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## Designing pre-bariatric surgery education: The value of patients' experiences

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## **Abstract**

**Background:** Education is paramount in teaching patients how to adapt to post-operative or post-treatment lifestyle and get the best health-related quality of life outcomes. Within bariatric surgery, education around the UK is not standardised and based mainly on clinical experience. This study used qualitative research and a structured framework to design a pre-operative psychosocial education course for patients undergoing surgery.

**Methods:** Qualitative interviews were performed, seeking information about pre-operative education and consequent lifestyle changes encountered by previous bariatric patients. Following analysis, a structured evaluation of pre-operative education highlighted areas of concern to patients which were missing from education within our trust, and an educational course re-designed to include missing content.

**Results:** Categories identified from the interviews included: realities of surgery, seeking psychosocial support, and 'tips and tricks'. Seven topics within these categories were identified as missing from pre-operative education.

**Discussion:** In order to ensure equal access to education and preparation around the UK, standardised educational should be provided. Qualitative research and structured evaluations would ensure that educational design is of maximum benefit to patients and professionals. This study provides a template from which other trusts could evaluate and improve their education.

**Introduction:**

Pre-operative education for new patients is important in improving outcomes following diagnosis of chronic disease such as diabetes, or surgical intervention such as bariatric surgery for obesity (Kruzik, 2009, Devine and Cook, 1986). This is particularly noticeable regarding health-related quality of life (HRQOL) (Fink et al., 2013, Shuldham, 1999b, Shuldham, 1999a). Diabetes and bariatrics often share patients; therefore many lessons can be learned from each field and used to improve services in the other. There is a paucity of literature regarding how educational courses are developed (Kruzik, 2009), with none relating to psychosocial preparation before bariatric surgery. Unlike diabetes care, within bariatrics there is no standardisation of pre-operative education around the UK, and it is predominantly based on clinical experience rather than evidence. Most pre-operative education focuses on physical health, complications and diet, with little regarding expected lifestyle changes. In order to help patients adjust more easily following bariatric surgery, pre-operative education must be improved (Jones et al., 2011).

We aimed to use qualitative research to inform the design of a psychosocial health-related quality of life (HRQOL) educational course, providing a template that can be used by other trusts or specialties.

**Methods:**

This was a two-phase study using a mixture of methods.

*Phase 1: Interviews*

The primary phase involved performing qualitative interviews, seeking information about what previous bariatric patients wish they had known before they had surgery.

Thirty patients who had undergone bariatric surgery within Sheffield Teaching Hospitals (STH) between January 2001 and December 2012 were approached, spanning a range of ages, gender, ethnicity and operation. A total of 12 interviews were conducted by one author (CO) between February and July 2013; data collection continued until saturation occurred.

Interviews focused on aspects of education and care that patients thought were lacking. Discussions explored in detail what patients wish they had been told before surgery, and what issues they thought new bariatric candidates should know in order to make the most of the surgical opportunity afforded to them. All interviews were recorded using a digital audio recorder and were transcribed verbatim.

Data was analysed with the use of NVIVO software (QSR International Pty Ltd., 2014) using a general inductive approach (Thomas, 2006). Data was grouped into categories on a detailed level, with any statement from the patient remotely relating to pre-operative education and information, of lack of such, being coded. Throughout the analysis, the researcher (CO) sought to interpret how the patient's experiences of having surgery meant that this information was important to adapt into an educational course. The list of categories was then compiled into similar groupings (subordinate categories), then again to produce superordinate categories, or "themes".

#### *Phase 2: Redesign of existing pre-operative course, including peer and service user involvement*

This phase used results from the analysed interviews to redesign the pre-operative psychosocial HRQOL education offered to patients within our trust.

Prior to the study commencing, a preliminary course had been designed, developed and run by two authors (CO and AS), based on clinical experience and existing literature.

This provided psychosocial information, and included the aspects of surgery which anecdotally patients had reported as being important to understand before undergoing

a bariatric operation. For example, some topics included: weight regain, expected weight loss, relationship with food and how personal relationships may change following surgery. This course was offered to prospective bariatric patients at the trust; using principals of adult learning theory (Kaufman, 2003), the course included auditory, visual and kinaesthetic learning techniques, and the inclusion of case studies. Practical exercises such as keeping emotional relationship with food diaries and mindful eating techniques as well as group discussions were included. This course supplemented the education already provided in the pre-operative seminar, and pre-operative consultations.

A 'table' of subordinate categories identified during the interview analysis was created; this topics included in this table were compared to the information provided in the existing pre-operative group seminar, pre-operative consultations and preliminary educational course (table 1). Any topics felt to be missing from any existing pre-operative material were then added to the preliminary educational course.

Feedback was sought from service users who had attended the preliminary educational course; suggestions for improvement were utilised and fed back into the design of the course.

### **Results:**

Demographics of interview participants are shown in Table 2. This sample is relatively characteristic of the patient cohort within our trust.

Analysis of the interviews identified a total of 29 subordinate categories, which fitted within the superordinate (overall) themes of "realities of surgery"; "understanding perceptions and seeking a support network" and "tips and tricks". Following the evaluation process in phase 2, seven of these categories were identified as being missing from any existing educational material (figures 1-3). The subthemes identified as

missing are presented in grey and discussed below, along with quotes from the interviews demonstrating their need for inclusion in pre-operative educational material.

### **Realities of surgery (Figure 1):**

Patient expectations following surgery often correlate with outcomes such as weight loss and adherence to dietary rules (Kaly et al., 2008), coping ability (Rankinen et al., 2007) and satisfaction with surgery (Wee et al., 2006); expectations do not always correlate with the realities of surgery (Wee et al., 2006, Kaly et al., 2008) which were often surprising to participants. They discussed topics such as exercise and eating, the likelihood of weight regain, why weight regain occurred and how their expectations pre and post operatively influenced them.

The only category in this superordinate theme not felt to have adequate inclusion in any educational material before the course redesign was “side effects”. This was more related to the issues of loose skin, changes to hair, teeth, nails and malabsorption.

*“All my teeth started dropping out and crumbling and eventually they put me on these little capsules and these big chalk tablets.... must be about eight or nine years before [the] department told me I should have been on special vitamins and calcium tablets” P4*

A presentation and discussion both on what to expect and how to help prevent these issues was therefore included in the redesigned course.

### **Understanding perceptions and seeking a support network (Figure 2)**

Support following bariatric surgery has been shown to have a significant impact on post-operative recovery and adaptation to lifestyle (Clark et al., 2003). The perceptions of bariatric surgery from family and friends may possibly influence this. Participants frequently discussed that they did not realise how their own, and the public’s perceptions would influence them, or how much support they would need following surgery. Each subtheme presented in figure 2 related to seeking that support, how the

participants felt about themselves, their perceptions of how they became obese, perceptions of how their lifestyle changed following surgery, or their perceptions of how people viewed them. In some cases this was related to emotional and psychological health, in other cases this was related to the types of support they felt they needed.

Given the number of concerns discussed by participants related to emotional and psychological health (i.e. self perceptions) as well as perceptions about surgery, it became apparent that accessing support was a particular concern for many patients. Following the analysis therefore, it seemed important to highlight just how important this support is, both psychologically and socially, in order to make surgery a success. Few of the participants felt this message had been adequately conferred.

*“You need someone to sit down with you and when you're feeling really awful and you're having a day where you can't cope. You need someone to phone up, they come to meet you and have a cup of coffee, you talk to them, and if you have to do that all the way through your plateau, that would help you get through. If you could do that, it would be successful, you wouldn't give up and that's what's important” P1*

Therefore in the redesigned course, information was included about how important it was to find an adequate support network pre-operatively, where patients could find this extra support both within the NHS or private healthcare systems, and from friends, family, or the wider community. Teaching patients more about the issues associated with support after surgery, how perceptions may influence them and how to adapt to these perceptions, rather than concentrating on medical problems is a unique course design for bariatric surgery candidates.

Related to this was the public perception of bariatric surgery, and the way patients often experience guilt or shame about their obesity or weight loss surgery, making them less likely to seek support or bariatric surgery.



*“What I said about people's perception about people being fat, and they're actually quite open and nasty about sometimes - 'you're costing us all this money on the National Health' and somebody actually said that, you know, what right have you got to have, spend all that money on an operation when all you've got to do is go on a diet?'. And I said 'do you drive a car?' 'Yeah'. What if you have an accident?' 'Why should we treat you if you have an accident?'. You know, it's National Health and you know, if you have a disorder there would be some intervention to stop it.” P11*

The public perception of surgery seems important in how patients feel about themselves, and it is possible that providing education or at least discussing the concepts of shame and public perceptions with patients preoperatively may help them to understand negativity following surgery is a natural reaction experienced by many, and that with a little help and support, they can learn to combat the negative feelings associated with these attitudes.

*“So there is that like shame of 'I'm embarrassed cause of what I do and I can't control it' and the guilt of spending NHS money on something that is elective really.... So there is a lot of judging about wasting NHS money and things like that, so when I was looking into it this time I particularly wanted to do it privately because.... I would feel less guilty” P6*

The other aspect of seeking support was related to addiction transference.

*“I've ended up an alcoholic... That's my personality, I have to be addicted to something... I've done quite a lot of research about it and I've spoken to the dietitian at length and she did say that quite a lot of people have had this problem with alcohol... and it's actually been quite frightening because it's been even more of a compulsion than eating was....” (P11)*

Although a controversial and not universally recognised phenomenon, a number of patients mentioned this and it was therefore felt to be important to advise patients on how to recognise and seek help for this problem after surgery.

### **Tips and tricks:**

Participants were very keen to share their advice and tips about how to prepare for surgery, and how to make the necessary lifestyle changes afterwards. Many of these had already been included in the pre-existing education at the trust however it was felt that more information was needed about eating out in public/ social life changes, and clothing.

*"It's taken me nearly three years to learn how to eat out. I can do that now successfully but I couldn't and that upset me terribly.... I eat a starter usually for my main meal. I'll either pick a starter or I wont have a starter- I'll try a mouthful of his and then he'll eat the rest of my main meal" P8*

Eating out was often described as a significant part of pre-operative lifestyle. Tips such as choosing a starter as a main meal, sharing with a friend or taking leftovers home for a meal the following day were included into a presentation in the redesigned course.

Clothing was a significant issue. Participants described how quickly clothing sizes changed, how they went about replenishing their wardrobe and how to accessorise in order to cover loose skin and make clothing last longer.

*"Initially there's groups on line that swap and sell clothes. Through the bariatric sites there's a few where people will either swap.... There's a lot of places online that sell, groups that you can go through, when you first come out of hospital you can go through a size of clothes in two or three weeks" P5*

Although these tips and tricks may not be relevant to all new patients, providing examples of how other patients have changed their lifestyle may be beneficial.

### **Discussion:**

This study has demonstrated that existing patients can be an invaluable resource when designing pre-operative educational courses within chronic conditions. Many of the lessons learned may be relevant to diabetes care. There were seven topics identified as

being important from the patient's perspective that were missing from pre-operative education. It is unclear why these particular topics were not included from the initial education package; it may be that we did not appreciate their importance to patients, or it is possible that the cohort of patients recruited were more expressive compared to post-operative patients who are routinely seen in clinic, as they had been given the opportunity to discuss their post-operative lifestyle during this study. Findings from this study suggest that we as health professionals should seek to explore and address issues that patients feel are important, rather than those deemed most relevant. The advantage of involving patients in the design of educational material is that they are able to provide advice from real-life experience.

Providing pre-operative education can particularly improve a patient's HRQOL (Lagger et al., 2010). HRQOL can be evaluated or measured in many ways, some aspects of which include physical, psychological and social health following surgery (Bakas et al., 2012). Evaluating HRQOL should include the patient's perspective, and pre-operative education designed to improve HRQOL should also be developed from this standpoint (Crosby et al., 2003, Kushner and Foster, 2000). Using qualitative research, which best facilitates exploring the issues most significant to service users is an extremely effective manner of ensuring that patient education is of the best possible quality (Merriam, 2002). The approach used in this study allowed for patients and professionals to be involved in the course redesign. This structured approach to the development of healthcare education provides an alternative to, for example, an established technique such as the Delphi method.

Using the insights and suggestions gained from patients in qualitative studies such as this, to design successful educational sessions, has been done in specialties such as diabetes (Cooper et al., 2003). However, this is the first study to describe exactly *how* the experiences of patients have been used to design education for bariatric surgery. Whilst other studies have published the results of their improved education, few, if any,

have published the process that they went through to evaluate and design their education programmes (Adams, 2010, Harris et al., 2008). This paper therefore provides a framework that can be used by other organisations looking to evaluate their educational programmes.

The educational course from this study is being used as the intervention in a controlled clinical trial (pilot study) assessing the effect of education on HRQOL outcomes. Further studies, including multi-centred trials of existing versus improved educational packages should be performed in other centres to determine if improved education such as this is beneficial in the long term.

### **Conclusion:**

Studies such as this could be a step towards standardizing pre-operative bariatric surgery education in the UK in the same way as other specialties such as diabetes. This may help to make information less confusing when being treated in different trusts. Our study has highlighted that patient education before bariatric surgery, even in an established and reputable bariatric centre can sometimes be incomplete from the patient's point of view; it is possible that in other specialties with chronic diseases, this may also be the case, especially where significant lifestyle changes occur as a result of treatment. Overall, the findings highlight the importance of patient involvement in the development of health care education; other centres may wish to evaluate their own education using a method such as this, to identify if there are areas in their own practice that could be improved upon, thus helping to provide a better service and patient experience.

**Tables and figures:**

Table 1: Table used to evaluate education based on topics identified within the interviews

<b>Theme</b>	<b>Topic</b>
Realities of surgery	Exercise after surgery
	Weight regain
	Unsatisfactory weight loss
	Patients cheating/ following the rules
	Side effects of surgery/ loose skin
	Physical ability to eat after surgery
	Expectations
Psychosocial support	Perceived relationship with food
	Accepting responsibility for weight
	Accessing psychological support
	Accessing surgical/ dietetic support
	Addiction transference
	Guilt and shame about needing surgery
	Self perceptions of eating habits
	Family and friends
	Telling people about surgery
	Public perceptions about surgery
	Perceived lifestyle changes
	Self perceptions of physical being
	Practical tips
Eating out/ social life	
Weight loss plateau/what to do when weight loss stops	
Travelling home after surgery	
Clothing	
Doing adequate research before surgery	
What to do about pregnancy after surgery	
Going back to work	
Changes to relationships	

Table 2: Phase 1 patient demographics

Demographic variables	Participants (n=12)
Gender (% female)	91.6
Race/ethnicity (% White or Caucasian)	91.6
Employment status (% working)	58.2
Employment status (% retired)	41.6
Relationship status (% married/cohabiting)	91.6
Average age	55 years (range 41-76)

**Conflict of Interest:** The authors declare that they have no conflict of interest.

**Informed consent:** Informed consent was obtained from all individual participants included in the study.

**Ethical approval:** This study was approved by the South Yorkshire NHS regional ethics committee (12/YH/0385). All participants provided written informed consent.

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