The experiences of young people and their families affected by excess weight

Evidence from existing research

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April 2022
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This work was funded by NHS England and NHS Improvement to support patient engagement in the Children and Young People’s Transformation Programme to develop Complications from Excess Weight (CEW) clinics.
The experiences of young people and their families affected by excess weight

Scoping the evidence: Outline of emerging issues, April 2022

Executive summary

As part of the development of new clinics to address the complications from excess weight, NHS England funded the Association for Young People’s Health (AYPH) to undertake a scoping review on evidence relating to children and young people’s and parents’ views of severe obesity, and their thoughts on services.

The scoping exercise revealed that there is a limited evidence base to draw on, and the lack of youth voice on this topic in the British literature is notable. After a process of screening, a total of 19 studies were included in this review, dating from 2009. As we have given priority to studies that give children and young people’s perspectives, the studies tend to relate to young people of secondary school age; there are very few studies that seek the views of younger children.

The main themes from the literature included young people’s experience of excess weight and its complications, their experiences of trying to access appropriate help, and their experiences of being recipients of specific services to help with excess weight. Children and young people are deeply affected by their experiences of obesity and the complications of excess weight. Their accounts reflect almost universal experiences of stigma and negative judgement, from both their peers and from health care professionals. They are much more likely to refer to aspects of their experiences that relate to mental health complications and social engagement than to physical health complications.

Young people and their families experience a number of barriers to accessing services for excess weight complications, some posed by lack of services but others posed by their own feelings and mental health issues, and they and do not always feel comfortable once they do reach an intervention. How they feel seems to significantly affect the success of the intervention, and has to be a major consideration if the programme is to have any effect.

Background

NHS England funded the Association for Young People’s Health (AYPH) to undertake a scoping review on evidence relating to children and young people’s and parents view of severe obesity, and their thoughts on services. This was being undertaken as part of the development of new clinics (CEW clinics), to address the complications from excess weight. The clinics are designed for children and young people aged 2-18 years.

The complications of excess weight in children and young people are clearly many and varied. Standard descriptions of the physical health complications of childhood obesity include the risk of Type 2 diabetes, high blood pressure and elevated blood cholesterol, liver disease, bone and joint problems, respiratory problems such as asthma, sleep disorders, early puberty and menstruation,
skin infections, and fatigue. Mental health complications include low mood, anxiety and depression, and the risk of eating disorders such as bulimia and atypical anorexia nervosa. Excess weight clearly also has a huge social impact on young people and their relationships with others.

Excess weight and obesity is acknowledged to be a highly multifaceted issue with influences and causes from cellular chemistry all the way up and out to socio-economic factors and government policy. However, in healthcare settings, the burden of the condition and most of the work in managing it falls to the individual patient and their families. In order to have clinics that are most effective at helping young people to manage weight and reduce their complications it is vital that their needs and perspectives (and those of their families) are placed at the centre. There is increasing evidence that the circumstances and experiences of patients influences their engagement with, and success in, complying with treatment plans (Doyle et al, 2013). And in light of this, services need to take young people’s experiences on board. In addition, more patient focused individually tailored and co-designed care plans are needed for patients with complex health and social needs.

Therefore, when designing new health services, the service users must be a part of the process to establish what they would consider to be good quality care, in terms of processes and outcomes.

Questions for the scoping review

The brief from NHS England was to produce a rapid review collating pre-existing evidence relating to the engagement of children and young people in excess weight services, and children and families’ experiences of severe obesity and comorbidities.

This set a fairly broad framework and could have resulted in lots of overlapping and indirectly relevant work. In addition, an initial search found very little on children’s participation in the primary school age range. We therefore refined the question to include three main points of focus including:

- Young people’s experiences of severe excess weight and its complications (regardless of whether they have accessed services), including feelings about self, stigma, labelling, as well as the physical consequences, issues with weight loss, and mental health consequences
- Young people’s experience of trying to access help - through primary care, education, or other primary and public health ‘ways in’
- Young people’s experiences of receiving health services where excess weight and obesity is the focus.

Methods

There is very little published evidence directly on children and young people’s experiences of excess weight complications in the UK. As a result a broadly inclusive approach was taken to the review, encompassing all types of studies and grey literature including policy reports. The approach was not exhaustive, but designed to be illustrative of the types of material available and the main findings. Relevant papers were identified through a call for evidence, online searches, and consultations with colleagues working in the field. Searches included Scopus, Healthwatch’s searchable database, the RCPCH&Us resources, Google, and following up leads in existing papers.

The call for evidence was sent out to AYPH’s contacts and network in October 2021, and resulted in 13 responses. These included alerts to published papers, examples of work in the field, and
summaries of engagement with young people. They included one paper relating to family experiences with a pre-existing excess weight clinic (Bristol).

After a process of screening, a total of 19 studies were included in this review, dating from 2009. As we have given priority to studies that give children and young people’s perspectives, the studies tend to relate to young people of secondary school age; there are very few studies that seek the views of younger children.

**Preliminary identification of main themes**

Overall, as expected the searches produced a limited amount of information specifically on the voice of the young person, but quite a lot on families and professionals expressing their concerns about young people’s experiences.

**(1) Young people’s experiences of excess weight and its complications**

The one major piece of work in this area in the UK in recent years is the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI-Centre) review of young people’s views on their experiences of obesity. From their overview of 30 qualitative studies representing 1400 young people, Rees et al (2014) concluded that young people’s experiences were generally stigmatising and abusive. Those with experience of obesity described “severe, unrelenting, size-related abuse and isolation”. They also described an environment that contained multiple barriers to weight loss. The implications were overwhelmingly social rather than health related; young people related how weight had impacted seriously on their ability to socialise with peers, and marked them out as being unacceptably different (Rees et al, 2014). Similarly, in a Norwegian longitudinal qualitative study of five young people living with obesity, Øen et al (2018) revealed three main themes; obesity as a multi-faceted and difficult to solve condition; obesity as a shameful and vulnerable subject; and obesity leading to bullying and fragile social relationships.

As well as issues of judgement and social consequences, individual studies of young people’s experiences of excess weight also often mention young people’s experiences of overlapping mental health problems, and the role of mental health in how they feel about their obesity (Yerges et al, 2021). This is part of a larger conversation around the links between body image and mental health and the effect of social media in exacerbating this. An example of this is the Mental Health Foundation’s recent participation project with a diverse group of young people aged 14-25 on their experiences of negative body image which stressed the same issue.

In the Rees et al (2014) review, young people of all weights – including those who were overweight – placed considerable emphasis on the role of personal responsibility in excess weight, rather than on the health implications. This was also noted by Lachal et al in their 2012 paper – that the feelings and perspectives a young person has about their weight and how it happened can be self-blaming and overly internalised. However, Lachal et al noted that young people also hold the perception that change will be the result of an external process – the weight loss programme for example – which it is hoped will fix all their problems, and that there is a fundamental mismatch between these two beliefs that creates some internal conflict. Reece et al (2015) note something similar; the mismatch between young people’s perceptions of the mechanisms driving causes and change.

We did not come across any direct studies of the experiences of young people with obesity that made much reference to the physical health implications. However issues around sleep did arise
(Zeller et al, 2015), as did the implications for physical exercise (Rees et al 2014; Viner, 2020). In patient participation undertaken (by AYPH) for Viner et al (2020)’s PROMISE study, young people were split into two age groups (11–14 years and 15–19 years) and each was asked what health problems they thought an overweight or obese young person might face. They identified a range of physical health problems from tired legs to heart disease and also suggested a range of mental health issues from anxiety to suicidal thoughts. The younger age group focused more on physical ailments, although they also did mention anxiety, being worried and fear of bullying. The older age group named more mental health issues including depression, mood swings and suicidal thoughts (Viner et al, 2020).

In Zeller et al’s (2015) quantitative quality of life study, 242 adolescents with severe obesity reported 16 comorbid conditions, the most prevalent were high blood lipid levels (74.4%), chronic pain (58.3%), and obstructive sleep apnoea (56.6%), and considerable quality of life impairment.

(2) Young people’s experiences of trying to access help

Very few studies have looked at the initial experiences of young people trying to get help specifically for excess weight, or what approach was taken by health professionals in flagging weight as a potential issue. Access problems may stem from when young people go to raise the issue themselves, or when the healthcare professional raises the issue with them.

Where studies do exist, there is a lot of similarity between the messages about young people’s experiences of getting help for weight loss services with accounts of experiences with other kinds of services including, for example, the need for services that are discrete and convenient. Issues raised in the obesity literature that also occur elsewhere include:

- Availability of appropriate services for the issue; difficulties of finding the right kind of help (Viner et al, 2020)
- Particular access challenges for particular subgroups of young people, for example those with autism and learning difficulties (Sanders, 2020)
- Issues around enabling GPs to signpost to other services and provide support around interventions, rather than just acknowledging it is a problem (NICE evidence review, 2014)
- The need of young people to feel safe to open up to someone (NICE evidence review, 2014)
- The barriers posed when young people are feeling awkward and uncomfortable (Rees et al, 2014).

However, some things do stand out particularly in regard to issues of weight and obesity. These include the strong concerns about being judged and experiencing stigma, and the damaging effect of prior negative experiences with health practitioners:

- Reluctance to seek help because of fears in advance around being judged, stigmatised and blamed (various, including Viner et al, 2020; Wild et al, 2020). Others also reported a fear of what might be asked of them by healthcare practitioners (Øen et al, 2018), and concern about the high level of commitment that might be required (Smith et al, 2014).
- Healthcare professionals using language that felt difficult or judgemental. This included children and young people’s perceptions of difficulties of talking to professionals, and feelings of stigma once in the consultation. Rees et al (2014) noted overall young people wanted less judgement and more help.
A mis-match of perceptions around what constituted a serious health concern; with the schools measurement programme for example, there have been some reports of parents and young people not thinking there was a weight problem – and health care professionals not being sensitive to their own beliefs about weight (Viner et al, 2020).

While weight may be often summarised by a metric (such as BMI), it needs acknowledging as a more emotive subject than simply that alone (NICE evidence review). For example, some young people do not describe themselves in ‘health’ terms, but use visual terms such as “sagging skin” (Lachal et al, 2012).

(3) Young people’s experiences of health services where excess weight is the focus

There are very few dedicated excess weight services for young people with obesity in the UK, but a few do exist and one has resulted in a paper about young people’s experiences, although only three young people were included (Cox et al, 2021). There are also qualitative papers from other countries including Norway and the USA. There were more papers on parental perceptions than on adolescent experiences. The categories of experiences recorded in the variety of studies we reviewed included the importance of motivation (including treatment adherence and the importance of family support), the kind of programme and its content, and the location and quality of consultation.

Motivation (including treatment adherence and family support)

- Young people report that improved psychological wellbeing such as confidence and self-esteem, or improved social outcomes such as reduced bullying and making friends, are strong motivators for programme participation (NICE evidence review, 2014). Similarly, lack of motivation is a serious barrier (Øen et al, 2018).
- The ability to initiate and sustain behaviour change is considered greater in patients who are intrinsically motivated; supporting families’ feeling of ‘self determination’ can thus be key to success, but this requires an environment that supports autonomy, competency and relatedness (Cox et al, 2020).
- Children, their families and providers have emphasised that awareness and acceptance of children being overweight or obese is a facilitator to programme adherence (Cox et al, 2020; Woolford et al 2016; Jones et al, 2018).
- Parents and children have described a range of individual and family demands, such as busy lifestyles, homework, work or family commitments, that can conflict with service demands and thus make it more difficult to engage. Parental support is an important facilitator of successful lifestyle weight management interventions (Perez et al, 2016; Jones et al, 2018).
- Young people report the need to be treated with dignity if programmes are to have effect (NICE evidence review, 2014), and also to be allowed a sense of autonomy (Cox et al, 2020).
- Young people report there is a need for prolonged programmes, not quick fixes; they can feel that six weeks might teach everything that is “needed”, but does not give time to make the change, or keep the changes up and sustain them (Reece et al 2016; Lachal et al 2012; Owen et al, 2009).
Kind of programme/content

- Providers, children and families value a delivery approach that incorporates family involvement in lifestyle weight management programmes, perceiving it to facilitate behaviour change (NICE evidence review, 2014; Lachal et al, 2012).
- Group-based sessions and interaction with peers are highly valued by some children and parents. Interventions incorporating group sessions or peer interactions have been perceived to be opportunities to share experiences, and give and receive support from people facing similar problems (eg, Schalkwijk et al, 2015). The parents in Cox et al (2020) emphasised the importance of connectedness.
- There is a strong emphasis in the engagement literature on the value of interventions addressing the individual personal needs of programme users. Programme users have commented on the importance of identifying and adjusting interventions to the needs, goals, motives or existing knowledge of individual participants (NICE evidence review, 2014; Nobles and Sharman, 2016; Jones et al, 2018).
- Programmes need to adjust for age and understanding (some 13-14 year olds can manage more than others); gender and culture (Cox et al, 2021).
- Opportunities for safe and non-stigmatising group exercise and participation are valued by parents and young people (Jones et al, 2018; Woolford et al, 2018). Both children and young people and their parents / carers have reported that active engagement of this kind in groups can be helpful, and parent / carers have noted that the structure it provided was also useful (NICE evidence review, 2014). Other studies have noted “normal” exercise classes are “full of fit people” - expensive and intimidating (Viner et al, 2020).
- Both parents and young people have suggested that psychological factors have to be a part of all programmes. These play a part in motivation, reacting to and coping with stigma, and helping with overall wellbeing. Programmes are aiming to result in a life change and that requires complete review of all aspects of young people’s lives. For example, participants expressed the desire for healthcare professionals to assess and discuss their psychological well-being during weight-related clinic visit in addition to physical behaviours and actions (Yerges et al, 2021).

Location and quality of consultation

- There has been a concern expressed that some of the key complications of obesity might be missed in consultations or services because of the nature of communications and the focus on what the doctor is discussing, particularly if young people and their parents feel this is being framed in a judgmental way, rather than as providing help for a health issue. The importance of good practitioner communicator skills is stressed in a number of studies (eg, Smith et al, 2014).
- Programme users valued the comfortable and welcoming environment of their programme venues (Smith et al, 2014).
- Timing of any service offers need to take into account the demands of school and work ie. evenings better than day time instead of being forced to regularly miss work or education (Skelton & Irby 2016; Smith et al 2014).
Conclusions

Children and young people are deeply affected by their experiences of obesity and the complications of excess weight. Coming at a time in their lives when they are hypersensitive to body image and peer comparisons, being seriously overweight results in a particular lack of self-esteem and self-blame. This is exacerbated by their almost universal experiences of stigma and negative judgement, from both their peers and from health care professionals. They are much more likely to refer to aspects of their experiences that relate to mental health complications and social engagement than to physical health complications.

Young people and their families experience a number of barriers to accessing services, some posed by lack of services but others posed by their own feelings and mental health issues, and they do not always feel comfortable once they do reach an intervention. How they feel seems to significantly affect the success of the intervention, and has to be a major consideration if the programme is to have any effect.

As a result, care providers need to be skilled in assessing each individual’s resources and interpretations of their condition, to be able to communicate in a developmentally appropriate, respectful, patient-centred manner and to assist young people to explore their ambivalence and set their own realistic goals (Øen et al, 2018). Everyone needs a shared understanding of what’s going on (Lachel et al, 2012), and to achieve that, young people’s own perspectives must be understood.

Limitations/challenges

As noted, there is a limited evidence base to draw on, and the lack of youth voice on this topic in the British literature is notable. Many of the studies are qualitative; quantitative data are few and far between. Even those that are qualitative can have extremely limited samples; perhaps partly a reflection of the sensitivity of the topic and the difficulty of getting engagement. In Cox et al (2020) for example, which we think is the only paper on the perceptions of non-successful families on attending a weight clinic in the UK, only three children were included. As a result most of the studies look at the perspectives of parents and clinicians, rather than the children and young people themselves.
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About AYPH

The Association for Young People’s Health (AYPH) is the UK’s leading independent voice for youth health. We work to improve the health and wellbeing of 10-24 year olds. For more information about our work email info@youngpeopleshealth.org.uk and visit our website ayph.org.uk

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