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Perceptions of non-successful families attending a weight-management clinic

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ABSTRACT

Objective This study seeks to understand family's perceptions of their care at a paediatric weight management service, with a view to informing service improvement.

Design A qualitative service review conducted via semistructured interviews with parents (n=11) and children (n=3) who attended the clinic. The recruitment was open to all, but those who were not succeeding in their weight-loss goals self-selected to participate. Self-Determination Theory was used as a framework to explore families' experiences of the clinic.

Setting Recruitment occurred during clinical appointments and interviews were conducted over the phone in the days following the appointments.

Patients The service sees paediatric patients with a body mass index >99th percentile, with comorbidities or safeguarding concerns.

Interventions The clinic's service includes appointments typically every 2 months, with a multidisciplinary team including consultant endocrinologists, a dietician, a clinical psychologist, a social worker and a clinical nurse specialist.

Main outcome measures Families' feedback on the multi-disciplinary team (MDT) clinic, and their perceptions of how improvements could be made.

Results Families perceive a lack of autonomy, competency and feel a lack of connectivity both in their lives broadly and within their experience at the clinic.

Conclusions Interventions in families struggling with weight improvements should see the clinical team placing more emphasis on working alongside parents to develop young people's sense of self-determination. Expectations must be set that success originates from changes outside of clinical appointments and that the clinical team is in place to support the family's development of sustainable, self-determined lifestyle habits.

INTRODUCTION

While obesity is fundamentally due to a prolonged period of higher energy intake than expenditure,¹ the causes are complex and numerous. These include socioeconomic environmental factors,² biological influences including genetic predispositions,³ medication side-effects⁴ or the psychological implications of stress or trauma.^{5 6} Regardless of aetiology, gaining a balance between energy intake and expenditure remains central to weight control, though these complexities provide competing challenges and barriers to success.

A qualitative review was undertaken to explore family's perceptions of a weight management service

What is already known on this topic?

- This weight-management clinic offers effective treatment for ~60% of patients, consistent with other weight-management interventions that typically struggle to achieve universal success.
- While some professionals consider continual professional support as the only treatment, others suggest that supporting patients' sense of self-determination can facilitate change.
- Self-determination requires an environment that supports autonomy, competency and relatedness. When these are met, patients show higher levels of engagement and success at weight-management.

What this study adds?

- Families in which their child's weight is not improving, experience low self-determination, reporting difficulties in maintaining their child's motivation and request increasing support from the clinical team.
- While increasing clinical care may create short-term success, adapting interventions to promote self-determination could enhance sustainability of interventions while improving well-being and family dynamics.
- Increasing the use of techniques such as expectation setting, self-monitoring and structured goal setting may be effective techniques to support self-determination.

for paediatric patients, to improve the service. The service sees young people with a body mass index (BMI) >99th percentile, with comorbidities or safeguarding concerns. A high proportion of the clinic have autism spectrum disorder (ASD) or diagnoses of learning difficulties, which can introduce complexities for families when compared with their typically developing counterparts.^{7 8} Fifty-eight per cent of attending patients achieve clinically significant weight loss, defined as a reduction of ≥ 0.35 BMI SD score.⁹

The clinic was previously based on a more traditional medical model of obesity management, staffed by a consultant endocrinologist, dietician and exercise therapist. Patients were seen 4 monthly. A service review in 2009¹⁰ suggested that patients from motivated and resourceful families succeeded to lose weight under this approach. However,

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unsuccessful families reported requiring greater support to overcome barriers to change.

Accordingly, the clinic now offers more frequent appointments, typically every 2 months, with a wider multidisciplinary team including consultant endocrinologists, dieticians, clinical psychologist, social worker and nurse specialist. This clinic seeks to offer a sustainable weight-management strategy, which is delivered over an 18-month period and that is maintainable long-term.

However, as many interventions report, successes are not universal,¹¹ often leading clinicians to question the motivation of families.¹² Some professionals recommend that obesity can only be treated by continuous medical care,¹³ with patients requiring the external motivation of accountability to staff to achieve their goals.¹⁴ But this resigns patients to a lifetime of clinical appointments, and with the financial limitations of services considered, is often unfeasible.^{15 16}

The ability to initiate and sustain behaviour change is considered greater in patients who are intrinsically motivated.^{17–19} Self-determination theory (SDT) proposes that while external motivators such as prizes, rewards and the praise of others can motivate some people in behaviour change, this motivation is contingent and often short-lived and requires continual reinforcement. Intrinsically motivated people do not require repeated external reinforcement, as the action is perceived valuable in and of itself. Being intrinsically motivated is possible when one's environment supports three fundamental psychological needs: feeling autonomous, competent and connected.^{17–19} In a weight management context, autonomy is feeling you can choose, self-endorse and take responsibility for initiating changes. Competency is defined as operating effectively in one's environment and having mastery over the skills needed to improve weight. Finally, relatedness is achieved when a person feels connected, accepted and supported.^{18 19} When a person does not experience self-determination, poorer well-being outcomes and engagement during behaviour change interventions are observed.²⁰

Exploring the family perspectives, it became clear that these three psychological needs were pertinent to their experience of the clinic and the support they requested and received. SDT was therefore employed to guide the analysis and provide a framework for understanding families' experiences.

METHOD

Approval

The service review had approval from Patient Experience and Involvement Team at University Hospitals Bristol.

Participants

Participants were recruited from a tier 3 paediatric weight management clinic. Sampling was opportunistic and did not target non-successful families. Thirty-seven families consented to being contacted. On follow-up, 23 did not respond to calls. Eleven parents and 3 young people participated in semistructured interviews exploring the experience of 12 families' perceptions. All but one family had not succeeded in losing a clinically significant amount of weight. The interview from the successful family was removed from the analysis as data saturation for this patient group was not met.

Interviews

Topic guides developed by JC and AS included items about family experiences and what they perceived as the clinic's strengths and limitations (see online supplemental appendix 1). Recruitment

Table 1 Participant details

Characteristics	Children who attended clinic (n=13)	Interviewed children (n=3)	Interviewed parents (n=11)
Gender			
Male /Female	10/3	1/2	0/11
Learning disability			
Autism	2	0	–
Other learning disabilities	1	1	–
Age			
<5			–
5–11	2	1	–
11–17	10	2	–

occurred during clinic and parents gave informed consent prior to interview. All but one of the interviews were conducted over the phone in the following days. One interview was conducted immediately after the patient's appointment. Interviews were conducted by JC, between January and August 2019, being audio-recorded and transcribed by JC. In keeping with the iterative nature of qualitative research, data were collected and analysed simultaneously with topic guides being revised accordingly.

Analysis

Each transcript was read and re-read for familiarisation by JC and AS prior to conducting thematic analysis.²¹ JC and AS independently coded transcripts and coding was refined through discussion until a definitive coding frame was achieved through consensus. While coding initially began inductively, reading of the literature informed the benefits of approaching this work within the framework of SDT to develop a pragmatic intervention to improve success in paediatric weight loss. Thus, this approach led to coding deductively.

The three psychological needs addressed in SDT stood as the themes following the coding procedure, with patient's experiences contributing to understanding the importance of self-determination in treatment outcomes.

RESULTS

Participants

Participant details are given in [table 1](#).

Autonomy

The ability to choose, self-endorse and take responsibility over the changes being made

Some families felt the onus of responsibility for their child's weight needed to be held by the clinical team ([table 2](#), a) and that solutions were out of their control. Some felt that the doctor would provide answers through diagnosing a medical condition ([table 2](#), b).

Other parents felt they held the responsibility for their child's weight ([table 2](#), c). Some parents explained feelings of guilt and self-blame that the children required the clinic's services ([table 2](#), d). However, parents reported holding this responsibility alone—with motivation not being echoed in the child ([table 2](#), e) leading parents to report needing to continuously supervise and 'nag' their child ([table 2](#), f). Often, parents described feeling frustrated, believing they had exhausted all their own strategies ([table 2](#), g). They wished to defer the responsibility to others

Table 2 Quotations for theme 'Autonomy'

a	'That they could do a plan, that someone could actually be able to pay for him to go which would help him in the long run, rather than the NHS having to pay loads of money when I can't get the weight off him' Parent of Boy, age 15, TD
b	'I'm still waiting on the results to come back to see if there is something hereditary' Parent of girl, age 13, TD 'That's why I wanted to see, the x-ray test and the blood test, to see if there is something else there or if it is just what he eats. Cos it is normal that a kid is hungry all the time, and eats quite a lot, it's all normal. Parent of boy, 13, TD
c	'I was concerned that he was putting on weight and I didn't want him to end up like me' Parent of boy, 13, TD
d	'I think he feels ashamed that he needs to come (to clinic). I definitely feel ashamed that he is coming' Parent of boy, age 12, TD
e	'I put the things we talked about in place, at the beginning he was really keen but has since fallen off the wagon. And I find it very difficult to keep him motivated. I think the biggest thing is that the motivation has to come from him, I can't force it. They gave him a lot of coping strategies that he hasn't really used' Parent of boy, age 16, TD
f	'Her dad's the same, he'll, he always watches how much she eats, what she eats, where she goes, what she does' Parent of girl, age 13, TD
g	'How can I put it...the fact we keep nagging him, all the time, and he says "I'm not doing that I'm going to my mates" I can't explain it, where I need the help' Parent of Boy, age 15, TD
h	'The other thing would be if I could have a plan for something that somebody else could do' Parent of boy 14, TD
i	'I think for (child's name) he needs a coach or someone, a medical person, that he is close with, to change his habits' Parent of boy, age 15, TD
j	'I get a bit nervous in the waiting room but then when we go in I cool down a bit' Boy, age 12, TD 'She's like "well, I'm trying" and it's as though they're not taking in what she's saying she is doing and um she can get, she can get very "oh I don't want to go, I don't want to go" and really anxious' Parent of girl, age 13, TD
k	'I think that there is a bit of a disconnect between wanting to be less heavy and really understanding how much in terms of practical stuff he needs to do differently, as well as sort of changing your mindset, which is actually a bit of a bigger deal to do' Parent of boy, age 15, TD
l	'She says, "I'm still a child, I'm 13 I'm not 24 so I don't know why he is talking to me' Parent of girl, age 13, TD

TD, typically developing.

(table 2, h) recommending that a 'third-party' would be better placed to mediate changes with their child (table 2, i).

For the child, pressure built around the clinical appointments with many reports of children feeling anxious and not wanting to attend (table 2, j). There was little evidence of children holding a sense of responsibility (table 2, k), with some expressing surprise at being addressed directly by clinicians during the appointments (table 2, l). Few children wanted to take part in the interviews.

Competency

Operating effectively in one's environment and having mastery over the skills are needed to produce weight loss.

Families described many barriers to implementing lifestyle change (table 3, a), particularly motivating their child to change their behaviour (table 3, b). Parents directly requested help to manage behaviour they found challenging (table 3, c) and reported feeling limited by their ability to engage their child, when others appeared to be able to (table 3, d).

Table 3 Quotations for theme 'Competency'

a	'I don't think we have ever made a plan at the clinic that we haven't already hoped for in life outside the clinic, but it doesn't seem possible. It doesn't seem very possible to make things happen' Parent of boy, age 15, TD 'So, on the activity level he is limited, on the changing the diet front he is limited. Yes he could swim but we don't have money for that, you have to pay for that, so it, we ought, we just sought of feel that we are trapped on a hamster wheel at the moment and there isn't really any- can't really see a way off it. We can't see a way out of the situation' Parent of boy 15, TD
b	'When it's the holiday he wouldn't go out and play. For 7 weeks he spends all the time without movement. Any movement. And that is quite - dangerous. I cannot get him psychologically to go out and play and do any activity. Ever' Parent of boy, age 14, TD
c	'I think it's boundaries and things like that I need help on, that we have one (a boundary). Cos obviously she can't get it at school, like school says, she can't eat at school, she can't snack at school' Parent of girl, 9, LD
d	'He is behaving much better there(at his dad's house), I must admit. About food. He would eat broccoli there, where at my place he wouldn't' Parent of boy, age 14, TD
e	'I just don't know if I am giving the right things or not. And maybe it's simple but I would like maybe it to be just from Monday to Monday, just to know what to follow' Parent of boy, age 14, TD
f	'(The dietician) said about using popcorn, and (child's name) was very interested in that... for about a week. And then he was bored of it, cos there is not new ideas coming through' Parent of boy, 13, ASD
g	'Last time I thought (dietetic support) was useless, even my husband said "well we have been doing that anyway", But they seemed, they seemed a lot better this time" (having moved their child onto a meal-replacement plan).' Parent of boy, age 15, TD
h	'We didn't have the doctor, we just saw the dietician the first time.(...) then this is the first time we have had the 'proper' clinic with the doctor' Parent of boy, age 12, TD
i	'We can only eat what is in the cupboard, a lot of that is from the food bank, its processed food and it's not the kind of food that. I am not blaming it on the food, I am just saying that getting the right food involves spending money that we don't really have' Parent of boy, age 15, TD
j	'We haven't been focusing too much on what his weights been doing recently. Um, partly because his mental health hasn't been brilliant and we don't want to make him too bad, but we will still have days when he will constantly hunt the cupboards, everywhere for food, for comfort. Um, and CAMHS have said again that they recognise that he has some mental health needs but that they don't have the services to deal with him' Parent of boy, age 12, ASD. CAMHS, child and adolescent mental health service.
k	'I think that (his father's death) has been a very, very big, probably the trigger that has brought us to the situation he is in now, and it's hard because he is being seen in a clinic about obesity, but the reason why he is obese, he really hasn't had NHS care for' Parent of boy, 15, TD
l	'As a parent, I have some knowledge, I can look up things, I can look up certain psychology things, but I am not really qualified to do so. And if I go wrong, I could end up doing him more harm than good' Parent of boy, age 12, ASD
m	'Even though I have tried to hide my unhealthy relationship with food, in terms of not, not overeating in front of the children, or...you know I don't really have large portions, it's more the secret bingeing that happens. I have always tried to hide that.(...) But, I am setting an example by my size that food is a way to medicate yourself from other problems. And food is a way to cope. And I know that even without doing it in front of them, you know, having portion size that are too big, I have sent them subliminal messages over the years' Parent of boy, age 15, TD

ASD, autism spectrum disorder; LD, learning difficulties; TD, typically developing.

Table 4 Quotations for theme 'Relatedness'

a	'He's got one friend that at school that he talks too. To be honest I don't really talk to my mum (child's grandparent), my mum's just a waste of space' Parent of boy, age 7, TD
b	'It was very difficult because services weren't coming together in (the local area) and actually it takes a trip to (the clinic) to get some answers' Parent of boy, age 14, ASD
c	(Having dis-engaged with local CAMHS team) 'I think the thing he didn't really understand, or wasn't able to understand, was that CAHMS would kind of be a key ally to have by our side through the hard times, and without them it is probably me that feels more vulnerable than anything' Parent of boy, age 15, TD
d	'I have got more than what I thought we were going to get when we first started. I thought we were just going to get put on a weight chart and go from there you know. So, no. (Child) got, all the support you guys have given him has been amazing, I could not have asked for anymore' Parent of boy, age 7, TD
e	'How can I put it... a little bit more help than what we're getting, cos we were getting cos we're getting no help really' Parent of boy age 15, TD
f	Parent: 'It's just that it looks like I am the one that's keeping on at him all of the time. Interviewer: Does this make relationships at home difficult. Parent: For me yes. Very much so' Parent of boy age 15, TD
g	'Maybe because I am nagging him to do it all the time? Maybe because he thinks I really want him to have that broccoli (he refuses), maybe with food I am not that good. Not that good at encouraging him' Parent of boy, 13, TD
h	'Especially when you are preparing his meal. With all this meat. Cooking, preparing everything and he is refusing it, it's really annoying me. But what can you do. And I know I shouldn't give him anything after it but I give him pizza because what else am I going to do now...' Parent of boy, age 13, TD
i	'It's better going to the hospital than going to the doctors, cos they just make him feel so small, and you're like - why? Why make him feel like he is a little pea in a big bowl, it's not good for him and then you guys laugh with him, make it all bubbly' Parent of boy, age 7, TD
j	'One of the people in there, they were like not like child friendly. And I know I'm not a child, but most of the people that were going were younger than me, like, and then they wasn't like, they were all like intrusive and all that' Girl, age 16, TD
k	'I know that nobody at the clinic is wanting to make people feel they have been battered with a big stick. It's just funny the things that are going on in your head about it, without anybody ever being overt in saying anything that would give you the impression they wanted to make you feel small or feel silly or feel bad. It's just there is so much shame attached to overeating' Parent of boy, age 15, TD
l	'If he were to feel that there were someone he could talk to and get alongside him, that understood and, that wouldn't judge him, that was always going to be consistent, or for a period of time going to be there in his life, I think that would help him'. Parent of boy age 14, TD
m	'I tend to undermine my problems like "yeah it's not that bad" so none of my friends really know the extent of how bad it is.' Girl, age 16, TD 'I would just rather not. It is none of their business to be honest' Boy, age 13 TD

ASD, autism spectrum disorder; TD, typically developing.

Other families felt they needed a structured meal-planned programme (table 3, e), struggling to expand on the example food-switches given (table 3, f). Frustration was felt that advice repeated what they already knew, when instead they expected a different, more radical approach (table 3, g), perceiving the doctor to be the person they really needed to work with for a solution (table 3, h). A lack of finances and access to healthy food products was cited as a barrier (table 3, i).

For those children experiencing mental health problems, including emotionally driven eating, binge eating (table 3, j) and difficulties resulting from trauma and bereavement (table 3, k), parents felt unqualified to support them (table 3, l). Parents with their own weight concerns were worried about the impact it had had on their child (table 3, m).

RELATEDNESS

Feeling connected to others, met with acceptance and supported

Families reported feeling unsupported by the wider community, including having poor social connections (table 4, a) and feeling let down by wider social services (table 4, b). The clinic then became a primary source of support for some families (table 4, c). They praised the staff's dedication (table 4, d) but requested increased assistance from them (table 4, e).

Families had complex home lives: parents and children often reporting fractious relationships that were exacerbated by attempts to manage diet and motivation (table 4, f). In some, the more that parents encouraged their child to follow guidelines, the more the child resisted (table 4, g). Often, the child was following a different diet to the rest of the family (table 4, h).

While most families noted the increase in their child's motivation and mood following clinic and saw it as an important source of support (table 4, i), some adolescents were surprised by the frank nature of communication (table 4, j). They did not always feel met with understanding (table 4, k). Developing supporting relationships via mentoring or peer support groups

was suggested (table 4, l). Many children did not share their feelings easily with family or friends (table 4, m).

DISCUSSION

A service review was undertaken to understand how families experience their time at a weight-management clinic to inform improvements. While the initial intention was to explore the feedback of a wide range of families, those families who had not lost a clinically significant amount of weight self-selected to participate. On reflection, this may be because of the way the work was framed as a means of informing service development. While this was not the original intention, and it is acknowledged that the data are not generalisable to all patient's experiences, it has enabled a focused assessment of how to improve the service for those who are currently unable to achieve their goals.

The data were analysed and presented within a SDT context, which shows that families and young people in particular were not experiencing fulfilment of the psychological needs required to use intrinsic motivation. Without feeling their outcomes were self-determined, young people were reluctant to participate: being difficult 'to motivate'. Family relationships were strained by the additional burden of weight-management and levels of anxiety were high both within and outside of clinical appointments.

In the previous clinic review,¹⁰ it was suggested that those who were unsuccessful reported requiring more support. Despite increases to the clinical time and diversity of the support available for patients since this first review; the feedback remains largely unchanged. The gratitude expressed by parents for the support available is testimony to the dedication of the team. However, providing enhanced clinical contact may be unsustainable long-term, feeding into the model of continuous care.¹⁴

Some families express wanting to enact change while others take a passive stance with the clinician holding overarching responsibility, as may be expected from other medical treatments.

However, without the child being invested, neither clinician or parental desire for change results in easy success, instead creating pressure and need for constant interventions that may exacerbate problems within family relationships.²² A further complication in some households is the parent's difficult relationship with their own weight and feelings of guilt that their child requires clinical support.

Rather than focusing on continual motivation of the child, interventions informed by SDT work to support the child to actively engage in the programme and find their own, intrinsic motivation. Parents and clinicians work together in roles of 'supporter',²³ setting parameters and ground rules which are followed by the whole family, while empowering the child to hold responsibility for enacting the specifics to reach goals that they themselves have set. Providing this improves well-being, weight-loss outcomes and supports longevity of the intervention²⁴ with additional benefits of improving relationships.¹⁹ Whole family approaches are supported by NICE guidelines.²⁵ Steps that can enhance autonomy have been defined by a new taxonomy of behaviour change techniques²⁶ and include providing opportunities for patients to make choice, exploring their life values and encouraging self-initiation.

The participating families experience lifestyle changes as unmanageable. While the clinic currently follows the latest guidelines encouraging a flexible approach to healthy eating, this is different to these families' expectations of following the prescriptive programmes that are commonplace in mainstream dieting culture.²⁷ Devaluing dietician's advice is reported, with families overlooking the small changes that can be the stepping-stones to success. While more 'clinical' measures are instigated at the clinic in only more severe cases (such a meal replacement drinks or medication), they are perceived by families as more acceptable and feasible than lifestyle change. To change this attitude, developing a family's sense of competency is necessary. Ensuring that interventions are clear, goal-led and importantly target a single, controllable change at a time, can offer structure and build feelings of competency. Other interventions have used journals or workbooks to document goals and progress and capture self-monitoring.²⁶ Setting expectations early with families is crucial.²⁶ While the endocrinologist plays an important role, for those families with no known underlying medical aetiology, the key to change is collaboration with dietician and MDT to instigate lifestyle changes outside of the clinic.

As an example, where Patient A may currently leave their bimonthly meetings feeling positive and motivated following the support of the clinical team where they receive reinforcement and praise, this motivation may wane after a few days. Other priorities such as school and friendships take precedent, and the patient is only cognisant of their goals at the clinic when reminded by mum who is deemed to be 'nagging'.

However, a SDT approach would see the patient leaving the clinic with an active goal that they have chosen themselves, that is meaningful to them and that feels achievable: they may be aware that their consumption of sugary drinks early in the day makes them feel tired, so reducing intake offers weight management gains and reward by improved concentration in school. Together with their clinical team, they would have chosen a means to record their progress (ie, personal journal/tracking chart/phone app). The patient knows they have the support of clinicians and their family but that they themselves hold the responsibility for creating change.

Notably, in some cases, enhanced professional support may be necessary. Families experienced difficulty accessing community services; thus, the clinic's recent inclusion of a social worker is

imperative to ensure families are supported.²⁸ Furthermore, a notable proportion of those interviewed experienced emotionally triggered eating patterns. In line with population level findings, this was expressed particularly by those who had experienced trauma,²⁹ and those with ASD.³⁰ These patients are currently supported by the clinic's psychologist and social worker, but external CAMHS services do not offer support for binge-eating. Targeted psychological support programmes for binge-eating have been shown to support weight-management and could prove a beneficial addition to the clinic or adjoining CAMHS services.^{31 32}

Strengths of this review were that the interviewer was external to the clinical team, and interviews were conducted outside of the clinic in the interests of impartiality and fostering participant candour. Regarding rigour, data analysis was assisted by a qualitative researcher experienced in engagement with health services (AS) with no prior relationship with the clinic. Both data analysts were of the consensus that saturation had been achieved in data from families finding weight-loss difficult; however, this review struggled to recruit successful families. Thus, the sample limits our ability to recommend the SDT approach for all patients despite its potential to have a broad benefit in supporting patients attending weight-management services. Future work should look to understand self-determination in patients who lose weight successfully.

This work describes the perspectives of families failing to lose weight at a paediatric weight-management service. These families, and particularly these young people, do not demonstrate feelings of self-determination. Interventions in families struggling with weight improvements should see the clinical team placing more emphasis on working with parents to use young people's intrinsic motivations by understanding their priorities from treatment, develop young people's competency through the process of making one, achievable change at a time and documenting these progresses, supporting autonomy by setting clear, early expectations that success originates from changes outside of clinical appointments and supporting young people to take responsibility for their care outcomes. Together, these components intrinsically build self-determination within the young person, helping them with the weight-management outcomes and also giving them transferable skills for self-management that are of benefit more broadly.

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