

The urgent need for greater parent support and better health system experiences to enhance outcomes for pediatric anorexia nervosa: A Commentary on Marchetti & Sawrikar (2023)

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Abstract

Marchetti and Sawrikar's (2024) systematic review of parent illness representations of their child's anorexia nervosa provides a valuable synthesis of 32 qualitative studies. The key themes that emerge paint a concerning picture of parents' perceptions of AN as: difficult to identify and understand; of chronic duration; uncontrollable; severe; and associated with serious consequences. A sense of hopelessness and low parental self-efficacy was identified. This Commentary explores the key findings of this review in four areas: AN treatment and recovery (control/cure); emotional representations of the illness; parent understanding of the illness (coherence) and its causes; and consequences of the AN. These illness perceptions are discussed along with relevant quantitative investigations of parent experiences, with a view to suggesting how the toll on parents might be reduced and how reducing burdens on parents might also lead to improved timely treatment outcomes. It is proposed that two broad features are needed: improved help-seeking experiences in the health care system; and, more parent-focussed support.

KEYWORDS

anorexia nervosa, children, eating disorders, family-based treatment, parents

1 | INTRODUCTION

Marchetti and Sawrikar's (2024) systematic review of parent illness representations of their child's anorexia nervosa (AN) offers a valuable synthesis of key themes from qualitative studies. The authors note that clinical recommendations for addressing parental distress are lacking and, accordingly, their article aims to identify parent illness perceptions which can lead to ideas for better supporting parents. They acknowledge parents as key agents of change in family-based therapy (FBT) and thus it is important to investigate their experiences to inform strategies for supporting them to enhance treatment outcomes. The authors concluded that parents viewed

AN as: difficult to identify and understand; of chronic duration; uncontrollable; severe; and associated with serious consequences. Overall themes of hopelessness and low parental self-efficacy were also identified.

The review complements this author's Forum publication that called for a more comprehensive investigation of parent experiences of their child's ED through a discussion of the findings from a large, quantitative Parent Survey ($N = 439$; 91.6% mothers) of children under 18 years old who had experienced an ED (81.9% AN cases) within the previous 3 years (Wilksch, 2023). This article formed the focus of a special section in *IJED* on Increasing Support for Parents of Children Experiencing an Eating Disorder.

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Marchetti and Sawrikar include 32 studies in their review – 31 were comprised of a total of $N = 382$ parents (mean N per study = 12.3), where 65.4% of parents were mothers ($n = 250$). The remaining study had a large sample with $N = 616$ carers, including $n = 543$ parents (92.8% mothers), and where 31.3% of the offspring with an ED were under the age of 18 years (Robinson et al., 2020). Across the studies, Marchetti and Sawrikar reported an M age = 20 years for the parents' offspring with AN with the samples typically ranging from 13–28 years. Indeed, 53.5% of studies included adult offspring in the ED sample. This broad age range presents some challenges in interpreting the findings of the review. While the optimal way to treat EDs does not suddenly change at 18 years of age, the differences in the parent role in an FBT approach versus an adult receiving individual treatment are substantial. Thus, the age of the person with AN should be considered when interpreting the findings. That said, there likely are some common features for parents regardless of their child's age.

The current paper discusses the Marchetti and Sawrikar findings for the illness representations most commonly explored in the studies reviewed: *control/cure (treatment and recovery)*, *consequences*, *emotional illness representation*, *coherence (understanding)* and *causes*, how they compare with the quantitative exploration of parents experiences (Wilksch, 2023), and offers pragmatic suggestions for improvements. FBT is the most efficacious treatment for pediatric AN and has many appealing features for the evidence-informed clinician. The findings discussed indicate that two broad strategies are needed to maximize treatment effectiveness and reduce the burden of AN: (1) Improvements in health system experiences, and (2) More direct support for parents.

1.1 | Control/cure

Parents were not optimistic about the ability of treatment to cure AN: Marchetti and Sawrikar identified just one study where parents believed treatment could achieve a cure. While parents reported that treatment improved family dynamics and mental health symptoms, many believed that it could only help with short-term improvements and viewed relapse as likely over the longer term (perhaps due to including parents of adults with AN). Competence of clinicians was a further concern of parents, a result that is consistent with another review where carers rated negative treatment experiences (e.g., low confidence in clinician) as the greatest barrier to treatment uptake (Daugelat et al., 2023).

Parental pessimistic views about treatment identified by Marchetti and Sawrikar concur with the Parent Survey findings (Wilksch, 2023) where parents needed to see $M = 3.55$ therapists before finding a clinician they believed could help their child and, parents had only a 14.7% chance of a helpful experience with both the first GP and therapist seen. Though not included in the report, a notable finding was that parent confidence in the likelihood of their child recovering significantly *reduced* in the early stages of treatment. Parents were not asked their reasons for this; one might speculate

contributing factors to include difficulties finding a helpful therapist; seeing their child's anxiety initially heighten with refeeding; and the illness' adverse impact on other parts of life.

These findings lead me to suggest that parent-only sessions need to become a more common feature of FBT, particularly in the early stages of treatment, to better support parents and to ensure that parents understand what to expect, possible timelines of progress, and critically, clear and consistent messaging that full recovery is the goal of treatment. Indeed, it would likely be useful for clinicians to spend more time defining and providing psychoeducation about recovery so that parents have informed expectations. Consistent with this, Gorrell and Le Grange (2023), suggested the addition of a session “0” to the FBT protocol where the clinician takes time to both focus more directly on parent wellbeing and to develop a thorough formulation with the parents regarding the child's ED, comorbidity, and adolescent development to inform any adjustments that could be made to maximize treatment success. Similarly, Lock and Le Grange (2018) proposed a 3-session Parental Intensive Coaching add-on for those families that are making insufficient early progress in treatment. These respective additions are likely to increase parental self-efficacy, an identified mediator of FBT outcome (Lock & Le Grange, 2019). They are also steps towards an accompanying need: for parents to have better experiences with the health system. Parents rated empathy, trust, knowledge, and skill at helping those experiencing an ED and their families as ideal clinician characteristics (Wilksch, 2023). It seems that all too often, clinicians with thorough ED training and skills not only need to set up effective treatment but also ‘undo’ unhelpful messaging that families have been exposed to from other health service providers.

1.2 | Emotional illness representation

Marchetti and Sawrikar (2024) found parents experienced a range of symptoms of emotional distress including fear, depression, anxiety, shame, and guilt. Clear themes of loneliness and isolation emerged, with many parents reporting a mix of feeling abandoned by their partner, child, and clinical staff. In the Parent Survey, parents of a child with an acute ED were four times more likely than parents of recovered children to meet clinical levels of depressive symptoms (39.0% vs. 10.1%) and five times more likely to meet clinical levels of anxiety (27.0% vs. 5.1%; Wilksch, 2023). Almost all (96%) parents rated their emotional health as worse than normal.

Marchetti and Sawrikar reported that some mothers felt lonely and that they couldn't count on their partners for support. Some believed that their partner could not manage their own emotions, so it felt easier to exclude them to protect themselves from becoming the carer of multiple family members. This corresponds with findings that the ratio of hours spent directly supporting the child with the ED is 2.5 to 1 for mothers versus fathers (Rhind et al., 2016). Once again, these findings illustrate the need for more parental support and nuance in how support is provided across parents and families. Clinicians should follow the manual and ensure that, where appropriate,

both parents are highly engaged in treatment. Moreso, there is discussion during parent sessions of the respective “load” each parent is bearing in supporting their child through recovery. While there is no one size fits approach, a drift in one parent's responsibility away from the child's recovery is a barrier to progress. Clinicians need to collaboratively formulate what parents might need in supporting their wellbeing with a view to this also augmenting the child's treatment. Other life-threatening pediatric conditions are managed by medical staff. AN is unique in that for outpatient treatment, parents (with support from clinicians) are the key agents of change, representing a significant burden to bear and one that is likely made much worse if it is perceived to be primarily endured alone.

Importantly, parents who received their own support from a health professional report significantly lower levels of depression and anxiety than those parents who had not, yet just under half of the sample (48.4%) in the Parent Survey had received such support (Wilksch, 2023). Perhaps appointments with an ED clinician are especially valuable to parents given the therapist's specific skill and knowledge and a lower likelihood of giving support that is inconsistent with the child's AN treatment potentially provided by a non-expert in ED. The evidence of distress experienced by parents suggests it would be helpful for parent-only support sessions to become a feature from early in FBT rather than only in response to slow treatment progress. Research is needed to investigate if there is an ideal frequency of such sessions. The evidence indicates a focus on the following is likely to help: (1) increasing psychoeducation for parents; (2) providing an opportunity for parents to speak openly; and (3) the therapist providing direct support to the parents. Offering this as parent-only sessions is also kinder to the young person who despite being strongly in the grips of AN, they are often concerned about the impact of the illness on loved ones.

Familial and social support systems have been rated as the greatest facilitators of treatment uptake by caregivers, clinicians, and patients (Daugelat et al., 2023). Here young patients have a distinct advantage over independent adult patients, as parents are highly motivated to seek treatment where fears for their child's health and wellbeing can override other barriers (e.g., shame, guilt, etc.). This means that younger patients are less likely to have an untreated illness. It also means that we need parents and families to have helpful experiences with primary care and timely access to ED treatment services to minimize illness duration and accompanying suffering for the whole family (Wilksch, 2023).

1.3 | Understanding (coherence) & causes

Marchetti and Sawrikar (2024) reported that parents were most likely to attribute the cause of their child's illness to themselves, while fewer studies found attribution to child-related factors (e.g., genetic, temperament) or external causes (e.g., traumatic events, social media). These findings suggest that most parents externalize the illness from their child which is a key foundation of FBT, likely to lead to more empathic parental response and lower levels of expressed emotion, which can restrict treatment progress.

The other critical part of externalizing AN, however, is for parents to not blame themselves for the illness. Unfortunately, many parents do self-blame which risks eliciting guilt and undermining wellbeing, coping, and being an agent of change for their child's treatment. The authors attribute self-blame to parents' poor understanding of AN, including: difficulties recognizing symptoms; confusion of symptoms with normative adolescent development; initially viewing weight loss as positive; extra challenges for identification in male children; and failing to understand why the child would not eat. It is also possible that parental self-blame could lead to heightened emotional expression where fears (e.g., of upsetting the child) could result in unhelpful accommodating behaviors (e.g., allowing food to be missed) that maintain the ED. I recommend enhancing parents' education about the multifactorial causes of AN, discussing their perceptions of the triggers of their child's illness, and emphasizing the crucial need for action in refeeding. Once again, helpful interactions with the health system are important, particularly in the early stages.

1.4 | Consequences

Marchetti and Sawrikar (2024) found numerous adverse consequences from the child's AN including: a profound impact on the whole family; feeling that other family members were being neglected; rupture in the parent-child relationship; negative impact on the parent's romantic relationship; the need to take leave from work; evidence of financial burden; and reduced social contact. These findings correspond closely to the Parent Survey (Wilksch, 2023), where: 92.7% of parents experienced a deterioration in their romantic relationship; 70.5% of parents reported worse physical health than normal; 91.8% incurred treatment costs in the private sector with median out-of-pocket expenses in the range of \$US7,443–\$14,887; households needed to take $M = 70.1$ days leave from work to support their child; and over 25% needed to either take a minimum of 6 months leave, resign from work or lost their job.

Parents who are concerned regarding a perceived rupture in the relationship with their child need to be given the opportunity to discuss this and provided with psychoeducation about common experiences during treatment and recovery (where lasting ruptures are rare). Clinicians also need to regularly inquire with the young person regarding features of parental management of the AN that they find helpful and if there are any approaches they find less helpful for which better strategies could be found.

Effective treatment for pediatric AN is a critical opportunity where the shorter the duration of the illness, the less destructive the consequences are likely to be. This again points to the need for efficient and helpful experiences with the health system. The key here would be to minimize ‘false starts’ in treatment to reduce the need to change treatment providers. Evidence suggests more efficient, cost-effective treatment with greater patient and parent satisfaction ratings are found in specialist ED settings than generalist mental health services (Wilksch, 2023). There exists an undeniable need for substantially increasing the number of specialized ED clinicians and treatment

services, especially for pediatric treatment where an important combination of skills and experience are required: being highly informed about EDs and skilled at working with young people and their families.

2 | CONCLUSION

Marchetti and Sawrikar's (2024) systematic review of qualitative studies paints a worrying picture that is broadly consistent with quantitative investigations of the impact on parents of their child's ED and help-seeking experiences. Several directions clearly emerge that largely fall under two categories: (1) Improving parent experiences with health care systems, and (2) Increasing targeted parental support to maximize self-efficacy and reduce emotional distress. FBT is the leading evidence-based treatment for pediatric AN. Thus, the more we can improve the systems in which it is offered (e.g., experiences with primary care referers) and grow the number of clinicians skilled in its delivery, the better. Increasing parental well-being and functioning during their child's illness needs to be viewed as a key goal of clinicians. It is likely to elevate treatment efficacy, efficiency, and greatly reduce the overall burden of EDs.

AUTHOR CONTRIBUTIONS

Simon M. Wilksch: Conceptualization; data curation; investigation; methodology; project administration; writing – original draft; writing – review and editing.

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