

Leave Me Alone, Help Me Recover

Adolescent Impressions of Family
Involvement in ED Treatment

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Disclosures

I, *Erin Parks, PhD*, have no commercial relationships to disclose.



The Dialectic

- Adolescents with eating disorders are often unable to make decisions that will foster recovery, and thus parents must be empowered to lead recovery.¹
- Caring for a child with an ED is an extremely stressful experience with high levels of caregiver stress, anxiety, and depression.²

1. Lock & Le Grange, 2012
2. For review, Anastasiadou et al., 2014



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The Resistance

- Parents – “I don’t want to ruin our relationship.”
- Adolescents – “I want independence. I can do this myself.”



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Hypotheses

Adolescents would report that family involvement was

- 1) an unpleasant experience *during* treatment
- 2) after treatment, their relationship with their parents was not negatively affected, and
- 3) after treatment, adolescents would feel gratitude for their parents' involvement.



Participants

- 64 families
 - Discharged from UC San Diego's Eating Disorders Center
 - Participated in PHP program
 - Average length of stay (PHP+IOP) = 4 months
 - Invited via email



Family Involvement

- Family Therapy Sessions
 - FBT and/or DBT
- Family DBT Skills Groups
- Family experiential groups
- Parent-only support and psychoeducation groups
- Parent Management Training
- Family group meals (4x/week)
- Parent phone coaching with family therapist
- Family sessions with treatment team (e.g., RD, MD)



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Mixed-method Design with a *complementarity* intent

- Quantitative and qualitative measures were interactively designed to measure the same phenomena using different methods with equal importance with the rationale of
 - *“increasing the interpretability, meaningfulness, and validity of constructs...by both capitalizing on inherent method strengths and counteracting inherent biases in methods”³*
- Respondents were
 - Adolescents
 - heterogeneous diagnosis and stage of recovery
 - asked to both reflect retrospective and comment on current feelings.

3. Greene, 1989



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7-point Likert scale

- 1 (very negative) to 7 (very positive)
- Retrospective assessment
 - “In the BEGINNING, when you FIRST started at UCSD, how did you feel about...)
- Current impressions
 - At the END, in your final week of treatment at UCSD, how did you feel about...).
- Family involvement:
 - family therapy
 - family groups
 - family meals
 - overall helpfulness of family involvement.
- Relationship:
 - With their parents
 - With their family therapist



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7-point Likert scale

TODAY, when you look back at your time with UCSD, how do you NOW feel about...

	Very negative			Neutral			Very positive		
Family Therapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Family Groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Family Meals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Your relationship with your family therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Your relationship with your parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
The helpfulness of family involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	



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Open-ended Questions

- When you FIRST started at UCSD, what did you think about having your family involved in treatment?
- Looking back, how do you NOW feel about having your family involved?
- What was UN-HELPFUL about having your family involved?
- What was HELPFUL about having your family involved?
- Discuss your relationship with you parents over the course of treatment and recovery; how did your relationship change from before treatment, during treatment, and now after treatment?
- Timing: do you think you family should have started treatment earlier? Later? When should your family have become involved?
- Other comments on family involvement:



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Results

- 29 adolescents (45% response)
- 12 and 21 years old (mean=16.6, $sd=2.21$)
- Diagnosis:
 - Anorexia: n=16 (55%)
 - Bulimia: n=8 (27.8%)
 - ED-NOS: n=5 (17.2%)

	Before	Now
Restricting	28 (97%)	8 (28%)
Over-exercising	16 (55%)	2 (7%)
Binging	6 (21%)	1 (3%)
Purging	12 (41%)	2 (7%)
Laxative abuse	4 (14%)	0
Self-harm	14 (48%)	3 (10%)
Substance Use	1 (3%)	2 (7%)



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Quantitative Impressions

t-Test: Paired Two Sample for Means (n=29)

	Impressions of Family Involvement		
	<i>Beginning</i>	<i>Now</i>	<i>p</i>
Family Therapy	2.66 (sd = 1.9)	5.00 (sd = 1.98)	< .0001
Family Groups	2.34 (sd = 1.47)	4.62 (sd = 1.66)	< .0001
Family Meals	2.55 (sd = 1.86)	5.28 (sd = 1.31)	< .0001
Relationship with family therapist	3.90 (sd = 2.24)	5.62 (sd = 1.80)	< .001
Relationship with parents	3.07 (sd = 1.81)	5.72 (sd = 1.28)	< .0001
Helpfulness of family involvement	3.00 (sd = 1.93)	5.62 (sd = 1.54)	< .0001



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Initial Thoughts on Family Involvement

- 26 (of 29) expressed anger, fear, and/or shame about their families being included.
 - “It made me very uncomfortable, I did not want my family to see how bad I became (eating disorder wise).”
 - “I was very cautious about having my family involved. The main reason that I went to treatment was to avoid the eating disorder from ruining my relationship with my mom. I really wanted to just recover by myself and not have help.”
 - “I thought it was not going to be helpful and just make things worse.”



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Current Thoughts on Family Involvement

- 28 (of 29) expressed positive impressions.
 - *“I thought it was valuable, even though I was annoyed.”*
 - *“I feel relieved. Even though it was an awkward transition at first, it helped in the long run because of how meaningful our relationship became and how much the support meant to me.”*
 - *“They helped make sure I was eating my meals and they monitored everything, even when I didn't want to. They definitely were a big part in recovery.”*
 - *“Looking back now, I'm glad my family was involved in my treatment because I was held accountable for my actions at home and was under constant supervision after and during meals. I'm also glad that they were present at UCSD because they were able to learn skills to help me and understood better how I was feeling and what I was working on in order to recover”*



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What was UN-HELPFUL about having your family involved?

- Wide ranging
 - loss of independence
 - perception of parents as “nagging” and intrusive when they were supervising for ED behaviors
 - guilt in reaction to their parents’ worries
 - critiques of how the parents could have done more.



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What was HELPFUL about having your family involved?

- Meal planning, preparation & plating
- “*Making me eat*” and “*[helping me] stay on track at home.*”
- Separating the eating disorder from the child
 - “*Even though it bugged me, as I look back I see how them being there would help me in later times when I was discharged, or I probably would have relapsed.*”
 - “*It was helpful to have someone to turn to when you needed it and have people to keep you accountable for your sleep hygiene plan, exercise plan, activity commitments, etc.*”
 - “*Having family groups on Saturday taught me many good coping skills and taught my parents to better understand what they needed to do to encourage me to be healthy.*”



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Relationship with your Parents over the course of treatment.

- While the parent-child relationships started in different places, ranging from hostile to very positive, all but one participant described their relationship as better than before.
 - “*During the beginning, I closed off from them, but through all of it and because of it we have grown closer.*”
 - “*Before treatment it was very bad, during there was a lot of stress and obsessing over my recovery, and now there is still stress but I appreciate them so much and my respect for them is a lot higher.*”



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Timing of Family Involvement

- 13 (of 29) wished their family would have put them in treatment earlier and/or they wished their parents would have been involved in treatment earlier
 - *“In hindsight, objectively, they should have begun a stricter treatment plan sooner.”*
 - *“My family should have started treatment earlier.”*
 - *“I think family therapy should start right away.”*



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Conclusions

- Both the quantitative and qualitative data align with what clinicians and parents have observed clinically—adolescents are initially resistant to including their parents in treatment.
- Regardless of their reasons for wanting to exclude their families from treatment, ultimately the adolescents reach the same conclusion upon discharge—family involvement was instrumental to recovery.
- The adolescents demonstrated a significant change in opinion on the helpfulness of all aspects of family involvement. This finding can encourage parents to participate in all aspects of treatment, regardless of initial reservations by their adolescent.



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Limitations

- Intensity of family involvement
- Modality of family involvement
- Response bias
- Self-report
- Unvalidated measures
- Small sample size
- Single site



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Final Message

- Just as adolescents aren't eager to include their parents, parents are also not necessarily eager to enter family therapy—something that is initially seen as vulnerable and uncertain.
- Reducing this barrier to engaging in family treatment, such as data demonstrating improved outcomes **and** improved relationships, will hopefully help more families to take the courageous step toward family-inclusive interventions.



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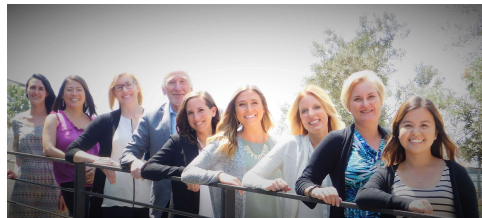
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Thank you!



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