



BODY IMAGE

What Families Say



WHAT FAMILIES SAY – REPORT BACKGROUND

In 2018 CEED undertook to develop a training to enhance clinician's skillset in supporting young people and their families to address body image issues throughout eating disorder treatment and recovery. This involved a number of important elements including eliciting feedback from families about their experiences of the impacts of body image on the recovery of their loved one, and exploring what they believe would have been helpful. We also asked for feedback from clinicians about the ways in which they work with young people around body image, and asked them to identify any gaps in their knowledge and skillset. Additionally, CEED clinicians consulted with Daniel Le Grange, founder of Family-Based Therapy (FBT) for adolescent eating disorders to discuss the applicability of targeting body image within the FBT therapeutic framework. Dr Rachel Rogers, an expert in the area of body image, provided additional insights regarding the current evidence base and interventions for body image concerns during adolescence.

This report documents the outcomes of these investigations and provides a context for our training "Working with the body image concerns of young people". This report is designed as pre-reading for the training and will be referred to during the workshop.

SUMMARY OF FAMILY PERSPECTIVES & CLINICIAN RESPONSES

In 2018, CEED invited families to respond to a survey requesting their perspectives on and experience of body image throughout treatment and recovery. A total of 39 parents of children who had recovered or were in treatment for an eating disorder (mostly anorexia nervosa) responded. CEED also invited clinicians from our youth services mailing list (n=35) to comment on their own understanding of and ways of working with the body image concerns of young people. Below is a summary of parent and clinician responses.

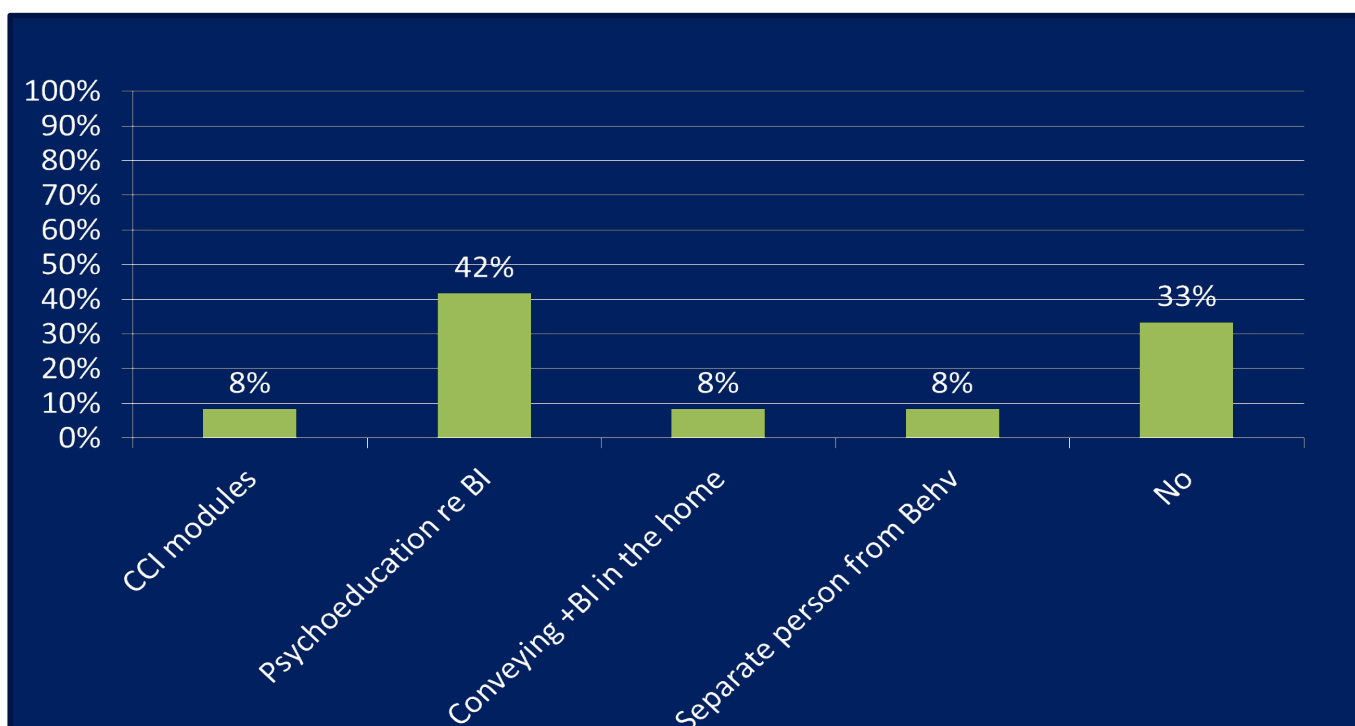
WAS BODY IMAGE AN IMPORTANT PART OF THE TREATMENT EXPERIENCE?

Parent feedback about the importance of body image in eating disorder treatment and recovery suggests that distress and concern about body appearance is extremely common, with 89.74% of the parents surveyed indicating that their child expressed body image concerns as part of their eating disorder/treatment and recovery experience. This is consistent with evidence that suggests that body image distress throughout treatment is the norm rather than the exception.

Furthermore, parents indicated that they felt under-equipped to deal with the body-related distress of their loved one during treatment. They identified a number of approaches that they felt would assist them to feel more confident and effective to manage this aspect of the treatment, including:

- Strategies/tools e.g. list of Do's and Don'ts, what to say, how to handle triggers, how to support therapy
- Education e.g. workshop for carers, psychoeducation re body distortion, how to manage distress
- Treatment team providing leadership in talking about body image, young person more likely to 'believe' treatment team information on body image distortions
- Resources e.g. diversity of bodies, starter conversations on social media and body image

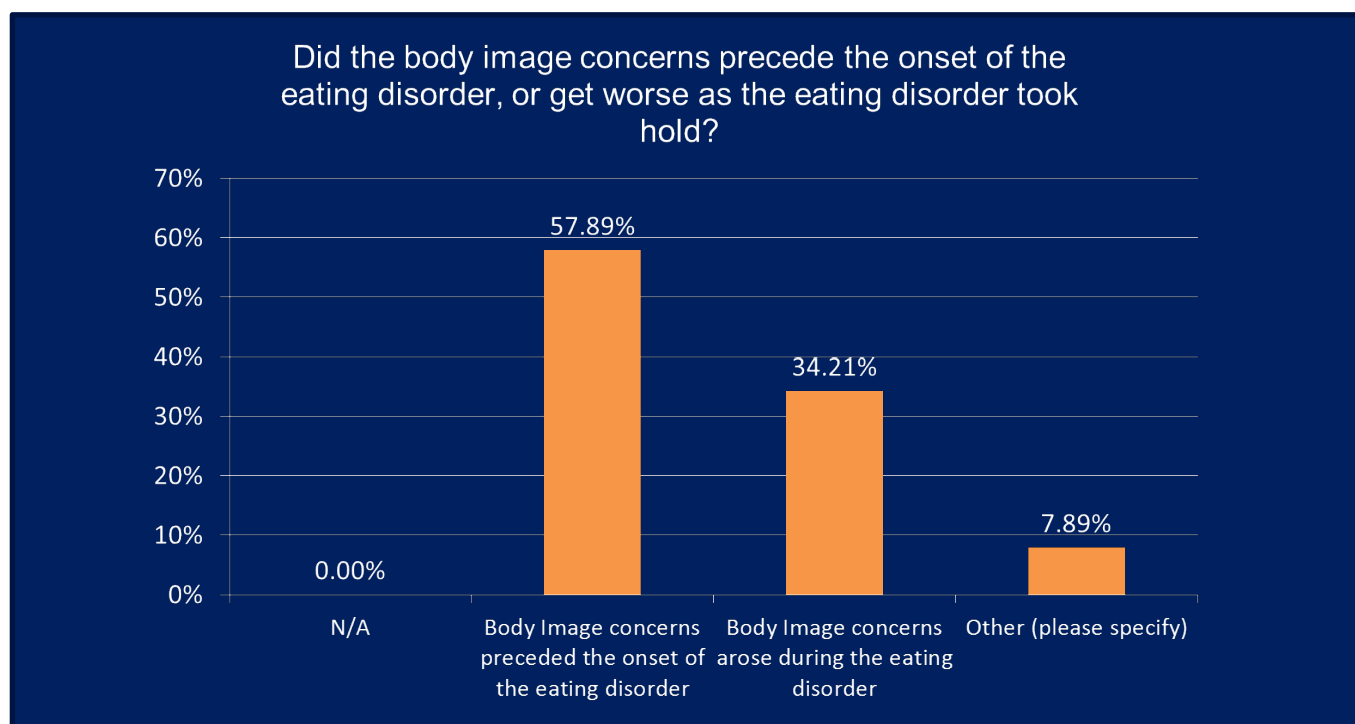
Interestingly clinicians who completed the survey also reported a lack of confidence in working with families in the area of body image, with 30% stating they did not address body image with parents at all (see Figure below). Other strategies clinicians did use with families and felt were helpful included using psychoeducational materials and worksheets (such as those on the Centre for Clinical Interventions, CCI, website) to inform parents, helping parents to model/convey positive body image in the home, and to separate the person from the behaviour/body image distress to be able to better respond in times of distress.



Despite body image distress being a normative part of eating disorder treatment and recovery, the survey responses from parents and clinicians suggested that neither families nor clinicians felt confident about ways of working collaboratively to support the young person in their distress, and in supporting the young person and their family to promote a more positive body image throughout treatment.

WHERE DOES BODY IMAGE DISTRESS FIT WITHIN THE TREATMENT-RECOVERY PROCESS?

Families reported mixed experiences about the presence of body image concerns during the course of the illness. As displayed in the figure below, most parents (58%) reported that their child was experiencing body image distress prior to the emergence of the eating disorder, however a significant proportion (34%) reported body image was not present prior to the eating disorder however arose during the course of treatment.



Furthermore, 51.85% of parents whose child gained weight as a result of treatment reported that their child's body image distress increased. Body image distress is an area that clinicians generally feel anxious about addressing (Turner, Tatham, Lant, Mountford, & Waller, 2014), and yet fully half of young people are likely to express increased distress as part of their treatment, according to the parents surveyed. Hence, clinicians who feel anxious and under skilled may not adequately support and equip parents to tolerate these intense periods, the implications of which may be treatment drop-out, relapse (Carter, Blackmore, Sutandar-Pinnock, & Woodside, 2004; Keel, Dorer, Franko, Jackson, & Herzog, 2005), and for body image disturbance to persist after treatment for an eating disorder even if other symptoms are diminished (Bachner-Melman, Zohar, & Ebstein, 2006; Federici & Kaplan, 2008). Despite this, body image disturbance has been overlooked in treatment programmes possibly because it is a complex area that tends to be resistant to more reasoning-based interventions (Ferrer-García & Gutiérrez-Maldonado, 2012). Additionally, body image treatments are mostly developed for those at or restored to healthy weight (Mountford et al, 2015). Addressing body image therapeutically engenders necessarily intense distress that may be circumvented by therapist, family and the young person.

WHAT FAMILIES SAY: TRIGGERS OF BI DISTRESS

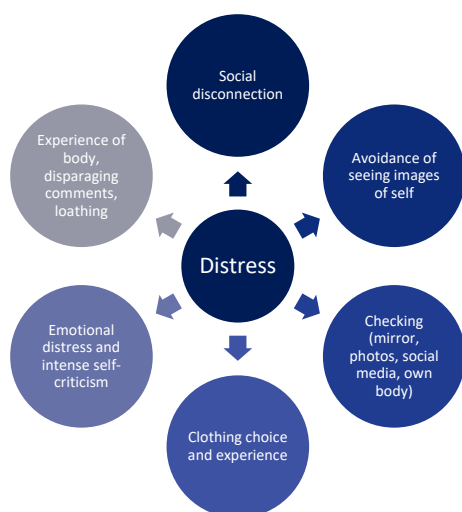
Therapists working with young people experiencing body image distress/disturbance or who are in treatment for an eating disorder for whom body image disturbance is likely to manifest therefore have a duty to better inform themselves of the ways in which families, the young person and treatment progress may be impacted by body image concerns throughout treatment. Below highlights a number of observations of families regarding what they notice in relation to body image distress in their loved one and the impacts of this on them and their families.

TRIGGERS OF BI DISTRESS

See Appendix A for a handout which compiles parent and clinician identified triggers of body image distress during treatment. This handout synthesises information gleaned from our survey and may be used as psychoeducational material to support parents and their loved one and as a tool to collaborate in the preparation for, identification of and planning to respond to body image distress

WHAT FAMILIES SEE: EXPRESSIONS OF BI DISTRESS

Families provided a rich description of how body image distress presented in their children. The themes raised by families corroborates much of what we know about reinforcing or maintaining mechanisms for over-evaluation of weight and shape.



"Highly suicidal, self-loathing, self-harm, cut the word 'FAT' into stomach with a razor blade, secret exercising at night & while shower running, distraught if she caught a glimpse of herself in mirror, complete body dysmorphia while ill"

Social disconnection	"Isolates herself from friends and family"	"Not being able to look anyone in the eye"
Avoidance of seeing images of self	"Avoids mirrors" "No mirrors in the home, showers in the dark, curtains closed in the bedroom"	"Expressions of distaste for looking at photos" "Won't shower or look down to avoid seeing her stomach"
Checking	"Too much time in front of mirrors" "Constantly checks appearance" "Body checking" "Constantly taking photos to check what she looks like and comparing herself to others"	"Spent a lot of time looking at social media" "She says 'I still look okay, right'" "Spent a lot of time looking at social media"
Clothing experiences	"Hates shopping for clothes" "Awful time shopping and major tantrums"	"Baggy clothing" "Always asking if clothes look good"

	<p>"Wear baggy clothes, t-shirts on the beach"</p> <p>"Hates fitted clothes and believes everything is tight and to small"</p>	<p>"Began to become uncomfortable in wearing bathers in a public place"</p> <p>"Wears super tight belts"</p>
Emotional distress	<p>"Crying and screaming about weight and size of body/ Yelling, screaming, crying, followed by intense exercising"</p> <p>"Expresses worry about 'being too fat'"</p> <p>"Says ugly and always has been"</p> <p>"Extremely critical of own body image, self-hate, self-harm"</p>	<p>"Reporting unhappy with shape and size, severe anxiety about weight gain"</p> <p>"Angry comments about certain body parts and the way they look"</p> <p>"Self-deprecating humour"</p>
Experience of body	<p>"Makes comments about not liking her body, feeling uncomfortable in it"</p> <p>"Expressed feeling unattractive, gross"</p> <p>"When at a very low weight she knew she was too thin and felt unattractive but did not feel as thin as she was. Now at a healthy weight she feels unattractive and overweight and greedy at times."</p>	<p>"At the beginning she used to pull and punch the areas she didn't like,</p> <p>"Unable to walk because of the feeling of her legs rubbing together"</p> <p>"Expressing negativity about people in the community who would be considered to have a higher than ideal body weight. Verbalising dissatisfaction about the way they look."</p>

WHAT FAMILIES EXPERIENCE: IMPACT

Having a family member with an eating disorder can send ripples through the family. Families spoke about how their experience impacted on them as parents, siblings and the family unit.

Siblings	Emotion	Family Unit
<ul style="list-style-type: none"> •Yelling at siblings if they try and console her. Can be very distressing for her younger siblings •Concern is how this impacts younger siblings idea of themselves, so far all good but something we remain aware of that it may create distorted views for other siblings •Her older brother who doesn't have an ED also talks about being a bit worried about his weight (he isn't overweight) but not obsessed. It does make us all a bit frustrated and anxious. •Critical of family members' body image. Makes home environment very stressful for everyone while long term effects family dynamics and relationships 	<ul style="list-style-type: none"> •Major impact on the family as we are constantly trying to reassure her that she looks great but she thinks she is fat. •Utter frustration as it's not based on reality, she does not see herself the way the world does. •Very distressing for family members. A very sad time. •So made me frustrated & angry as I did not understand what was happening •This disconnect is hard for other family members to understand and respond to. 	<ul style="list-style-type: none"> •Impact was we as a family would avoid situations that would make her uncomfortable, like going to the beach or taking family photos •Impact: huge family disharmony, huge financial stress and emotional stress in supporting her through her distress to eventually recover. Years of lots hours of work, needing to be home supporting her.

89.19% of parents indicated that assistance with body image issues would be or would have been helpful as part of their child's treatment, 8.11% thought this would possibly be helpful, 2.7% believed it would not.

Parents

- It is very hard and distressing to watch her like that. Especially seeing there is nothing I can do to make her feel better.
- Extreme stress, sadness, frustration when trying to get child to see reason about their body image
- Try to stay calm but it makes me feel stressed and sad that she thinks so little of herself that she thinks she is fat and ugly
- I was shocked, I had an idea it came out in an FBT session
- I feel anxious as it is a sign that she isn't feeling great or may be more likely to not comply with eating plan or exercise restrictions.
- I feel distressed that she's not comfortable in her own skin, I think I mask my distress?
- Anger frustration disbelief. She was clearly not fat!
- Huge spike in fear, worry & anxiety, frustration & sense of guilt, stress about finding the help
- Distress, disbelief, right
- Felt shocked and distressed.
- distraught, sad, very defensive.
- Huge fear at her level of self hate and distress.
- I used to want to stop her, to intervene. It caused me grief.
- I feel very sad as she still looks so small but she can't see that.
- Frustration - it is so constant.
- Confusing - how can she not see that she's thin? How can she possibly think she's fat? Very distressing.
- Was concerned but hoped it was a phase. Wasn't sure how to respond.
- I was stunned that my child saw herself so differently and negatively as compared to how I saw them.

WHAT FAMILIES HAVE TRIED

Parents indicated that they tried different strategies to help their child with their body image distress. Upon reflection, they identified strategies they felt were likely helpful, and some that were not so helpful. This demonstrates that parents are both aware of, and attempting to respond to the body image distress of their loved ones as best they can. Enhanced support from treating teams and opportunities for parents to reflect upon and develop their own skills and resources would likely facilitate greater feelings of confidence and collaboration between treating teams, families and the young person, use of more helpful responses and thus reduce the likelihood of treatment drop out due to unattended/poorly attended body image factors.



WHAT IS HELPFUL? WHAT IS NOT HELPFUL?

Below is an overview of what parents identified as being helpful and unhelpful responses to the body image disturbance/distress of their loved one. Parents indicated wrestling with a desire to want to fix/reassure their loved one, and feeling pain at seeing their loved one so disparaging of themselves and their body. Parents indicated some confusion about the helpfulness of their strategies and that discussion about likely helpful versus unhelpful approaches with the treatment team would be immensely beneficial and reassuring.

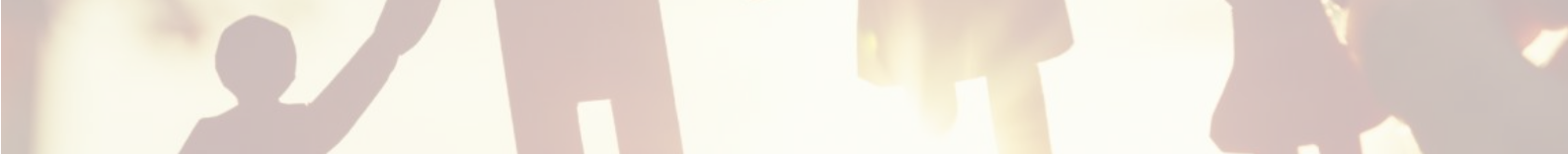
Not helpful

Parents indicated that they felt engagement with social media/appearance-based images and exposure to judgmental comments by others were unhelpful to the recovery of their loved one. They also noted parent responses of ignoring/dismissing feelings, and reassurance about appearance or overly accommodating the young person's body image distress were not helpful. Parental disunity and body weight/shape of parents were also identified by parents as unhelpful to addressing the body image concerns of the young person. Interestingly some parents felt that talking about body image was unhelpful and parents were unsure about how to address issues of parents own body size and possible impacts of this.

Reassuring ignoring & accommodating: Parents described attempts to reassure their loved one of their inherent goodness and the unfounded nature of their current body image experience. Parents described telling their loved one that they were beautiful, reminding them of their positive qualities and their love for them regardless of size. Parents described engaging in logical arguments/reasoning to try and convince their loved one of the inaccuracy of their current self-image, or by attempting to undermine the veracity of the body image disturbance by indicating how 'silly' it was. Parents also attempted to persuade their loved one that the eating disorder was overruling reality. Often this was met with frustration of the young person, and frustration for parents at not being able to penetrate the damaging self-schema of their loved one. Parents described that the difference in their perception and the perception of their loved was were so disparate and nothing rational helped to change the young person's perception. Parents described feeling extremely distressed, sick to the stomach and sad, but attempting to be strong against the eating disorder despite this.

Helpful

Validating and changing topics: Parents described a shift in their focus or thinking that allowed them to respond in a more validating way to their loved one, and that this seemed to be more effective than reassurance. Parents described a change in thinking from body image distress being an attempt at attention seeking, to seeing this as how they see themselves. This move toward greater understanding and empathy helped parents to be able to label what they were seeing, and to acknowledging how difficult this must be. Parents were also able to set compassionate boundaries and redirect unhelpful discussion to focus on addressing distress rather than the concerns or to respond much more matter-of-factly about the impact of the distress on the young person's wellbeing and reasons for not engaging in unhelpful dialogue. Parents reported that reacting in a calm manner and attempting not to show distress was helpful, and that having opportunities to feel the impact of this was also essential; "I learned to show tough love with loving compassion in front of her & save tears for behind closed doors". Unfortunately some parents reported that they found nothing to be helpful, which suggests that lack of support and strategies could impact the degree to which parents feel they have a sense of agency and hope in response to body image distortion.



General recovery: Parents also reported that body image distress was addressed through general recovery that did not focus on body image, and that weight gain also assisted to reduce body image distress in around 50% of cases. This suggests that parents see working with other aspects of the young person's life outside of the eating problem and re-engaging in valued activity as useful. In addition, it points to the important interconnections between symptoms and body image, and that working on eating pathology impacts body experience and vice versa. 48.15% of parents stated that the body image distress of their loved one decreased as a result of weight restoration.

Modelling and environment: Parents indicated that they had an important helpful role in altering the young person's environment and exposure to messaging that enhances body experience. Parents described ways in which they could remove environmental triggers of body image distress, foster discussion and conversation that broadened the families and young person's perspective on body image, and modelled body acceptance of themselves and others. Parents also indicated that their own understanding of body image in the context of an eating disorder and the maintaining mechanisms of this was extremely helpful in activating them to have more informed discussions and better clarified for them responses that were more likely to be helpful vs unhelpful.

QUOTES FROM FAMILIES RE OWN RELATIONSHIP WITH BODY DURING ED TREATMENT

Self-care has gone out the door.
Any sense of vanity feels like it's wrong.

I hate my body as I've put on weight during the re-feeding

It makes you rethink everything from your attitude, talk, self-talk, thoughts about your own body image

I've lost 5kgs due to stress, and am trying hard not to let this go further because she has noticed - bad example.

I definitely think about my own relationship with my body but always keep those thoughts to myself.

Our language did change to never passing comment EVER on how someone looked

I think this process makes us more conscious of how appearance focused we are and how unhelpful and unhealthy that can be

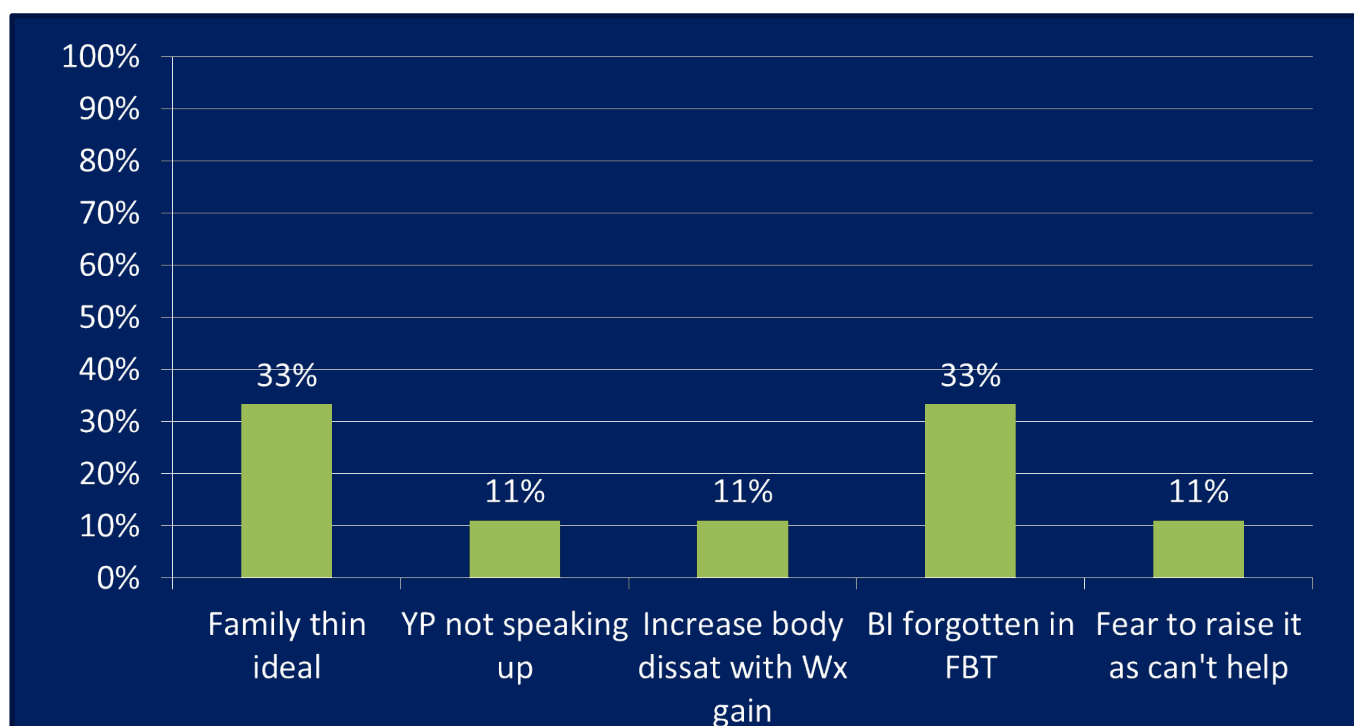
I have gained weight during re-feeding. I am 59 post-menopausal and do not need the extra weight but cannot diet at this time. I don't like the way I look or feel

78.95% of parents indicated they would have found it useful to discuss body image issues with the treatment team without the young person present. A further 7.89% were unsure.

Parents highlight important issues about the significant positive influence of family responses to body image distress and the confusion or lack of confidence that might undermine this. Parents themselves are not immune to body image concerns and distress and these are likely to be exacerbated or conversely 'go underground' during eating disorder treatment and recovery. Parents describe wrestling with their own body image and finding this difficult in light of the struggles of their child. Many are indicating a desire to work closely with teams in understanding how they can best support their loved one. Thus, treating teams are called to consider and collaborate non-judgmentally around how best to support parents and their loved ones in responding in more helpful ways.

WHAT CHALLENGES DO CLINICIANS IDENTIFY IN WORKING WITH BODY IMAGE

As shown in the Figure below, Clinicians identified family thin ideal (33%), failure of the young person to raise body image as an issue (11%), lack of attention to body image in FBT (33%) and increased body dissatisfaction with weight gain (11%) as challenges specific to FBT, but that that likely translate in working with young people more generally or using other models. A small number of clinicians indicated a fear of discussing and addressing body image concerns due to feelings they would not be able to help.



Furthermore, clinicians identified challenges related to parental weight bias, sporting culture, self-esteem, social media, working with people in larger bodies and working with families with limited resources as challenges that impact upon their confidence and competence to address body image with young people. Taken together, clinicians describe barriers that are both systemic, individual and related to clinicians own confidence and knowledge that impact the degree to which they directly address body image in treatment.



HOW DO CLINICIANS CURRENTLY WORK WITH THE BODY IMAGE OF YOUNG PEOPLE?

Of the 35 clinicians who responded to the survey, 9 (25%) indicated use of specific body-image interventions in the work with young people. These included normalising/validating concerns, working on self-esteem & confidence, reducing social media use/auditing this and reducing appearance-based media use, education regarding the diversity in body size, use of the CBT-E pie-chart to illustrate and work with over-evaluation of weight and shape and body as functional, self-compassion, direct targeting of maintaining behaviours such as checking & avoidance, and cognitive restructuring. This suggests that a small number of clinicians are using body image interventions with their clients, which is promising. However, rather than endorsing a broad range of interventions from which they choose, clinicians tended to endorse one or two approaches, and appropriate application of these remains unclear. Taken together this suggests that clinicians would benefit from developing a variety of strategies to address body image and to develop critical thinking regarding their application across treatment.

SUMMARY OF FINDINGS

Findings from our survey indicate that body image distress is a significant contributor to parent's experience of eating disorder treatment and recovery in their loved ones. Parents are positioned to describe, identify and respond to triggers and indicators of body image distress that treating teams are not, and parents are indicating a desire to be supported and to respond helpfully. Parents are a wonderful resource for supporting positive body image culture however they are not immune to sociocultural pressures and report their own difficulties in reconciling cultural narratives regarding ideal body size and diet culture. Parents report that body image distress has significant impact upon their family and that at times they are uncertain as to whether the way they respond to their child's distress is helpful in progressing toward recovery. If not directly addressed in an open and collaborative manner, we run the risk of underutilising family strengths and failing to address processes that may be undermining recovery and thus treatment teams are called to be more active in involving and informing parents about body image distress across the course of treatment.

Clinicians identify a number of challenges to addressing body image with young people, and many did not feel confident to address this within FBT, or in other treatment approaches. Despite parents wanting increased support with managing body image distress, clinicians overwhelmingly reported a lack of confidence and guidance in doing so. Additionally, and not covered in this report, we believe there is a need for clinicians themselves to identify their own body image experience and beliefs, and potential for this to undermine or enhance treatment progress, confidence in addressing body image concerns and having open, non-judgmental conversations with parents and the young person. Furthermore we believe the clinician can play a powerful role in modelling non-stigmatising language within the care team and advocating for young people and their families in relation to the seriousness of body image distress, helpful ways to respond and in honouring diversity in body size as well as identifying and addressing body-related stigma as this relates to recovery.

Common Body Image Distress Triggers

The following list was compiled from the responses of families who completed a survey by CEED which asked about their experience as carers of a young person currently or previously in treatment for an eating disorder. CEED clinicians also added some common triggers from clinical experience. Please use this as a guide, however we do note that every young person is different. You may note many or few of these as important triggers for yourself/your loved one. Always be guided by what you know about yourself/your loved one, and feel free to add to this list for your own records.

What families identify

- Eating
- Buying or trying on clothing
- Tight fitting clothing
- Weight gain or loss in others
- Anxiety/stress
- Comments from others about size and shape – healthy or unhealthy
- Seeing own body - mirrors, shower, windows
- Other bodily experiences e.g. constipation, bloating
- Images of others e.g. social media
- Photos of self
- Being weighed/finding out weight
- Eating with people who are slim/thin and having to eat more
- Tiredness and hunger
- 'unhealthy' food options
- Not being able to exercise

What clinicians identify

- Approaching 'fear weight'
- Changes in temperature, feeling hot/cold
- Requiring to wear lighter clothing/bathers
- Physical sensations (i.e., legs touching, rubbing)
- Changes in clothing size
- Weight redistribution
- Developmentally appropriate body changes
- Breasts, hips, thighs, ↑ adipose tissue
- Fluid retention
- Reaching set point/genetic predisposition that is not the cultural/internalised ideal

What we notice