A Study of Online Bariatric Support Groups and Their Participants

Sofia Shepsis
Pacific University

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A Study of Online Bariatric Support Groups and Their Participants

Abstract
Obesity affects physical and psychological health and impacts society (Ogden et al., 2006). Internet bariatric support groups may help in weight loss and are largely unexplored (Wing & Hill, 2001). This pilot study aimed at describing such groups. Twenty two members of internet bariatric support groups completed a survey. Information on demographics, weight loss, support group and psychological comorbidities was gathered. Quality of life (QOL) was measured using the World Health Organization Quality of Life Index (WHOQOL group, 1996). Results indicate differences in QOL and psychological co-morbidities by age, gender, experience with weight loss and surgery and group structure. Larger samples are suggested to explore these trends further. Results may guide recommendations for participation in online bariatric support groups.

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Subject Categories
Psychiatry and Psychology

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A STUDY OF ONLINE BARIATRIC SUPPORT GROUPS AND THEIR PARTICIPANTS

A THESIS

SUBMITTED TO THE FACULTY

OF

SCHOOL OF PROFESSIONAL PSYCHOLOGY

PACIFIC UNIVERSITY

PORTLAND, OREGON

BY

SOFIA SHEPSIS

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE IN CLINICAL PSYCHOLOGY

APRIL 13, 2010

APPROVED:

Daniel Munoz, PhD
Abstract

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Introduction

*Obesity – the scope of the problem*

Obesity is a national epidemic which affects individuals’ health, psychological well-being and has far-reaching impacts on our society. The prevalence of obesity in adults in the United States was estimated to be 32.2% in 2003-2004 (Ogden et al., 2006). Overweight is defined as 20% or more over ideal body weight for height, age and sex. Severe obesity is at least 100% overweight or body mass index (BMI) greater or equal to 40 kg/m². It has been estimated that 0.5% of the overweight population are severely obese (Brownell, 1995). Severe obesity is associated with increased risk for developing hypertension, hypertrophic cardiomyopathy, pulmonary insufficiency, degenerative arthritis, dyslipidemia, non-insulin-dependent diabetes mellitus, gallbladder disease, certain types of malignancies, and plays a role in individual’s socio-economic and psychosocial impairment (National Institutes of Health Consensus Development Conference Panel, 1991). It is also associated with increased mortality (Drenick, Bale, & Seltzer, 1980; Lew & Garfinkel, 1979; VanItallie & Lew, 1992).

*Treatments*

Treatments that are often effective for mild to moderate obesity, such as behavior therapy and the use of various diets, including very low calorie diets, are usually ineffective for severe obesity (Stunkard, Stinnett, & Smoller, 1986; T. A. Wadden, 1993). The same holds true for pharmacological agents given on their own, such as the case for the most widely publicized combination of d-fenfluramine and phentermine (Goldstein & Potvin, 1994). Because of lack of efficacy with nonsurgical interventions, the National Health Institutes Consensus Development Panel in 1991 recommended that gastric
restriction or bypass surgery should be considered for well-informed, motivated, severely obese individuals in whom surgical operative risks are acceptable (National Institutes of Health Consensus Development Conference Panel, 1991). Panel also recommended that some less severely obese patients with BMI between 35 and 40 kg/m² should be considered for surgery if they have developed high-risk, comorbid conditions or conditions that interfere with lifestyle as a result of their obesity. This decision has a far-reaching impact, as approximately 4 million Americans have a BMI between 35 and 40 kg/m², and 1.5 million have a BMI over 40 kg/m².

**Psychological aspects of obesity**

The number of bariatric surgeries conducted in the United States increased nearly 450% between 1998 and 2002 (Nguyen, Root, & Zainabadi, 2005) and further doubled over the following two years (T. Wadden, Sarwer, & Williams, 2006). Bariatric surgery is technically demanding and carries significant risk of complications, including mortality which is estimated between 0.3% and 1.6% (Brolin, Robertson, & Kenler, H. A. et al, 1994; Kellum, Kuemmerle, & O’Dorisio, T. M. et al, 1990). Limited research exists in the field describing motivations among patients choosing to undergo the bariatric surgery. In one study 32% of patients endorsed psychological and body image related reasons as their primary motivation to seek bariatric surgery compared to 24% who were motivated primarily by their current medical condition (Foster, Wadden, & Phelan, 2001). Munoz & Lal found 73.4% of respondents endorsed current medical ailments as their primary reason for seeking weight loss surgery, and self-esteem was the primary motivation in only 3% of patients (Munoz et al., 2007). The discrepancy and the paucity of data
pertaining to the psychological factors influencing the decision to undergo the bariatric surgery highlights the importance of further research in this field.

It is important to note that there is no consensus in the field of bariatric psychology as to whether obesity by itself is associated with psychiatric disturbances. Studies on psychopathology among the obese found no increase in psychiatric disturbances among the mild to moderately overweight individuals, whether or not they sought treatment for weight reduction (Stunkard & Wadden, 1992). In contrast, several studies have found a high rate of psychopathology among severely obese subjects seeking treatment for weight loss: the life-time prevalence of major depression among this population varied from 29% to 51% (Berman, Berman, & Heymsfield, 1993; Goldsmith, Anger-Friedfeld, Beren, Boeck, & Aronne, 1992; Halmi, Long, & Stunkard, A. J. et al, 1980). Although these studies did not analyze control groups and hence must be interpreted with a great deal of caution, these numbers are noticeably higher than the prevalence of major depression in the general population, estimated between 4.2 and 17.1% (Kessler, McGonagle, & Zhao, 1994; Robins, Helzer, & Weissman, M. M. et al, 1984).

Several investigators have found that preexisting major depression does not affect the weight-loss outcome of bariatric surgery (Halmi et al., 1980; Valley & Grace, 1987). However new episodes of depression may occur in some individuals after surgery. In one study 40% of severely obese patients with no history of depression developed depression after surgery and 50% of those required treatment for depression (Ryden, Olsson, & Danielsson, 1989). A high rate of suicide in post bariatric surgery patient population is an alarming outcome of psychological problems present in these patients. Hsu et al. (1998)
reviewed four cohorts of patients followed after bariatric surgery for a period of 1 to 14 years (Capella & Capella, 1996; L. K. G. Hsu, Benotti, Dwyer, Roberts, Saltzman, & Shikora, 1998; Macgregor & Rand, 1993; MacLean, Rhode, & Forse, 1990; Pories, Swanson, & MacDonald, K. G. et al, 1995). Among 1785 subjects there were 8 suicides (0.4%), which is in stark contrast to suicide rate among the general population, reported to be 0.014% (Caruso, ; National Institute of Mental Health, 2009). It is clear that bariatric population might have a greater prevalence of psychopathology in general and the surgery, although being effective with short-term weight loss, can sometimes have adverse effects on psychological well-being of patients, especially for those dealing with multiple complications (Ryden et al., 1989). Van Hout et al. (2006) found a significant minority of their subjects who experienced negative psychological effects following bariatric surgery (van Hout, G. C. M., Boekestein, Fortuin, Pelle, & van Heck, 2006). Maddi et al. (2001), however, found the opposite positive effect of bariatric surgery on psychological functioning (Maddi et al., 2001). It is therefore reasonable to propose that this population should be more carefully followed by mental health care workers and more data is necessary to identify individuals at risk and intervene successfully at appropriate stages.

Support groups

Many studies have found that bariatric surgery leads to improvement in socioeconomic performance and psychosocial functioning, and that patients experience an increase in social acceptance after weight loss (Bull, Engels, Engelsmann, & Bloom, 1983; Harris & Green, 1982; Larsen & Torgersen, 1989; Rand, Kuldau, & Robbin, 1982). Other studies have found that the patients’ initial postoperative improvement in
psychosocial functioning had largely dissipated by 3 years after the surgery, even among those with good weight and health outcome (Pories, 1991). It is possible that new social skills are often required to cope with increased social acceptance, and creation of new social structures is critical to these patients. Support groups might play an important role in the psychological well-being, psychosocial functioning and even long-term weight loss maintenance and medical outcome for bariatric patients.

Social support groups exist in all spheres of health and psychological environments. Eysenbach et al. (2004) reviewed 45 publications on effect of health related virtual communities and electronic support groups and found a lack of studies which focused on isolating the effects of online support groups controlling for other interventions (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). Smoking cessation was by far the most common theme analyzed with some mixed results, but overall a positive trend. Depression, social support in general, healthcare use, eating disorders, weight loss and diabetes control were additional domains in which studies have been conducted. These publications most often studied depression and social support as outcomes and the majority of them did not find an effect. Authors also concluded that there was no evidence to support concerns over virtual communities harming people (Eysenbach et al., 2004).

Despite the prevalence of peer support groups in the community, the evidence for their effects on well-being is mixed at best. Support groups for people with cancer (Helgeson & Cohen, 1996), caregivers (Bourgeois, Schulz, & Burgio, 1996; Lavoie, 1995) people facing the transition to parenthood (Cowan & Cowan, 1986), people recently divorced (Hughes, 1988), and people who have been victimized (Coates & Winston,
1983) do not show clear benefits. One possible explanation for mixed data might come from the fact that some individuals benefit from the support group intervention, some are unaffected, and some are even harmed. Biased or unbiased selection of particular individuals therefore affects the studies’ outcome. In the field of cancer peer support groups, Andersen (Andersen, 1992) suggested the level of support from family and friends might moderate the effectiveness of an intervention. People with more problematic social relations might benefit the most from a peer support-group intervention. This premise was partially based on findings that new cancer patients have not experienced any benefit from the peer support group participation because they were satisfied with their social network relations (Wandersman, 1982). More recently a study of women with breast cancer has shown that peer discussion groups were helpful for women who lacked support from their partners or physicians, yet harmful for women who had high levels of support (Helgeson, Cohen, & Schultz, 2000).

*Support groups relating to obesity*

As obesity is considered a chronic medical condition by many professionals – with the typical attributes of such illnesses, including an almost-normal life span, choice of various interventions, potential for symptomatic regression as well as recurrence of signs and symptoms of the condition – the study of effect of peer support group in the bariatric population is a formidable task in a largely unchartered field. There are very limited controlled studies demonstrating that peer support group works for weight loss and weight loss maintenance, and no study to date evaluated the psychological aspects of this intervention. The Weight Watchers program is the only major national weight-loss program with a published clinical trial lasting 2 years. Individuals who were assigned to
the groups with most weekly meetings maintained the largest weight loss during the 2-
year study period. Overall, the Weight Watchers group lost 5.3% of initial weight at 1
year and maintained a loss of 3.2% at 2 years, whereas the control self-help intervention
arm lost only 1.5% of initial weight and did not maintain any weight loss at 2 years
(Heshka et al., 2003).

Internet-based support groups

Support groups using computer-mediated communication offer a new delivery
mechanism for psychological services, yet the functioning and efficacy of these
electronic support groups remain largely unexamined. In the early 1990s, internet-based
support groups for specific medical conditions emerged (Ferguson, 1996). An estimated
33 million Americans have used the internet as a health resource (Miller & Reents, 1998).
By the year 2000 internet access had expanded to reach 41.5% of American households
(National Telecommunications and Information Administration, 2000). Internet support
groups operate both asynchronously, largely via emails, or synchronously. Most internet
groups employ asynchronous communication, which involves the composition of
message off-line that are then sent to individuals or to larger groups.

With the development of internet support groups, individuals have formed virtual
communities where members regularly communicate, form relationships, and provide
information and support to one another (Rheingold, 1993). People participate in virtual
communities and find the opportunity to converse electronically with others they might
never meet face-to-face. Studies show that individuals using internet groups
communicate more frequently, emphasize the merit of message over the status of
communicator, encourage wider participation from group members, and express greater
candor in their communication than people who communicate face-to-face (Kim, 1994; Kollock & Smith, 1996). Electronic communication offers many advantages over face-to-face support group format. The greatest advantage is that members need not be physically present for the group to function. These groups can be used conveniently by people worldwide, and users can participate at any time.

With continuous availability participants are able to obtain support whenever necessary without burdening their own existing support system, such as family, relatives, coworkers and friends, at inconvenient times. Reluctant or shy members can also feel more comfortable by inactive participation until they gain confidence to request or provide support directly. These groups do not require financial support, minimize differences in social status among the participants, allow for uninhibited discussion, and provide significant anonymity to participants (Schneider & Tooley, 1986). At the same time, internet-based forums are not without potential problems. Low motivation, lack of personal and immediate contact and longer time periods required to develop trust in the group may interfere with the effectiveness of the support group intervention. Because members of internet group may not receive immediate feedback on their comments, a climate of warmth and concern may take longer to develop in internet-based forums than in face-to-face groups. More importantly, however, as participation is largely open to anyone with access to the server, there is little control over who may participate in the group, the regularity and length of a member’s participation, and the accuracy of information and feedback provided to group members.

Given the potential benefits and the rapid growth in the number of internet-based support groups, it is surprising how little is known about the functioning and the efficacy
of these groups. The first report was published in 1986, evaluating the effectiveness of an online behavioral smoking cessation program (Schneider & Tooley, 1986) which lacked control arm and therefore its largest merit was the introduction of the novel methodology. In the Alzheimer’s caregivers’ study the use of the internet-based support group led to a greater perceived confidence in the ability to care for family members (Gallienne, Moore, & Brennan, 1993). In an AIDS trial, use of the computer-based communication system reduced self-reported isolation (Brennan, Ripich, & Moore, 1991). Analysis of messages posted on eating disorder electronic support group revealed that self-disclosure was the main reason for posting, amounting to 31%, followed by requests for information (23%) and the direct provision of emotional support (16%) (Winzelberg, 1997). Characterization of an internet support groups for patients with depression revealed that users had high depression severity scores, were socially isolated and perceived considerable benefit from the group. Moreover, heavy users of the internet groups were more likely to have resolution of depression during follow-up than less frequent users, whereas social support scores did not change during follow-up (Houston, Cooper, & Ford, 2002).

Internet-based bariatric support groups

The research on bariatric internet-based support groups is lacking, with the existing literature focusing primarily on weight loss outcome. Wing et al. (2006) found the amount of weight regain was significantly greater in the control group compared with face-to-face or internet-based intervention groups (Wing, Tate, Gorin, Raynor, & Fava, 2006). However, this was a directed intervention by method of an internet-based communication, and not an analysis of a self-formed community created around the theme of weight loss. What is currently lacking in the field is a detailed characterization
of this entity to pave the way for further analysis of the effect of these communities on health-related and psychological well-being of its members.

A convenient and inexpensive methodology for reaching members of online groups and conducting a study of online support groups is via an electronic survey. However, electronic surveys have distinctive technological, demographic, and response rate characteristics that affect their design, distribution, and response rates (Sohn, 2001). Surveys are imperfect vehicles for collecting data. They require participants to recall past behavior that can be more accurately captured through observation (Schwarz, 1999). The lack of internet central registries prevents researchers from identifying all the members of an online population along with multiple email addresses for the same person and invalid or inactive email address. Most important, electronic survey selection is limited to nonrandom and probabilistic sampling (Cooper, 2000; Dillman, 2000). Nevertheless, web-based surveys are the most appropriate format for surveys when research costs are a constraint, timeliness is important and the nature of the research requires it (Andrews, Nonnecke, & Preece, 2003). Piloting and preliminary analysis was shown to improve the participants’ response rates, increase compliance among hard-to-involve online population (Andrews et al., 2003).

Characterization of a bariatric internet-based support community is a critical aspect of research into one of the cornerstones of successful weight loss maintenance and psychosocial well-being of obese patients. Electronic survey appears to be the most suitable method for this task and a pilot characterization of this community is the first task towards achieving the overarching goal of robust assessment of the communities’ effect on long-term health benefits and psychological well-being.
This study aims at describing online bariatric support group communities and their participants, including participants’ experience with weight loss process and bariatric surgery and medical care, their experience related to their participation in online support groups and their self-reported quality of life and psychological co-morbidities.
Method

Participants

Members of online bariatric support groups were recruited to participate in an observational cohort study. A total of 39 people participated in the study, including males and females 34 to 64 years of age. Additional demographic data is presented in Table 1.

Procedure

Participants were recruited by means of posting an invitation to take a survey on several online bariatric support group websites. Online support groups were chosen from Facebook.com, yahoo groups, and by searching the internet. A description of the study along with an agreement to conduct research form was e-mailed to group leaders or webmasters listed on each support group website. Upon receipt of an e-mail response and agreement to conduct research from group leaders or webmasters an invitation to participate in a survey along with a link to the survey was posted on the main website of each online support group. Upon following the link to the survey participants first read and acknowledged the study description and the informed consent giving their permission to the researcher to gather data. The participants then took the survey containing several questionnaires (Appendices A-G). The study was anonymous in nature. Participants were not compensated for completing the survey. Participants were not debriefed after the study due to its transparent nature.

Measures

Participants completed the survey through online survey software SurveyMonkey. The questionnaire consisted of five parts: Demographics questionnaire (Appendix A),
Questionnaire on weight (Appendix B), Questionnaire about online support group (Appendix C), Social support and quality of life questionnaire (Appendix D), including WHOQOL-BREF (World Health Organization Quality of Life Index) (Appendix E) (WHOQOL group, 1996), and Psychological co-morbidities questionnaire (Appendix F).

Demographics Questionnaire

Demographics Questionnaire was used to gather basic demographic information in a multiple choice format. Questionnaire on Weight was used to gather information about participants’ current and previous weight, their weight loss practices and attitudes, and their experience with bariatric surgery, in a multiple choice format. Questionnaire about Online Support Group was used to gather information about participants’ current participation in a specific online bariatric support group, their past experiences participating in other online bariatric support groups and their current experience with medical care following bariatric surgery, in a multiple choice and 5-point Likert rating scale format.

Social Support and Quality of Life Questionnaire

Social Support and Quality of Life Questionnaire was used to gather information about participants’ perception of social support they received, degree of isolation and quality of life.

WHOQOL-BREF

Included in the Social Support and Quality of Life Questionnaire of the survey was WHOQOL-BREF (World Health Organization Quality of Life Index), a 26-item self-report measure, which was used to gather information about participants’ general quality of life, in the domains of physical (Domain 1) and psychological (Domain 2)
health, social relationships (Domain 3) and environment (Domain 4) (WHOQOL group, 1996), in a 5-point Likert rating scale format. Overall, WHOQOL-BREF appeared in the literature to have good psychometric properties in an international study using a large sample of healthy people and individuals with mental and physical problems. Cronbach’s alphas were acceptable (>0.7) for Domains 1, 2 and 4, i.e. physical health 0.82, psychological 0.81, environment 0.80, but marginal for social relationships 0.68. Discriminant validity was best demonstrated in the physical domain, followed by the psychological, social and environment domains. Item–domain correlations ranged between 0.48 for pain, to 0.70 for activities of daily living (Domain 1), from 0.50 for negative feelings to 0.65 for spirituality (Domain 2), from 0.45 for sex to 0.57 for personal relationships (Domain 3) and from 0.47 for leisure to 0.56 for financial resources (Domain 4). (Skevington, Lotfy, & O’Connell, 2004)

The WHOQOL-BREF measure was scored according to the scoring instructions specified by the WHOQOL group (WHOQOL group, 1996). (Hawthorne, Herrman, & Murphy, 2006) reported preliminary general community norms for interpreting WHOQOL-BREF. Their results showed that general norms for the WHOQOL-BREF domains were 73.5 ($SD = 18.1$) for the Physical health domain, 70.6 ($SD = 14.0$) for Psychological wellbeing, 71.5 ($SD = 18.2$) for Social relationships and 75.1 ($SD = 13.0$) for the Environment domain. In general scores declined slightly by age group, according to the authors. For females scores were stable across the lifespan with an accelerated decline after the age of 60 years. Males exhibited a more consistent and even decline across the lifespan. There were significant differences in WHOQOL-BREF scores when
reported by health status, with those in poor health obtaining scores that were up to 50% lower than those in excellent health.

*Psychological Co-morbidities Questionnaire*

Finally, Psychological Co-morbidities Questionnaire was used to gather basic information about possible psychological co-morbidities, in a Yes/No question format.

*Outcomes and Analysis*

Our main outcome was quantitative and qualitative characterization of bariatric internet-based support groups, using the pooling of descriptive variables and scoring from WHOQOL-BREF measure. The data were examined for missing data points. Individuals who did not complete the entire survey were excluded from the data analysis. Descriptive statistics and summaries of data were used to interpret the information about the sample. A Pearson product-moment correlation was used to examine the relationship between BMI change and group satisfaction.
Results

Of 39 people who took the survey 22 completed the entire survey, yielding a 56% survey completion rate. The majority of participants were white females over 45 years old. Table 1 summarizes demographic information of respondents broken down by whether a survey was completed or only partially completed. All of the results presented were collected from current members of online bariatric support groups.

Table 1

**Demographic information**

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Completed entire survey, n (%)</th>
<th>Completed demographic information, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(N_{\text{Total}}=22)</td>
<td>(N_{\text{Total}}=39)</td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34-44</td>
<td>7 (32%)</td>
<td>12 (31%)</td>
</tr>
<tr>
<td>45-54</td>
<td>11 (50%)</td>
<td>13 (33%)</td>
</tr>
<tr>
<td>55-64</td>
<td>3 (14%)</td>
<td>6 (15%)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>5 (23%)</td>
<td>6 (15%)</td>
</tr>
<tr>
<td>Females</td>
<td>17 (77%)</td>
<td>33 (85%)</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>22 (100%)</td>
<td>38 (97%)</td>
</tr>
<tr>
<td>Relationship Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>16 (73%)</td>
<td>25 (64%)</td>
</tr>
<tr>
<td>Single</td>
<td>3 (14%)</td>
<td>5 (13%)</td>
</tr>
<tr>
<td>Cohabitating</td>
<td>1 (5%)</td>
<td>4 (10%)</td>
</tr>
<tr>
<td>------------</td>
<td>-------</td>
<td>--------</td>
</tr>
<tr>
<td>Divorced</td>
<td>2 (9%)</td>
<td>4 (10%)</td>
</tr>
</tbody>
</table>

**Employment Status**

| Full-time     | 8 (36%) | 17 (44%) |
| Part-time     | 2 (9%)  | 2 (5%)   |
| Unemployed or other | 12 (55%) | 20 (51%) |

**Household Annual Income**

| Greater than $80,000 | 6 (27%) | 12 (31%) |
| $60,000 - $80,000   | 5 (23%) | 6 (15%)  |
| $40,000 - $60,000   | 6 (27%) | 9 (23%)  |
| $20,000 - $40,000   | 3 (14%) | 7 (18%)  |
| Less than $20,000   | 2 (9%)  | 5 (13%)  |

**Living Situation**

| With significant other/spouse | 17 (77%) | 28 (72%) |
| Alone                        | 4 (18%)  | 9 (23%)  |

**Highest Education Level**

| High-school or GED | 6 (27%) | 14 (36%) |
| Some college (undergraduate) | 3 (14%) | 9 (23%)  |
| Completed undergraduate | 4 (18%) | 5 (13%)  |
| Some graduate         | 7 (32%) | 8 (21%)  |

Participants of sampled online bariatric groups have been trying to lose weight for 25 years on average (range = 3-57 yrs) and sixty one percent of participants reported it
was “extremely difficult” to lose weight. Eighty one percent of respondents underwent some type of weight-reduction surgery. The surgeries listed can be grouped into the following categories – 66% Roux-en-Y Gastric Bypass, 24% Lap Band, with 6% remaining unspecified. Participants reported having a surgery on average 1.9 years (range 0-9.7 years) before the survey was conducted. From the height and weight information in the survey BMI was calculated for each participant at three points in time: prior to surgery, at the time of joining online support group and current (at the time of taking the survey). Pre-surgery BMI of respondents is summarized in Figure 1.

Figure 1

*Pre-surgery BMI of respondents who underwent weight-reduction surgery*

<table>
<thead>
<tr>
<th>BMI Range</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>36-45</td>
<td>31%</td>
</tr>
<tr>
<td>46-55</td>
<td>28%</td>
</tr>
<tr>
<td>56-68</td>
<td>15%</td>
</tr>
<tr>
<td>Did not specify</td>
<td>26%</td>
</tr>
</tbody>
</table>

Participants indicated medical reasons and improving physical quality of life as the most important reasons for seeking bariatric surgery. Secondary reason was mainly improving physical quality of life (see Table 2 for details).

Table 2

*Reasons for having a bariatric surgery*

<table>
<thead>
<tr>
<th>Reasons for having surgery</th>
<th>Named as primary</th>
<th>Named as secondary</th>
</tr>
</thead>
</table>


<table>
<thead>
<tr>
<th></th>
<th>(% of respondents)</th>
<th>(% of respondents)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$N = 30$</td>
<td>$N = 29$</td>
</tr>
<tr>
<td>Improve physical quality of life</td>
<td>30%</td>
<td>45%</td>
</tr>
<tr>
<td>Improve self-esteem</td>
<td>3%</td>
<td>21%</td>
</tr>
<tr>
<td>Medical preventative reasons</td>
<td>20%</td>
<td>14%</td>
</tr>
<tr>
<td>Medical reasons</td>
<td>40%</td>
<td>14%</td>
</tr>
</tbody>
</table>

Overall the majority of respondents reported to have lost the weight they intended (75%) with little or minor difficulties in keeping the weight off. Consistent with this is that majority of participants also reported being satisfied with the result of the surgery (see Figure 2 for a detailed report). Also noteworthy is that 89% of respondents reported they engaged in little to moderate amount of physical activity of “less than two hours a week” or “two to eight hours a week” (each reported by 44%).

Figure 2

*Difficulty in keeping weight off and satisfaction with weight loss results*

<table>
<thead>
<tr>
<th>Difficulty in keeping weight off</th>
<th>Satisfaction with weight loss</th>
</tr>
</thead>
<tbody>
<tr>
<td>$N = 28$</td>
<td>$N = 33$</td>
</tr>
</tbody>
</table>
The main reasons for joining online bariatric support group were divided between receiving support and encouragement (36%), providing support and encouragement (20%), sharing experience (16%) and learning about a medical procedure (16%). The length of participation in the online support group varied widely, but the frequency of group participation was for the most part once or twice per week (see Figure 3 for details). Tracking positive results of satisfaction with overall weight loss, the majority of participants (64%) reported they were “fairly” to “moderately” successful in achieving their initial goal when joining the group. Satisfaction with the online group did not mimic satisfaction with weight loss or achieving weight loss goals. Forty two percent of respondents were “somewhat satisfied” with their groups while 25% were “not sure.”

Figure 3

**Duration and frequency of online group participation**

How long have you been in this online group? On average, how often did you visit this group in the past month?

* $N = 25$
In terms of particular group selection, majority of participants found the group by searching the internet and made their selection based on the discussion content. Table 3 presents particular factors in selecting the online group.

Table 3

*Factors in group selection*

<table>
<thead>
<tr>
<th>How did you find this group?</th>
<th>What is the main reason you chose this group?</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>N = 25</em></td>
<td><em>N = 25</em></td>
</tr>
<tr>
<td>Referred by a friend</td>
<td>12% Discussion content</td>
</tr>
<tr>
<td>Referral by a professional medical</td>
<td>8% Recommendation</td>
</tr>
<tr>
<td>Searched online</td>
<td>68% Size</td>
</tr>
<tr>
<td>Other</td>
<td>12% Structure</td>
</tr>
<tr>
<td></td>
<td>Other</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Sixty four percent indicated they had participated in another online bariatric support group and 65% of people reported they were still active members of another group. Ninety six percent of participants did not feel they spent too much time in the group.

Respondents were asked to rate their usual mood or state of mind on a scale from 1 to 7 (from very negative, to very positive, respectively) at the time of deciding to log into their respective online groups. The results are summarized in Table 4.

Table 4

Mood rating at the time of deciding to visit the group

<table>
<thead>
<tr>
<th>Mood</th>
<th>Percentage of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = very negative</td>
<td>0%</td>
</tr>
<tr>
<td>7 = very positive</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>0%</td>
</tr>
<tr>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>3</td>
<td>16%</td>
</tr>
<tr>
<td>4</td>
<td>16%</td>
</tr>
<tr>
<td>5</td>
<td>20%</td>
</tr>
<tr>
<td>6</td>
<td>20%</td>
</tr>
<tr>
<td>7</td>
<td>24%</td>
</tr>
</tbody>
</table>

N 25

Rating average 5.1
Analysis of responses by gender revealed some differences, none of which were statistically significant due to the small number of male participants (6), however still worthy of mention. Largest proportion of male respondents (40%) indicated they joined the group mainly to provide support, whereas 45% of women reported they joined in order to receive support. Men also tended to post more comments indicating a more active participation. Also the largest proportion of male respondents (40%) reported they were “extremely successful” in achieving their online group goal, while only 5% of women reported being “extremely successful” (see Figure 4).

Figure 4

*Success in achieving main goal of joining group by gender*

While 80% of men and 22% of women reported they participated in in-person support groups, women preferred in-person groups (65%) while men preferred internet groups (60%).

Participants were asked to describe their groups as either having a leader or not. Forty eight percent reported their group having a leader, but only 20% indicated there
was an “ask an expert” feature in their forums. Among groups with leaders, 33% of members described leaders as peers, 33% could not define the leaders precisely, 8% described them as physicians and 8% described them as social workers. Figures 5 and 6 illustrate differences in goals for joining the group and success in achieving those goals broken down by presence of a group leader.

Figure 5

Goals for joining the group by presence of a group leader

Figure 6

Success in achieving the goals for joining the group by presence of a group leader
The differences between several other selected responses by presence or absence of a leader in an online support group are summarized in Table 5.

Table 5

*Table 5: Differences in responses by presence or absence of a group leader*

<table>
<thead>
<tr>
<th></th>
<th>With leader, n (%)</th>
<th>Without leader, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Difficulty of losing weight</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extreme</td>
<td>9 (75%)</td>
<td>6 (46%)</td>
</tr>
<tr>
<td>Moderate</td>
<td>3 (25%)</td>
<td>4 (31%)</td>
</tr>
<tr>
<td>Slight</td>
<td>0</td>
<td>3 (23%)</td>
</tr>
<tr>
<td><strong>Frequency of visiting online support group</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weekly</td>
<td>4 (33%)</td>
<td>2 (15%)</td>
</tr>
<tr>
<td>Twice a week</td>
<td>4 (33%)</td>
<td>2 (15%)</td>
</tr>
<tr>
<td>Every day</td>
<td>0</td>
<td>4 (31%)</td>
</tr>
<tr>
<td>Requesting emotional support in discussions</td>
<td>Rarely</td>
<td>Occasionally</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------------</td>
<td>--------</td>
<td>--------------</td>
</tr>
<tr>
<td>2 (18%)</td>
<td>1 (8%)</td>
<td>3 (27%)</td>
</tr>
<tr>
<td>Discussion of diet</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>2 (18%)</td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>2 (15%)</td>
<td></td>
</tr>
<tr>
<td>Half of all discussions</td>
<td>5 (39%)</td>
<td></td>
</tr>
<tr>
<td>Significant portion</td>
<td>2 (18%)</td>
<td></td>
</tr>
<tr>
<td>Discussion of exercise</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>4 (36%)</td>
<td></td>
</tr>
<tr>
<td>Occasionally</td>
<td>3 (27%)</td>
<td></td>
</tr>
<tr>
<td>Half of all discussions</td>
<td>2 (18%)</td>
<td></td>
</tr>
<tr>
<td>Significant portion</td>
<td>3 (27%)</td>
<td></td>
</tr>
<tr>
<td>Participate in peer-to-peer groups</td>
<td>4 (36%)</td>
<td></td>
</tr>
<tr>
<td>Membership in other bariatric online support groups</td>
<td>9 (75%)</td>
<td></td>
</tr>
<tr>
<td>Mood when log in (scale 1-7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 (very negative)</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>1 (8%)</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>2 (17%)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>2 (17%)</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>2 (17%)</td>
<td></td>
</tr>
</tbody>
</table>
Forty two percent of respondents indicated they were satisfied with the group. A correlation was found between BMI change from before weight loss surgery to current BMI v. group satisfaction rating \(r(22) = .60, p < 0.05\) with a large effect size \(r^2 = .36\) (Figure 7).

Figure 7

*Correlation plot of BMI change v. group satisfaction.*
Analysis of responses by whether or not participants underwent weight-reduction surgery revealed the following differences, which are summarized in Table 6.

Table 6

*Differences in responses by weight loss surgery status*

<table>
<thead>
<tr>
<th></th>
<th>Had surgery, n (%)</th>
<th>Did not have surgery, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6 (21%)</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>23 (79%)</td>
<td>7 (100%)</td>
</tr>
<tr>
<td><strong>Reasons for joining group</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Receive support</td>
<td>7 (37%)</td>
<td>2 (33%)</td>
</tr>
<tr>
<td>Provide support</td>
<td>5 (26%)</td>
<td>0</td>
</tr>
</tbody>
</table>
Participation in discussions varied widely. Forty two percent of respondents stated that they rarely posted comments, 25% posted sometimes and 21% of respondents usually posted comments. When participants were asked to describe the discussion topics within their online support groups, 50% indicated socialization was present occasionally, 46% reported sharing experiences was present in a significant portion of all discussions, 48% reported emotional support was provided frequently, 42% reported request for emotional support in half of all discussions, and 48% reported advice giving present in half of all discussions. Twenty nine percent of participants indicated diet discussions were present in a significant portion of all discussions, while another 29% reported they were present in a significant portion of all discussions, 44% said medical care was the topic of half of all discussions, and 32% reporting discussing exercise was part of half of all discussions.

Respondents continued to receive medical care as pertaining to their obesity and weight loss with medical providers. Sixty seven percent of all respondents reported receiving follow-up care at a bariatric surgery clinic and 72% continued to see their
primary care physicians. Fifty four percent of participants were somewhat or extremely satisfied with their follow up medical care. When asked about their communication with the doctor, 32% reported they told their doctor about the online support group and 44% indicated participating in this group improved their communication with the doctor.

Participants of sampled online bariatric support groups reported significant levels of psychological distress. Figure 8 summarizes the results of the psychological distress questionnaire.

Figure 8

*Overall psychological problems*

Reporting of presence of psychological problems was compared by gender (Figure 9), by presence or absence of an online discussion group leader (Figure 10) and by whether respondents underwent weight-reduction surgery (Figure 11).

Figure 9

*Psychological problems by gender*
Figure 10

*Psychological problems by presence of a group leader*

Figure 11

*Psychological problems by having had surgery*
Participants’ quality of life was examined using the WHOQOL-BREF measure. The scaled scores (0-100) on WHOQOL-BREF are summarized in the following tables by age range (Table 7), gender (Table 8), current BMI (Table 9), years since weight loss surgery (Table 10), income (Table 11), living situation (Table 12), and other selected categories (Table 13).

Table 7

*WHOQOL-BREF scaled (0-100) scores by age range*

<table>
<thead>
<tr>
<th>WHOQOL-BREF</th>
<th>&lt; 45 (n=7)</th>
<th>45-54 (n=11)</th>
<th>&gt; 54 (n=3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domain 1 – Physical health</td>
<td>61.9 31.7</td>
<td>61.0 22.6</td>
<td>85.7 4.0</td>
</tr>
<tr>
<td>Domain 2 – Psychological</td>
<td>43.0 28.6</td>
<td>50.7 17.4</td>
<td>72.7 14.4</td>
</tr>
<tr>
<td>Domain 3 – Social relationships</td>
<td>50.0 16.8</td>
<td>46.0 19.7</td>
<td>60.3 7.5</td>
</tr>
<tr>
<td>Domain 4 – Environment</td>
<td>69.7 24.5</td>
<td>70.5 19.8</td>
<td>79.3 7.5</td>
</tr>
</tbody>
</table>
Table 8

*WHOQOL-BREF* scaled (0-100) scores by gender

<table>
<thead>
<tr>
<th>WHOQOL-BREF</th>
<th>Gender</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males</td>
<td>SD</td>
<td>Females</td>
</tr>
<tr>
<td></td>
<td>M</td>
<td></td>
<td>(n=5)</td>
</tr>
<tr>
<td>Domain 1 – Physical health</td>
<td>82.8</td>
<td>12.0</td>
<td>59.4</td>
</tr>
<tr>
<td>Domain 2 – Psychological</td>
<td>63.8</td>
<td>14.2</td>
<td>49.4</td>
</tr>
<tr>
<td>Domain 3 – Social relationships</td>
<td>50.0</td>
<td>16.5</td>
<td>49.6</td>
</tr>
<tr>
<td>Domain 4 – Environment</td>
<td>83.8</td>
<td>9.6</td>
<td>68.5</td>
</tr>
</tbody>
</table>

Table 9

*WHOQOL-BREF* scaled (0-100) scores by BMI

<table>
<thead>
<tr>
<th>WHOQOL-BREF</th>
<th>BMI</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>20-30</td>
<td>31-40</td>
<td>41-47</td>
</tr>
<tr>
<td></td>
<td>(n=9)</td>
<td>(n=9)</td>
<td>(n=4)</td>
</tr>
<tr>
<td>Domain 1 – Physical health</td>
<td>72.4</td>
<td>22.9</td>
<td>59.3</td>
</tr>
<tr>
<td>Domain 2 – Psychological</td>
<td>59.0</td>
<td>19.2</td>
<td>50.1</td>
</tr>
<tr>
<td>Domain 3 – Social relationships</td>
<td>49.2</td>
<td>13.8</td>
<td>55.6</td>
</tr>
<tr>
<td>Domain 4 – Environment</td>
<td>77.2</td>
<td>13.3</td>
<td>64.7</td>
</tr>
</tbody>
</table>

Table 10
WHOQOL-BREF scaled (0-100) scores by years since surgery

<table>
<thead>
<tr>
<th>WHOQOL-BREF</th>
<th>(0-6 mos)</th>
<th>(6-12 mos)</th>
<th>1-3 years</th>
<th>3-10 years</th>
<th>Unspecified</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=4)</td>
<td>(n=0)</td>
<td>(n=6)</td>
<td>(n=6)</td>
<td>(n=6)</td>
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<tr>
<td>Domain 1 – Physical health</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WHOQOL-BREF</td>
<td>M SD</td>
<td>M SD</td>
<td>M SD</td>
<td>M SD</td>
<td>M SD</td>
</tr>
<tr>
<td>Domain 2 – Psychological</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WHOQOL-BREF</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domain 3 – Social relationships</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WHOQOL-BREF</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Domain 4 – Environment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WHOQOL-BREF</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 11

WHOQOL-BREF scaled (0-100) scores by income

<table>
<thead>
<tr>
<th>Income</th>
<th>0-20,000</th>
<th>20-40,000</th>
<th>40-60,000</th>
<th>60-80,000</th>
<th>Over 80,000</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n=2)</td>
<td>(n=3)</td>
<td>(n=6)</td>
<td>(n=5)</td>
<td>(n=6)</td>
</tr>
<tr>
<td>WHOQOL-BREF</td>
<td>M SD</td>
<td>M SD</td>
<td>M SD</td>
<td>M SD</td>
<td>M SD</td>
</tr>
<tr>
<td>Domain 1 – Physical health</td>
<td>50.0</td>
<td>26.9</td>
<td>63.0</td>
<td>25.0</td>
<td>61.7</td>
</tr>
<tr>
<td>Domain 2 - Psychological</td>
<td>37.5</td>
<td>26.2</td>
<td>60.3</td>
<td>35.8</td>
<td>51.2</td>
</tr>
<tr>
<td>Domain 3 – Social relationships</td>
<td>31.0</td>
<td>0.0</td>
<td>50.0</td>
<td>22.6</td>
<td>55.0</td>
</tr>
</tbody>
</table>


Table 12

*WHOQOL-BREF scaled (0-100) scores by living situation*

<table>
<thead>
<tr>
<th>Living situation</th>
<th>With partner (n=17)</th>
<th>Without partner (n=4)</th>
</tr>
</thead>
<tbody>
<tr>
<td>WHOQOL-BREF</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Domain 1 – Physical health</td>
<td>62.0</td>
<td>24.3</td>
</tr>
<tr>
<td>Domain 2 – Psychological</td>
<td>50.5</td>
<td>23.5</td>
</tr>
<tr>
<td>Domain 3 – Social relationships</td>
<td>51.5</td>
<td>17.9</td>
</tr>
<tr>
<td>Domain 4 – Environment</td>
<td>71.1</td>
<td>21.2</td>
</tr>
</tbody>
</table>

Table 13

*WHOQOL-BREF scaled (0-100) scores by selected sub grouping*

<table>
<thead>
<tr>
<th>Surgery</th>
<th>Employment</th>
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<tbody>
<tr>
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<td>Yes (n=16)</td>
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<tr>
<td>WHOQOL-BREF</td>
<td>M</td>
</tr>
<tr>
<td>Domain 1 – Physical health</td>
<td>72.1</td>
</tr>
<tr>
<td>Domain 2 - Psychological</td>
<td>56.3</td>
</tr>
<tr>
<td>Domain 3 – Social relationships</td>
<td>47.6</td>
</tr>
<tr>
<td>Domain 4 - Environment</td>
<td>71.9</td>
</tr>
</tbody>
</table>
Discussion

Evaluating bariatric support groups is an important step towards future exploration of the impact of these groups on well-being and health status of participants and identification of positive and negative features of these groups to help guide bariatric patients towards optimal resources in the community and online. This is a small pilot study that attempts to characterize online support groups. The main limitation of this study is the small number of respondents, which does not allow for robust statistical analysis and hence the results can only be viewed as possible trends, needing further verification and validation. The second limitation is intrinsic to electronic survey methodology (Andrews et al., 2003) – only responses of those who responded to the questionnaire are analyzed and therefore cannot be generalized to the entire online community. These limitations must be considered carefully when using the data generated by this pilot study. Nevertheless, these findings provide a preliminary platform for further characterization of this entity growing in size and popularity.

Demographic analysis, as presented in Table 1, indicates that the majority of participants are no older than 54 years of age, which could be associated with a higher computer literacy rate in younger population (Horrigan, 2008; J. Hsu et al., 2005). However if we consider the quality of life scores in Table 7, it appears that with age quality of life in online bariatric group participants improves. Likewise, based on responses generated by this survey, more women participate in support groups, and women in our study had lower quality of life scores across all four domains (Table 8). It is therefore possible, that those seeking psychological support online are those with worse quality of life scores. This hypothesis could be further investigated among bariatric
Almost all respondents were white, as opposed to a largely equal distribution across education background and household income. It would be extremely important to determine whether this is a true phenomenon – and only white bariatric patients seek online support groups, or this is influenced by the inability or lack of desire to participate in our and other survey studies, therefore skewing the true representation of other races in these electronic groups. It is interesting to note that in Munoz et al study of patients seeking bariatric surgery the sample was overwhelmingly female ($N = 88, 81\%$), and approximately two-thirds Caucasian ($N = 69, 63\%$) (Munoz et al., 2007). The trend of a higher proportion of white members in support groups in general can be seen in studies pertaining to other health issues. For example, in a study of breast cancer group support interventions conducted in racially diverse city of Pittsburg, Pennsylvania, 93% of women were Caucasian (Helgeson et al., 2000).

The majority of patients in our survey were married or in a relationship. Of contrast, internet support groups for depression had a higher proportion of socially isolated members, with over half of members unmarried (Houston et al., 2002). This comparison suggests that there is no universally identifying description of online community members, but rather each community has specific characteristics based on the underlying health-related issue. Moreover, participants who lived with a partner had lower quality of life scores across three of the four domains – physical health, psychological health and environment domains (Table 12). This also reinforces our
previous observation that more members with lower quality of life scores seek participation in online bariatric communities.

Survey responses showed a relatively consistent distribution of participants from high school level to graduate degree and across various income levels. This is in line with previously published assessment of online support groups and their effect on minimization of differences in social status among the participants (Schneider & Tooley, 1986).

Eighty one percent of respondents in this survey underwent weight-reduction surgery. This is an important aspect of this population cohort. Several interpretations could be proposed. These members might bond and continue online dialogue centered around a common experience, in this case the weight reduction surgery. Alternatively, people who are drawn to either in-person and/or online support groups are those who seek active management and hence there is a higher representation of those who have already sought a surgical intervention, which is clearly advocated by medical authorities as the most effective method of weight loss. Further characterization of this population might give answers to this dilemma and offer new insights into organization and function of online bariatric support groups.

Munoz et al. (2007) analyzed patient motivation before weight reduction surgery and found that medical health was the main motivation in 73% of patients, whereas physical quality of life in only 1%. In this survey of patients who already underwent surgery, medical reasons accounted for 40% and improvement of physical quality of life for 30%. The differences in these numbers could be due to self-recall bias, inherent differences in clinic and online bariatric populations, and the research methodology. It
would be important to further characterize the motivation in online patients who have not yet undergone surgery in order to establish whether bariatric patients participating in online communities differ from those who do not in terms of their motivations factors for undergoing surgery.

Our survey asked participants to determine whether they were able to achieve the desired weight loss after surgery. Unfortunately, we do not know what that desired weight loss was a priori. Nevertheless, the individual’s self-assessment of that achievement is likewise a critical factor and should not be overlooked. Forty six percent of respondents stated that it was easy to keep weight off after surgery. When Wing & Hill (2001) defined maintaining 10% of intentional weight loss at 1 year as weight-loss success, they found in their National Weight Control Registry that only 20% of their subjects were able to achieve this goal (Wing & Hill, 2001). Moreover, 64% of our respondents were content with their weight loss. It would be very important to determine in future studies whether self-perceived success correlates with scientifically defined parameters.

Alternatively, members of the subpopulation of the online bariatric community, who have already undergone surgery, could be enriched by individuals who were successful at maintaining their weight, if compared to the general post-surgical bariatric population. If true, further comparison of online population to the general population might yield answers to why these patients achieve greater success to increase the effectiveness of surgery and other methods in general population.

It is striking that members were roughly divided in terms of goals from online group participation between those seeking support and those wishing to provide it. Indeed,
the search for further medical information was limited to a minority of participants. This finding fits well with analysis of mood at the time of electronic discussion. It appears congruent that the decision to give a hand to a fellow member is accompanied by a concomitant lack of negative mood.

The analysis of data by gender revealed interesting trends. Women in our survey tended to be less successful in achieving intended weight loss, had a worse mood at the time of log in and, overall, preferred in-person mode of group communication, when compared to men (Figure 4). This correlates well with lower quality of life scores in women, when compared to men in our survey (Table 8). However, due to small numbers this correlation must be viewed with great caution and healthy skepticism until further data is obtained and statistical analysis is performed.

Gravitation of members towards groups with a leader or without one might be intrinsic to individual needs, personality traits or reasons to join the online community. There was a trend towards more difficulty with achieving weight loss among members who were members of groups with a leader (Figure 6). It might be explained by the fact that these individuals are seeking counseling and need a figure of authority, more so than members more successful in their goals and joining the groups for the sole reason of sharing their positive experiences. At the same time members without a leader also feel that the group has more effect on their ability to lose weight than members in groups with a leader. It would be critical to determine whether there is indeed an outcome effect or this difference simply represents self-selection bias. Only a randomized trial of assigning bariatric patients to either a group with a leader or to a leaderless group would be able to
answer this question and therefore be further promoted in medical community for better bariatric outcomes.

Analysis of differences in responses by the surgical status reveals the following trends. Among members who did not undergo surgery, there were no men in our survey. These members have been part of the online community for less than one year, in contrast to post-surgery members, among them 37% were members for longer than one year. A possible explanation could be that most pre-surgery patients either end up undergoing surgery within a year or stop participating in the online community. Determining the outcome for these pre-surgery patients at the end of one year would be a useful investigation for further targeting this population in the event they stop seeking further medical attention while continuing to be overweight.

Members’ satisfaction with medical care is rather poor, considering that only 54% of participants were somewhat or extremely satisfied with their follow up medical care. This satisfaction should be compared to the general population of bariatric patients in a similarly anonymous fashion to determine whether this is an overall trend of poor medical care or is intrinsic to the community seeking support online. This data could provide more impetus for the medical establishment to improve the delivery of information, necessary services and professional support either in general or in response to individual needs, as could be further determined by more detailed surveys of online bariatric community.

It is not surprising that there is a high prevalence of psychological issues among the members of bariatric support groups, as detailed in our study. Moreover, it appears that psychological issues are sometimes more prevalent in members who have undergone
surgery in comparison to those who have not, a finding which is supported by other studies. Using projective techniques, Ryden, Olsson, & Danielsson (1989) found no depression among 21 severely obese patients before bariatric surgery. However, 8 developed depression after surgery, and 4, including 3 with satisfactory weight loss, required treatment for the depression. Suicide is a major cause of death after bariatric surgery (L. K. G. Hsu, Benotti, Dwyer, Roberts, Saltzman, Shikora et al., 1998). Our findings also indicate a trend towards a greater prevalence of suicidal thoughts in patients who have undergone surgery. Whether depression and suicidal thoughts after bariatric surgery occurs more commonly than expected in the general population is unclear. It is also unclear whether the depression is triggered by the surgery, the weight loss, or other psychosocial or biological factors. Applying data from the research of internet support groups for depression (Houston et al., 2002), it appears that heavy users of the internet groups were more likely to have resolution of depression during follow-up than less frequent users. Ninety six percent of our respondents replied that that spent not a significant amount of time online. It would be tremendously important to determine whether heavier user of online communication with peers would lead to better psychological outcomes for the bariatric online community members, and if so – to determine how to promote greater access and more extensive use of this critical resource for these patients.

Seventy seven percent of members feeling depressed and thirty two percent of members experiencing suicidal thoughts are alarming numbers. These high rates alone suggest that this population is very vulnerable and should be heavily targeted by social services and medical and psychological care providers.
Summary and future direction

This is a small pilot study that began the process of characterization of online bariatric support groups. It identified several interesting trends, which should be further studied in larger surveys and ultimately in prospective trials involving participation of patients in various support groups. Observed differences in perceived success in losing weight and attaining goals between genders, age groups and group structure (i.e. group expert) should be further investigated with a larger sample size. It would also be instructive to further investigate why motivations for surgery in the online support group were found to be different from previous studies surveying clinical patients. A separate study could also focus on the correlation of self-perceived success with scientifically defined parameters. Apparent dissatisfaction with the quality of medical care should also be further looked into as it could provide valuable information on improving delivery of information and medical services to the post-surgery population. Another important outcome of an enlarged study would be to compare quality of life and perceived and actual success rates of keeping the weight off to in-person support groups.

Results of this study, especially if fortified with a larger sample size and several above mentioned follow-up investigations, could be used to enhance mental health of post bariatric surgery patients in several important ways. Once it is clearer whether online support groups have a positive impact on perceived and actual success rate of keeping the weight off, the online option could be promoted as an easy alternative to in-person groups. Once the impact of gender and group structure is better understood, health professionals could better customize how to direct their patients for most effective results. It is clear that patients will continue to seek the most accessible route of communication and
harnessing the power of this venue and directing it towards improvement in health outcome and psychosocial wellbeing of these exceedingly vulnerable individuals is critical if we are to successfully fight the national epidemic of obesity.

There is an important trend in medicine which is characterized by individualization of therapies. No two people are alike, and hence no two people can be treated in an exactly the same manner. Support groups, be it peer-to-peer, or online, might be helpful to some, yet harmful to others. At this point the entity of online support community is not well studied to be able to predict how a certain individual will react to this intervention. The ability to predict the outcome of this intervention will be useful in improving long-term outcomes in terms of weight reduction, weight maintenance and psychological well-being. This ability hinges on our detailed knowledge of bariatric online support groups, and this study pilots the exploration into this field.
Appendix A

Demographics Questionnaire

1. What is your age?
   ____ years old

2. What is your gender?
   a) male
   b) female
   c) transsexual / transgendered

3. What is your relationship status?
   a) married
   b) co-habitating
   c) in relationship
   d) single
   e) divorced
   f) widowed
   g) other (specify) ____

4. How would you describe your employment?
   a) employed full-time
   b) employed part-time
   c) unemployed
   d) other (specify) ____

5. What is your household income?
   a) $0 - $20,000
b) $20,000 - $40,000
c) $40,000 – 60,000
d) $60,000-80,000
e) over $80,000

6. What is your race / ethnicity?
   a) Hispanic
   b) American Indian or Alaska Native
c) Asian
d) Black or African American
e) Native Hawaiian or Other Pacific Islander
   f) White
g) Other (specify) ____

7. With whom do you currently live?
   a) Significant other / spouse
   b) Parents / relatives
c) Roommates
d) Alone
e) Other (specify) ____

8. What is the highest education level you have completed?
   a) High school or GED
   b) Some college (undergraduate)
c) Some graduate (post-Bachelor, for example Master’s, Doctorate)
d) Other (specify) ____
Appendix B

Questionnaire On Weight

1. What is your current weight?
   ___ lbs

2. What is your current height?
   ___ ft  ___ in

3. What was your weight when you joined the group?
   ___ lbs

4. For how long have you been trying to lose weight?
   ___ years  ___ months

5. How difficult do you find it to lose weight?
   Not at all  Slightly  Moderately  Extremely
   difficult            difficult            difficult            difficult
   1                   2                   3                   4

6. Did you have weight loss surgery?
   a). Yes  b). No (skip to question 14)

7. What kind of weight loss surgery did you have?
   a) Lap band
   b) VBG (Vertical Banded Gastroplasty)
   c) BPD (Biliopancreatic Diversion)
   d) RYGBP-E (Extended (Distal) Roux-en-Y Gastric Bypass)
   e) Roux-en-Y Gastric Bypass
   f) Other (specify) ____

8. What was your pre-surgery weight?
____ lbs

9. How long ago was your weight loss surgery?
   ____ years   ____ months

10. What was the most important reason you decided to have weight loss surgery?
    a) Medical reasons
    b) Medical preventative reasons
    c) Improve self-esteem
    d) Improve physical quality of life
    e) Improve social quality of life
    f) Improve a relationship
    g) Other (specify) ____

11. What was a secondary reason you decided to have weight loss surgery (if any)?
    h) Medical reasons
    i) Medical preventative reasons
    j) Improve self-esteem
    k) Improve physical quality of life
    l) Improve social quality of life
    m) Improve a relationship
    n) Other (specify) ____
    o) No secondary reason

12. Did you lose the weight you intended to lose post surgery?
    a). Yes       b). No

13. How difficult do you find it to keep the weight off post surgery?

        Very easy       Somewhat       Moderately       Very difficult       Impossible
14. How content are you with your weight loss?

<table>
<thead>
<tr>
<th>Very content</th>
<th>Somewhat</th>
<th>Not sure</th>
<th>Not very</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

15. How often do you engage in physical activity?

- a) < 2 hours/week
- b) 2-8 hours/week
- c) 2 hours / day
- d) > 2 hours / day
Appendix C

Questionnaire About Online Support Group

1. What was the main goal you were hoping to achieve by joining this online group?
   a) Receive support and encouragement
   b) Provide support and encouragement
   c) Learn about weight loss
   d) Learn about medical care or procedure (e.g. surgery)
   e) Share your experience with others
   f) Other (specify) ____

2. How successful are you in achieving this goal?

   Not at all  Somewhat  Unsure  Fairly  Extremely successful successful
   1                2                3                4                5

3. How long have you been in this online group?
   ____ days  ____ months  ____ years

4. Is there an “ask an expert” feature on the website of this group?
   a). Yes                      b). No

5. Do you have a group leader?
   a). Yes                      b). No

6. If you answered “Yes” to the previous question, who is the leader (if you answered “No” skip to question 7)?
   a) Peer
   b) Nurse
   c) Dietician
d) Doctor

e) Psychologist

f) Social worker

g) Religious leader

h) Other (specify) ____
i) Don’t know

7. How did you find this group?

   a) Referred by a medical professional
   b) Searched online
   c) Referred by a friend
   d) Saw an advertisement
   e) Other (specify) ____

8. Why did you choose this group?

   a) Structure
   b) Size
   c) Recommendation
   d) Discussion content
   e) Other (specify) ____

9. On average, how often did you visit this group in the past month?

   a) once
   b) twice
   c) weekly
   d) twice a week
   e) every day
   f) more than once a day
   g) other (specify) ____
10. How often do you post comments?

<table>
<thead>
<tr>
<th>Always</th>
<th>Usually</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

11. How often are the following topics present in this group’s discussions?

<table>
<thead>
<tr>
<th></th>
<th>Very rarely</th>
<th>Occasionally</th>
<th>Half of all discussions</th>
<th>Significant portion of discussions</th>
<th>Present in all discussions</th>
</tr>
</thead>
<tbody>
<tr>
<td>a). Socializing</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>b). Sharing experiences</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>c). Providing emotional support</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>d). Requesting emotional support</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>e). Advice giving</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>f). Discussing diet</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>g). Discussing exercise</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>h). Discussing medical care</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>i). Other discussions</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

12. How much does your participation in this online support group help with weight loss?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very little</th>
<th>Not sure</th>
<th>Some</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
13. Do you get tips from experts in this online support group about diet?
   a). Yes       b). No

14. Do you get tips in this online support group about cooking?
   a). Yes       b). No

15. Do you get tips in this online support group about eating habits?
   a). Yes       b). No

16. Do you get tips in this online support group about exercise?
   a). Yes       b). No

17. Do you get tips in this online support group about wound care?
   a). Yes       b). No

18. Do you get tips in this online support group about plastic surgery?
   a). Yes       b). No

19. Do you get tips in this online support group about relationships?
   a). Yes       b). No

20. Do you get tips in this online support group about coping?
   a). Yes       b). No

21. How satisfied are you with this group?

          Extremely satisfied  Somewhat satisfied  Not sure  Somewhat dissatisfied  Extremely dissatisfied
          1                      2                    3             4                    5

22. Do you also participate in an in-person support group?
23. Assuming access is not an issue, what would you prefer?
   a). internet support group
   b). weekly in-person support group

If you had weight loss surgery, answer the following questions, if not, skip to question 31.

24. Do you receive your follow-up care at a weight loss (bariatric) surgery clinic?
   a). Yes frequency ____ / month b). No

25. Do you see a primary care physician?
   a). Yes frequency ____ / month b). No

26. Do you participate in a mentoring program?
   a). Yes frequency ____ / month b). No

27. Do you participate in an in-person support group?
   a). Yes frequency ____ /month b). No

28. How satisfied are you with the quality of your follow-up medical care?

<table>
<thead>
<tr>
<th>Extremely satisfied</th>
<th>Somewhat satisfied</th>
<th>Not sure</th>
<th>Somewhat dissatisfied</th>
<th>Extremely dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

29. Have you told your doctor about this internet support group?
   a). Yes b). No
30. Does participating in this online group improve your communication with your doctor?
   a). Yes    b). No

31. Have you participated in other online bariatric support groups?
   a). Yes    b). No

32. If you answered “Yes” to question 30, are you still an active member of any other online support groups?
   a). Yes    b). No

33. If you answered “No” to question 31, why did you leave that (or those) online group / groups?
   Explain ____

34. Do you feel your use of this online group is excessive?
   a). Yes    b). No

35. What is usually your state of mind, or mood, when you decide you want to log in to visit this group?

(Please use the following rating scale to rate your mood from 1 = very negative to 7 = very positive)

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
Appendix D

Social Support And Quality Of Life Questionnaire

The following questions ask you how you perceive your quality of life and the social support you receive.

1. How isolated do you feel?

<table>
<thead>
<tr>
<th>Completely isolated</th>
<th>Somewhat isolated</th>
<th>Not sure</th>
<th>Slightly isolated</th>
<th>Not at all isolated</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

2. How was your social life affected by surgery?

<table>
<thead>
<tr>
<th>Significantly improved</th>
<th>Somewhat improved</th>
<th>Unchanged</th>
<th>Somewhat worsened</th>
<th>Significantly worsened</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

3. How satisfied are you with the social support you get from friends and family currently?

<table>
<thead>
<tr>
<th>Extremely satisfied</th>
<th>Somewhat satisfied</th>
<th>Not sure</th>
<th>Somewhat dissatisfied</th>
<th>Extremely dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
4. Would you able to get to in-person support groups considering their location and accessibility?
   a). Yes   b). No

5. Would you describe yourself as having a “go getter” attitude?
   a). Yes   b). No
Appendix E

WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks.

<table>
<thead>
<tr>
<th>Very poor</th>
<th>Poorest</th>
<th>Neither poor nor good</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

1. How would you rate your quality of life?

<table>
<thead>
<tr>
<th>Very dissatisfied</th>
<th>Dissatisfied</th>
<th>Neither dissatisfied nor satisfied</th>
<th>Satisfied</th>
<th>Very satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

2. How satisfied are you with your health?

The following questions ask about how much you have experienced certain things in the last four weeks.

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little</th>
<th>A moderate amount</th>
<th>Very much</th>
<th>An extreme amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

3. To what extent do you feel that physical pain prevents you from doing what you need to do?
4. How much do you need any medical treatment to function in your daily life?

5. How much do you enjoy life?

6. To what extent do you feel your life to be meaningful?

7. How well are you able to concentrate?

8. How safe do you feel in your daily life?

9. How healthy is your physical environment?

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

10. Do you have enough energy for everyday life?

11. Are you able to accept your bodily appearance?

12. Have you enough money to
13. How available to you is the information that you need in your day-to-day life?

14. To what extent do you have the opportunity for leisure activities?

15. How well are you able to get around?

16. How satisfied are you with your sleep?

17. How satisfied are you with your ability to perform your daily living activities?

18. How satisfied are you with your capacity for work?

19. How satisfied are you with
yourself?

20. How satisfied are you with your personal relationships?

21. How satisfied are you with your sex life?

22. How satisfied are you with the support you get from your friends?

23. How satisfied are you with the conditions of your living place?

24. How satisfied are you with your access to health services?

25. How satisfied are you with your transport?

The following question refers to how often you have felt or experienced certain things in the last four weeks.

26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?

(The WHOQOL Group, 1998)
Appendix F

Psychological Co-Morbidities Questionnaire

1. Have you ever been told or thought you might have

   a). Depression       Yes   No

   b). Suicidal thoughts Yes   No

   c). Alcoholism       Yes   No

   d). Social anxiety   Yes   No

   e). Other anxiety    Yes   No

   f). Other (specify)  Yes   No
References


Foster, G., Wadden, T., & Phelan, S. e. a. (2001). Obese patients’ perceptions of treatment outcomes and the factors that influence them. *Archives of Internal Medicine, 161*, 2133-2139.


