Research Project

What Barriers to Medical Services do Morbidly Obese Persons Living in British Columbia Experience?

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For:

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Abstract

A purposive sampling survey was conducted through the British Columbia Weight Loss Surgery (BC-WLS) site located in Yahoo groups which asked respondents to record their thoughts and feelings about barriers to medical services experienced by morbidly obese persons living in British Columbia. The survey also asked the respondents to identify issues affecting their everyday lives. The fifteen surveys used in the analysis identified the following; surgery is not completed in a time manner; reconstructive surgery is generally not covered in British Columbia; there are serious physical and psychological issues associated with morbid obesity; morbid obesity is not regarded as a serious health issue; Discrimination is experienced in all walks of life.

Introduction

Morbid obesity or Obese Class III is a medical term to describe individuals who have a body mass index (BMI) in excess of forty or are more than one hundred pounds overweight (Health Canada, 2003). People who experience morbid obesity face both blatant and subtle discrimination in all walks of life, as well as significant physical and mental health issues. Clients in British Columbia wishing to have surgery are forced to wait years and the options are limited unless they are willing to self pay. In addition to this there is currently no residential treatment program for morbid obesity in the province, and it is difficult to find an eating disorder counsellor specializing in this area. There are inconsistencies in services offered between the provinces which impacts the overall health and well-being of morbidly obese clients.

The Canadian Charter of Rights and Freedoms prohibits “discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability” (Department of Justice Canada, n.d.). What this means is that an employer or service provider could

discriminate on the basis of size or appearance, and unless it can be argued successfully that a person's morbid obesity is a physical disability it is unlikely that a legal procedure would yield results. Morbid obesity has many negative connotations including; "weak-willed, ugly, and awkward, "lack[ing in] self-control, and lazy (Foster, Wadden, Makris, Davidson, Swain Sanderson, Allison & Kessler, 2003). Sadly, these descriptors came from medical doctors.

Pervasive attitudes towards morbid obesity which include distaste, blaming the victim, seeing it as a failure in character rather than a disease, and not acknowledging the seriousness of the condition contribute to a lack of services received in a timely fashion. A few are listed:

1. There are no in-patient eating disorder treatment facilities for morbidly obese patients in British Columbia.
2. Weight loss surgery patients can circumvent the many years long wait list if their condition is deemed as life threatening. Medical services do not acknowledge serious emotional aspects of morbid obesity as life threatening.
3. 'Self-pay' clients do not experience long wait times and have more surgery options available.
4. British Columbia currently covers only one type of surgery under MSP, even though other options are available in other provinces.
5. Reconstructive surgery for skin redundancy after massive weight loss that is available and covered in Saskatchewan is not covered under the Hospital Reciprocal Billing Agreement and the Medical Reciprocal Billing Agreement.
6. Under the auspices of Ontario's diabetes strategy the province announced the investment of "...$75 million to increase bariatric surgery capacity, also known as gastric bypass surgery,

from 244 to 1,470 a year at four centres of excellence by 2011/2012" (Ontario Ministry of Health and Long-Term Care, 2003).

Personal Reflection

This topic selected me. I have lived much of my life as a morbidly obese individual and suffered from numerous co-morbidities including mental illness and a life of isolation. I allowed the label of morbid obesity to be my sole identity marker for many years and stopped living life. I was unable to obtain the services I deemed necessary for my overall wellness. I was unable to obtain the following services in British Columbia;

1. Residential treatment program for Binge Eating Disorder.
2. Bariatric surgery. I opted for out of country self-pay (Biliopancreatic diversion with duodenal switch- BPD-DS).
3. Reconstructive surgery. I opted for out of country self-pay.

As I slowly relinquish the shame associated with morbid obesity my ability to recognize that this population is marginalized in large part by systemic and institutional factors rather than personal failings and that we/they are deserving of timely compassionate care has prompted me to put together a collective voice in the form of a survey which identifies gaps in our medical system. My personal goal is to see a holistic bariatric program on Vancouver Island and to work in such a program as a social worker. As an insider I come with my own unique issues related to my journey and was hopeful that barriers I experienced would emerge as issues for the majority of the respondents. I have been significantly impacted by the emotional toll of morbid obesity and much of my concern with the British Columbia health system was its failure to acknowledge emotional/psychological issues as life threatening and therefore a reason to reduce the wait time

for surgery. I felt I needed to be careful not to have my concerns come out in the form of leading questions in the survey. As such I am aware that my knowledge as an insider will be reflected in my findings and making meaning of the data collected from the survey.

The Research Question

What barriers to medical services do morbidly obese persons living in British Columbia experience was the overarching research question and this question was answered. The answers reflected societal, systemic, and institutional barriers. The project did something else that is somewhat less tangible but of critical importance when addressing the needs of marginalized groups. The survey allowed a group of people who are marginalized because of their appearance an opportunity to share their experience without fear of attracting negative attention. Respondent five spoke of how morbid obesity impacted her life-"I lived afraid to stand out and be noticed for any talent I had or intelligence".

Objectives of the Study

In November 2008 there were three reasons given for conducting the research project.

1. To validate the felt experience of the respondents and to empower them in their journey to wellness. Respondents will be provided a copy of the research results which they can use as part of their tool kit when they are self-advocating.

While the survey reflected similar feelings and experiences for many of the respondents it also gave them an opportunity to express themselves as individuals and to be heard without fear of judgement. Respondents who request a copy of the survey results will also receive a shorter accompanying briefing note.

2. To produce a document to be presented to MSP, The Honourable George Abbott, Minister of Health in British Columbia, and the MLA for the Comox Valley, The Honourable Stan Hagen.

The current Minister of Health is The Honourable Kevin Falcon. The MLA for Comox Valley as of August 2009 is Don McRae. A briefing note will be prepared and presented to the Minister and MLA as well as NDP health critic Adrian Dix.

3. As a formerly morbidly obese female I was denied approval to attend an accredited eating disorder centre for clients with Binge Eating Disorder, and unable to get approval for surgery which I needed to save and change my life. This is my way of advocating for others who are experiencing roadblocks in their recovery.

As a result of completing this survey and reading the heartfelt responses I am personally committed to advocating and working for a centre of bariatric excellence on Vancouver Island.

Methodological Framework

The project utilized a phenomenological approach. The questions were centred on the day to day lived experience and struggles of the morbidly obese. For example it is important to know that a doctor's office does not have a chair to accommodate a large person, or a surgical gown that covers the body, or a scale that will accurately weigh a patient. A phenomenological approach would acknowledge this and give respect and credibility to the respondent's worldview. The project is not about the causes of morbid obesity but what it is like to live in their world. The responses have conveyed the 'essence' of being a large person (Denscombe, 2007) and show that there are significant gaps in the BC healthcare system. We get to see through their eyes what their lived experience is really like. It is how everyday activity normally

taken for granted and feelings associated with it that is at issue for the respondents. The ultimate goal is to show that it is how everyday life is lived (or not lived) as being the reason for needing more (and timelier) medical services.

The use of a phenomenological approach can ultimately empower the marginalized and ultimately benefit the respondent. Reality is socially constructed and this knowledge can be used to help them see that dominant discourse and its acceptance causes marginality.

The Respondents

The survey focussed on respondents who are or have previously been medically classified as morbidly obese and living in British Columbia, who were recruited primarily through an internet support site called BC-WLS (British Columbia Weight Loss Surgery) in Yahoo Groups. The web site is for people who are considering or have had weight loss surgery. Although not a prerequisite many of the members are clients of Dr. Brad Amson who performs bariatric surgery at Jubilee hospital in Victoria. Respondents were invited through a posting to this web site to complete the questionnaire. As an insider to this group since 2006 my involvement was primarily as a 'lurker' and my actions included asking an occasional question and reading daily postings. My relationship to the group has changed in two ways since embarking on the research project:

1. On a professional level I have gone from being a passive member to member/researcher.
2. My relationship to the web site and the members has undergone change as my personal story has evolved. I have gone from being a morbidly obese member to

a 'normal weight' member, as well as undergone reconstructive surgery to remove redundant skin.

These changes have affected my vulnerability and ability to live as an insider.

Methods

The research project was a purposive sampling survey (Appendix II) which was made available through BC-WLS (British Columbia Weight Loss Surgery) - BC-WLS@yahoogroups.com in Yahoo Groups and the BC Association of Bariatric Advocates (BCABA) - www.bcaba.net (Appendix I). In October 2008 initial contact was made with Shari Lychak (Appendix III) who is a member of the BC-WLS web site as well as the Nanaimo Weight Loss Surgery Support Group co-chair and secretary of the BC Association of Bariatric Advocates. Shari also referred me to the BC Association of Bariatric Advocates web site.

Shari invited me to attend the October 2008 meeting of the Nanaimo Weight Loss Surgery Support group which was held at Nanaimo Hospital on October 15th where I was given the opportunity to tell the group about the research project as well as solicit questions they thought would need to be asked in order to draw out the issues and barriers faced with obtaining medical services in British Columbia. During the course of the project I attended subsequent meetings in Nanaimo as well as the support group in Courtenay.

In November 2008 the project was tested by members of BC-WLS and BCABA which resulted in minor changes being made to the survey. The final survey was introduced to the web sites February 2009. A total of forty-five completed (all questions answered) surveys were received. For the scope and size of this project fifteen of the forty-five completed surveys were chosen for analysis. The selection process was determined in the following way; the starting

point was whether or not the respondent was pre or post surgery. The subject group were all members of a support group for surgery and the connection to surgery is certainly relevant

- Sixteen of forty-five or 35% were classified as not yet having surgery. This equates to five out of fifteen.
- Twenty-nine of forty-five or 65% identified as having had surgery. This equates to ten out of fifteen.
- Nine of the twenty-nine or 31% who have had surgery had their surgery out of country. This equates to three of the fifteen.

Thus, the fifteen surveys consisted of;

Three who had surgery outside of Canada- respondents 1-3.

Seven who had surgery in Canada- respondents 4-10

Four who had not yet had surgery- respondents 11-14.

One who was unsure about having surgery- respondent 15.

The fifteen were chosen randomly based on the above categories.

The actual survey had both open-ended and closed questions. The main purpose of the closed questions was to obtain demographic information. The bulk of the questions were open and aimed at gathering qualitative information about the felt experience and needs of the respondents. There are deficiencies in the survey. It is highly unlikely that there are enough responses to reach the saturation point for each question. By saturation point I mean the point at which no more pertinent information will be gleaned by interviewing more respondents. The survey that was conducted through the internet may have involved sample bias and subsequently may not accurately reflect the overall target audience.

The type of web site targeted makes the assumption that the respondent has some interest in bariatric surgery. It is unknown what percentage of morbidly obese clients are or are not interested in weight loss surgery as an option, or if the website precludes certain groups of potential respondents. Many morbidly obese people have experienced their disease as a personal failing and have not reached out for help or support, which may make the survey unavailable to an isolated segment of the population. Morbid obesity is an isolating disease.

Survey information was collected and stored on the "Free Surveys Online" website. The results were stored in two formats; First, as individual surveys and second with cumulative responses for each question.

Questions 1-7 were quantitative/demographic questions.

Questions 8-14 were answered by people who have had surgery (ten respondents)- with both qualitative and quantitative questions being asked.

Questions 15-21 were answered by people waiting for surgery or an initial consultation (five respondents) with both qualitative and quantitative questions being asked.

Question 22 was meant for respondents who were unsure about having surgery. Respondent 15 answered this question.

The remaining questions (23-34) were for all respondents and were a combination of both quantitative and qualitative.

The answers to the questions were analysed through quantitative and qualitative coding (Esterberg, 2002). The qualitative questions were analysed using an open coding process in order to develop themes for categorizing and making sense of the responses

Ethical Considerations

The main ethical consideration was for the safety of the respondents in that they may become triggered by the questions, and this was addressed in the following manner in the consent form; "There is a potential risk to you that by participating in this research and you may be emotionally triggered. To prevent or to deal with these risks the following steps will be taken. Please contact the BC Crisis Centre at 1-800-784-2433 or BC NurseLine at 1-866-215-4700. Both these telephone numbers are accessible 24 hours a day".

Other ethical considerations were identified in the consent form:

Benefits

The potential benefits of your participation in this research include having a chance to be heard and to express what you personally need to reach your wellness goals. Your collective voice will be used to bring attention to the serious nature of morbid obesity and to express what it is like to walk in your shoes.

Voluntary Participation

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will be used only if you give permission.

Researcher's Relationship with Participants

Bonnie Blackhall had bariatric surgery July, 2006 and has lost 150 pounds. She regularly reads the posts on the BC-WLS@yahoogroups.com support site. To help prevent this relationship from influencing your decision to participate, the following steps to prevent coercion have been taken. You will only be invited through the Yahoo group website or moderators to participate.

Anonymity

In terms of protecting your anonymity there is no way to tie your email address with your response. Portions of your written responses may be used in the final report.

Confidentiality

Your confidentiality and the confidentiality of the data will be protected. The data that is submitted and entered on the survey is stored on the FreeSurveysOnline.com data servers, but belongs to Bonnie Blackhall. Only Bonnie Blackhall and FreeSurveysOnline.com will have access to individual results.

Dissemination of Results

It is anticipated that the results of this study will be shared with others in the following ways ; Directly to participants, The Honourable Minister of Health, George Abbott; MLAs; Melvin Peters.

Disposal of Data

Data from this study will be disposed of in the following manner; Paper copies will be shredded. Electronic data will be purged in April, 2009, however, FreeSurveysOnline does keep backups, and some of those backups are kept for a year, and would allow them to restore the data.

Presentation of the Data

1. *Your age?*
   The respondents ranged in age from 32 to 65 with the average age being 41.9 years.

2. *Sex?*
   All respondents were female with the exception of respondent 13 who identified as male.

3. *Where is the closest city to your residence?*
   Seven identified Nanaimo.
   Three identified Victoria.

Two identified Vancouver.
One identified Prince George.
One identified Cranbrook.
One identified Qualicum Beach.

4. *Weight Classification. If you have had weight loss surgery please indicate the amount just before surgery.*

   0-75 pounds overweight- Zero respondents
   76-10 pounds overweight- Two respondents.
   100+ pounds overweight- Thirteen respondents.

5. *Gross annual family income*.
   Under $10,000.
   $10,001- 15,000- One respondent
   15,001- 20,000- One respondent
   20,001- 25,000- One respondent
   25,001- 30,000
   30,001- 40,000- Two respondents
   40,001- 55,000- One respondent
   $55,001- 70,000- Four respondents
   70,001+- Three respondents
   Prefer not to say- Two respondents

6. *Total number of people living in the household.*
   The number of family members in the household ranged from 1-5 with the average being 2.2. The mode was 1 (Seven respondents).

7. *Have you had weight loss surgery?*
   Respondents 1-10 have had surgery.
   Respondents 11-15 have not had surgery.

The next set of questions was answered by respondents 1-10. *Please answer questions 8-14 if you have had surgery.*

8. *When was your surgery?*
   Surgery ranged from as early as 2002 (one respondent) to 2008 (one respondent) with the mode being 2007 (five respondents).

9. *How long did you wait for your initial consultation with the surgeon?*
   The waiting period ranged from 2 months (one respondent) to 2 years and 2 months (one respondent. The average wait time was 14.3 months.

10. *How long did you wait (including the initial consultation) until your surgery date? Did you develop medical complications while you waited? What were they?*
The waiting time ranged from 5 months to 48 months. The average wait time was 26 months. There were four respondents who had wait times of 2 years or less. These respondents were self-pay (1, 2, 4 and 10). Their average wait time was 12.75 months. For the six respondents whose surgeries were covered by MSP the average wait time was 36 months. The results indicate that wait times decrease significantly (by almost 2 years) when opting for self-pay.

Respondent 10 "developed several physical and mental problems including type 2 diabetes, high blood pressure and severe depression." Respondent 13 developed diabetes while waiting for surgery.

11. *What type of surgery did you have?*
Eight respondents had Roux-en-Y (RNY) bariatric surgery and two (4 and 10) had gastric banding.

12. *What city was your surgery in and who was your surgeon?*
Six respondents had their surgery in Victoria with Dr. Bradley Amson. Three were out of country- two in the United States, one in Mexico and one is unknown.

13. *If your surgery was out of province or country please explain why?*
This question applied to respondents 1 through 3.
All three identified wait time as the reason. Respondent 3 said, "I had to wait another 2-3 years before surgery after a 2 year wait for my first consult."
Respondent 2 also identified attitudes as a factor: "Yes, because I was dissatisfied with the attention and information received at appointments with the surgeon and could not afford the time it would take to be done in BC."

14. *Was your surgery covered by MSP? If it was not covered why do you think it was not paid for, and how much did you pay? After answering the question please proceed to number 23.*
Six surgeries were covered.
Four surgeries were not covered. Respondent 1 paid $8,500 USD.
Respondent 2 paid $12,500 USD.
Respondent 4 paid $13,000 and identified that gastric banding was not covered by MSP.
Respondent 10 paid $15,443 (gastric banding).

The next set of questions was answered by respondents 11-14. *Please answer questions 15-21 if you are on a wait list for an initial consultation or surgery.*

15. *How long did you wait for your initial consultation? If you have not had your initial consultation please go to the next question.*
    With the exception of respondent 13 who waited one month the wait time for the initial consultation was 12 months. Respondent 14 noted "I have now been waiting for surgery for four years."

16. *If you have not had your initial consultation when did you first go on the waiting list and when is your appointment anticipated?*
    There were no responses to this question.

17. *When is your surgery estimated to be?*
    Two of the four respondents did not have a date. Respondent 11 said "I have been told any time but that has been for the last 3 years." Respondent 12 said "I am unsure of my surgery date. I saw Dr. Amson February 2008 and he said one year at that point. His medical staff said two at the least."

18. *What type of surgery do you think you will have?*
    Respondents 11, 12, and 13 answered the RNY.
    Respondent 12 said "I decided on the RNY but just now found out that the sleeve is now covered in BC so I would like to explore that too."
    Respondent 14 will have the gastric sleeve but said, "If I had the money I'd have the gastric banding."

19. *What city will your surgery be in and which doctor will perform it?*
    All four indicated their surgery will be in Victoria. Dr Rusnak will perform one of the surgeries and Dr. Amson the other three.

20. *If your surgery will be out of province or country please explain why?*
    The only response to the question was from respondent 12: "I am considering the lap-band procedure in Monterrey Mexico also as I am experiencing so many problems with being obese. I fear I will not be able to work for much longer if I do not receive surgery."

21. *Will your surgery be covered by MSP? If not why do you think it is not being covered. After answering this question please proceed to number 23.*
    All answered yes and 12 made the following comments; "The RNY is covered but not the banding. I would prefer the banding and am learning more about the sleeve. I do not have a clue why the lap band is not covered."

The next question was for respondents who were unsure about having surgery.

22. *Why are you undecided?*
    There was one respondent to this question. Number 15 said "don't know enough about it yet. Feel it's very drastic but it may be the only alternative left- I've tried everything else."

23. *Which surgery has been or was offered to you under MSP?*
    Twelve respondents said RNY.
    Two also answered gastric sleeve.
    Two did not answer.
    One said they would only consider banding

24. *If cost and availability were not a consideration which surgery would you (have)choose (chosen)?*
    Six said the RNY.
    Five said gastric banding with the following comment from respondent 1; "I think gastric banding would have been a less invasive surgery for me but it wasn't offered in Canada and I didn't know where to go for it."
    One said gastric sleeve.
    One said BPD/DS
    One did not answer.

25. *What medical services have you received in relation to your weight? Please include both physical and psychological/support services, i.e. nutritionist, eating disorder counsellor?*

- Medication- seven respondents.
- Nutrition- seven respondents. Respondent six wrote "The nutritional help I received from medical services I found not to be very understanding."
- Blood work/tests- six respondents.
- Counselling- four respondents.
- Weight loss support group- four respondents. Respondent 6 said "The best advice I received was from other weight loss patients."
- Endocrinologist- three respondents.
- Respirologist- two respondents.
- Physiotherapy/orthotics- two respondents.
- Skin removal- one respondent.
- High blood pressure- one respondent.

26. What services are not available to you? Please include both physical and psychological/support services, i.e. nutritionist, eating disorder counsellor?

- Counselling- four respondents. Respondent 10 commented "I would have to pay for therapy."
- None- three respondents.
- No answer- three respondents.
- No services available- one respondent.
- Nutritionist- one respondent.
- Diabetic nurse- one respondent.
- Gym services- one respondent.

Two respondents made comments about doctor /care:

Respondent 6- "My doctor seems to think that the surgery was a cure all for all my complaints, so therefore nothing is wrong or everything is just 'good enough' as I am better off than I was."

Respondent 15- "I would appreciate it if more doctors took some initiative and made more suggestions and looked beyond general blood tests and prescribing pills as a way to appease my concerns that I am having real trouble losing weight. Meanwhile, they just keep pressing diet and exercise and sending me on my way without even thinking that there could be something medical that could be causing an imbalance or that weight could be a result of something else."

27. Have you experienced discrimination as a result of being overweight? If yes, please elaborate.

With the exception of respondent 4 who could not positively identify an experience all said yes.

- Employment was identified as an area of discrimination by six respondents. Respondent 6 said "Workplace is another area where I have been severely discriminated against for being fat. Apparently, if you are overweight you are untrustworthy, uneducated, lazy and unsightly".
- Made fun of – five respondents. This category includes 'looks' from the public, people whispering and or pointing, or people making rude noises.
- Not treated well or ignored- three respondents.
- Inadequate seating or accommodations- three respondents
- Medical attention- two respondents

Two comments capture how completely discrimination can affect their lives.

Respondent 7- "It is only when I lost the weight that I realized how badly and frequently. I am treated differently in society now. People are friendlier, I don't go unserviced in stores, I

can walk down the street without being stared at, and I can access everything (seats/chairs, airplanes, buses). I know I'm still the same person, but I am not. I feel I've been admitted to the human race; I fit in finally."

And

Respondent 10- "Yes, unfortunately we wear our disorder for everyone to see. Unlike the other eating disorders, our obesity is seen as lack of self discipline and is not revered in our society. When I lost weight people were more attentive."

28. Is your family supportive? Please explain why or why not.

Nine respondents said yes.
Four respondents gave a mixed answer.
Two respondents said no.

29. What are some of the physical issues you have experienced as a result of being overweight?

There were numerous issues related to being overweight.

- Knee pain/degeneration- seven respondents.
- Sore fee/ankles/numbness- seven respondents.
- Back pain- five respondents.
- Diabetes- four respondents.
- Fatigue- four respondents
- High blood pressure- four respondents
- Respiratory- four respondents.
- Skin infections from folds of skin- three respondents.
- Leg pain/numbness- three respondents.
- Sleep apnea- three respondents.
- Fertility (lack of) - two respondents.
- Mobility issues- two respondents
- Depression- two respondents.
- The following issues were each identifies by one respondent; no sex life, thyroid, hip, gall bladder, fibromyalgia, acid reflux, osteo-arthritis, arthritis, head-aches, mood swings, and painful joints, ingrown toenails, stress incontinence, urgent diarreha, irritable bowel, uterine cancer, stretch marks, personal hygiene.

30. What are some of the emotional/psychological issues you have experienced as a result of being overweight?

- Low self esteem/self-hate- ten respondents. Respondent two said "Hated myself. Never went out, even sending my husband with the list to do the shopping. I always looked

down if I had to go to the mall. Because I was 60 and fat, I never got treated well, even when getting my hair done."

- Depression- six respondents.
- Social isolation/loneliness- three respondents- Respondent 15 said "I don't like leaving my house except to work. I would rather stay home."
- Mobility issues- one respondent.
- Low sexual esteem- one respondent.
- Suicidal ideation/ thoughts- one respondent. Respondent six said "Very depressed afraid to go places or meet people. Very low feeling of self worth, total lack of confidence, feeling like nothing really matters because I'll be dead soon anyway."

31. Please describe how morbid obesity impacts/has impacted your everyday life.

- Could not/ would not participate- five respondents. Respondent 7 said, "Everyday was difficult. Because of sleep apnea, I never slept properly, resulting in my always feeling tired. I would fall asleep at a matinee movie. I would arrive at work and wonder if I was going to be able to get out of the car that day-my back hurt that much. I had to go on part-time disability because I could not physically do it anymore. I was a teacher who couldn't go on field trips. I couldn't travel. I couldn't eat at certain restaurants because I couldn't fit in their booths. I was lonely because I cut myself off from the dating world in the belief that no one would want me as I was. Everywhere I went, people stared. I napped a lot. I couldn't do things with my friends because I was in such poor shape. I couldn't go to concerts or sporting events because I couldn't fit in the seats. I was alive, but I wasn't living."

  Respondent 8- "unable to tie my own shoes or walk for more than five minutes."

- Isolated myself- three respondents.
- Tired- three respondents.
- Painful to move- three respondents.
- Feeling like a failure- two respondents. One of the most poignant responses comes from respondent 12. "I fell in the tub again yesterday. One leg was in and one leg was out. I barely managed to get up and walk to my room where I sat and cried hysterically. I was terrified. In an almost identical situation I had fallen out of the tub last year, cracked my head on the opposite wall and almost bit my tongue off. I couldn't talk for days. One of my deepest devastating fears is that I injure myself by falling like this, I am naked, helpless and cannot be moved and/or as a result of the fall I lose my ability to move myself around independently. Ultimate humiliation. I want the feeling of physical freedom. I am trapped by my body and the weight I carry. I want out.

  I have worked so hard to become or live as who I was meant to be. I have found some mental, emotional and spiritual freedom and peace as I have grown and learned in

my life. I have had to have help to do this. I have never found the help to achieve anything but a short term measure of physical freedom.

Like many people, what I wouldn't give to weigh what I weighed when I was 14 years old. As a 14 year old who weighed 175 lbs. I saw myself as, and was told I was, fat, ugly, huge, not feminine, etc. I was broken and no one was there to help me mend. I was a beautiful, large young woman. I never had a clue or a hope. I feel more whole and beautiful now at 450 lbs. But that is in spite of my weight.

I would like to weigh about 200 lbs. As the woman I am now I do not feel broken anymore but I do feel blocked by my lack of being able to make what feel like insurmountable changes in my life. I get so overwhelmed by the current physical aspects of my life I do not want to connect with the feelings. I want to be the normal large woman I was meant to be until I started becoming so isolated, eating so much crap, becoming depressed or conversely manically starving myself because I thought it would ensure my lovers approval and ongoing love.

I ride a roller coaster of emotions about being super morbidly obese. I feel so much fear, I feel shame, I judge myself and I feel anger at those who judge me. The same is true for feelings of shame and pity. I feel those feelings for myself and at the same time fight to protect myself from the feelings of others. When I was a young adult I used to hide myself and not look up so I would not see the reactions of others...The other day as I was getting in the pool I gently shook my head and finger at a young girl who was excitedly pointing me out to her friends, that was a good day. I had a bad day the other day when I was in a line up at the mall and a teenage boy, in the next line, was commenting to a friend about me. I told him to &*%^ right off...

Living in my head, or my intellect, has been a coping tool that has allowed me to achieve goals that I would not have otherwise if I were present to the pain of being obese. If I did not stay in my head I would be immobilized by the fear and worry...

I need this surgery because I cannot accomplish weight loss on my own."

32. *Discrimination often comes from a place of not understanding. People who do not have weight issues may wonder why you don't just lose the weight by going on a diet. How would you explain the answer to them?*

- If I could have done it without surgery I would have- four respondents.
- We are all different- three respondents.
- I have never tried to or can't explain- two respondents.
- Even the doctor can't explain it- one respondent
- Lose motivation- one respondent.
- .It's an addiction- one respondent
- Walk a mile in my shoes- one respondent.
- I can't explain it- one respondent.
- I'm doing it for my health- one respondent

33. *What do you think would be the first thing you would do when you reached your desired goal?*

- Buy new clothes- seven respondents.
- Experience life rather than watch it- three respondents.
- Be proud- two respondents
- Roller coaster- two respondents
- The following each had one response: date, swim, buy a bike, can't get to gaol, trim toe nails, travel, sit in a normal seat, go to the spa, and thank God.

34. *Finally, if you could meet with The Honourable George Abbott (The Minister of Health for British Columbia) what would you tell him about your struggles with morbid obesity, and what would you ask for?*

- More timely surgery- seven respondents.
- Reconstructive surgery to be covered- seven respondents.
- We need more understanding/ less discrimination- five respondents.
- More bariatric surgical options to be offered and covered by MSP - five respondents.
- Morbid obesity leads to co- morbidities which are straining the medical system. More timely surgery would reduce medical visits for other illnesses resulting from morbid obesity- two respondents.
- Open a bariatric clinic- one respondent.
- We have so many barriers- one respondent.
- Morbid obesity is isolating- one respondent.
- Public education- one respondent.
- Thank-you- one respondent.

Most responses included more than one request/comment:

Respondent 1-"Morbid obesity is an epidemic, not a choice. Morbidly obese need choices to lose weight to become healthier and reduce health issues, i.e. hypertension, diabetes, high cholesterol."

Respondent 2- "More surgery time available so others who can't afford to leave the country can get their surgery in a timely manner, and for myself, I would like to have reconstructive surgery, but doubt that I will be able to afford it."

Respondent 3- "The waiting list should not be this long and that plastic surgery after weight loss surgery should be covered by MSP."

Respondent 4- "I would ask that there be more public education regarding obesity and the toll our aging and overweight population will be taking on the health care system."

Respondent 5- “I would tell him about the discrimination I’ve felt and exactly what it is like to live in a fat suit. Then I would ask him to do his part to reduce wait times and seek coverage for plastic surgery after weigh loss has been maintained.”

Respondent 6- “Morbid obesity is a DISEASE of the mind and body- NOT a personality flaw. Sp PLEASE treat it as such and allow us to have all the medical treatments available in a timely fashion. Including surgery to remove the extra flesh that’s holding us down from being truly successful.”

Respondent 7- “I would like to thank him for the fact that MSP saved my life, first and foremost. Then I would show him the scar on my leg from where the ulcer was. That ulcer developed three years after my referral to Dr. Amson. More timely treatment could have saved me tremendous pain and suffering as well as the psychological trauma of a horrible scar on my lower leg that everyone stares at. And then I would ask him why a woman who has a mastectomy has her reconstruction paid for by MSP, yet I had to pay for my redundant skin, which is easily as psychologically damaging.

Respondent 8- “How isolating obesity is and how it affects more people than you might think. You don’t really see obese people because they don’t go out. They isolate themselves because they literally do not fit into the world. I would ask for several, but at least one, ‘Centre for Excellence’ in treating obesity. A facility with experts trained in nutrition, psychology & psychiatry, lifestyle/exercise, and bariatrics. At the very least I would like to see more pressure put on the individual health authorities to set up bariatric programs, and have RNY, BPD-DS and banding procedures funded (choice of surgery being that of the doctor and patient based on what is best for the patient, not a government office).”

Respondent 9- “Post plastic surgery for skin removal.”

Respondent 10- “I would ask him to consider the fact that obesity is not about self-discipline or the lack thereof. It is physiological first and becomes psychological afterward! I would ask him to fund these life saving surgeries.”

Respondent 11- “I would ask that the wait time not be so long, I strongly believe that you need to be in the right frame of mind, that can take several months, but there is nothing worse than being promised surgery in the next year and that year takes 4 plus years to happen. I am worse being told promises than I think I would have been if I was told it was a 4 yr wait.”

Respondent 12- “Please support short wait lists and various options for weight loss surgery. I am going to die without it.”

Respondent 13- “More understanding and a more surgical option paid by MSP.”

Respondent 14- "I would tell him that people are that are overweight have so many barriers to overcome on their own and being put on a five yrs waitlist is not what they need to hear. I would ask for my money to be put into getting more surgery time for weight loss surgery."

Respondent 15- "Morbid obesity should be treated like any other 'illness' in which the body is not functioning properly and doesn't respond to treatments. If there were less of a stigma attached to being overweight then doctors would be able to intervene earlier and prescribe more pro-active and medically monitored treatments that might end up reducing the number of patients who reach the level of morbid obesity. I wish I had a way to prove that I have been doing what the doctors prescribe (diet and exercise) so that they can look beyond that and see what else might be affecting my body, instead of thinking I'm just lazy and looking for a quick fix. Personally, I'd prefer NOT to have surgery at all. I'd like to use all means possible to lose the weight and I don't think that has been done not do I think anyone really knows what to look for. But if it turns out that I've exhausted all options without success, then I will consider surgery as a last resource, but as a tool, rather than a 'fix'. When it comes to MSP and coverage I will never understand is why they choose to fund the more expensive surgeries that are higher risk and can lead to other complications, when there is a cheaper and lower risk options available (the band). Why not insert more bands in more patients for a cheaper price and reduce the wait list? As for MSP covering 'cosmetic surgery' to remove excess skin after WLS- I don't know why it's not considered as the second half of the 'treatment'. There's no question that after losing over 100lbs, you're going to have excess skin, so if there's a medical reason to have it removed/reduced it should be covered. (Similar requirements are needed for a breast reduction, aren't they?)"

Content Analysis

The responses to the survey identified gaps in British Columbia's medical system as they pertain to morbid obesity as well as some of the contributing factors that have led to the ongoing issues the respondents face.

One of the issues the respondents brought forward outside the survey was depression and to a lesser extent suicide. I had the opportunity to speak to two people after one of the weight loss support meetings about suicidal thoughts. Both were hesitant to address the issue with medical professionals for fear of being deemed not fit to have surgery.

Gaps

1. Surgery wait times are too long. The average wait time for the ten respondents who have had surgery was 26 months. Further breakdown shows that the four who opted for self-pay waited an average of 12.75 months while the six who were covered through MSP waited an average of 36 months. The results suggest that there is a two- tiered health system- self-pay and MSP.
2. Surgery options are limited for MSP clients. For many clients the only option available was the RNY. It appears that the gastric sleeve was recently added as an option. 5 respondents would prefer to have gastric banding which is not currently covered in British Columbia. Respondent 1 identified banding as less invasive and respondent 15 believed it to be cheaper than the other options. Although not researched through MSP the general consensus at the Nanaimo WLS support group is that banding is both the least expensive and least invasive bariatric surgery.
3. Treatment for morbid obesity involves more than just one discipline. The province needs a comprehensive Centre for Excellence to deal with the issues that incorporate the mind body and spirit in a holistic manner. This idea suggested by respondent 8 was adopted in February in Ontario with the announcement of four Centres and the infusion of $75 million (Ontario Ministry of Health and Long-Term Care, 2009). It is telling to note that the development in Ontario was announced under the auspices of its diabetes strategy and not a separate strategy dealing with morbid obesity. Perhaps it is easier to substantiate the expense under the category of diabetes?
4. Reconstructive surgery for redundant skin should be included as part of the treatment plan.

Attitudes.

1. There appears to be a disconnect between what the province and the respondents deem to as emergency or life saving surgery. This distinction is important because the wait time for emergency surgery is considerably less than elective surgery. Morbid obesity is a personal failing. Respondents encountered this myth from both the general public and medical professionals.
2. Discrimination related to obesity is encountered in all walks of life. In employment, socially, accommodation, and services including medical service. It is subtle and it is blatant. Respondents spoke of literally not fitting in and not being part of the human race.

Process Analysis

The main critique of the survey is that the required size of the project for the university versus the information gathered was not congruent. My concern as the writer of the report is that the urgency felt by the respondents is not honoured in the final report. As an anti-oppressive researcher my goal was to give the reader a tangible document outlining the gaps in the British Columbia medical system as well as capture the essence of the respondents.

The report shares a very small portion of the respondent’s comments and is not necessarily the most important points each respondent would have chosen to convey in the final report. And what value is to be assigned to those surveys that were not chosen for the analysis? Coding of the data was interpreted through the writer’s lens. On a personal level I found myself resonating with certain responses. For example, I strongly believe that a Centre of Excellence is

necessary for British Columbia and have highlighted the comments to this affect from respondent 8. I also personally resonated with respondent 10's answer to question 32.

At this point in time the people who have benefited from the survey are the respondents who were given a voice and myself as a student.

Action

Once the report is reviewed and changes made it will be made available to respondents who request a copy. It will also be published on the BC-WLS web site. A briefing note will also be prepared and forwarded to The Honourable Minister of Health for British Columbia, the Comox Valley MLA, and the NDP health critic.

As a future social worker I am more determined to work in the field of bariatrics and promote a long-term program that incorporates a holistic approach to wellness.

Conclusion

The experts have had an opportunity to collectively relay to you the reader what barriers they have experienced in the British Columbia medical system, identified issues that inhibit them from completing everyday tasks, and identified pervasive attitudes that exist both inside and outside the medical system. We ask that you hear our voices. As an insider to the issue of morbid obesity I was honoured to read the heartfelt comments of *all* the respondents and felt an obligation to accurately reflect their voices.

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