

Concerns about Bariatric Surgery: Internet Postings of Patients

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Abstract

There is very sparse literature on the social, psychological and emotional concerns of patients following bariatric surgery. Due to the rapidly increasing popularity of this medical procedure, this study attempts to examine some of the major issues faced by patients. Internet postings are analyzed from a popular bariatric surgery Internet support site. Themes identified using a grounded theory approach are identified as depression, fear of dying, nutrition, and supplements. Implications for practice are presented.

INTRODUCTION

Bariatric surgery is an increasingly popular option for weight loss both in the United States and internationally. Although this article focuses on the issues related to surgery among patients in the United States, it is hoped that it has broader applicability. The currently accepted criterion for bariatric surgery is morbid obesity, a Body Mass Index (BMI) of at least 40 (approximately 100 pounds overweight for men and 80 for women). Individuals who have a Body Mass Index (BMI) between 35 and 39.9 who also have a serious weight-related health problem may also qualify.^[1]

Increasing numbers of people are electing to undergo weight loss surgery. A recent article estimates that bariatric surgeries in the United States increased from 13,365 in 1998 to over 72,000 in the year 2002. It has been estimated that about 130,000 patients had surgery in 2005, and this number is projected to reach 218,000 in 2010.^[2]

With publicity surrounding the amount of obesity in youth in the United States, interest in surgical approaches to weight loss for youth and adolescents has escalated. Currently, the National Institute of Health is conducting a research study looking at the risks and benefits of bariatric surgery for adolescents. This study, called Teen-LABS takes place at numerous sites across the United States.^[3]

Presently, the National Institute of Health suggests that multidisciplinary pre-surgery assessments be conducted, on all patients, although less than 50% of programs actually perform these evaluations.^[4] It is important to assess not only

the physical risks and benefits to bariatric surgery for all age groups, but the psychological, emotional and social factors as well. Berman underscores the importance of psychological assessment prior to surgery.^[5]

It has been argued that it is critical to explore mental health problems, as well as cognitive, social, and/or family issues that are likely to impact post-surgery success and adjustment. The Mayo Clinic (www.mayoclinic.com/health/) refers to mood changes that may occur after surgery, suggesting that this area needs greater attention. Nevertheless, mood can stabilize or improve after bariatric surgery. The American Association for Metabolic and Bariatric Surgery suggests that up to 55% of depression in obese patients may be resolved as a result of bariatric surgery (www.asbs.org). Clearly, more attention needs to be paid to the emotional consequences and adjustment issues that occur after surgery.

The psychological, emotional and social needs of patients as they adjust to life after weight loss surgery have largely been unexplored. One of the best ways to examine the needs of patients clearly is to listen to their voices directly. An unobtrusive method involves accessing postings on public Internet sites.

While few research studies have examined the postings of patients on health-related Internet sites, their use has increased. More than 97 million people are thought to have accessed the Internet in any given year, and of those, 74% have gone to a medically-oriented web site for health

information.^[6] The Internet can provide a powerful support and information system for people. Having a sense of privacy and anonymity contributes to the experience of being able to connect in a support community.^[7]

The Internet also makes self-segregation possible by helping people find others who have had similar experiences.^[8] Interestingly, there is very little published research on Internet postings for bariatric surgery patients. There are some analyses of pro-eating disorder websites and support groups that espouse the positive aspects of eating disorders.^[9] These sites, however, are clearly unrelated to bariatric surgery. It is more common to find weight loss programs on-line that have support components, rather than analyses of the on-line postings of bariatric surgery patients.^[10,11]

The present study attempts to understand and articulate the concerns and issues of bariatric surgery patients, from their own perspectives, as reflected on a bariatric Internet site. This work begins to fill an important gap in the research literature. Gleaning information from the patients themselves will assist medical and psychological professionals in better preparing patients for surgery and in addressing their post-surgery needs, thus encouraging successful outcomes.

METHOD

Attendees at a large support group meeting held by the bariatric surgery center of a major hospital in a Midwestern city were asked to indicate if they sought support on the Internet, and if so, on what site(s) they sought this support. One site was overwhelmingly mentioned by the majority of patients. On this site there are 10 forums specifically related to the concerns of bariatric surgery patients. Certain surgeries have their own forum. For example, there is a forum devoted to concerns about the LapBand® procedure. Since broader perspective on the issues of bariatric surgery patients was sought for this study, the main forum of this site was examined since it addresses general concerns about bariatric surgery. Individuals (posters) who had undergone or planned to undergo any type of surgical bariatric procedure were welcome on this forum.

The procedure for this study entailed sampling postings on this site over a two week period. It was thought that a two week period would provide enough variety in responses. Every fifth topic was sampled until 8 topics were selected per day. This procedure was followed for six days over the course of a two week period of time. A total of 191 postings were examined, representing the voices of 122 patients.

Although this was an arbitrary method with which to use to select postings, a systematic way to sample was needed.

All postings were thoroughly read and coded. The actual themes chosen for analysis were derived inductively through a grounded theory approach through line by line coding. Analytic categories were then identified as they arose from the coding scheme.^[12] A Constant Comparison method was then used where categories were combined into themes and were systematically compared with the rest of the emerging data. Similar themes were compared and then ultimately combined.^[13]

The use of grounded theory favors analysis over description, and the development of original categories over preconceived ideas. This method is different from others since it involves the researcher in data analysis while collecting data. Based on this method, the following themes were identified: depression, fear of dying, nutrition, and supplements. Before presenting these themes, some descriptive data about the sample will be presented.

RESULTS AND DISCUSSION

SAMPLE CHARACTERISTICS

A total of 191 total postings were analyzed, as written by 122 different patients who identified themselves by a username. Clearly, no one dominated the conversation, allowing a wide variety of voices to be heard. The typical poster included a picture of her/himself with their state of residence. All posters resided in the United States. The type of bariatric surgery, date of surgery and the surgeon's name were often also listed. Some posters included a graphic that stated their highest weight, weight at surgery, current weight and ultimate weight loss goal. Others included their BMI. Clearly, there was a great deal of personal disclosure on this site.

The majority of the posters were female, with only three being identified by picture or name as male. Four other posters did not include a picture and used a name that could be considered to be gender neutral; thus, their gender could not be established. Ninety-seven posters identified the procedure they had undergone. Of this number, the vast majority identified their procedure as the Roux en Y (86 posters). Only four had the LapBand® procedure, and four identified their procedures as the duodenal switch. Two posters had a revision surgery and one listed her surgery as a VSG.

Slightly over one-third of the posters publicly stated their

weight loss goal. The number of pounds ranged from 81 to 217, with the average desired weight loss goal being 150 pounds. Once again, a great deal of personal disclosure occurred on the site. There were no incidents of criticism or negative remarks about a poster's weight, goal or progress.

THEMES

Depression. The postings about post-surgery depression were most compelling because they were frequent, serious, and full of emotion. Respondents shared intimate feelings by saying, for example: "I'm going to cry at any minute! I feel like I've been on a moving train." Supporters jumped in by making such comments as: "I cannot stress enough that the post-op blues can be dangerous." One person even said "my own depression post-op nearly killed me. I am happy and stable now, but I must always be on guard."

Others did not fare as well. G shared the following in response to a poster sharing her experience with depression:

You and me both. I'm horribly depressed. I am not motivated to do anything. I don't talk on the phone, do anything around my house. I rarely even leave the sofa.

Posters jumped in and offered support and often shared their own personal stories of post-surgery depression. Many suggestions were made including encouraging posters to seek medical help and get information from websites on depression and treatment. Actual names and addresses of websites were given as resources.

Many posters seemed to have theories about the role of hormones and protein in the development of post-surgery depression. According to H:

Depression is very common post-bariatric surgery in women. Fat cells in women store estrogen, so as you are losing weight, more estrogen is circulating in your system.

Others talked about the ability of hormonal imbalance to create "havoc with moods," while still others compared their post-surgery experience to their experiences with post-partum depression.

In addition to hormonal imbalance, many posters mentioned the role of lack of sufficient protein in the post-surgery diet as contributing to depression. In responding to someone talking about depression, one of the first things that was often asked by other posters was, what was the amount of

protein being consumed? Posters talked about different sources of protein from soy preparations to protein bars. Lots of advice was given in response to a poster struggling from depression who has "been focusing everyday trying to get more protein in."

Interestingly, the conversations about depression seemed to be restricted to discussions of hormones and nutrition as being the cause. Virtually no mention was made of the psychological effects of extreme weight loss on mood. A lot has been written on the impact of various illnesses and even medication taking on the sense of self.^{[14][15]} Illness, medical procedures and medication itself can have profound effects on mood and self-esteem. However, these changes in the perceptions of self do not seem to have had relevance for the posters in this study. One would think that dramatic weight loss could create a new sense of self that might be a challenge with which to deal.

Fear of Dying. Although the general forum was mainly used by posters who were post-surgery, a few people had their surgeries scheduled and were awaiting their surgery dates. There was a great deal of fear and anxiety expressed about the dangers of bariatric surgery. This is especially difficult to deal with given the high risk associated with obesity. It puts patients in a difficult situation, realizing that their obesity is a health risk, yet the surgery to help address this condition is also made more risky by the obesity. Posters responded compassionately to the fears and anxieties expressed. Some responded with personal information and used their experience as a guide. Others evoked religion as a coping tool. E. talked about her own experience by saying:

I dealt with my fear to some degree by updating my will, writing out all my desires in detail..especially about what I would want done if I ended up in a vegetative state, planning my funeral, writing letters to various people.

D. reminded posters that the risk of death with bariatric surgery is still actually quite small. He said, "Keep in mind that the surgical stats regarding death have fallen dramatically. I think it's less than 1 in 1,000 today, which is less than cardiac surgery or kidney transplants."

Other posters evoked religion by making references to God and encouraging people to rely on their faith during times of anxiety. Some quoted bible passages as support. C. used humor when she said that she was not ready to die and leave her family yet, "if God decides to take me I will begin another wonderful journey, and will hopefully be at my

target weight immediately.”

Understandably, there is a great deal of fear and anxiety about death from bariatric surgery, and it takes much courage to move forward despite these fears, unrealistic though the magnitude of these fears may be. Posters seemed to gain much needed support from others as they discussed these fears. Again, no critical or negative comments about these fears were observed.

Nutrition. Posters seemed very willing to fully disclose the details of their eating patterns and seemed most anxious for the feedback and approval of others, with a special emphasis on quoting protein intake levels. This conversation supports the American Society for Bariatric Surgery guidelines that suggest that patients expect some protein deficiency in the first three months after surgery. With successful weight loss, this deficiency is usually corrected by 18 months post-surgery (www.lapsurgery.com/Bariatric).

Posters talked a great deal about post-surgery nutrition, and it was apparent that patients understood the message that proper nutrition was essential to their success. In the words of K., “since surgery I have been conscious about food. It is as if my light bulb has gone on.” Most of the discussion on nutrition involved posters actually sharing details about what they had recently eaten, with others commenting on the choices. For example, N. provided a detailed inventory some of which will be excerpted below:

Early Breakfast: ½ cup oatmeal, ¼ cup skim milk
Second Breakfast: protein shake made with water,
vanilla powder and crystal light
Lunch: 2 oz. Gorton’s blackened Cajun white fish,
½ cup slaw, 1 tsp. salsa

Some of the talk on nutrition took the form of criticizing others for their food choices, especially mothers allowing children to eat junk food. K. rather angrily talked about a woman who gave into screams at the checkout at the grocery, giving them candy. She said:

To me, it’s as bad as child abuse. They (kids) are innocent and have new bodies. Why pour glunk and gook down their throats when we can be nourishing them?

The talk about nutrition was more detailed than postings on the other themes. It was also the only place where posters reacted with some harshness and criticism about each others’ choices.

Supplements. Posters seemed to know and be concerned about the need to supplement their calcium and vitamins after surgery. In fact, since, in some surgeries, absorption sites are blocked, the American Society for Bariatric Surgery calls supplementation mandatory after bariatric surgery (www.lapsurgery.com/Bariatric). Posters offered advice to each other on the types of supplements to use and even how to use them. The difficulty in taking calcium pills was widely noted and discussed, as were solutions. For example, P. wrote, “The darn calcium pills were so big, they cause a bit of pouch discomfort.” Some suggested that the pills be cut in half.

Most commonly, posters recommended that the calcium pills be either crushed or that the calcium be taken in powder or liquid form. According to S. “when I was newly post-op, I crushed everything. I crushed my calcium and mixed it with applesauce, pudding or mashed potatoes.” Talking about a brand name calcium powder, B. said, “the fine powder goes into your mouth like a pixie stick. It dissolves quickly and smoothly,” In promoting a liquid product, C. said, “I keep the bottle in the fridge so it’s nice and cold and just take a sip in the evening.”

Clearly, having to take supplements can be time consuming, confusing and difficult. For example, L. admitted that she had not taken her vitamins or calcium, and that she was having trouble remembering to take them. J. reported the following: “OK so I feel like crap today. I have stopped my vitamin (it’s so gross).” Right away, another poster admonished her for not complying, strongly saying “you have to take your vitamins or you will feel worse than ever.”

The Internet forum was a place for posters to seek both education and advice about supplementation. In response to requests for help, posters actually provided the names of products and instructed others in how to obtain these products. This included phone numbers, addresses and web addresses. They also responded with great support and empathy to the concerns and questions of posters.

CONCLUSIONS AND IMPLICATIONS

Posters on this selected Internet bariatric surgery site created a dynamic and supportive sense of community. Very personal information was freely disclosed ranging from exactly what one ate during the day to their current and goal weights. These posters, who were largely female, also shared stories of hormone fluctuation, depression and fear. This suggests there is a need for a strong support program after bariatric surgery and the on-line forum seemed to play a role

in meeting needs after surgery. Only when discussing specific food choices did some criticism arise. This Internet forum served as a safe haven for its posters. A strong recommendation based on this study is that surgery programs consider offering more supportive services to patients following surgery. This could involve small group formats or even using successful patients as mentors.

Considering the extensive and comprehensive nature of the changes that occur in the body after bariatric surgery, it was surprising that more of the on-line discussion was not related to psychological issues and emotional changes. When depression was discussed, it was primarily in relation to hormones and protein levels. The posters in this study did not seem to develop the sense of a disordered-self that has been found in other research on illness and medication [16]. This area needs further research exploration. It could be that the stigma associated with mental health problems prevented more in-depth discussion. It could be that framing depression as being caused by hormones or protein deficiency carries less stigma than attributing it to a change in the sense of self. It is also possible that the implications and impact on the self of long-term weight loss are not felt immediately. As patients cope with the large number of physical demands and changes with which they are faced, they may not be ready to address the psychological.

One of the strongest implications of this study is that patients need to be educated about the changes they can expect after surgery and how to manage the new demands on their bodies. More information needs to be given about protein and hormone changes by the surgery centers. It seems that patients could benefit from very specific and concrete information regarding how to maximize their protein intakes. Explicit information regarding vitamin and calcium supplementation also seems important.

The postings on this on-line bariatric surgery site lead to the conclusion that more post-surgery support would be helpful for patients. Large support meetings sponsored by physicians might not be sufficient as patients try to adjust to life after surgery. This study serves as an initial attempt to identify the needs and concerns of patients. Further studies should

examine a variety of websites and talk to patients directly in order to more effectively identify their needs, concerns and issues.

Although based in the United States, this study raises issues and questions that might be considered internationally. It would be interesting to elicit responses from other countries to determine if these same dynamics and recommendations do apply.

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