EXPECTATIONS AND OBESITY EXPERIENCE OF PATIENTS PRIOR TO BARIATRIC SURGERY: A QUALITATIVE STUDY

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ABSTRACT

Objectives: This study aimed to understand the experience and expectations of people seeking bariatric surgery in England and identify implications for behavioural and self-management interventions.

Design: A qualitative study using modified Photovoice methods, triangulating photography with semi-structured in-depth interviews analysed using Framework techniques.


Participants: 18 adults (14 female and 4 male) accepted for bariatric surgery and aged between 30 and 61 years. Participants were recruited through bariatric surgery multi-disciplinary teams.

Results: The experience of participants indicate that the nature and extent of the burden of obesity. Problems included stigmatisation, shame, poor health, physical function and reliance on medications. Participants expected surgery to result in major physical and psychological improvement. They described how this expectation was rooted in their experiences of stigma and shame. These feelings were reinforced by previous unsuccessful weight loss attempts. Participants expected extreme and sometimes unrealistic levels of weight loss, as well as improvements to physical and mental health. The overall desire and expectation of bariatric surgery was of 'normality'. Participants had received previous support from clinicians and in weight management services. Despite this all reported that their unrealistic expectations of surgery and experience of stigmatisation had not been addressed.
Conclusions: The unrealistic expectations identified here may negatively affect post-operative outcomes. The findings indicate the importance of services addressing feelings of shame and stigmatisation and modifying patient's expectations and goals for the post-operative period.
Article Summary

Strengths and limitations of this study

Strengths and weaknesses

• The primary strength of this study lies in its use of a modified Photovoice methodology that triangulated photographs with interview data, this combination of method could be applied to other groups where obtaining detailed in-depth evidence is challenging because of the trust required by participants, their social isolation and the sensitivity of the topic.

• Participants were recruited from two hospital Trusts based in one geographical area with similar populations, this supports the transferability of findings to areas with comparable populations.

• The weakness of the study lies in its small sample size, however as the aim of the study was to generate in depth insight this was an appropriate sample size and compares with other studies of a similar nature.

• The sample contained only three men, however this reflects the gender of people accessing services.

What is already known?
• Bariatric surgery is a cost-effective intervention for severe obesity but a significant proportion of patients do not achieve positive outcomes, or do not sustain them.

• Previous qualitative studies exploring factors that might influence patient outcomes have largely been retrospective and have not examined pre-operative expectations and experiences.

• There is a lack of evidence on patients' experience of the UK tiered obesity services as a route to bariatric surgery.

What the study adds

• Complex psychological factors associated with living as an obese person underpinned participants' unrealistic expectations of normality following bariatric surgery.

• The study identified the importance of addressing the impacts of stigma and shame related to obesity prior to bariatric surgery.

• Pre-operatively, practitioners should be supporting patients to modify their expectations of surgery and prepare strategies to maintain the required self-management and behaviour change.

• Triangulating data from photographic images with interview data allowed us to generate a nuanced interpretation of the participant experience from socially isolated individuals; similar methods might be usefully deployed with other populations where there is a need for generating detailed understandings of experience of barriers to achieving changes in health.

Introduction
Morbid or severe obesity (Body Mass Index (BMI) of >40kg/m²) is rapidly increasing, with 2.4% of UK adults in that category. [1-2] There is an associated health burden for patients due to obesity related conditions including type 2 diabetes mellitus, cardiovascular disease and certain cancers.[3-5] Severe obesity also carries an increased risk of psychological morbidity, [5] as well as stigmatisation, intrusive reactions from others and social isolation.[6] Estimated heath care costs associated with obesity stand at £5 billion per year, a figure set to double by 2050.[7] Bariatric surgery is a recommended cost effective evidenced-based intervention to reduce weight and associated comorbidities in severely obese people.[4-5,8-11] Surgery is offered to patients meeting strict criteria (see Box 1). Surgery rates in England have nearly doubled, increasing from 4200 (2008/09) to over 8000 (2012/13).[12]

**Box1: Current NHS eligibility criteria for bariatric surgery:**

- BMI of 40kg/m² or more, or between 35 kg/m² and 40kg/m² or greater in the presence of other significant diseases.
- Medical evaluation led by a formalised multi-disciplinary team.
- Morbid/severe obesity has been present for at least five years.
- Individual complied with a non-surgical tier 3 / 4 service for the duration of 12-24 months.

NHS Commissioning Board 2013

In England, the NHS recommends that weight loss and obesity services are delivered through a tiered model, [13] Tier 1 and 2 being universal and lifestyle intervention. Tier 3 deliver specialist obesity services by a multi-disciplinary team. Tier 4 are surgically-led multidisciplinary specialist services providing predominantly bariatric surgery.[14-15] Delivery of this tiered model across England varies and responsibilities for commissioning the tiers lie with different organisations. The tiered model should ensure patients are appropriately selected for bariatric surgery and receive adequate physical, psychological and educational preparation. Pre-operative preparation could include support regarding the post-operative behaviour change
that is required following bariatric surgery. Self-management may be effective in promoting behavioural change prior to and following bariatric surgery within a tiered service pathway, [16] however there is no research demonstrating this.

Severely obese people, who have repeatedly lost and gained weight, consider surgery to be the "last resort". [17-19] There is an indication that the desire for bariatric surgery is associated with high, even transformational, expectations of improved physical, emotional and relational wellbeing.[18-20] However, some bariatric surgery patients fail to sustain weight loss and reasons for this remain unclear.[6] In order to maximise the attainment of positive outcomes following bariatric surgery, there is a need for research examining the effectiveness and experience of behavioural and self-management interventions.[21] There is a requirement to better understand patients' expectations and experience across the service pathway. Little is known about the weight related pre-surgery experiences and expectations of bariatric surgery patients who have gone through a tiered service model. This paper reports a qualitative study, using a modified Photovoice approach, to provide an account of patient experience elicited shortly before bariatric surgery. It will help to inform the commissioning and delivery of weight management services that provide the required preparation for patients prior to bariatric surgery.

Design

This qualitative study used a modified Photovoice methodology incorporating photography, semi-structured individual interviews and Framework Analysis techniques.[22-23] Photovoice is a participative research approach traditionally used in a community context where participants take photographs to illustrate their
experiences of the issue of concern and the meanings they hold for participants. In this study the focus of concern was obesity and bariatric surgery. Photographs were taken by individual patients, rather than community members, and used to guide the semi-structured individual interviews [22].

**Setting**

The study was conducted in areas served by two bariatric surgery multi-disciplinary teams in the North of England.

**Sample**

Eighteen participants were recruited prior to bariatric surgery through two bariatric surgery multi-disciplinary teams. Sixteen had been to obesity services with access to dieticians, obesity nurses, talking therapist and general practitioner. Three others were referred directly from a primary care physician, as their area did not have a Tier 3 service. All participants were over 18 years of age, having surgery for the first time and undergoing a gastric bypass, gastric band or gastric sleeve. Purposive sampling was used to select participants to ensure that the sample had the necessary variety of characteristics in terms of age, gender, employment comorbidities and marital status. The study team did have access to medical records so comorbidities were self-reported by the participants. During the study period we were only able to recruit three male patients however this is reflective of the proportion of men within the surgical population. The characteristics of the sample are summarised in Table 1.

**Table 1: Sample characteristics**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Marital Status</th>
<th>Comorbidities</th>
<th>Employment Status</th>
<th>Referral Route</th>
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<tbody>
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<td>Divorced</td>
<td>Joint pain</td>
<td>Unemployed</td>
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</tr>
<tr>
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<tr>
<td>2</td>
<td>54</td>
<td>F</td>
<td>Married</td>
<td>Type 2 Diabetes, Cardiovascular Disease, Depression</td>
<td>Unemployed</td>
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</tr>
<tr>
<td>3</td>
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<td>F</td>
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<td>Depression, Osteoporosis, Asthma, Hypermobility syndrome,</td>
<td>Unemployed</td>
<td>Tier 3 Weight Management Service</td>
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<tr>
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<td>Married</td>
<td>Type 2 Diabetes, Cardiovascular Disease, Psoriasis, Thyroid Disease, Obstructive Sleep Apnoea</td>
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<td>Joint pain</td>
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<tr>
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<td>GP</td>
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<td>Married</td>
<td>Depression, Asthma</td>
<td>Unemployed</td>
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<td>Single</td>
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<td>Unemployed</td>
<td>Diabetic Consultant and Tier 3 Weight Management Service</td>
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<tr>
<td>15</td>
<td>48</td>
<td>M</td>
<td>Married</td>
<td>Type 2 Diabetes, history of depression</td>
<td>Full Time Employed</td>
<td>Diabetic Consultant and Tier 3 Weight Management Service</td>
</tr>
<tr>
<td>16</td>
<td>49</td>
<td>F</td>
<td>Cohabiting</td>
<td>Joint pain, history of depression</td>
<td>Full Time Employed</td>
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<td>Polycystic Ovary Syndrome, Diverticulitis</td>
<td>Full Time Employed</td>
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<tr>
<td>18</td>
<td>52</td>
<td>F</td>
<td>Married</td>
<td>Joint pain</td>
<td>Full Time Employed</td>
<td>Tier 3 Weight Management Service</td>
</tr>
</tbody>
</table>

**Study procedure**

Participants were recruited through the bariatric surgery multi-disciplinary teams (MDT). The Photovoice tasks and interview schedule were developed through consultation with the MDTs, patient and public involvement with previous bariatric surgery patients, and relevant literature. Photovoice tasks or ‘assignments’ were given to participants prior to the interviews. The assignments included safety instructions for taking photographs and explained what would happen to the photographs. Participants were given prompts on what the photographs could include. These were to explore life as an obese person, the decision to be referred for the surgery, preparation for surgery and expectations of how life will change after the surgery. The resultant photographs were used as prompts in the interview.
The study received NHS Research Governance approval. Ethical approval was obtained from Leeds East NHS Research Ethics Committee. The study had independent scientific review through Collaborative Leadership in Applied Health Research and Care - South Yorkshire (CLAHRC-SY) and a patient and public involvement group with CLAHRC-SY.

Data collection and analysis

Seventeen of the eighteen interviews were carried out in the participants’ homes and one in the principal investigator’s office in the research centre. Interviews started by asking the interviewee to show the researcher their photographs and explain why they took them and what they meant. The interview schedule was referred to throughout. Any topics not covered by the photographs were asked at the end. The interview schedule explored history of weight, decision to have surgery, expectations of the surgery, and type of support received.

Interviews were recorded, transcribed and checked before being entered onto NVivo version 10. Semi-structured interviews ranged between 32 and 104 minutes. Fifteen participants took part in the Photovoice tasks. Data was analysed using Framework Analysis.[23] Framework Analysis involves a systematic process of sifting, charting and sorting the material into key issues and themes allowing the integration of pre-existing themes into the emerging data analysis. Analysis was led by the principle investigator (CH). AMT audited the analysis process by reading seven of the transcripts to verify the themes. The other authors (AT and PA) reviewed transcripts, contributed to the analysis and final results by providing additional interpretation.
Results

The findings are reported under three broad headings: the negative experience of obesity; experience of weight management services; and expectations of normality. Quotes are provided to illustrate the findings in boxes two, three and four.

Negative experiences of obesity

The combination of photographic and interview data revealed how profound the impact of obesity was on the participants emotional wellbeing and quality of life (see box 2). For some people this was so marked that they described their life as not worth living: "I don’t care anymore, just get me out of this world, I’ve had enough" (P7). The impact was compounded by years of weight cycling through attempts at weight loss techniques, diets and exercise regimes. Surgery was considered by all participants to be the last resort. Most said that without surgery they may as well be dead or would not have long left to live.

Participants who suffered from weight related co-morbidities that required multiple medications found this poly-pharmacy burdensome and constricting, and also impaired their quality of life.

Employed participants described work as having a positive effect on self-esteem. Work and the interaction with colleagues gave them a purpose in their life and an identity other than just being a "fat person". However, unemployed participants described how their weight and associated poor health prevented them applying for, or staying at work, further reducing their self-esteem.
Most participants reported feeling stigmatised because of their weight and some had received negative and judgemental comments from strangers. However, such negative responses were not just received from strangers. Participants described how family members and health care professionals did not understand their position and appeared to judge or blame them for their obesity and related health problems. Participants reported how their families did not understand their weight struggles, and viewed the surgery as an easy or soft option. This lack of understanding from the health care profession and of those closest to them meant participants felt increasingly marginalised from networks they regarded as their support.

Participants described long standing shame and embarrassment regarding their appearance, day to day activities, and health. Participants were self-critical and many had reached a stage where they avoided social situations, family and friends. They felt ashamed of their appearance and were worried others would think they had "let themselves go". Activities normal to others for example trips and holidays often caused anxiety. Female participants with children found getting their children ready for school and the journey to school challenging. It was worsened by a fear of being talked about by other parents because of their weight. As a result, they avoided situations that required speaking to other parents. Participants described being a burden to others in the family and blamed themselves for restricting their family's social lives, opportunities for holidays and enjoyment of life, all worsening their self-esteem.

Navigating space both inside and outside the home presented daily functional challenges for the participants. This meant they were unable to live what they considered to be a "normal life". Even attempts to lose weight were hampered by feelings of not belonging in places where "thin people go", for example, gyms. Home
became a haven and was seen as a safe space offering protection from the outside world and five of the participants only left the house when absolutely necessary.

Excess weight created practical problems and was reported as being associated with pain, comorbidity and immobility; these gradually reduced their ability to perform daily tasks, such as climbing stairs, cooking, cleaning, and personal hygiene. These practical difficulties had reinforced the negative psychological impact.

**Box 2. Negative experiences as an obese person of self-blame, shame, and stigmatisation**

"Let’s say I’ve got to do it [bariatric surgery] because I know that I’d be dead if I didn’t...... it’s [obesity] affecting my life in that I can’t run around, I can’t walk far. I’ve got to do something about it, I realise that, because I know I’ll be in a wooden box if I don’t do anything about it." (P10)

"You’re fat, it’s your own fault, do something about it, get on with your life. But when you feel that low it’s not easy. See and then you don’t talk about it because it makes you cry and then you feel like a silly cow because you’re crying. And it’s only because you know it’s your weight and it’s your own fault, and that’s what I do, I blame myself all the time. And it is my fault and I know it’s my fault, and I hate crying because it makes me look so weak and pathetic" (P5)

"I would like somebody to walk in my shoes every day and see what I have to put up with, the gestures that you get off people saying oh fat this, fat that." (P6)

"I don’t go on picture. I’m always the one to take the pictures. Do you know what I mean, I get out of it that way - oh I’ll take them! Because if I look at myself, in my mind I’m saying to myself oh my God, I need to get shot of that, I need to burn it. I’ve found loads of photographs and burnt them. Put them in fire, ripped them up, put them in fire, and if we’ve had fire out then put them in a bag" (P7)

"I get it into my mind I’m going shopping, food shopping for the house. I go out, do it and come home. It’s done, that’s a job done. I’ve got to go to hospital and have this, this and this done, home. On the way there I’m thinking how long am I going to be there before I get home? My home’s my lifeline, it’s my haven; it’s where I hide." (P7)

"You see mums talking in the playground and they’re all socialising, but I don’t know anybody, I drop my kids off and I come straight back out. I don’t talk to anybody" (P12)

"That’s sort of the window in the door, meaning like to go outside, and the blinds are closed because then I can’t see the outside and it can’t see me......It’s a protection thing, it’s complete protection. If I don’t have to go outside into the outside world then I’m safe in here. This is my safe place." (P1).
Experience of weight management services

Participants experience of tiered weight management services are illustrated by the quotes in box 3. Prior to referral and, in particular, the development of the tiered service framework few participants realised that NHS funded bariatric surgery could be available to them. In desperation they had tried to access privately funded procedures. Participants reported problems when negotiating clinical pathways to access the right departments for weight management. Once patients had realised funded surgery was a possibility they became fixated on the notion of it as the only solution to their obesity.

Tier 3 weight management services operated differently across the geographical areas of this study, largely due to changing commissioning policy and service specifications. Participants who had access to, and attended a 12 week weight management service felt this was not long enough. One participant proposed that treatment for obesity should be like that for addictions and not time limited. All participants who attended Tier 3 weight management services commented that they were delivered in a non-judgemental way. This compared favourably with participants contact with other health professionals in other settings where they recalled feeling blamed because of their obesity and related health conditions.

Participants hampered by mobility problems and low self-esteem found it challenging to attend weight management sessions that were held in central locations and required long journeys. Employed participants referred to the struggle for them or family members to fit appointments around work. Those that attended exercise sessions praised the impact they had on mobility and health. They also reported
feeling comfortable as they were exercising with "similar" people. However they were often deterred from exercise at the end of the 12 weeks when they were encouraged to attend public sessions with people who were not obese. Cost was also a consideration for many; exercise classes were free or at a reduced rate in the first 12 weeks but some felt they couldn't afford to attend at unsubsidised cost.

All participants had tried dieting in the past and despite information about portion sizes and healthy eating being widely available, participants reported the benefit of receiving specific advice from specialist weight management dieticians. The personalised information rather than a generic "diet sheet" and the opportunity to revisit concerns about diet were deemed to be helpful in maintaining improved eating habits.

There was variation in the level of knowledge about bariatric surgery amongst participants. Some had friends who had already had surgery; for others it was their GP or Tier 3 service staff who first mentioned surgery. There was some evidence of staff at Tier 3 attempting to prepare participants for what life would be like after surgery and trusted websites were given for patients to undertake their own additional research. However, during the transition between Tier 3 community weight services and Tier 4 specialist bariatric services patients felt unsure where to access support. Once referred for surgery, participants attended an information seminar at a hospital. In the cases of the two who had not had any additional weight loss support this was one of the first occasions they had realised there were "others like me" or were given any information about the surgery. There were contrasting experiences of the seminars. Some thought that the seminars were informative and dispelled myths and concerns the participants had whilst helping them to decide which type of
surgery best suited them. Others commented the seminars were basic and offered no new information they could not have found on the internet.

Generally participants were surprised at the speed of the process between primary care and weight management services and the bariatric surgery team. However, once referred for bariatric surgery, co-morbidities such as obstructive sleep apnoea needed to be controlled prior to surgery; this lengthened the referral process and frustrated participants. At all stages of the surgery pathway there is an expectation that patients demonstrate commitment to changing and maintaining their eating and exercise behaviours in order to be listed for surgery. Many participants in this study emphasised their fear of being refused what they perceived to be life changing surgery if they did not change their behaviour or manage co-morbidities. They were determined to show the commitment required.

Box 3. Experiences of tiered obesity services

Participant explaining previous experiences of trying to access surgery before the tiered system: "I went to see my doctor because I got, you know, depression with the size that I am, and she just happened to say have you considered a gastric band, which I'd been trying for the last three, four year, and I just got pushed from one department to another" (P2)

The Tier 3 service: "It's not long enough. It's not long enough. People who've got a smoking or a drinking problem or a drug problem get longer than that, and you know, and weight is an issue. And it is an illness" (P11)

"I did get involved with that, [exercise groups at Tier three] but the only problem is I've got to go there, and a lot of the time I can't get out because of my ankles and my legs swell up…… so I have to get taxis which is very difficult. I've got limited income as well, so that makes it very difficult as well" (P14)

"...the problem with the [Tier 3 service] is, because they do groups and they do sort of weighing sessions, but they're all when I'm working, so it's absolutely useless for me now. Unless I have made an appointment it doesn't work. And even the last appointment that was available was I had to go to work early to get in to finish to get there, so it was difficult to access everything all the time, because it wasn't flexible"
"I wouldn’t go to gym because you’d feel stupid because I did try it after but I thought I can’t, I was like having panic attacks and I thought I’ve got to get out of here. But going to that it really helped. If there was somewhere like that I could go to on a regular basis I’d love to do that" "Do they not continue then that after your 12 weeks?" “No it finishes then" “You can’t keep going?" “No it finishes” (P5)

"That [hospital seminar] were brilliant. If I’d had that information before, I’d have known exactly what I were going to go for. I went in thinking right, I’m having gastric, I’m going to go for the gastric band, I come out thinking right, I’ve put my name down for a gastric sleeve, which is completely opposite” (P2)

“they [Tier 3 service] are big on checking that everyone’s ready for what they’re doing, and they won’t even put you forward if they don’t think you’re ready….because you have to show commitment if you don’t show that you’re committed to doing what they’re asking you to do they’re not going to refer you for the surgery” (P13)

Expectations of normality

Unrealistic expectations of surgery were reported by all participants (see box 4). There was an expectation of improved health and an eradication or reduction in co-morbidities. They looked forward to a time after surgery, when burdensome medication for weight related co-morbidities would not be required. Participants anticipated the stigma and blame they experience from health professionals because of their weight would reduce or disappear completely because of the extent of their presumed post-operative weight loss.

All participants acknowledged that changes to diet and physical activity were essential if the surgery was to be successful in the long term. However people varied in terms of the extent to which they described a commitment to change behaviour. Surgery was commonly referred to as a "tool" to control eating, rather than participants needing to take responsibility for their eating behaviour. Whilst some
recognised that personal control would still be required, others had unrealistic expectations that surgery would remove the need for their decision to eat or not. Most participants knew others who had had surgery and used their experiences and success as a benchmark for the extent of behaviour change required. Unrealistic hopes that they could retain some current behaviour and still lose weight after surgery were derived from the personal stories of other people.

Female participants had taken photographs of clothes and underwear against furniture to indicate "how big" they were. Contrastingly other photographs of smaller sizes clothes in shops demonstrated the hopes that came with the surgery. Whilst participants were extremely optimistic about the anticipated physical changes they also raised concerns about the reactions of close family and friends provoked by changes to image and identify. This was particularly apparent in those who reported they "had always been big". Social isolation was anticipated to reduce as many hoped changes in their weight would mean they would have more confidence to go out without worrying what strangers thought about them.

All participants were aware of potential problems concerning excess skin, but didn't believe this would be an extensive or distressing issue for them. They anticipated that the improved changes to appearance from losing weight would, by far, overcome any concerns they had about excess skin. Older (50 years plus) female participants joked how they would "just tuck it in".

Participants had great hopes and expectations regarding increases in confidence, motivation and overall zest for life following their surgery. They reasoned that weight loss and improved mobility and health would remove their life and emotional challenges and help them to feel like a "normal" person again. Participants
anticipated that the weight loss following surgery meant they would no longer be
viewed as "different". They expected their confidence to increase to an extent they
would be able to manage any negative comments and stressful situations, even with
small weight loss.

Box 4. Expectations of normality following surgery

"I don't want to be slim, I want to be normal, I want to be healthy and that's all I want
to be. I don't want no miracles". (P5)

"The diabetes will go, hopefully, the apnoea will go, hopefully, a lot of these things
will correct themselves so that will have a big, big effect on my life." (P10)

"But with this bariatric bypass then it's supposed to get rid of like most of the
diabetes cases. So I'm hoping to do away with all that medication, which it's a pain
every morning. I'm 61, I get forgetful, sometimes I forget to take my tablets, if I get
up feeling great, and then it'll dawn on me when I start to feel terrible later on in the
day, I think oh no I've not had my tablets. And so like you're dashing about having
these tablets and injections, and then it throws your routine out and it's a bind, it is a
bind." (P11)

"I can go back to doctor's well look I'm skinny, I've still got this problem what are you
going to do about it? Because something they always relate back to is it's because
of your weight. So if the weight's not a problem what else can they do?" (P17)

"If you're just on a diet you think oh we're going to go for a meal tomorrow, oh I'll
have a day off. But once you've had that surgery there isn't any having days off is
there" (P15)

"I need to figure out how I'm going to change it to incorporate these social events.
But like again my friend's sister she drinks like a trooper and she's had it done. So
it's not that she can't ever drink again, it's just that there's a limited time that you can"
(P17)

"I'm so excited about this bariatric treatment because I'm going to get into that dress,
and I will get into it" (P9)

"It's to do with just normal things and confident to be able to go to Alton Towers and
confident to walk into a shop and know that something's going to fit me or that sort of
confidence. And confidence as well that I can lose weight and continue to do it,
because it's something that I've never been able to do." (P17)
Discussion

This research responds to the call for more evidence to increase understanding of bariatric surgery patient experience.[24] The study provides new insight into the pre-operative period for people referred for bariatric surgery in England. The findings indicate the extent of obesity related distress experienced in life prior to bariatric surgery. Desperation for surgery and extensive expectations of life after surgery were evident. This study supports previous findings in terms of the extent of bariatric surgery patients’ psychological and physical morbidity.[18-20] However, this study adds new information about how the impacts of obesity play out in everyday lives, creating low self-esteem, social avoidance and poor quality of life prior to surgery. Taking refuge at home increased social isolation and intensified feelings of worthlessness. Such preoperative experiences were seen, in this study, to exacerbate unrealistic aspirations for post-operative normality.

There is growing evidence that patients face problems because of excess skin post-surgery.[25] Despite being informed by the MDT’s of the possible consequences, the majority of the participants in this study rejected the notion that excess skin would be a problem for them. They did not anticipate that excess skin would obstruct their journey to "normality". Previous evidence has focussed on the weight loss goals of patients. This study provides new insight of participants' broader expectations of "normality" regarding weight and appearance, eating and activity behaviour, social life, and emotional resilience following surgery. Questions emerge regarding how feasible these expectations of normality are and, if unrealistic, how this could impact on the success of surgery outcomes.

The social and emotional burdens of obesity were reported as major factors to patients accessing bariatric surgery services. Participants reported negative
reactions from others in the past regarding their obesity, which often led to social avoidance. The tiered service framework provided access to support and information in preparation for surgery. However, unrealistic expectations of surgery had not been detected, challenged or modified. The hope and belief that life following bariatric surgery would become "normal" was evident across all interviews but there were differences in the extent to which people indicated an ability or willingness to embark on behaviour change and self-management strategies themselves. Whilst some participants saw surgery as a trigger for change, others saw it as a tool that meant little effort was required from them to change behaviours. There were no examples of Tier 3 services providing advice about behaviour change or self-management strategies or how people could access such help following surgery. These preoperative experiences, expectations and lack of access to behaviour change and self-management services have the potential to impact upon post-surgery outcomes.

Commissioning guidance for weight assessment in weight management clinics identifies a lack of evidence on the effectiveness of Tier 3 weight management services.[15-16] Whilst this study does not set out to evaluate Tier 3 services it does highlight the need for such services to prepare people for bariatric surgery by, for example, providing access to behaviour change and self-management strategies and modifying unrealistic expectations. The structured obesity service pathway provides opportunities to support people who have spent many years trying to lose and sustain weight loss. The participants appreciated the fact services were provided in a non-judgemental manner but there is potential to expand on current services. Despite being a cost effective treatment, the extent of the success of bariatric surgery relies on patient's long term commitment to behaviour change. Some
participants here viewed the surgery as a physical tool to change eating rather than relying on their will power or eating decisions. This suggests naivety regarding post-operative lifestyle change. The potential of positive outcomes following surgery are reduced if patients do not accept the need to modify their eating behaviours. Unrealistic expectations regarding the perceived level of effort required indicates the need for additional interventions pre-and post-surgery. There is the potential to learn from behavioural, self-management interventions in other conditions, for example the Expert Patient Programme in long term conditions, and the DESMOND programme for newly diagnosed type 2 diabetes. Many such behaviour change interventions are routed in psychological theory and aim to improve psychological wellbeing as well as promote behaviour change. This study indicates such an approach may be appropriate with in the bariatric surgery population. The findings here raise the question of whether similar interventions such as DESMOND could be developed for people referred for bariatric surgery. Such services could be introduced prior to surgery to prepare people more effectively but be continued post-surgery to promote sustained self-management and behaviour change. Further research is required to inform the development of such interventions and evaluate their impact on behaviour change, self-management and achieving positive outcomes.[26]

Conclusion

This study provides insight into the expectations and experiences of patients in England who have been referred for bariatric surgery. The findings reveal factors that influence their expectations of surgery, and indicate that despite having accessed Tier 3 weight management services these expectations were not always realistic. The study highlights the importance of weight management services assessing and modifying patient's expectations as appropriate. The importance of
providing behaviour change and self-management support is also emphasised and 
this support needs to take into account the impact of stigmatisation and shame if 
positive outcomes are to be maximised following surgery. Future research examining 
post-surgery will be useful to determine the extent to which expectations of the 
procedure and future life are met and to develop and evaluate the required 
interventions.

References

1. World Health Organization. Physical status: the use and interpretation of 

2013.

3. World Health Organisation. Obesity: Preventing and Managing the Global 

identification, assessment and management of overweight and obesity in 

5. Picot J, Jones J, Colquitt JL et al. The clinical effectiveness and cost-
effectiveness of bariatric (weight loss) surgery for obesity: a systematic review 

6. da Silva SSP, da Costa MA. Obesity and Treatment Meanings in Bariatric 
Surgery Candidates: A Qualitative Study. Obesity Surgery 2012;22(11):1714-
1722

Department for Innovation; 2007

aid weight reduction for people with morbid obesity. Technology Appraisal 
Guidance – No 46. London; 2002


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Competing interest declaration

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Details of contributors
We thank all the participants who contributed their time, shared their experiences and their personal stories. We also thank the advisory group which included clinicians, academies and lay advisors.

Contributors: CVH and AMT had the idea for the study. CVH was principal investigator, led the data collection and analysis, and wrote drafts of the manuscript. CVH and AMT designed the study, develop the methods, collected and analysed the data. ART helped draft the paper, provided critical reviews and intellectual content. All authors have seen and approved the final version of the manuscript. CVH is the guarantor. PA and EG are on the supervisory team for CVH PhD study.

Ethics approval
The study obtained ethics approval from Leeds East NHS Research Ethics Committee. (REC reference 12/YH/0194) and Research Governance approval from Sheffield Teaching Hospitals (Reference STH16456) and Doncaster Bassetlaw Hospitals Trust (Reference 0487/2012/NCT).
All participants gave informed consent before taking part.

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Study sponsor
The study sponsor was Sheffield Hallam University (SHU). CVH is an employee of SHU. SHU have supported the decision to submit the article for publication

Data integrity
All authors, external and internal, had full access to all of the data (including data reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Data sharing
Anonymised data will be made available on request to the corresponding author at c.homer@shu.ac.uk
Transparency Declaration
The lead author* affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

*The manuscript’s guarantor
Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Expectations and obesity experience of patients prior to bariatric surgery: a qualitative study

Developed from:

**YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE**

<table>
<thead>
<tr>
<th>No.</th>
<th>Item</th>
<th>Guide questions/description</th>
<th>Response</th>
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<tr>
<td></td>
<td>Domain 1: Research team and reflexivity</td>
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<tr>
<td></td>
<td>Personal Characteristics</td>
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<tr>
<td>1.</td>
<td>Interviewer/facilitator</td>
<td>Which author/s conducted the interview or focus group?</td>
<td>CVH</td>
</tr>
<tr>
<td>2.</td>
<td>Credentials</td>
<td>What were the researcher's credentials? E.g. PhD, MD</td>
<td>All have PhD except CVH. This research forms part of CVH PhD.</td>
</tr>
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<td>3.</td>
<td>Occupation</td>
<td>What was their occupation at the time of the study?</td>
<td>Academic</td>
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<tr>
<td>4.</td>
<td>Gender</td>
<td>Was the researcher male or female?</td>
<td>3 x women, 2 x men</td>
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<tr>
<td>5.</td>
<td>Experience and training</td>
<td>What experience or training did the researcher have?</td>
<td>AMT, ART, PA and EG are experienced health service researchers who supervised CVH. ART is also a registered clinical psychologist</td>
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<td></td>
<td>Relationship with participants</td>
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<tr>
<td>6.</td>
<td>Relationship established</td>
<td>Was a relationship established prior to study commencement?</td>
<td>N/A</td>
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<td>7.</td>
<td>Participant knowledge of the interviewer</td>
<td>What did the participants know about the researcher? e.g. personal goals, reasons for doing the research</td>
<td>Consent processes followed. Information about the research team and goals included in participant</td>
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<tr>
<td>Domain 2: study design</td>
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<td><strong>Theoretical framework</strong></td>
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<td>9. Methodological orientation and Theory</td>
<td>What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</td>
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<td></td>
<td>Qualitative methodology and Framework analysis</td>
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<td><strong>Participant selection</strong></td>
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<tr>
<td>10. Sampling</td>
<td>How were participants selected? e.g. purposive, convenience, consecutive, snowball</td>
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<tr>
<td>11. Method of approach</td>
<td>How were participants approached? e.g. face-to-face, telephone, mail, email</td>
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<tr>
<td></td>
<td>Participants were approached through letters from the multi-disciplinary team inviting them to take part in the research.</td>
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<td><strong>Setting</strong></td>
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<td>14. Setting of data collection</td>
<td>Where was the data collected? e.g. home, clinic, workplace</td>
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<td></td>
<td>Interviews took place in the participants home or convenient location.</td>
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<tr>
<td>15. Presence of non-participants</td>
<td>Was anyone else present besides the participants and researchers?</td>
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<td></td>
<td>In three cases family members were present.</td>
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<tr>
<td>16. Description of sample</td>
<td>What are the important characteristics of the sample? e.g. demographic data, date</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>People who had met and been referred for bariatric surgery. Participants were aged between 30 and 61 years, 4x men and 14x women</td>
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<tr>
<td><strong>Data collection</strong></td>
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<tr>
<td>17. Interview guide</td>
<td>Were questions, prompts, guides provided</td>
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<td></td>
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<td></td>
<td>Data collection</td>
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</table>
by the authors? Was it pilot tested? was guided by the use of individual interview schedules that had been developed through consideration of relevant literature and informed by discussion with the project Advisory Group. Participants completed a Photovoice assignment that was also used to guide discussion in the interviews.

<table>
<thead>
<tr>
<th>18. Repeat interviews</th>
<th>Were repeat interviews carried out? If yes, how many?</th>
<th>N/A</th>
</tr>
</thead>
<tbody>
<tr>
<td>19. Audio/visual recording</td>
<td>Did the research use audio or visual recording to collect the data?</td>
<td>Audio-recorded</td>
</tr>
<tr>
<td>20. Field notes</td>
<td>Were field notes made during and/or after the interview or focus group?</td>
<td>Yes.</td>
</tr>
<tr>
<td>21. Duration</td>
<td>What was the duration of the interviews or focus group?</td>
<td>32-104 minutes</td>
</tr>
<tr>
<td>22. Data saturation</td>
<td>Was data saturation discussed?</td>
<td>No. N/A</td>
</tr>
<tr>
<td>23. Transcripts returned</td>
<td>Were transcripts returned to participants for comment and/or correction?</td>
<td>N/A</td>
</tr>
</tbody>
</table>

**Domain 3: analysis and findings**

**Data analysis**

<p>| 24. Number of data coders | How many data coders coded the data? | All the researchers were involved in coding. Transcripts independently coded by 2 researchers. Preliminary findings and thematic frameworks were discussed at analysis meetings. |</p>
<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
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<tbody>
<tr>
<td>25. Description of the coding tree</td>
<td>Did authors provide a description of the coding tree?</td>
</tr>
<tr>
<td>26. Derivation of themes</td>
<td>Were themes identified in advance or derived from the data?</td>
</tr>
<tr>
<td>27. Software</td>
<td>What software, if applicable, was used to manage the data?</td>
</tr>
<tr>
<td>28. Participant checking</td>
<td>Did participants provide feedback on the findings?</td>
</tr>
<tr>
<td>Reporting</td>
<td></td>
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<tr>
<td>29. Quotations presented</td>
<td>Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number</td>
</tr>
<tr>
<td>30. Data and findings consistent</td>
<td>Was there consistency between the data presented and the findings?</td>
</tr>
<tr>
<td>31. Clarity of major themes</td>
<td>Were major themes clearly presented in the findings?</td>
</tr>
<tr>
<td>32. Clarity of minor themes</td>
<td>Is there a description of diverse cases or discussion of minor themes?</td>
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</tbody>
</table>

Once you have completed this checklist, please save a copy and upload it as part of your submission. When requested to do so as part of the upload process, please select the file type: Checklist. You will NOT be able to proceed with submission unless the checklist has been uploaded. Please DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.
EXPECTATIONS AND OBESITY EXPERIENCE OF PATIENTS PRIOR TO BARIATRIC SURGERY: A QUALITATIVE STUDY

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Key words: Bariatric surgery, obesity, shame, stigmatisation, patient expectation, framework analysis
EXPECTATIONS AND OBESITY EXPERIENCE OF PATIENTS PRIOR TO BARIATRIC SURGERY: A QUALITATIVE STUDY ABSTRACT

ABSTRACT

Objectives: This study aimed to understand the experience and expectations of people seeking bariatric surgery in England and identify implications for behavioural and self-management interventions.

Design: A qualitative study using modified Photovoice methods, triangulating photography with semi-structured in-depth interviews analysed using Framework techniques.


Participants: 18 adults (14 female and 4 male) accepted for bariatric surgery and aged between 30 and 61 years. Participants were recruited through hospital based Tier 4 bariatric surgery multi-disciplinary teams.

Results: The experience of participants indicate the nature and extent of the burden of obesity. Problems included stigmatisation, shame, poor health, physical function and reliance on medications. Participants expected surgery to result in major physical and psychological improvement. They described how this expectation was rooted in their experiences of stigma and shame. These feelings were reinforced by previous unsuccessful weight loss attempts. Participants expected extreme and sometimes unrealistic levels of sustained weight loss, as well as improvements to physical and mental health. The overall desire and expectation of bariatric surgery was of ‘normality’. Participants had received previous support from clinicians and in weight management services. However they reported that their expectations of surgery had not been reviewed by services and expectations appeared to be unrealistic. Likewise, their experience of stigmatisation had not been addressed.

Conclusions: The unrealistic expectations identified here may negatively affect post-operative outcomes. The findings indicate the importance of services addressing feelings of shame and stigmatisation and modifying patient's expectations and goals for the post-operative period.
STRENGTHS AND LIMITATIONS OF THIS STUDY

- One strength of this study is its use of a modified Photovoice methodology that triangulated photographs with interview data. This combination could be applied to research with other groups where obtaining detailed in-depth evidence is challenging, for example, where it is necessary to build trust with participants who may be socially isolated or where the topic is sensitive.
- Participants were recruited from two hospital Trusts based in two towns. The populations of both towns have similar significant levels of deprivation, that reflects the demographic of the population accessing funded bariatric surgery, which is relatively deprived. This supports the transferability of findings to areas with comparable deprived populations.
- The study has a small sample size, however as the aim of the study was to generate in depth insight this was an appropriate sample size and compares with other studies of a similar nature.
- The sample contained only four men; this reflects the gender balance of the population accessing bariatric surgery services.
- This study focuses on patients experiences and expectations. It would be useful to expand this research to include health care professionals and examine their views on the patient journey, expectations and the findings regarding weight related stigmatisation, and support required post bariatric surgery.

What is already known?

- Bariatric surgery is a cost-effective intervention for severe obesity but a significant proportion of patients do not achieve positive outcomes, or do not sustain them.
- Previous qualitative studies exploring factors that might influence patient outcomes have largely been retrospective and have not examined preoperative expectations and experiences.
- There is a lack of evidence on patients experience of the UK Tiered obesity services as a route to bariatric surgery.
Introduction

Morbid or severe obesity (Body Mass Index (BMI) of >40kg/m2) is rapidly increasing, with 2.4% of UK adults in that category. [1-2] There is an associated health burden for patients due to obesity related conditions including type 2 diabetes mellitus, cardiovascular disease and certain cancers.[3-5] Severe obesity also carries an increased risk of psychological morbidity, [5] as well as stigmatisation, intrusive reactions from others and social isolation.[6] UK Health care costs associated with obesity have been estimated at between £5 and £7billion per year, a figure set to double by 2050.[7-8]. Obesity accounts for up to seven percent of health care spending in developed countries [8]. Bariatric surgery is a recommended cost effective evidenced-based intervention to reduce weight and associated co-morbidities in severely obese people.[4-5,9-12] Surgery is offered to patients meeting strict criteria (see Box 1 for summary and NHS Commissioning Board [13]). Surgery rates in England have nearly doubled, increasing from 4200 (2008/09) to over 8000 (2012/13).[14] Expected outcomes from bariatric surgery include a significant and sustained reduction in weight, comorbidities and mortality and therefore reduced demand on health care services [8, 13].

Box1: A summary of the current NHS eligibility criteria for bariatric surgery:

- BMI of 40kg/m2 or more, or between 35 kg/m2 and 40kg/m2 or greater in the presence of other significant diseases.
- Medical evaluation led by a formalised multi-disciplinary team.
- Morbid/severe obesity has been present for at least five years.
- Individual complied with a non-surgical tier 3 / 4 service for the duration of 12-24 months.

NHS Commissioning Board 2013
In England, the National Health Service (NHS) recommends that weight loss and obesity services are delivered through a Tiered model, [13] Tier 1 and 2 being universal and lifestyle intervention. Tier 3 deliver specialist obesity services by a multi-disciplinary team. Tier 4 are surgically-led multidisciplinary specialist services providing predominantly bariatric surgery. [15] Delivery of this Tiered model across England varies and responsibilities for commissioning the Tiers lie with different organisations including NHS England, Clinical Commissioning Groups and Local Authorities. The Tiered model should ensure patients are appropriately selected for bariatric surgery and receive adequate physical, psychological and educational preparation.

Pre-operative preparation should include support regarding the post-operative behaviour change that is required following bariatric surgery. Self-management may be effective in promoting behavioural change prior to and following bariatric surgery within a Tiered service pathway, [16] however there is no research demonstrating this.

Severely obese people, who have repeatedly lost and gained weight, consider surgery to be the "last resort". [17-19] There is an indication that the desire for bariatric surgery is associated with high, even transformational, expectations of improved physical, emotional and relational wellbeing. [18-20] However, some bariatric surgery patients fail to sustain weight loss and reasons for this remain unclear. [6] In order to maximise the attainment of positive outcomes following bariatric surgery, there is a need for research examining the effectiveness and experience of behavioural and self-management interventions. [21] There is a requirement to better understand patients' expectations and experience across the service pathway. Little is known about the weight related pre-surgery experiences and expectations of bariatric surgery patients who have gone through a Tiered service model. This paper reports a qualitative study, using a modified Photovoice approach. The study aimed to answer the following questions, first, what are the experience and expectations of people seeking bariatric surgery in England and second, what are the implications of the findings for behavioural and self-management interventions. The aim was to provide an account of patient experience elicited shortly before bariatric surgery. The intention is to generate insight and understanding to help inform the commissioning and delivery of weight management services that provide the required preparation for patients prior to bariatric surgery.

**Design**

This prospective qualitative study used a modified Photovoice methodology incorporating photography, semi-structured individual interviews and Framework Analysis techniques. [22-24] Photovoice is a participative research approach traditionally used in a community context where participants take photographs to
illustrate their experiences of the issue of concern and the meanings they hold for participants. [22] In this study the focus of concern was obesity and bariatric surgery. Photographs were taken by individual patients, rather than community members, and used to guide the semi-structured individual interviews. Framework analysis was used as it enables the use of a priori knowledge in the development and refinement of the thematic framework. An inductive approach was used, where emerging data was used to develop, refine and verify themes and findings.

Setting

The study was conducted in areas served by two hospital based bariatric surgery multi-disciplinary teams in the North of England. Data was collected between August 2012 and April 2013.

The study was conducted prior to the NHS England commissioning guidance published in April 2014 [13]. This guidance sets out eligibility criteria for the commissioning and delivery of NHS funded morbid obesity surgery, stating the requirement for all patients to have accessed Tier 3 support prior to referral for Tier 4 surgery. The two hospitals received referrals from areas which differed in the routes to bariatric surgery. Participants in this study were recruited from three areas which referred patients through the recommended community Tier 3 services and one area which referred via the Primary Care Physician.

Sample

Eighteen participants were recruited prior to bariatric surgery through two bariatric surgery multi-disciplinary teams. Sixteen had been to Tier 3 community obesity services with access to dieticians, obesity nurses, talking therapists and general practitioners (GP). Three others were referred directly from a primary care physician, as their area did not have a Tier 3 service. All participants were over 18 years of age, having surgery for the first time and undergoing a gastric bypass, gastric band or gastric sleeve. Purposive sampling [23, 25] was used to select participants to ensure that the sample had the necessary variety of characteristics in terms of age, gender, employment co-morbidities and marital status. The study team did not have access to medical records so co-morbidities and BMI were self-reported by some of the participants. During the study period we were only able to recruit four male patients however this is reflective of the proportion of men within the surgical population. The characteristics of the sample are summarised in Table 1.
Table 1 Sample characteristics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Gender</th>
<th>Marital Status</th>
<th>Comorbidities</th>
<th>Employment Status</th>
<th>Referral Route</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>35</td>
<td>F</td>
<td>Divorced</td>
<td>Joint pain</td>
<td>Unemployed</td>
<td>Tier 3 Weight Management Service</td>
</tr>
<tr>
<td>2</td>
<td>54</td>
<td>F</td>
<td>Married</td>
<td>Type 2 Diabetes, Cardiovascular Disease, Depression</td>
<td>Unemployed</td>
<td>Tier 3 Weight Management Service</td>
</tr>
<tr>
<td>3</td>
<td>46</td>
<td>F</td>
<td>Divorced</td>
<td>Depression, Osteoporosis, Asthma, Hypermobility syndrome,</td>
<td>Unemployed</td>
<td>Tier 3 Weight Management Service</td>
</tr>
<tr>
<td>4</td>
<td>61</td>
<td>M</td>
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<td>Diabetic Consultant and Tier 3 Weight Management Service</td>
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<td>F</td>
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<td>Polycystic Ovary Syndrome, Diverticulitis</td>
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<td>Joint pain</td>
<td>Full Time Employed</td>
<td>Tier 3 Weight Management Service</td>
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**Study procedure**

Participants were recruited through hospital based bariatric surgery multi-disciplinary teams (MDT). The Photovoice tasks and interview schedule were developed through consultation with the MDTs, patient and public involvement with previous bariatric surgery patients, and relevant literature. Photovoice tasks or 'assignments' were given to participants prior to the interviews. The assignments included safety instructions for taking photographs and explained what would happen to the photographs. Participants were given prompts on what the photographs could include. These were to explore life as an obese person, the decision to be referred for the surgery, preparation for surgery and expectations of how life will change after the surgery. The resultant photographs were used as prompts in the interview. The study received NHS Research Governance approval. Ethical approval was obtained.
from Leeds East NHS Research Ethics Committee. The study had independent
scientific review through Collaborative Leadership in Applied Health Research and
Care - South Yorkshire (CLAHRC-SY) and a patient and public involvement group
with CLAHRC-SY.

Data collection and analysis

At the time of interview none of the participants had a confirmed date for their
surgical procedure, they were either waiting to see or had recently met their surgeon
for the first time. Seventeen of the eighteen interviews were carried out in the
participants’ homes and one in the principal investigator’s office in the research
centre. Interviews started by asking the interviewee to show the researcher their
photographs and explain why they took them and what they meant. An interview
guide was referred to throughout. This guide was developed by the research team,
with reference to the research questions and aims, and informed by relevant
literature and policy [24]. The photographs were discussed first to ensure the
participant’s experiences led the data collection. Any topics not covered by the
photographs were asked at the end. The interview schedule explored history of
weight, decision to have surgery, expectations of the surgery, and type of support
received. Interviews were recorded, transcribed and checked before being entered
onto NVivo version 10. Semi-structured interviews ranged between 32 and 104
minutes. Participation in the Photovoice methodology was left to the discretion of the
participants. Fifteen participants took part in the Photovoice tasks, the other
interviews were guided purely by the interview schedules. Photograph data were
also entered into NVIVO.

The intention was to stop data collection and the recruitment of new participants
once no new themes were emerging from the analysis, and data saturation was said
to be reached [26]. This was at 15 participants. However, 18 participants were finally
recruited to ensure we had a sufficient sample if anyone decided to withdraw from
study.

Data were analysed using Framework Analysis.[23] Framework Analysis involves a
systematic process of sifting, charting and sorting the material into key issues and
themes allowing the integration of pre-existing themes into the emerging data
analysis. The photographs were used alongside the interview transcripts in the
familiarisation stage to generate an initial thematic framework. Knowledge from
existing evidence and policy was also integrated into the initial thematic framework.

The interview transcripts were then coded to test, expand and verify the initial
thematic framework. In this way previous evidence and pre-conceptions were
challenged. As a result themes were added, removed and merged following
discussion with the project team. The photographs were used alongside the
transcripts to check, challenge and confirm the ongoing interpretation in an inductive
way. Using the photographs alongside the transcript data added to the depth of
Insight, and enabled tangible verification of the interpretation of the written data. Analysis was led by the principle investigator (CH). AMT audited the analysis process by reading seven of the transcripts alongside the photographs to verify the themes. The other authors (AT and PA) reviewed the transcripts and photographs. They contributed to the analysis and final results by providing additional interpretation.

Results

The findings are reported under three broad headings: the negative experience of obesity; experience of weight management services; and expectations of normality. Quotes and individual participant’s experiences are provided to illustrate the findings (Boxes 2, 3 and 4). Figure 1 displays the services participants accessed at each tier and some of the key themes that were evident at each stage.

Figure 1 - Tiered service model

Negative experiences of obesity

The combination of photographic and interview data revealed how profound the impact of obesity was on the participants emotional wellbeing and quality of life (see box 2). For some people this was so marked that they described their life as not worth living: “I don’t care anymore, just get me out of this world, I’ve had enough” (P7). The impact was compounded by years of weight cycling through attempts at weight loss techniques, diets and exercise regimes. Surgery was considered by all participants’ to be the last resort. Over half of the participants said that without surgery they may as well be dead or would not have long left to live.

Participants who suffered from weight related co-morbidities that required multiple medications found this poly-pharmacy burdensome and constricting, and also impaired their quality of life.

Employed participants described work as having a positive effect on self-esteem. Work and the interaction with colleagues gave them a purpose in their life and an identity other than just being a "fat person". However, unemployed participants described how their weight and associated poor health prevented them applying for, or staying at work, further reducing their self-esteem.

Nearly all participants reported feeling stigmatised because of their weight and some had received negative and judgemental comments from strangers. However, such negative responses were not just received from strangers. Participants described how family members did not understand their position and appeared to judge or blame them for their obesity and related health problems. Prior to being referred to
specialist obesity services participants identified that health care professionals had also been judgemental regarding their weight. Participants reported how their families did not understand their weight struggles, and viewed the surgery as an easy or soft option. This lack of understanding from the health care profession and of those closest to them meant participants felt increasingly marginalised from networks they regarded as their support.

Participants described long standing shame and embarrassment regarding their appearance, day to day activities, and health. Participants were self-critical and many had reached a stage where they avoided social situations, family and friends. They felt ashamed of their appearance and were worried others would think they had "let themselves go". Activities normal to others for example trips and holidays often caused anxiety. Female participants with children found getting their children ready for school and the journey to school challenging. It was worsened by a fear of being talked about by other parents because of their weight. As a result, they avoided situations that required speaking to other parents. Participants described being a burden to others in the family and blamed themselves for restricting their family's social lives, opportunities for holidays and enjoyment of life, all worsening their self esteem.

Navigating space both inside and outside the home presented daily functional challenges for the participants. This meant they were unable to live what they considered to be a "normal life". Even attempts to lose weight were hampered by feelings of not belonging in places where "thin people go", for example, gyms. Home became a haven and was seen as a safe space offering protection from the outside world and five of the participants only left the house when absolutely necessary.

Excess weight created practical problems and was reported as being associated with pain, co-morbidity and immobility; these gradually reduced their ability to perform daily tasks, such as climbing stairs, cooking, cleaning, and personal hygiene. These practical difficulties had reinforced the negative psychological impact.

Box 2. Negative experiences as an obese person of self-blame, shame, and stigmatisation

"Let’s say I’ve got to do it [bariatric surgery] because I know that I’d be dead if I didn’t.... it’s [obesity] affecting my life in that I can’t run around, I can’t walk far. I’ve got to do something about it, I realise that, because I know I’ll be in a wooden box if I don’t do anything about it." (P10)

“You’re fat, it’s your own fault, do something about it, get on with your life. But when you feel that low it’s not easy. See and then you don’t talk about it because it makes you cry and then you feel like a silly cow because you’re crying. And it’s only because you know it’s your weight and it’s your own fault, and that’s what I do, I blame myself all the time. And it is my fault and I know it’s my fault, and I hate crying because it makes me look so weak and pathetic” (P5)
"I would like somebody to walk in my shoes every day and see what I have to put up with, the gestures that you get off people saying oh fat this, fat that." (P6)

"I don’t go on picture. I’m always the one to take the pictures. Do you know what I mean. I get out of it that way - oh I’ll take them! Because if I look at myself, in my mind I’m saying to myself oh my God, I need to get shot of that, I need to burn it. I’ve found loads of photographs and burnt them. Put them in fire, ripped them up, put them in fire, and if we’ve had fire out then put them in a bag" (P7)

"I get it into my mind I’m going shopping, food shopping for the house. I go out, do it and come home. It’s done, that’s a job done. I’ve got to go to hospital and have this, this and this done, home. On the way there I’m thinking how long am I going to be there before I get home? My home’s my lifeline, it’s my haven; it’s where I hide." (P7)

"You see mums talking in the playground and they’re all socialising, but I don’t know anybody, I drop my kids off and I come straight back out. I don’t talk to anybody" (P12)

"That’s sort of the window in the door, meaning like to go outside, and the blinds are closed because then I can’t see the outside and it can’t see me.....It’s a protection thing, it’s complete protection. If I don’t have to go outside into the outside world then I’m safe in here. This is my safe place." (P1).

Experience of weight management services

Participants experience of Tiered weight management services are illustrated by the quotes in box 3. Prior to referral and, in particular, the development of the Tiered service framework few participants realised that NHS funded bariatric surgery could be available to them. In desperation they had tried to access privately funded procedures. Participants reported problems when negotiating clinical pathways to access the right departments for weight management. Once patients had realised funded surgery was a possibility they became fixed on the notion of it as the only solution to their obesity.

Tier 3 weight management services operated differently across the geographical areas of this study, largely due to changing commissioning policy and service specifications. Participants who had access to, and attended a 12 week weight management service felt this was not long enough. One participant proposed that treatment for obesity should be like that for addictions and not time limited. All participants who attended Tier 3 weight management services commented that they were delivered in a non-judgemental way. This compared favourably with
participants contact with other health professionals in other settings where they recalled feeling blamed because of their obesity and related health conditions.

Participants hampered by mobility problems and low self-esteem found it challenging to attend weight management sessions that were held in central locations and required long journeys. Employed participants referred to the struggle for them or family members to fit appointments around work. Those that attended exercise sessions praised the impact they had on mobility and health. They also reported feeling comfortable as they were exercising with "similar" people. However they were often deterred from exercise at the end of the 12 weeks when they were encouraged to attend public sessions with people who were not obese. Cost was also a consideration for many; exercise classes were free or at a reduced rate in the first 12 weeks but some felt they couldn't afford to attend at unsubsidised cost.

All participants had tried dieting in the past and despite information about portion sizes and healthy eating being widely available, participants reported the benefit of receiving specific advice from specialist weight management dieticians. The personalised information rather than a generic "diet sheet" and the opportunity to revisit concerns about diet were deemed to be helpful in maintaining improved eating habits.

There was variation in the level of knowledge about bariatric surgery amongst participants. Some had friends who had already had surgery; for others it was their GP or Tier 3 service staff who first mentioned surgery. Participants did describe that staff at Tier 3 attempted to prepare participants for what life would be like after surgery and trusted websites were given for patients to undertake their own additional research. However, during the transition between Tier 3 community weight services and Tier 4 specialist bariatric services patients felt unsure where to access support. Once referred for surgery, participants attended an information seminar at a hospital. In the cases of the two participants who had not had any additional weight loss support this was one of the first occasions they had realised there were "others like me" or were given any information about the surgery. There were contrasting experiences of the seminars. Some thought that the seminars were informative and dispelled myths and concerns the participants had whilst helping them to decide which type of surgery best suited them. Others commented the seminars were basic and offered no new information they could not have found on the internet.

Generally participants were surprised at the speed of the process between primary care and weight management services and the bariatric surgery team. However, once referred for bariatric surgery, co-morbidities such as obstructive sleep apnoea needed to be controlled prior to surgery; this lengthened the referral process and frustrated participants. At all stages of the surgery pathway there is an expectation that patients demonstrate commitment to changing and maintaining their eating and exercise behaviours in order to be listed for surgery. Many participants in this study emphasised their fear of being refused what they perceived to be life changing
surgery if they did not change their behaviour or manage co-morbidities. They were determined to show the commitment required.

**Box 3. Experiences of tiered obesity services**

Participant explaining previous experiences of trying to access surgery before the tiered system: "I went to see my doctor because I got, you know, depression with the size that I am, and she just happened to say have you considered a gastric band, which I’d been trying for the last three, four year, and I just got pushed from one department to another" (P2)

The Tier 3 service: "It's not long enough. It's not long enough. People who've got a smoking or a drinking problem or a drug problem get longer than that, and you know, and weight is an issue. And it is an illness" (P11)

"I did get involved with that, [exercise groups at Tier three] but the only problem is I've got to go there, and a lot of the time I can't get out because of my ankles and my legs swell up....... so I have to get taxis which is very difficult. I've got limited income as well, so that makes it very difficult as well" (P14)

"...the problem with the [Tier 3 service] is, because they do groups and they do sort of weighing sessions, but they're all when I'm working, so it's absolutely useless for me now. Unless I have made an appointment it doesn't work. And even the last appointment that was available was I had to go to work early to get in to finish to get there, so it was difficult to access everything all the time, because it wasn't flexible for working people" (P17)

"I wouldn't go to gym because you'd feel stupid because I did try it after but I thought I can't, I was like having panic attacks and I thought I've got to get out of here. But going to that it really helped. If there was somewhere like that I could go to on a regular basis I'd love to do that" "Do they not continue then that after your 12 weeks?" "No it finishes then" "You can't keep going?" "No it finishes" (P5)

"That [hospital seminar] were brilliant. If I'd had that information before, I'd have known exactly what I were going to go for. I went in thinking right, I'm having gastric, I'm going to go for the gastric band, I come out thinking right, I've put my name down for a gastric sleeve, which is completely opposite" (P2)

"they [Tier 3 service] are big on checking that everyone’s ready for what they’re doing, and they won't even put you forward if they don't think you're ready....because you have to show commitment if you don't show that you're committed to doing what they're asking you to do they're not going to refer you for the surgery" (P13)

**Expectations of normality**

Unrealistic expectations of surgery were reported by all participants (see box 4). There was an expectation of improved health and an eradication or reduction in co-
morbidities. They looked forward to a time after surgery, when burdensome medication for weight related co-morbidities would not be required. Participants anticipated the stigma and blame they experience from health professionals because of their weight would reduce or disappear completely because of the extent of their presumed post-operative weight loss.

All participants acknowledged that changes to diet and physical activity were essential if the surgery was to be successful in the long term. However people varied in terms of the extent to which they described a commitment to change behaviour. Surgery was commonly referred to as a "tool" to control eating, rather than participants needing to take responsibility for their eating behaviour. Whilst some recognised that personal control would still be required, others had unrealistic expectations that surgery would remove the need for their decision to eat or not. Half of the participants knew others who had had surgery and used their experiences and success as a benchmark for the extent of behaviour change required. Unrealistic hopes that they could retain some current behaviour and still lose weight after surgery were derived from the personal stories of other people.

Female participants had taken photographs of clothes and underwear against furniture to indicate "how big" they were. Contrastingly other photographs of smaller sizes clothes in shops demonstrated the hopes that came with the surgery. Whilst participants were extremely optimistic about the anticipated physical changes they also raised concerns about the reactions of close family and friends provoked by changes to image and identify. This was particularly apparent in those who reported they "had always been big". Social isolation was anticipated to reduce as many hoped changes in their weight would mean they would have more confidence to go out without worrying what strangers thought about them.

All participants were aware of potential problems concerning excess skin, but didn't believe this would be an extensive or distressing issue for them. They anticipated that the improved changes to appearance from losing weight would, by far, overcome any concerns they had about excess skin. Older (50 years plus) female participants joked how they would "just tuck it in".

Participants had great hopes and expectations regarding increases in confidence, motivation and overall zest for life following their surgery. They reasoned that weight loss and improved mobility and health would remove their life and emotional challenges and help them to feel like a "normal" person again. Participants anticipated that the weight loss following surgery meant they would no longer be viewed as "different". They expected their confidence to increase to an extent they would be able to manage any negative comments and stressful situations, even with small weight loss.
Box 4. Expectations of normality following surgery

"I don't want to be slim, I want to be normal, I want to be healthy and that's all I want to be. I don't want no miracles". (P5)

"The diabetes will go, hopefully, the apnoea will go, hopefully, a lot of these things will correct themselves so that will have a big, big effect on my life." (P10)

"But with this bariatric bypass then it's supposed to get rid of like most of the diabetes cases. So I'm hoping to do away with all that medication, which it's a pain every morning. I'm 61, I get forgetful, sometimes I forget to take my tablets, if I get up feeling great, and then it'll dawn on me when I start to feel terrible later on in the day, I think oh no I've not had my tablets. And so like you’re dashing about having these tablets and injections, and then it throws your routine out and it's a bind, it is a bind." (P11)

"I can go back to doctor's well look I'm skinny, I've still got this problem what are you going to do about it? Because something they always relate back to is it's because of your weight. So if the weight's not a problem what else can they do?" (P17)

"If you're just on a diet you think oh we're going to go for a meal tomorrow, oh I'll have a day off. But once you've had that surgery there isn’t any having days off is there" (P15)

"I need to figure out how I'm going to change it to incorporate these social events. But like again my friend’s sister she drinks like a trooper and she’s had it done. So it’s not that she can’t ever drink again, it’s just that there’s a limited time that you can" (P17)

"I'm so excited about this bariatric treatment because I'm going to get into that dress, and I will get into it" (P9)

"It’s to do with just normal things and confident to be able to go to Alton Towers and confident to walk into a shop and know that something’s going to fit me or that sort of confidence. And confidence as well that I can lose weight and continue to do it, because it’s something that I’ve never been able to do." (P17)

Discussion

This research responds to the call for more evidence to increase understanding of bariatric surgery patient experience.[27] The study provides new insight from the perspective of the participants, into the period prior to bariatric surgery in England. The findings indicate the extent of obesity related distress experienced in life prior to bariatric surgery. Desperation for surgery and extensive expectations of life after surgery were evident. This study supports previous findings in terms of the extent of bariatric surgery patients’ psychological and physical morbidity.[18-20, 28] However; this study adds new information about how the impacts of obesity play out in
everyday lives, creating low self-esteem, social avoidance and poor quality of life prior to different types of bariatric surgery. Taking refuge at home increased social isolation and intensified feelings of worthlessness. Such preoperative experiences were seen, in this study, to exacerbate unrealistic aspirations for post-operative normality.

There is growing evidence that patients face problems because of excess skin post-surgery.[29] Our participants reported similar problems. What is new in this study is the finding that, despite being informed by the MDT’s of the possible consequences, the majority of the participants in this study rejected the notion that excess skin would be a problem for them. Whilst the participants knew about excess skin prior to surgery, they thought it may be a problem for others but wouldn’t be for them. They did not anticipate that excess skin would obstruct their journey to "normality".

Previous evidence has focussed on the weight loss goals of patients. This study provides new insight of participants' broader expectations of "normality" regarding weight and appearance, eating and activity behaviour, social life, and emotional resilience following surgery. Questions emerge regarding how feasible these expectations of normality are and, if unrealistic, how this could impact on the success of surgery outcomes.

The social and emotional burdens of obesity were reported as major factors to patients accessing bariatric surgery services. Participants reported negative reactions from others in the past regarding their obesity, which often led to social avoidance. The Tiered service framework provided access to support and information in preparation for surgery. However, unrealistic expectations of surgery had not been detected, challenged or modified. The hope and belief that life following bariatric surgery would become "normal" was evident across all interviews but there were differences in the extent to which people indicated an ability or willingness to embark on behaviour change and self-management strategies themselves. Whilst some participants saw surgery as a trigger for change, others saw it as a tool that meant little effort was required from them to change behaviours. There were no examples of Tier 3 services providing advice about behaviour change or self-management strategies or how people could access such help following surgery. However this may have been a problem with recall and that they were offered or received the help but couldn't remember. The preoperative experiences, expectations and lack of access to behaviour change and self-management services have the potential to impact upon post-surgery outcomes.

Commissioning guidance for weight assessment in weight management clinics identifies a lack of evidence on the effectiveness of Tier 3 weight management services.[15-16] Whilst this study does not set out to evaluate Tier 3 services it does highlight the need for such services to prepare people for bariatric surgery by, for example, providing access to behaviour change and self-management strategies and modifying unrealistic expectations. The variability in Tier 3 service provision
supports the requirement of commissioning guidance for a structured obesity service pathway to provides opportunities to support people who have spent many years trying to lose and sustain weight loss.

Participants appreciated the fact services were provided in a non-judgemental manner but there is potential to expand on current services. Despite being a cost effective treatment, the extent of the success of bariatric surgery relies on patient’s long term commitment to behaviour change. Some participants here viewed the surgery as a physical tool to change eating rather than relying on their will power or eating decisions. This suggests naivety regarding postoperative lifestyle change. The potential of positive outcomes following surgery are reduced if patients do not accept the need to modify their eating behaviours.

Unrealistic expectations have been indicated in this study regarding the perceived level of effort required regarding eating behaviour and weight loss following surgery indicates the need for additional interventions pre-and post-surgery. Such expectations are understandable if people do not have the opportunity to identify and access the support they require in modify expectations, identify factors that may impede progress and access support in maintaining healthy eating behaviour. Pfeil et al (2013) highlights the additional support that could be provided by bariatric nurses and health care professionals in the pre-operative stages.

There is the potential to learn from behavioural, self-management interventions in other conditions, for example the Expert Patient Programme [30] in long term conditions, and the DESMOND programme for newly diagnosed type 2 diabetes [31] Many such behaviour change interventions are routed in psychological theory and aim to improve psychological wellbeing and illness beliefs, as well as promote behaviour change. These programmes can be cost-effective additions to the management of long term conditions and help modify illness beliefs. Furthermore Knutsen and Foss (2010) suggest that mandatory lifestyle courses using empowering education methods may be a powerful approach. [32] This study indicates such an approach may be appropriate within the bariatric surgery population. The findings here raise the question of whether similar interventions such as DESMOND could be developed for people referred for bariatric surgery. Such services could be introduced prior to surgery to prepare people more effectively but be continued post-surgery to promote sustained self-management and behaviour change. Further research is required to inform the development of such interventions and evaluate their impact on behaviour change, self-management and achieving positive outcomes.[33]

The use of Photovoice methodology provided additional insight into the lives of obese people. Participants who engaged with the methods were able to prepare for their interview, considering how their obesity affected their day to day lives and how they expected this to change following their surgery which added to the richness of the data. Photovoice methodology was a useful way of exploring the experience of
obese people who by the nature of the condition maybe a socially isolated and marginalised group of individuals. However, using Photovoice techniques in research places an additional demand on participants. The three participants who did not take photographs cited two main reasons which included a lack of time to prepare for the interview and more specific to obese people a dislike of having their photographs taken as a result of their obesity.

Conclusion

This study provides insight into the expectations and experiences of patients in England who have been referred for bariatric surgery. The findings reveal factors that influence their expectations of surgery, and indicate that despite having accessed Tier 3 weight management services these expectations were not always realistic. The study highlights the importance of weight management services assessing and modifying patient's expectations as appropriate. The importance of providing behaviour change and self-management support is also emphasised and this support needs to take into account the impact of stigmatisation and shame if positive outcomes are to be maximised following surgery. Future research examining post-surgery will be useful to determine the extent to which expectations of the procedure and future life are met and to develop and evaluate the required interventions.
References


25. Coyne IT. Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? Journal of Advanced Nursing 1997; 26; 623-630


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Competing interest declaration

All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Details of contributors

We thank all the participants who contributed their time, shared their experiences and their personal stories. We also thank the advisory group which included clinicians, academics and lay advisors.

Contributors: CVH and AMT had the idea for the study. CVH was principal investigator, led the data collection and analysis, and wrote drafts of the manuscript. CVH and AMT designed the study, develop the methods, collected and analysed the data. ART helped draft the paper, provided critical reviews and intellectual content. All authors have seen and approved the final version of the manuscript. CVH is the guarantor. PA and EG are on the supervisory team for CVH PhD study.

Ethics approval

The study obtained ethics approval from Leeds East NHS Research Ethics Committee. (REC reference 12/YH/0194) and Research Governance approval from
Sheffield Teaching Hospitals (Reference STH16456) and Doncaster Bassetlaw Hospitals Trust (Reference 0487/2012/NCT).
All participants gave informed consent before taking part.

**Funding**
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**Study sponsor**
The study sponsor was Sheffield Hallam University (SHU). CVH is an employee of SHU. SHU have supported the decision to submit the article for publication.

**Data integrity**
All authors, external and internal, had full access to all of the data (including data reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

**Data sharing**
Anonymised data will be made available on request to the corresponding author at c.homer@shu.ac.uk

**Transparency Declaration**
The lead author* affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

*The manuscript’s guarantor
Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Expectations and obesity experience of patients prior to bariatric surgery: a qualitative study

Developed from:

**YOU MUST PROVIDE A RESPONSE FOR ALL ITEMS. ENTER N/A IF NOT APPLICABLE**

<table>
<thead>
<tr>
<th>No.</th>
<th>Item</th>
<th>Guide questions/description</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Interviewer/facilitator</td>
<td>Which author/s conducted the interview or focus group?</td>
<td>CVH</td>
</tr>
<tr>
<td>2</td>
<td>Credentials</td>
<td>What were the researcher's credentials? E.g. PhD, MD</td>
<td>All have PhD except CVH. This research forms part of CVH PhD.</td>
</tr>
<tr>
<td>3</td>
<td>Occupation</td>
<td>What was their occupation at the time of the study?</td>
<td>Academic</td>
</tr>
<tr>
<td>4</td>
<td>Gender</td>
<td>Was the researcher male or female?</td>
<td>3 x women, 2 x men</td>
</tr>
<tr>
<td>5</td>
<td>Experience and training</td>
<td>What experience or training did the researcher have?</td>
<td>AMT, ART, PA and EG are experienced health service researchers who supervised CVH. ART is also a registered clinical psychologist</td>
</tr>
<tr>
<td>6</td>
<td>Relationship established</td>
<td>Was a relationship established prior to study commencement?</td>
<td>N/A</td>
</tr>
<tr>
<td>7</td>
<td>Participant knowledge of the interviewer</td>
<td>What did the participants know about the researcher? e.g. personal goals, reasons for doing the research</td>
<td>Consent processes followed. Information about the research team and goals included in participant information.</td>
</tr>
<tr>
<td>8. Interviewer characteristics</td>
<td>What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic</td>
<td>Knew researchers conducting interviews were independent academics, not connected to services</td>
<td></td>
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<tr>
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<td></td>
</tr>
<tr>
<td><strong>Domain 2: study design</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Theoretical framework</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Methodological orientation and Theory</td>
<td>What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</td>
<td>Qualitative methodology and Framework analysis</td>
<td></td>
</tr>
<tr>
<td><strong>Participant selection</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Sampling</td>
<td>How were participants selected? e.g. purposive, convenience, consecutive, snowball</td>
<td>Purposive</td>
<td></td>
</tr>
<tr>
<td>11. Method of approach</td>
<td>How were participants approached? e.g. face-to-face, telephone, mail, email</td>
<td>Participants were approached through letters from the multi-disciplinary team inviting them to take part in the research.</td>
<td></td>
</tr>
<tr>
<td>12. Sample size</td>
<td>How many participants were in the study?</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>13. Non-participation</td>
<td>How many people refused to participate or dropped out? Reasons?</td>
<td>None</td>
<td></td>
</tr>
<tr>
<td><strong>Setting</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Setting of data collection</td>
<td>Where was the data collected? e.g. home, clinic, workplace</td>
<td>Interviews took place in the participants home or convenient location.</td>
<td></td>
</tr>
<tr>
<td>15. Presence of non-participants</td>
<td>Was anyone else present besides the participants and researchers?</td>
<td>In three cases family members were present.</td>
<td></td>
</tr>
<tr>
<td>16. Description of sample</td>
<td>What are the important characteristics of the sample? e.g. demographic data, date</td>
<td>People who had met and been referred for bariatric surgery. Participants were aged between 30 and 61 years, 4x men and 14x women</td>
<td></td>
</tr>
<tr>
<td><strong>Data collection</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Interview guide</td>
<td>Were questions, prompts, guides provided</td>
<td>Data collection</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Details</td>
<td></td>
<td></td>
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<tr>
<td>----------</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>18. Repeat interviews</td>
<td>Were repeat interviews carried out? If yes, how many?</td>
<td>N/A</td>
<td></td>
</tr>
<tr>
<td>19. Audio/visual recording</td>
<td>Did the research use audio or visual recording to collect the data?</td>
<td>Audio-recorded</td>
<td></td>
</tr>
<tr>
<td>20. Field notes</td>
<td>Were field notes made during and/or after the interview or focus group?</td>
<td>Yes.</td>
<td></td>
</tr>
<tr>
<td>21. Duration</td>
<td>What was the duration of the interviews or focus group?</td>
<td>32-104 minutes</td>
<td></td>
</tr>
<tr>
<td>22. Data saturation</td>
<td>Was data saturation discussed?</td>
<td>No. N/A</td>
<td></td>
</tr>
<tr>
<td>23. Transcripts returned</td>
<td>Were transcripts returned to participants for comment and/or correction?</td>
<td>N/A</td>
<td></td>
</tr>
</tbody>
</table>

### Domain 3: analysis and findings

#### Data analysis

<table>
<thead>
<tr>
<th>Question</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>24. Number of data coders</td>
<td>How many data coders coded the data?</td>
</tr>
<tr>
<td>25. Description of the coding tree</td>
<td>Did authors provide a description of the coding tree?</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>26. Derivation of themes</td>
<td>Were themes identified in advance or derived from the data?</td>
</tr>
<tr>
<td>27. Software</td>
<td>What software, if applicable, was used to manage the data?</td>
</tr>
<tr>
<td>28. Participant checking</td>
<td>Did participants provide feedback on the findings?</td>
</tr>
<tr>
<td>29. Quotations presented</td>
<td>Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number</td>
</tr>
<tr>
<td>30. Data and findings consistent</td>
<td>Was there consistency between the data presented and the findings?</td>
</tr>
<tr>
<td>31. Clarity of major themes</td>
<td>Were major themes clearly presented in the findings?</td>
</tr>
<tr>
<td>32. Clarity of minor themes</td>
<td>Is there a description of diverse cases or discussion of minor themes?</td>
</tr>
</tbody>
</table>

Once you have completed this checklist, please save a copy and upload it as part of your submission. When requested to do so as part of the upload process, please select the file type: *Checklist*. You will NOT be able to proceed with submission unless the checklist has been uploaded. Please DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.