Differences Between Parents of Young Versus Adult Children Seeking to Participate in Family-to-Family Psychoeducation

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Objective: **Parents of individuals with mental illness often play a central role in initiating and supporting their children's treatment. This study compared psychological symptoms and experiences of parents of younger versus older consumers. Parents were seeking to participate in a family education program for relatives of individuals with mental illness.** ***Methods:*** **Domains of caregiving and distress were assessed among parents of youths (N=56), of young adults (N=137), and of adults ≥30 (N=72) who were seeking to participate in the National Alliance on Mental Illness Family-to-Family program.** ***Results:*** **Parents of youths endorsed greater burden, difficulties, and emotional distress than parents of young adults, who in turn endorsed greater burden, difficulties, and emotional distress than parents of older adults.** ***Conclusions:*** **Findings suggest that burden, difficulties, and emotional distress among parents seeking participation in this program may be highest when children with mental health concerns are younger and that the burdens recede as children age. (*Psychiatric Services* 65:247–250, 2014; doi: 10.1176/appi.ps.201300045)**

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Family involvement has been identified as an important component of the care of individuals with mental illness (1). Parents often serve significant support and advocacy roles in the recovery process. Supporting a child of any age with mental illness is often stressful, incurring both objective and subjective burdens (2,3). Family members of minors may be particularly vulnerable to difficulties related to caregiving and securing appropriate mental health care for their children (4).

The National Alliance on Mental Illness (NAMI), a self-help and advocacy organization established by family members of individuals with mental illness, has attempted to address some aspects of unmet family need through its Family-to-Family (FTF) program, a free 12-session information and support course for family members (5). FTF attendees' experiences may be quite diverse. Understanding the experiences and emotional well-being of parents with children at different developmental stages may help refine interventions to address their needs, inform effective engagement, and improve services for young people as they transition from pediatric to adult systems of care.

This study compared parents of youths (ages eight to 18), parents of young adults (ages 19 to 29), and parents of adults (ages 30 and older) with mental illness on several measures. Parents were seeking to participate in FTF. Given the additional responsibilities associated with parenting a younger person, we hypothesized that parents of youths would report more objective burden associated with their children's care, more negative experiences of caregiving, and greater anxiety and depression than parents of older consumers (young adults and adults).

Methods

This study included baseline information for parents who participated in a randomized controlled trial investigating the effectiveness of FTF (6). Data were collected from 2006 to 2009. The study was conducted in five diverse regions of Maryland served by NAMI affiliates: Baltimore metropolitan region (Baltimore City and Baltimore County) and Howard, Montgomery, Frederick, and Prince George's counties. All parents of consumers are welcome to participate in FTF and do not need release of

Table 1

Characteristics of three parent groups seeking to participate in Family-to-Family

Variable	Range	Parents of youths (N=56)		Parents of young adults (N=137)		Parents of adults (N=72)		χ^{2a}	p[b]	η^{2c}
		N or M	% or SD	N or M	% or SD	N or M	% or SD			
Descriptive information										
Mother of consumer		42	75	102	75	54	75	.01	ns	
Married or living as married		41	73	99	72	43	60	4.05	ns	
Race										
White		37	66	92	67	57	79	4.53	ns	
Black		13	23	36	26	12	17			
Other		6	11	9	7	2	4			
High school diploma		55	98	136	99	70	97	1.37	ns	
Income >$50,000		45	80	101	74	50	69	1.90	ns	
"Very involved" with consumer		51	91	116	85	61	85	1.50	ns	
Age of consumer (M±SD)	7–57	15.93[d]	2.48	23.16[d]	3.03	37.97[f]	6.11	528.24	<.01	
Age of parent (M±SD)	28–79	47.84[d]	8.33	52.75[d]	5.17	64.21[f]	6.55	120.59	<.01	
N household residents (M±SD)	1–11	3.96[d]	1.24	3.29[d]	1.40	2.22[f]	.76	34.09	<.01	
Brief Symptom Inventory (T scores) (M±SD)										
Somatic symptoms	38–81[g]	49.95	8.97	50.08	9.43	48.10	7.98	1.19	ns	.01
Depression	38–81[g]	55.25[d]	9.99	51.12[d]	9.83	50.20[f]	7.37	5.26	.02	.04
Anxiety	38–81[g]	55.00[d]	10.86	52.81[d,e]	10.08	49.81[e]	7.92	4.54	.04	.03
Global severity index	33–81[g]	54.63[d]	9.79	52.12[d,e]	10.12	50.23[e]	6.89	3.45	ns	.03
Experience of Caregiving Inventory (M±SD)										
Negative scale										
Difficult behavior	0–4[g]	2.42[d]	.65	2.07[d]	.84	1.93[e]	.85	5.90	.01	.04
Negative symptoms	0–4[g]	2.58	.74	2.34	.81	2.26	.93	2.59	ns	.02
Stigma	0–4[g]	1.58[d]	.88	1.32[d,e]	.84	1.21[e]	.72	3.43	ns	.03
Problems with service	0–4[g]	2.01	.84	1.86	.88	1.77	.89	1.25	ns	.01
Effect on family	0–4[g]	2.01[d]	.79	1.66[d]	.80	1.49[e]	.82	6.23	.01	.05
Need for backup	0–4[g]	2.14	.70	2.23	.83	2.20	.76	.24	ns	<.01
Dependency	0–4[g]	2.58[d]	.74	2.28[d]	.81	2.05[e]	.69	7.75	<.01	.06
Loss	0–4[g]	1.97	.76	1.86	.80	1.86	.69	.45	ns	<.01
Positive scale										
Positive personal experience	0–4[h]	2.30	.76	2.15	.67	2.06	.73	1.73	ns	.01
Good aspect of relationship	0–4[h]	2.35	.66	2.26	.67	2.15	.70	1.34	ns	.01
COPE Scale (M±SD)										
Positive coping	4–16[h]	12.04	3.07	11.93	2.97	11.42	2.86	.89	ns	.01
Denial	4–16[h]	5.18	1.77	4.84	1.55	4.99	1.52	.92	ns	.01
Religious coping	4–16[h]	11.35	5.05	12.03	4.25	10.64	4.69	2.25	ns	.02
Emotional coping	4–16[h]	11.88	3.08	12.24	3.31	11.66	3.34	.77	ns	.01
Acceptance	4–16[h]	12.81	2.06	12.61	2.41	12.31	2.76	.69	ns	.01
Family Assessment Device (M±SD)										
General family functioning	12–48[h]	24.76	5.37	25.19	6.09	25.99	6.08	.71	ns	.01
Family problem solving	6–24[h]	12.87	2.76	13.11	2.81	13.37	2.84	.48	ns	.01
Family Empowerment Scale (M±SD)										
Within family	1–5[h]	3.58[d]	.51	3.41[d,e]	.63	3.30[e]	.65	3.33	ns	.03
With service providers	1–5[h]	3.79[d]	.52	3.20[d]	.83	2.97[e]	.82	18.53	<.01	.12
Within community	1–5[h]	2.48	.63	2.39	.76	2.35	.82	.50	ns	<.01
Family Problem-Solving Communication Scale (M±SD)										
Affirming communication	0–15[h]	10.87	2.91	10.73	2.69	11.09	2.92	.38	ns	<.01
Incendiary communication	0–15[g]	5.95	3.29	5.74	2.97	5.47	3.28	.36	ns	<.01
Total	0–30	19.96	5.87	19.99	5.26	20.63	5.76	.35	ns	<.01
Knowledge About Mental Illness Scale (M±SD)	0–100[h]	12.34[d,e]	3.42	12.39[d]	3.81	11.07[e]	3.90	3.19	ns	.02
Family Experiences Interview Schedule (M±SD)										
Subjective burden subscale										
Worry	0–4[g]	2.62	.74	2.65	.74	2.72	.77	.32	ns	<.01
Displeasure	1–5[g]	2.87	.84	2.66	.85	2.82	.83	1.63	ns	.01
Objective burden composite	0–2[g]	1.01[d]	.46	.71[d]	.47	.38[f]	.33	33.14	<.01	.20
Daily living assistance	0–1[g]	.50[d]	.24	.35[d]	.24	.19[f]	.17	31.12	<.01	.19

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Table 1

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Variable	Range	Parents of youths (N=56)		Parents of young adults (N=137)		Parents of adults (N=72)		χ^{2a}	p[b]	η^{2c}
		N or M	% or SD	N or M	% or SD	N or M	% or SD			
Supervision scale	0–1[g]	.22[d]	.19	.13[d]	.16	.06[f]	.12	16.19	<.01	.11
Injury or threat	0–1[g]	.17[d]	.25	.08[d]	.19	.02[e]	.10	9.85	<.01	.07
Attention-seeking behavior	0–1[g]	.50[d]	.38	.18[d]	.31	.10[e]	.22	29.71	<.01	.19
Night disturbances	0–1[g]	.25[d]	.35	.18[d,e]	.26	.09[e]	.25	5.76	.01	.04
Suicidal ideation or attempts	0–1[g]	.11[d]	.21	.07[d,e]	.17	.02[e]	.07	5.15	.02	.04
Drinking	0–1[g]	.09	.23	.10	.22	.06	.18	1.08	ns	.01
Drugs	0–1[g]	.10[d,e]	.26	.11[d]	.25	.03[e]	.13	3.41	ns	.03
Embarrassing behavior	0–1[g]	.31[d]	.34	.21[d]	.30	.10[e]	.23	8.33	<.01	.06
Hospitalized in past 6 months	Yes or no	24	43	56	41	17	24	6.90	ns	.11[i]

[a] df=2

[b] Probability from 3 × 2 chi square or univariate analysis of variance. All p values, except those for the descriptive information, were adjusted for a false discovery rate.

[c] Effect size (small, .010; medium, .059; large, .138)

[d,e,f] Means that share a superscript did not significantly differ when a Bonferroni correction was used.

[g] Range represents range of possible scores. Higher scores indicate worse outcomes (for example, more depression, stigma, or worry).

[h] Range represents range of possible scores. Higher scores indicate better outcomes (for example, more effective coping, empowerment, or problem solving).

[i] Effect size Cramer's V (small =.10, medium=.30, large=.50)

information or consent from their children. After providing informed consent, participants (N=265) completed baseline assessments via telephone before attending FTF.

Several self-report measures were used (6–13). Psychological symptoms were measured by the Brief Symptom Inventory. Negative and positive experiences of caregiving were measured by the Experience of Caregiving Inventory, different aspects of coping by the COPE Scale, family functioning by the Family Assessment Device, empowerment by the Family Empowerment Scale, and communication style by the Family Problem-Solving Communication Scale. Knowledge about mental illness was assessed by a knowledge measure. Subjective and objective burden was measured by the Family Experiences Interview Schedule. The methods have been described in detail elsewhere (6). All procedures were approved by the University of Maryland Institutional Review Board.

Data were analyzed across the three parent group: 56 parents of youths, 137 parents of young adults, and 72 parents of adults. Multivariate analyses of variance (ANOVAs) were used to detect omnibus differences on all measured variables. Univariate ANOVAs with Bonferroni adjustments were used for pairwise comparisons between parent subgroups. To control for multiple testing, a false discovery rate adjustment was employed. Effect sizes (η^2) were reported for ANOVAs of the dependent measures. Missing data accounted for less than 1% of all data and were deleted pairwise.

Results

Results are presented in Table 1. Compared with parents of both young and older adults, parents of youths reported more problems with managing difficult behaviors, preventing injury to their child and others, and managing attention-seeking behaviors. With respect to their own emotional well-being, parents of youths reported more symptoms of depression than the other two groups.

Parents of youths reported greater empowerment with service providers compared with the other parent groups. In addition, parents of youths reported significantly more empowerment within their families compared with parents of older adults. No significant group differences were observed in family coping, communication, functioning, subjective burden, and positive caregiving experiences.

Discussion

This study found higher burden in certain areas among parents of ill children compared with parents of young adults, who in turn showed higher burdens in certain areas compared with parents of older adults. Specifically, the higher burdens included some that would be expected given the developmental needs of youths, independent of mental illness (for example, dependency), as well as some that might reflect the nature of emerging mental illness among adolescents (for example, suicidal behavior and threat of injury). Responsibilities, which may entail frequent crisis management, reflect the daily burden and stress encountered by parents of youths with mental illness. The findings also reflect to a lesser degree the burden and stress experienced by parents of young adults with mental illness, compared with parents of older adults.

Several plausible explanations can be offered for the group differences. We did not find significant differences in diagnoses or in the variable used as a proxy for severity of illness (recent hospitalization), suggesting that neither diagnosis nor severity were the primary drivers of our findings. It is likely, however, that younger consumers and their parents may be coping with more recent illness onset and diagnosis than older consumers and their parents. Research on families'

experiences indicates that the period surrounding the diagnosis of a family member's illness is often characterized by crises, confusion, trauma, anger, and feelings of loss (14). Burdens and distress may arise that are specific to the newness of the mental health concerns. Given these potential burdens, it is not surprising that parents of younger consumers tended to score significantly higher on measures of depression, compared with the other two groups. Anxiety scores were also higher for parents of youths compared with parents of older adults. These findings emphasize the importance of reminding parents of youths that they are not alone and incorporating developmentally informed psychoeducation into mental health services.

Despite this pattern of greater burden and depression among parents of younger consumers, parents of youths reported significantly more feelings of empowerment within the mental health service system compared with parents of adults. This finding may reflect the family-centered approach of many pediatric mental health services. Parents of minors are typically required to consent for treatment and may be more routinely consulted regarding their preferences than parents of consumers who are 18 and older. Because of these responsibilities, parents of younger consumers may feel more confident navigating systems of care and advocating for their child. It is also possible that baseline empowerment is related to help seeking and that more empowerment is required of parents of younger children in order to seek help from FTF. Alternatively, differences in empowerment scores could reflect a lowering of expectations among parents of older consumers, who have been dealing with mental health services longer.

Findings suggest potential areas of emphasis for programs oriented toward caregivers of young consumers. For instance, issues related to objective burden seemed very salient for parents of youths compared with parents in the other two groups. Curriculums that emphasize emotional and instrumental support for parents struggling with threat of injury, attention-seeking and embarrassing behavior, and perhaps suicide might be particularly helpful for parents of youths. This parent subgroup may also benefit from psychoeducation and behavior management training interventions. Elevated depression scores among the parents of youths may be another relevant concern for some parents. Adult-focused referral information for family members experiencing clinically significant depression may be particularly useful. Finally, parents of youths were more likely than parents of adults to have a larger number of household members. Responsiveness to this group's needs might include having child care or separate youth-friendly activities available during FTF sessions.

In 2008, some NAMI affiliates began to offer a peer-to-peer course designed to meet the needs of families of young consumers. NAMI Basics (www.nami.org/basics) emphasizes issues specific to the challenges faced by families of youths with mental health problems, such as managing difficult behaviors and securing educational services (15). Given the additional stressors reported by parents of youths in our sample, programs such as NAMI Basics may provide benefits that are tailored to the needs of this parent subgroup.

Conclusions

The study documented differences between parents of youths with mental illness and parents of older individuals with mental illness. These differences likely stem from many factors and could inform recommendations for programs such as FTF that serve family members of consumers of various ages.

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