible biased participation in the RCT because a sizable number of participants expressed a desire to avoid randomization. Combining the participants in the RCT who attended FTF with those in the observational study who attended FTF provides a larger and more representative sample of family members seeking self-help services through FTF. We hypothesize that due to additional stressors reported at

baseline by family members of youth [19], these participants stand to benefit most from the FTF program on a variety of outcomes. Specifically, we hypothesize a moderation effect whereby relatives of youth will experience a greater decline in scores reflecting negative caregiving experiences, depression, and anxiety from pre- to post-FTF assessment, as compared to family members of adults who also attended the program.

METHODS

Setting and Design

The study was conducted in five regions of Maryland served by NAMI affiliates: Baltimore metropolitan region and Howard, Frederick, Montgomery, and Prince George's counties. Procedures were approved by the University of Maryland Institutional Review Board. Recruitment took place between March 15, 2006, and September 23, 2009.

This study includes individuals who participated in a randomized controlled trial (RCT) or an observational arm of the same study. All persons who contacted the NAMI Maryland office or a participating affiliated site and expressed interest in FTF during this time period were referred to the state FTF coordinator. The coordinator then spoke with each person to gauge whether FTF would be an appropriate fit for the caller. If so, she described RCT and determined the caller's eligibility and willingness to participate. Research assistants then obtained informed consent for the RCT via telephone for eligible willing participants. Consenting participants completed a baseline assessment and were then randomized to either begin participation in FTF immediately or join a wait-listed control group. Control group participants could use any other supports offered by NAMI, mental health professionals, or community services. Approximately midway through the RCT, we became concerned about the potential for biased participation in the RCT and initiated an observational arm that included individuals who were eligible for the RCT but declined to participate. By far the most common reason for declining to participate in the RCT was the desire to avoid randomization. Individuals in the observational arm provided informed consent to participate in baseline and post-FTF assessments, but were not randomized. The study did not interfere with the structure, content, or delivery of FTF classes, and classes included both research participants and nonparticipants.

For individuals in both the RCT and the observational arms, assessments were conducted via telephone at baseline (prior to attending any FTF sessions) and three months later by research assistants blind to the study conditions of RCT participants. Upon completion of the follow-up interview, participants were asked about the number of FTF classes attended and their use of other supports during the past three months.

Participants

Individuals were eligible for participation in the overall study if they were 21–80 years old, desired to enroll in the next FTF class due to experiences with a family member or significant other, and spoke English. For this study, pre- and post-FTF data from the RCT and observational arms of individuals who attended at least one FTF class were used to examine change from baseline after participation in FTF. The research coordinator screened

1,532 interested individuals and found 1,168 to be eligible for participation. Of those who were eligible, 318 consented to the RCT. Of the 318 randomized, 113 in the FTF condition completed pre- and post-interviews and attended at least one FTF class. Despite being originally randomized into the control condition for the original RCT, ten participants who were supposed to be in the control group completed both baseline and follow-up assessment and attended at least one FTF meeting. These individuals were included in the analyses and were considered participants within the current study as they had exposure to FTF intervention as well as the same assessment procedures as the intervention group. Additionally, 90 individuals who had declined participation in the RCT but completed baseline and follow-up interviews in the observational arm were included in the current study, yielding a total sample of 213 participants. It is important to note that although this study used data from a larger RCT, the current study is not reporting on the RCT aspect of the larger project. Participants in the current study (those randomized to both conditions, as well as those who declined randomization) were all considered as a single cohort of FTF participants.

Measures

To accomplish the aims of the primary study, a number of measures were used to assess family burden, empowerment, coping, communication, and distress [12]. The current study focused on a narrower range of variables on which baseline differences were found between caregivers of youth and adults participating in both the randomization and observational arms of the protocol [21]. These variables include facets of caregiver experiences as well as psychological distress (i.e., anxiety and depression).

Experiences relating to the care of a mentally ill relative were assessed using the 66-item Experience of Caregiving Inventory (ECI) [26]. The ECI assesses caregivers' perceptions of and responses to mental-illness-related demands (i.e., "subjective" rather than "objective" burden), thus making it optimal for measuring improvement in relatives' beliefs and attitudes toward their caregiving role. The ECI factors divide into eight negative subscales (difficult behaviors, negative symptoms, stigma, problems with service, effects on family, need for backup, dependency, loss) and two positive subscales (rewarding personal experiences and good aspects of relationship with patient). The ECI additionally generates "total negative" and "total positive" scale scores subsuming these ten subdomains. In validation samples, all ten subscales were found to be internally consistent with Cronbach's alpha ranging from 0.74 to 0.91, and caregivers' ECI scores were significantly associated with consumer disability, caregiver social support, and caregiver mental health [26–27]. Differences in ECI scores on subscales representing negative effects on family, dependency, stigma, and difficult behaviors, as well as total negative scale scores, were found between caregivers of youth and caregivers of adults seeking to participate in FTF [21].

Participants' psychological distress was assessed using the Brief Symptom Inventory (BSI), which was designed primarily for use in nonclinical, community populations [28]. The BSI is well suited to capture distress associated with illness-related demands as opposed to primary psychopathology, and has been used to measure distress among parent, spouse, and adult child caregivers of individuals with a wide range of mental and physical health

concerns [29–31]. The BSI contains 18 items yielding anxiety, depression, and somatization subscales as well as a total score representing overall distress. The BSI-18 has well-established reliability and validity [28, 33]. For current analyses, raw scores for BSI symptom dimensions were converted to area t -scores based on community male and female norms.

Data Analysis Plan—Demographic and family characteristics were compared between groups (youth consumers, adult consumers) with chi-square, independent t , and Wilcoxon tests.

We used linear mixed-effects multilevel regression models (SAS Proc Mixed) to test for a moderation effect whereby relatives of youth will experience a greater decline in scores reflecting negative caregiving experiences, depression, and anxiety from pre- to post-FTF assessment, as compared to family members of adults who also attended the program. The models tested for significant interactions between time (baseline, three months) and consumer age groups (youth, adult). A random intercept was used to account for nonindependence of the repeated measures, and class was also included as a random variable because participants taking the same class may be more similar in their responses to the intervention than people from different classes. Because of the small class cluster size ($M = 4.32$, $SD = 2.94$), we did not attempt to fit a separate variance component due to family.

RESULTS

The analysis sample included 213 participants who attended at least one FTF class. Participants included 180 relatives of adult consumers 19 years and older and 33 relatives of youth 18 years and younger. Results from chi-square, independent t , and Wilcoxon tests indicated that relatives of adults did not significantly differ from relatives of youth with regard to gender, race, education, income, marital status, or employment status ($p > 0.05$). Compared to relatives of adults, relatives of youth were significantly younger, more likely to be parents (as opposed to some other relation) of an individual with mental illness, less likely to report that their relative with mental illness resided independently, and more likely to describe themselves as “very involved” in supporting their relative. Relatives of youth also reported providing significantly higher levels of objective daily living assistance and supervision. Demographic statistics are in Table 1.

Changes from pre- to post-FTF in distress and experiences of caregiving among family members of youth and family members of adults attending FTF are presented in Table 2. After attending FTF, group means for family members of both youth and adult consumers changed in the anticipated direction for all subscales of the BSI and ECI. Within the entire sample of FTF participants, mean scores were significantly lower following FTF attendance on scales reflecting the following domains: anxiety, difficult behaviors, negative symptoms, stigma, problems with service, need for backup, dependency, loss, and the ECI negative scale. Mean scores of the sample as a whole were significantly greater at follow-up on the positive domains (positive personal experiences, good aspects of relationship, ECI positive scale) measured by the Experience of Caregiving Inventory (ECI).

Although anxiety was the only BSI subscale evidencing significant improvement following FTF when considered within the entire sample, examination of interaction effects indicated different patterns of change for relatives of youth and relatives of adults. Results from the regression analysis indicated that FTF participants attending for youth consumers had significantly greater improvements in psychological distress as measured by the BSI than did FTF participants attending for adult consumers. Regression results are presented in Table 3. From baseline to follow-up, family members of youth showed significantly greater reductions in depression scores and a trend toward greater reductions in anxiety scores relative to family members of adults. Figure 1 illustrates pre- to post-FTF anxiety and depression score changes among family members of youth and adults.

Age of the consumer also moderated changes in ECI scores following FTF attendance. Participants attending for youth consumers in FTF showed significantly decreased negative experience subscale scores, but no significant difference in the change on positive experience subscale scores, as compared to FTF participants attending for adult consumers (see Table 3). The ECI Effect on Family and Loss subscales also showed significant interaction effects (see Table 3). Figure 2 illustrates pre- to post-FTF ECI positive and negative subscale score changes among family members of youth and adults.

DISCUSSION

Results from the current noncontrolled study suggest that attending FTF is associated with decreases in family members' self-reported experiences of burden and distress, and increases in positive attitudes related to relatives's caregiving roles. These results align with findings observed in the randomized controlled trial of FTF suggesting significant improvements in family members' knowledge, empowerment, acceptance, and problem-solving as well as decreases in their self-reported experiences of burden, depression, and anxiety [14]. That our findings are consistent with the RCT lends confidence to the pattern of changes observed. Although the current study was not an RCT, the larger group of participants included in current analyses allows us to focus on comparing results of FTF between caregivers of youth and caregivers of adults.

Given the differences found at baseline between caregivers of adults and caregivers of youth, suggesting that caring for a youth with mental illness presents some relatively demanding stressors [21], we hypothesized that relatives of youth who attended FTF would particularly benefit from participation in the program. Consistent with our hypothesis, family members of youth in FTF reported more pronounced changes on their depressive symptoms, negative perceptions, and experiences, relative to family members of adults. Depression scores from the BSI were particularly notable with regard to the differential impact of FTF on relatives of youth compared to relatives of adults. This is an important distinction. In the overall group of participants, depression scores did not significantly decrease from pre- to post-FTF. Separate analyses for the subgroup of families of youth, however, found that in this subsample depression did decrease. This suggests that FTF's impact on depression may be unique to parents of youth. As the negative effects of parental depression on children are well established [34], this finding of decreased depression may confer benefits not only on the families but also directly on the youth.

With more acute stressors at baseline (e.g., problems obtaining mental health services, greater anxiety and depression, more negative experiences related to their caregiving role), relatives of youth may have been particularly receptive to the FTF intervention. There are several possible explanations for the more pronounced changes in depression scores and negative ECI subscales after FTF among relatives of youth. For instance, increased distress among relatives of youth at baseline may increase their motivation to engage with FTF [35], and therefore their participation and engagement in the curriculum may have been particularly high. Additionally, it is possible that the experiences and challenges faced by relatives of youth were particularly well “matched” with FTF intervention targets [36], and thus the intervention provided relevant and focused resources and support that were of benefit. Additionally, family members of youth were more often parents (as opposed to other relations) and reported higher rates of day-to-day involvement, assistance, and supervision of care. In FTF they were provided support that is particularly practical to them in managing challenges experienced by parents (e.g., navigating school-related health care systems, making treatment decisions on behalf of children, participating in parenting-skills enhancement programs) [37]. Parents of youth often report significant negative experiences related to stigma, blame, and isolation [38–39]. As this program is led by peers who are, in a sense, role-models for other family members, the social validation and acceptance that parents of youth experienced through their participation in FTF may have been particularly important and even unique to them. Regardless of the mechanism, the current findings suggest that FTF provides not only benefits for relatives of adults, but also relevant and specific benefits for relatives of youth.

Limitations

These results do not reflect randomized participation in FTF, and thus improvements cannot be definitively attributed to FTF participation. Previously published RCT data, however, supported the conclusion that FTF participation was associated with significant benefits in multiple domains [14], thus lending confidence to our observations within this naturalistic sample.

Relative to family members of adults, it is likely that family members of youth were more likely to be parents, and thus the pronounced effects of FTF for relatives of youth might also reflect unique benefits of FTF for *parents* of mental health consumers regardless of consumer age. Because caregiving responsibilities shift somewhat from parents to other relatives (spouses, siblings) as consumers age into adulthood, we elected not to control for parenting status due to concerns with the inappropriate use of statistical “control” that might negate important contextual differences between these participant subgroups [40]. Nonetheless, the unique role of parenting may contribute in part to findings specific to relatives of youth. An additional limitation concerns the generalizability of these findings from a geographically limited region (Maryland). Although results may not generalize to FTF programs in other areas, results for this region were strong and reflect data from FTF classes in urban, suburban, and rural parts of the state, and were carried out in full fidelity with the NAMI model.

Implications for Practice

Findings from the current study support the effectiveness of FTF as a resource for family members of youth with mental health concerns. NAMI and other consumer- and family-advocacy programs might consider making efforts to ensure that child-focused providers are aware of FTE and know how to refer families to the program. Clinicians may increase their effectiveness by directly addressing issues of family burden and distress while also providing referrals to supplemental community supports such as FTF. Family psychoeducation on consumers' mental health in itself, as well as on caregiver strain and well-being, should be an ongoing focus of regular mental health care. Psychoeducation regarding the particular effectiveness of NAMI FTF for relatives of young consumers might be especially relevant for some families.

The NAMI Basics course, a peer-to-peer-led program designed to address specifically the needs of relatives of young consumers, may represent a promising direction for these families. The Basics program, a relatively new addition to the NAMI offerings, focuses on unique concerns related to youth with mental illness, such as managing difficult behaviors and securing school-based services. Although it lacks the evidence base of a large RCT, pilot data from a small, naturalistic sample suggests that the Basics program may be beneficial to participants, particularly in the areas of self-care and empowerment [41]. A controlled trial of Basics, comparing this new program to FTF and/or a "control" condition, would be helpful in determining the most beneficial programs for parents of young consumers seeking psychoeducation and peer support.

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FIGURE 1.

Pre- to post-FTF anxiety and depression scores measured by the BSI among family members of youth and adults.

FIGURE 2.
Pre- to post-FTF positive and negative subscale scores measured by the ESI among family members of youth and adults.

TABLE 1

Participant Information	Consumer age			
	Overall (N = 213)	18 or under (n = 33)	19+ (n = 180)	
Age (Yrs.)	53.3 (SD = 11.0)	49.2 (SD = 9.4)	54.0 (SD = 11.1)	
% Male	54 (25.4%)	8 (24.2%)	46 (25.6%)	
Race				
Asian	6 (2.8%)	0 (.0%)	6 (3.4%)	0.109
Black	36 (17.0%)	6 (18.2%)	30 (16.8%)	
Hispanic	4 (1.9%)	0 (.0%)	4 (2.2%)	
White	158 (74.5%)	23 (69.7%)	135 (75.4%)	
Other, specify	8 (3.8%)	4 (12.1%)	4 (2.2%)	
Education				
Less than high school	4 (1.9%)	1 (3.0%)	3 (1.7%)	0.088
High school graduate	25 (11.7%)	6 (18.2%)	19 (10.6%)	
Some college	46 (21.6%)	7 (21.2%)	39 (21.7%)	
College graduate	54 (25.4%)	12 (36.4%)	42 (23.3%)	
Postgraduate	84 (39.4%)	7 (21.2%)	77 (42.8%)	
% Family income >\$50,000	163 (77.6%)	29 (87.9%)	134 (75.7%)	0.123
Relationship to consumer				
Parent	133 (62.4%)	30 (90.9%)	103 (57.2%)	0.002
Child	9 (4.2%)	0 (.0%)	9 (5.0%)	
Sibling	24 (11.3%)	0 (.0%)	24 (13.3%)	
Spouse/partner	28 (13.1%)	0 (.0%)	28 (15.6%)	
Other kin	16 (7.5%)	3 (9.1%)	13 (7.2%)	
Non-kin/friend	3 (1.4%)	0 (.0%)	3 (1.7%)	
% Married or living as if married	144 (67.6%)	24 (72.7%)	120 (66.7%)	0.494
% Currently in school or college	20 (9.4%)	4 (12.1%)	16 (8.9%)	0.525
% Work full-time	123 (57.7%)	21 (63.6%)	102 (56.7%)	0.456

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Notes:
^a chi-square test,
^b *t*-test,
^c Wilcoxon test,
^d *F*-test,
^e Fisher exact,
^f Kruskal Wallis,
^g Median.

TABLE 2

Pre- and Post-FTF Group Means

Measure	Baseline		Follow-up	
	Consumer 18	Consumer 19	Consumer 18	Consumer 19
	M (SD)	M (SD)	M (SD)	M (SD)
BSI subscale score				
Global severity index	53.82 (11.89)	50.92 (9.11)	49.7 (9.42)	49.76 (8.54)
Depression	54.94 (11.60)	51.14 (8.42)	50.12 (9.08)	50.44 (8.82)
Anxiety	55.03 (12.07)	51.85 (9.09)	50.24 (9.64)	50.26 (7.69)
Somatization	49.45 (10.01)	48.22 (8.35)	47.36 (8.28)	47.82 (8.16)
ECI subscale score				
Difficult behaviors	2.37 (0.81)	1.97 (0.82)	1.90 (0.92)	1.70 (1.82)
Negative symptoms	2.53 (0.84)	2.28 (0.88)	2.18 (0.98)	2.01 (0.89)
Stigma	1.58 (0.98)	1.21 (0.83)	1.21 (0.82)	1.03 (0.72)
Problems with services	1.98 (1.03)	1.79 (0.87)	1.71 (0.86)	1.63 (0.83)
Effects on family	2.07 (0.9)	1.58 (0.79)	1.55 (0.76)	1.49 (0.78)
Need for backup	2.26 (0.83)	2.00 (0.83)	2.00 (0.82)	1.88 (0.78)
Loss	2.04 (0.76)	1.73 (0.72)	1.53 (0.69)	1.46 (0.62)
Dependency	2.52 (0.72)	2.06 (0.79)	2.15 (0.85)	1.80 (0.72)
ECI negative scale	17.34 (5.37)	14.56 (4.52)	14.23 (5.13)	13.00 (4.25)
Good relationship	2.24 (0.7)	2.15 (0.65)	2.43 (0.81)	2.27 (0.68)
Positive experiences	2.37 (0.73)	2.13 (0.72)	2.38 (0.7)	2.30 (0.71)
ECI positive scale	4.61 (1.23)	4.28 (1.18)	4.81 (1.27)	4.57 (1.17)

TABLE 3

Regression Results Showing Differences from Baseline to Follow-Up, Differences Between Consumer Age Groups, and Interaction Effects

Measure	Timepoint (post-FTF vs. baseline)				Consumer age (18 vs. 19)				Interaction*			
	β (SE)	df	t	p	β (SE)	df	t	p	β (SE)	df	t	p
BSI – Brief Symptom Inventory												
General severity index	-1.15 (0.64)	52	-1.81	0.077	3.87 (1.70)	17	2.27	0.036	-2.97 (1.62)	17	-1.84	0.083
Somatization	-.39 (0.60)	52	-.64	0.522	1.30 (1.60)	17	.81	.427	-1.70 (1.52)	17	-1.12	.278
Depression	-.68 (0.66)	52	-1.03	0.308	4.28 (1.68)	17	2.55	.021	-4.14 (1.67)	17	-2.47	.024
Anxiety	-1.60 (0.62)	52	-2.57	0.013	4.26 (1.65)	17	2.59	.019	-3.19 (1.57)	17	-2.03	.058
ECI – Experience of Caregiving Inventory												
Difficult behaviors	-0.27 (0.06)	52	-4.75	<0.001	0.41 (0.16)	17	2.61	0.018	-0.20 (0.14)	17	-1.40	0.178
Negative symptoms	-0.27 (0.06)	52	-4.21	<0.001	0.26 (0.17)	17	1.51	0.150	-0.08 (0.16)	17	-0.46	0.653
Stigma	-0.17 (0.05)	52	-3.58	<0.001	0.43 (0.15)	17	2.89	0.010	-0.20 (0.12)	17	-1.65	0.118
Problems with services	-0.16 (0.06)	52	-2.73	0.009	0.17 (0.16)	17	1.05	0.306	-0.11 (0.15)	17	-0.73	0.478
Effects on family	-0.09 (0.05)	52	-1.74	0.088	0.49 (0.15)	17	3.28	0.004	-0.43 (0.13)	17	-3.22	0.005
Need for backup	-0.12 (0.05)	52	-2.55	0.014	0.27 (0.15)	17	1.74	0.100	-0.14 (0.12)	17	-1.20	0.245
Dependency	-0.26 (0.05)	52	-5.56	<0.001	0.48 (0.14)	17	3.34	0.004	-0.11 (0.12)	17	-0.95	0.355
Loss	-0.27 (0.04)	52	-6.14	<0.001	0.31 (0.13)	17	2.42	0.027	-0.24 (0.11)	17	-2.14	0.047
Positive experiences	0.16 (0.04)	52	3.85	<0.001	0.21 (0.14)	17	1.56	0.137	-0.15 (0.11)	17	-1.40	0.179
Good aspects of relationship	0.13 (0.05)	52	2.75	0.008	0.09 (0.13)	17	0.73	0.474	0.06 (0.12)	17	0.51	0.619
ECI positive scale	0.29 (0.07)	52	4.09	<0.001	0.31 (0.23)	17	1.37	0.189	-0.09 (0.18)	17	-0.51	0.617
ECI negative scale	-1.57 (0.26)	52	-5.96	<0.001	2.90 (0.86)	17	3.37	0.004	-1.55 (0.67)	17	-2.32	0.033

Notes:

* Proc MIXED was used, two random intercept statements with Sub = Class and Sub = PId(Class).

Significant effects are bolded.