‘For the cases we’ve had. . . I don’t think anybody has had enormous confidence’ – Exploring ‘Uncertainty’ in adolescent bariatric teams: an interpretative phenomenological analysis

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What is already known about this subject?

- Bariatric surgery is more effective for weight loss in severe obesity than lifestyle interventions.
- The number of bariatric surgery procedures carried out in England in adults has almost doubled between 2008 and 2011.
- Bariatric surgery is increasingly being offered to adolescents with severe obesity.

What this study adds

- A predominant theme of ‘uncertainty’ around adolescent bariatric surgery emerged from the interviews.
- In the absence of empirical data, professionals bracket away this uncertainty by a variety of means, including the acceptance of surgery as inevitable.
- This study has implications for the effective counselling of adolescents and their families around bariatric surgery.

Introduction

In 2010, just over one-quarter of adults in England were classified as obese, with a body mass index of 30 kg/m² or over (1). The National Institute for Health Research, Health Technology Assessment (2) concluded that bariatric surgery is a clinically effective and cost effective intervention for moderately to severely obese individuals in comparison to non-surgical treatments. Bariatric surgery aims to reduce severe obesity, reverse or improve associated diseases, and improve quality of life. The evidence seems to suggest that lifestyle interventions have a limited effect on weight loss (3), whereas bariatric surgery has a greater effect on weight loss, durability of weight loss and impact on significant comorbidities, such as type 2 diabetes, than conventional therapies (4,5). In line with the apparent success of these interventions, the number of recorded bariatric weight loss procedures carried out in England rose...
from just over 4200 in September 2008 to 8000 in November 2010 (6).

There is no national database to record bariatric surgery performed specifically in adolescents, although since the publication of National Institute for Clinical Excellence guidelines (7) to include young people, anecdotal evidence suggests this too is increasing. O’Brien et al. (8) conducted the largest randomized controlled trial of laparoscopic adjustable gastric banding in comparison with intensive lifestyle intervention in severely obese adolescents. Researchers found that 84% of individuals in the gastric band group lost more than 50% of excess weight in comparison with only 12% of individuals in the lifestyle group. Two years after surgery, metabolic syndrome was present in none of the gastric band group and 22% of the lifestyle group, compared with 40% in both groups at entry. However, despite promising short-term outcomes, there is a dearth of high-quality randomized controlled trials into the long-term effects of bariatric surgery on weight loss and psychosocial outcomes in adolescents.

National Institute for Clinical Excellence (NICE) guidelines indicate that bariatric surgery is not generally recommended for children or young people and should only be offered in ‘exceptional circumstances’ (7). Although it might seem logical to postpone surgery as long as possible, there is evidence that weight loss surgery may be less effective the longer it is delayed, and the health risks of obesity increase (9–11). Decision-making in relation to bariatric surgery for adolescents is clearly an area fraught with many medical and ethical dilemmas (12). There are no guidelines as to what constitutes ‘exceptional circumstances’, and in the absence of long-term outcome data, it is likely that decisions are made by bariatric surgery teams on a case-by-case basis based on their own clinical experience. How healthcare professionals make decisions in these circumstances, in the absence of clear guidelines, is under-researched and remains poorly understood (13,14). The purpose of this study therefore is to investigate the process of decision-making around bariatric surgery for adolescents. Nine clinicians from a range of different professional backgrounds, working within multidisciplinary teams (MDTs) offering weight loss surgery to adolescents, have been interviewed. The aim is to understand how professionals manage in the context of limited research and guidelines around bariatric surgery for young people in order to reach a decision as to which adolescents should be offered surgery and which should not.

Methods

Participants

Three leading National Health Service (NHS) centres offering bariatric surgery to adolescents were approached, and two of these agreed to participate. The third centre declined because of their own research commitments. Nine clinicians out of the 10 approached agreed to participate, with one declining because of work commitments. These clinicians represented a variety of different professional backgrounds, including surgeons, physicians, psychologists, psychiatrists, nurses and dieticians.

Procedure

Potential participants were sent a copy of an information sheet outlining the details of the study and requesting that they take part in a research interview. Informed written consent was obtained from all participants prior to interview. It was anticipated that the experiences of clinicians with regard to adolescent bariatric surgery were likely to be complex and varied. A qualitative methodology was chosen to avoid imposing a set of preconceived ideas or variables. A semi-structured interview was designed to allow participants to ‘tell their own story’ and for the research to follow up on any areas of complexity. This interview schedule has not been used in any other studies and can be seen at the end of the article. The development of key themes within this schedule was informed by the existing literature on decision-making around bariatric surgery as well as a more general social science literature on decision-making within conditions of uncertainty.

Interviews with nine participants were completed at both sites and lasted approximately 45 min (range from 25 min to 1 h 15 min). Questions focused on the following areas of discussion: background (e.g. history of service, current pathway for adolescents), how the team makes decisions, issues that influence the decision that surgery would and would not be appropriate, how evidence and experience are drawn upon when making decisions, how the NICE guidelines are interpreted, ways the team supports a young person to make a decision and developments that the team would like to see for adolescents considering surgery. All interviews were digitally recorded and subsequently transcribed. At this stage, digital recordings were destroyed.

Analysis

Investigators PB, SC and JD analysed the nine written transcripts using interpretative phenomenological analysis (IPA), following procedures outlined by Smith & Osborne, (2008) (15). In line with IPA, the thematic analysis was especially focused on the various ways in which participants sought to make sense of and construct meaning within the situations being described, developing an ‘insider’s perspective’ (15) of how these professionals experienced the phenomena being described. Initial parallel analyses were completed by JD and SC, and a combined preliminary outline of themes was produced. Investigator
PB completed secondary analysis of transcripts and added to the conceptual framework to produce a final thematic analysis of the data.

Results

In a qualitative study, the aim is to study the experiences of clinicians in depth rather than breadth. It is not possible within the scope of this article to include all quotations from all clinicians. Following analysis of the data, extracts have been taken from various interviews which are characteristic of the dominant themes emerging within the data analysis. In order to protect the anonymity of participants, names will not be used in this article. Clinicians will be referred to by a number indicating the order in which interviews were completed (C1–C9).

Pervasive uncertainty

The predominant theme of ‘uncertainty’ emerged from analysis of interviews, as captured in these extracts.

- It’s not like a blood test with a plus or minus answer. . . it’s a judgement call. (C7: 165–166)
- . . .I guess you do have a bad feeling about some people and it’s non-specific you just . . . it’s just a very woolly thing. (C9: 235–236)

The sources of uncertainty were numerous as outlined below.

1. Uncertainty around a lack of data/guidance

Clinicians agreed that bariatric surgery was an effective treatment for weight loss, but that research investigating the effect of surgery on psychosocial outcomes was lacking, and without this evidence, it was difficult for teams to decide who might benefit from surgery.

- I think the reality is that we’re doing surgery with young people without really knowing. . . you know there aren’t good long term data on outcome and what constitutes who is likely to have a good prognosis so we’re to some extent going in blind. (C6: 250–253)
- . . .we know where it is indicated and it is not indicated roughly, but there are no clear guidelines . . . for adolescents. (C3: 117–120).

Well, I mean the evidence is that it produces good weight loss and weight loss maintenance, it improves metabolic status of individuals and so on. Does it make them happier? Don’t know. Does it make them more productive socially? Don’t know. (C1: 625–627)

2. Bariatric surgery as a medical treatment like no other

The apparent discomfort in relation to offering bariatric to young people appeared to be exacerbated by the perception of bariatric surgery as a complex procedure unlike other treatments.

- . . .normally a surgeon does an operation to remove something that shouldn’t be there or to untwist something that got twisted or to put right something that went wrong. Bariatric surgery is quite the reverse. The surgeon is going in there to actually create an abnormality . . . an abnormal physiology and structure for a greater good. So I do think that that is conceptually quite a different surgery. (C1: 493–499)

3. The complex nature of adolescence

There was also speculation about the extent to which young people have the capacity to make long-term treatment decisions. Much of this speculation arose from clinicians’ concerns about the relative influence of ‘adolescence’ with the majority perceiving adolescence as a potential obstacle to good decision-making.

- . . .they’re physically mature but do they really understand? . . .the whole concept of ‘future self’ is something people have to be aware of. (C7 158–160)
- one of the concerns is at what age do you have the consent that you are having this not to feel better today, but for a greater good over the next 20 years? . . .do adolescents take out life insurance? No they don’t. You know, do adolescents drive cars very slowly because they think of their life ahead? No they don’t. Do adolescents engage in safe sex? No they don’t. I mean that is not an age where usually you are thinking about your life ahead of you. (C1: 522–525)
- . . .it’s quite challenging for them to make these life changing decisions that are going to affect them for the rest of their lives at a time when they are already in quite a turbulent period of their lives. (C2: 26–28)

4. Adolescent Bariatric surgery as a ‘risky’ business

Bariatric surgery was considered a novel and relatively controversial treatment for obesity in adolescence, especially in the public domain, which reinforced a sense of risk and uncertainty around offering this treatment to some young people.

- Yeah. I mean so far I think it’s been fairly contentious. We’ve been on the front page of the press on a couple of occasions. (C8: 413–414)
- . . .the younger we consider them the more uncomfortable it becomes. You can argue 16–17 are nearly adults erm. . . both physically and psychologically. But 9 years old it’s a different ball game and I’m not sure if the UK is ready for it. (C3: 176–180)

Participants appeared to use a range of strategies to overcome these multiple layers of uncertainty, although some of these strategies were in themselves a source of uncertainty. The most common approaches towards overcoming uncertainty are outlined below.
Overcoming uncertainty?

1. Look for individual behavioural ‘signs’ of a good outcome: ‘insight’ and weight targets

One potential solution to uncertainty involved looking for particular ‘signs’ from the individual that they were appropriate for surgery as a way of ensuring a good outcome. For some clinicians, the adolescent’s capacity for ‘insight’ helped guide decision-making process.

...it worries me if a patient isn’t able to tell me why they have a weight problem so if they can’t describe what it is that’s made them overweight then it’s hard to see how surgery will help change that. (C2: 210–212)

Well, one of the questions I ask all my patients, be they adults or children is ‘why are you overweight?’ and I like it when they say ‘because I eat too much’. About two thirds of them do say that and at least they’ve got a grasp of why they’re overweight. About 30–40% of them look at me and say ‘dunno doctor, it’s my glands doctor, it’s this doctor, it’s that doctor’ and you just think ‘ooeurggh’ you know, they’re more difficult to work with when they do that. So yeah, I’d like to see a grasp of a) why they’re overweight and b) the fact that this surgery isn’t a magic wand, it makes them eat less, and that’s how they lose weight. So as long as they’ve grasped that then that’s fine. (C9: 90–98)

Some participants described feeling reassured when young people made pre-operative behavioural changes to diet and weight, considering this an indication of engagement with treatment. However, the majority of participants perceived pre-operative weight targets as flawed and illogical. This debate is outlined below.

...if they’ve changed the ways that they eat before surgery they should technically lose some weight! So I guess it’s as an indicator of how well they’ve taken that information on board and the fact that they are able to make some of those changes. (C5: 63–66.)

I wouldn’t expect them to have been losing weight before we’ve offered it because I think that’s a bit futile really. By definition, it’s a last resort. If they’re losing weight then why operate on them?. (C8: 327–330)

2. Looking for a ‘supportive social context’

Other participants considered the role of the family or wider social context as significant in considering who will/will not do well after surgery. This ranged from looking for signs that family members would not sabotage success and an active avoidance of adolescents coming from more complex social backgrounds.

I think the adolescent is going to be a lot more successful if the whole family is engaged rather than just them. It’s going to make it difficult for them if their family isn’t engaged in what they’re doing. (C5: 124–126)

Where the family seem reasonably coherent and cohesive. Erm... going back to things that would ring alarm bells – children who have been ‘looked after’ children, you know where there are safeguarding issues. They’re often children of high need but you’re just not entirely convinced that we have the decision-making basis there, given the numbers we’ve done in paediatrics so far. (C8: 115–119)

3. MDT working

The clinicians described using MDT meetings to discuss patients and make joint decisions. There were mixed views as to the usefulness of the MDT process. Some participants valued the role of the MDT in moderating uncertainty as is outlined below.

MDT is a core process. It’s nearly as important as surgery. Erm... you will assess the patient only from one perspective – psychological, surgical, purely medical – and you might miss key pieces of information if you just assess the problem from one angle. You need different angles. (C3: 141–144)

...it’s good to have a multidisciplinary focus because from the surgeon’s perspective they see very much the surgical problem that they can fix with surgery and then I think the dieticians will see an eating behaviour that they want to help fix and we all see different things. (C2: 222–226)

...the MDT has to be unanimous for this sort of surgery because it is to a certain extent still contentious. Unless everyone feels it’s appropriate we probably would say ‘well this is probably not the right thing, let’s review it in 6 months/a year’. (C8: 79–82)

Other participants questioned the value of the MDT, and for some, this was an area of additional uncertainty, particularly with regard to the issue of clinical responsibility.

Now, at the adolescent meetings they have been quite large because what we also had of course is adolescent psychology services, adolescent social work services, sometimes paediatric, sometimes adolescent psychiatry... so there have been at times quite large numbers of people, which of course doesn’t always mean that decision-making is good. (C1: 82–86)

[S]ome of these decisions are very, very subjective and it’s your own feeling or view and it’s quite difficult when you draw out a care pathway, you know do you have X, Y, Z. And personally I’m not overly keen on that because I think it takes away that element of ‘I’m just not sure that’s the right thing to be doing’ which can sometimes, and that’s what our MDT is a little bit about people... it’s more of the ‘hmmm what do you think? Hmmm just not sure’. (C8: 308–313)
Some saw clinical responsibility as residing with the surgeon, whereas others saw the surgeon as technician, the person who carries out the MDT decision.

So . . . (the surgeon) is the one who physically erm . . . does the operation even though it is a team decision; it requires a lot of ground work. So in the event that things don’t go as planned it is . . . (the surgeon) who will be blamed . . . (C3 11–14).

Because ultimately it’s the surgeon’s decision whether he wants to take the risk. And so it feels as if it’s the surgeon’s decision but the patients are under the care of [paediatrician] so there is I think a little bit of a how does one reconcile and negotiate that and whose decision is it? (C4: 365–368)

. . . in many ways it’s other people making the decisions as to who is appropriate to refer to . . . (the surgeon) and then obviously . . . (the surgeons) make decisions about which operation and that sort of thing. (C9: 12–14)

Other participants also questioned the role of the psychologist and psychiatrists within the MDT and the potential role as ‘gate-keeper’ to the provision of surgery, whereas others questioned what kind of psychological professional is best suited participate in the decision-making.

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. . . traditionally, psychology has been thought of as the gate keeper to whether people have surgery or not. (C6 72–73)

. . . the role of the psychologist is the role of a psychologist so it’s always controversial. So it depends on if you are taking a mostly biological view or psychological view. (C3: 351–353)

I think there is always a question about what the role of a psychiatrist is as opposed to a psychologist or another type of therapist. (C4: 330–331)

4. Bypass adolescence

One major source of the dilemmas around adolescent bariatric surgery is related to the perceived nature of the developmental period of adolescence. One solution generated to overcome this dilemma was to treat people under the age of 18 as adults or to bypass adolescence completely.

[W]e just don’t treat them any differently from how we treat the adult patients . . . we don’t do anything different. (C9: 84–87)

I’m not saying this is something we do tomorrow, but I actually as a . . . if you like a hypothesis, would argue that actually it may be far easier for a child of 8 or 9 to cope, adapt and be supported through surgery than a child of 14 or 15 in the throes of a ghastly adolescence. (C1: 146–149)

NICE guidelines specify that bariatric surgery should only be performed in young people who have reached physiological maturity. However, clinicians here have argued that this particular developmental stage is fraught with emotional turmoil, and psychologically, this may not be the most appropriate time for surgery. This has led to them to suggest that surgery might best be postponed until adulthood or be done prior to the arrival of adolescence. To our knowledge, the suggestion of performing bariatric surgery in childhood was hypothetical, and the authors are not aware of surgery being performed in individuals as young as 8 or 9 years. All participants spoke only of surgery performed in the UK with adolescents who had indeed met physiological maturity.

5. Accepting the inevitability of surgery

Although participants made reference to debates around the type of procedure and agreement that weight loss surgery should be considered a ‘last resort’ treatment for young people, there was also a perceived inevitability of surgery. Many commented on the potential of bariatric surgery to allow the young person to live a ‘normal life’, given the apparent ineffectiveness of other treatments for obesity.

And you know if you say well ‘we’re not sure about A, B, C or D’, the surgeon may say well what else have you got to offer them? (C1: 742–743)

. . . every piece of research that shows the ineffectiveness of other interventions is another nail in the coffin I think for anything other than bariatric surgery. (C4: 136–137)

. . . I fully admit that it is in my opinion a hundred percent psychological . . . or ninety percent psychological. Having said that, when they are massive I personally think that the surgery is pretty much the only thing that works. (C9: 109–113)

But I do I think that if you can help somebody change at that point in their life before they get all the comorbidities that come with that . . . like diabetes for example, and give them a shot at having a normal life as an adult. (C2: 473–475)

[T]hese young people they haven’t really started adult life yet. So you can actually make them start a proper life, a proper healthy life. (C3 171–173)

Discussion

This paper demonstrates that making decisions about bariatric surgery for young people is a challenge for healthcare professionals in bariatric surgery teams across the UK, characterized by multiple uncertainties. To our knowledge, there has been only one other study
investigating the views of medical professionals on this topic. Bailey and Pemberton (16) conducted a qualitative study to understand Canadian physicians’ attitudes to the treatment of paediatric obesity. Physicians were more accepting of medical treatment and lifestyle management of obesity in young people than surgical treatment and showed scepticism for this in the absence of long-term data. In our UK study, the challenges were described as coming from the perception of adolescent bariatric surgery as a controversial subject for the public and as a complex intervention unlike other medical treatments, with limited outcome data to guide decision-making. This is further complicated by a view of adolescence as being a turbulent developmental period, with some professionals querying whether adolescents are capable of future-orientated thinking that is thought to be necessary for good post-operative outcomes.

Social scientific research into decision-making amidst uncertainty suggests that a range of different ‘tools’ is drawn upon to manage uncertainty (17). These include more rational–calculative approaches, based on empirically ‘proven’ knowledge or non-rational strategies, e.g. decisions based on beliefs, hopes or emotions. Trust, as placed in either the patient, other colleagues or self-judgement, enables uncertainty to be ‘bracketed away’ and complexity reduced, thus facilitating decisions and action (18). In this study, professionals are unable to draw upon the preferred method of making decisions based on empirically derived knowledge. In the absence of this, professionals manage uncertainty by looking for other knowledge (i.e. behavioural information and signs of an adolescent’s ability to make pre-operative changes), signs which appear to make intuitive sense to the professional, building his/her confidence that it is safe to proceed to surgery. Trust in the workings of the multidisciplinary process is also one way in which the dilemmas around surgery are bracketed away, although this too is a source of uncertainty, with a number of professionals questioning the value of a consensus decision, doubt around the roles of different professionals and who ultimately has legal responsibility for decision. Some professionals therefore have looked for other ways of managing uncertainty, arguing that adolescence should be bypassed completely. Furthermore, viewing surgery as inevitable and a treatment which can ‘normalize’ allowed teams to dispel many of the uncertainties connected to the provision of a treatment is still relatively controversial to the public.

Current NICE guidelines with regard to bariatric surgery emphasize the need for a multidisciplinary approach to decision-making. However, up until now, there has been very little written about the nuances and complexity of these interactions with adolescents and healthcare professionals. At present, professional decisions appear to be driven by intuition and ‘judgement calls’ rather than empirical data. This is not to suggest that empirically derived knowledge is superior or that patients are deliberately being misled; however, it is argued that this process needs to be made transparent. Revealing the ways in which clinicians work through, and reach, decisions amidst uncertainty facilitates greater awareness of difficulties and a more reflective practice as a result. A ‘shared decision-making model’ is one means of reaching an agreement regarding appropriateness of surgery (19), yet this approach potentially becomes more problematic when dealing with adolescents in terms of heightened power asymmetries. It is also potentially complicated by the active process of bracketing away uncertainty by both professionals and adolescents.

This study has made use of IPA as an insightful analytical framework for exploring participants’ experiences of the phenomenon in question while recognizing that this involves interpretation by the onlooker. However, many have argued that language is not merely a means to express reality but instead prescribes what we can feel and think, i.e. that language both reflects and shapes reality (20). One medium by which professionals moderate the dilemma around surgery for young people is to accept the inevitability of surgery. Surgery is seen as something that can have profound effects to ‘normalize’, and there is an implicit acceptance that offering something (surgery) is possibly better than doing nothing. It is argued here that these assumptions need to be interrogated and questions asked as to how did this way of thinking come to be taken for granted. Brown (21) has argued that that examining these interactions has implications for policy and practice in ‘underlining for practitioners the significant interpretive scope to which their actions/utterances are liable’. These questions are essential as the discourses around the inevitability of surgery for a normal life are ones that adolescents themselves take up, and therefore, within this context, the option not to choose surgery if it is offered is potentially rendered invisible. It is argued that the uncertainty that professionals experience, around what is known and not known, needs to be shared with potential patients. However, professionals must also question the social context that informs their thinking, such that if surgery is offered, the choice to accept or not to accept surgery is both able to be regarded as legitimate decisions.

Moves towards a shared decision-making model could usefully include the following developments:

1. Professional agreement about the limits of knowledge as regards adolescent bariatric surgery and support for staff to communicate this information in a context where patients often believe that ‘doctors know best’;
2. Parent and adolescent friendly information leaflets outlining what is know and not known about adolescent bariatric surgery;
3. Adolescent specific support groups and web-based resources for young people battling overweight, such that adolescents are in a position to become more equal partners in medical consultations around managing overweight and considering the pros and cons of surgery.

There are a number of limitations to this study. The research has taken place in the UK where adolescent bariatric surgery is an emerging field. It therefore may not be representative of the views of professionals where surgery for young people is more readily available, e.g. in the USA and Australia. Investigating whether these countries have been through a similar process in the early stages of the availability of bariatric surgery and how this has been managed may be of interest.

**Conflict of interest statement**

No conflict of interest statement.

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**References**


**Appendix Adolescent Bariatric surgery: clinician interview**

1. **Introductions:**

   Explaining research and confidentiality again. If happy to proceed, acquire signatures of consent.

2. **Understanding the context**

   i) How long have you worked with this service, and what is your role?

   ii) Could you outline the current bariatric surgery pathway for adolescents from referral onwards?

3. **Relevant issues in adolescent bariatric surgery?**

   i) What issues might you consider relevant when making a decision about bariatric surgery for an adolescent?

   ii) In what situations might you think that a person should not have bariatric surgery, despite their obesity?

Prompt: Remember to explore meanings of words, e.g. ‘readiness’ or ‘suitability’ for surgery, e.g. when you say X, what are you looking for, what are the indicators of X would you say?
iii) What informs your thinking about which young people should or should not have surgery?

Prompt: Are there specific guidelines that you adhere to, e.g. NICE guidelines or is there specific research to inform your thinking? Are these guidelines of use, and if not, why not and in what ways?

4. Differences between clinicians?

i) You mentioned that you look for . . . in considering whether a young person should have surgery. Do you think these factors are commonly viewed as important across the service?

ii) Are there factors you think others might consider that differ from your own?

iii) Have there been times where you have felt uncertain about supporting a young person to have surgery? Why?

iv) Have your colleagues had the same uncertainty or have there been differences of opinion?

5. Differences between adolescents and adults? (Check whether clinician also works with adults having bariatric surgery.)

i) Are there any specific adaptations made for adolescents in comparison to adults having bariatric surgery?

Prompt: e.g. adaptations made to information given, the way in which information is given or who is involved in the decision.

If yes, what are they, and why do you think this is important?

6. The future of adolescent bariatric surgery?

i) Have you noticed any changes in the service for adolescents?

ii) What do you believe drove these changes?

iii) What has been the result of these changes?

iv) Are there any developments you’d like to see incorporated into the service for adolescents and why?

7. Closing the interview

i) We are coming to a close now. Are there any questions you thought would be relevant to ask in this interview that I haven’t yet asked?

ii) Do you have any questions for me? (Explain again what happens now, i.e. anonymized interview will be transcribed, and then, interview recording will be destroyed, etc.)