

Patients' perspective on obesity surgery

*Expectations, experiences and self-reported
outcomes*

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ABSTRACT

Overweight and obesity constitute a major challenge to human health worldwide, involving over 1.4 billion people. In Sweden, more than a third (36%) of the population is overweight, and 13% are obese. For the vast majority of morbidly obese patients, conventional treatment (e.g. dieting, pharmacotherapy and behavioural therapy) often fails in the long-term. Bariatric surgery is currently the only successful treatment. In 2011, 8,600 patients underwent such surgery in Sweden. In bariatric surgery research, the patient's perspective is rarely highlighted, which means that there is a lack of knowledge about problems that patients might experience, how they address them and whether these problems affect the outcome.

Aim: To explore patients' expectations, experiences and self-reported outcomes in connection with bariatric surgery in order to determine whether or not and how these aspects affect HRQoL, everyday life, weight loss, eating behaviour and gastrointestinal side-effects.

Methods: The effort to acquire scientific knowledge included seeking the unique in each individual case as well as group correlations and differences. For this reason, the data collection methods were both inductive and deductive, comprising interviews and questionnaires.

Results: Eating behaviour, HRQoL, and everyday life were reported to be very poor before surgery. The patients viewed bariatric surgery as the last resort to regain control over eating and weight and thereby their overall health. The surgery per se was considered the control mechanism and few patients felt that they were involved in the treatment.

In the first year after the procedure, overall health, eating behaviour and social life were improved dramatically due to the physiological restriction brought about by surgery and subsequent weight loss. In the second year, the

patients reported good but slightly decreased HRQoL, eating behaviour and everyday life compared to the previous year. During this year most patients experienced a weaker physiological restriction and were aware that willpower was essential in order to maintain what they had achieved. A small group of patients experienced loss of control over eating, leading to a negative self-image and fear of future weight gain. Several patients viewed dumping as something positive and wished for it to return when it ceased. Surplus skin was a major concern for the majority of patients two years after surgery, something they wished to correct by means of plastic surgery.

Comparison of laparoscopic Gastric Bypass (GBP) and Duodenal Switch (DS) surgery for super-obesity two years after the operation revealed that DS patients had significantly more gastrointestinal problems (diarrhoea; $p=0.002$, anal leakage of stool; $p=0.015$, and daytime defecation; $p=0.007$) than GBP patients. Both groups reported a significant improvement in psychosocial function, eating behaviour and HRQoL after surgery and no significant difference between the groups was evident.

Patients who experienced poor control over eating two years after surgery had significantly lower HRQoL in seven out of eight domains in the SF-36 Health Survey questionnaire ($p < 0.05$) compared to those who had control over eating. They also reported more Emotional ($p < 0.001$) and Cognitive Restraint eating ($p < 0.05$) and did not exhibit a significant weight loss between the first and second year after surgery ($p=0.15$) in contrast to patients who experienced being able to control their eating ($p < 0.001$).

Conclusion: From the patients' perspective, the issue of controlling food intake seems to play an important role for surgery outcome as well in their everyday lives. This knowledge can be used to make the patients more involved in their treatment and strengthen their belief in their own ability to influence the outcome as opposed to solely relying on the physiological constraint created by the operation, which seems to decrease over time. Healthcare resources would probably be better employed by identifying the small group of patients with poor post-operative control at an early stage and providing extra interventions for them.

Keywords: Bariatric surgery, patients' perspective, loss of control, eating behaviour, health related quality of life, well-being, surgery outcome, patient reported outcomes, gastrointestinal functions

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SAMMANFATTNING PÅ SVENSKA

Övervikt och fetma utgör en stor utmaning för människors hälsa runt om i världen och Världshälsoorganisationens (WHO) beräkningar visar att 1,4 miljarder människor är drabbade. I Sverige är mer än en tredjedel (36%) av befolkningen överviktig-, och 13% är feta. Ett tillstånd, som ofta leder till följsjukdomar som diabetes, hjärt-kärl sjukdomar, infertilitet och ökar risken för vissa typer av cancersjukdomar, samt även påverkar det psykiska välbefinnandet och sociala livet. För de allra flesta sjukligt överviktiga individer har traditionella behandlingsalternativ (t.ex. bantning, läkemedel och beteendeterapi) dåliga långtidsresultat och idag finns bara en vetenskapligt bevisad behandling som fungerar och det är så kallad Bariatrisk kirurgi. Den här typen av operationer har mer än tiofaldigats senaste decenniet och år 2011 opererades 8 600 personer i Sverige. För de allra flesta patienter innebär ingreppet en bestående viktnedgång, och ett friskare, mer välmående liv jämfört med innan operationen. Men senare tids forskning har visat att en mindre del av de patienter som opereras har svårt att behålla sin viktminskning och livskvalitet några år efter ingreppet. Orsakerna till detta är inte helt klarlagda.

Inom forskningen gällande den bariatrisk behandling är patientens perspektiv sparsamt belyst. Det saknas kunskap om vilka eventuella problem som patienterna upplever med behandlingen, på vilket sätt de bemöter dessa problem och om de påverkar utfallet efter kirurgi. Vid utvärderingar av medicinska behandlingar är det viktigt att detta perspektiv tas med då det många gånger skiljer sig från vårdgivarens perspektiv gällande en behandling och dess mål. Utifrån den här bakgrunden framkom avhandlingens övergripande syfte; att undersöka patienternas förväntningar, erfarenheter och självrapporterade utfall i samband med kirurgi. Även hur behandlingsresultatet påverkas efter kirurgi, det vill säga den hälsorelaterade livskvaliteten, det vardagliga livet, patientens viktminskning, eventuella biff effekter samt ätbeteende.

För att undersöka patientens erfarenhet av sin sjukdom och behandling användes induktiv, hypotesskapande forskningsmetod genom att genomföra semi-strukturerade intervjuer. Den framkomna texten analyserades med fenomenologisk hermeneutik eller grundad teori. Den deduktiva forskningsansatsen användes för att testa hypoteser. Detta gjordes genom att patienterna fyllde i enkäter som utvärderade upplevelse av hälsorelaterad livskvalitet, sjukdomsspecifik livskvalitet, gastrointestinala symtom samt ätbeteende.

Totalt ingick 70 patienter i någon eller några av avhandlingens delarbeten. Alla patienter var sjukligt feta och stod på väntelista för bariatrisk kirurgi. Större delen av studiepopulationen var inkluderad i en randomiserad klinisk prövning; ASGARD – Aker Sahlgrenska Gastric bypass and Duodenal switch study där två olika operationsmetoder vid super-obesitas (Body Mass Index [BMI] 50-60 kg/m²) jämfördes och utvärderades. Båda metoderna innebär att individens möjlighet till födointag och näringsupptag minskas genom restriktion och malabsorption.

Resultat: Före operation framkom det att patienterna upplevde låg livskvalitet, försämrat hälsotillstånd och ett ohälsosamt ätbeteende, faktorer som påverkade livet i stor utsträckning. Kirurgen sågs som en sista utväg och en extern kontroll mekanism för att återta kontrollen över födointag och vikten. Endast ett fåtal patienter såg sig själva som delaktiga i sin behandling.

Första året efter operationen var den allmänna hälsan, ätbeteendet och det sociala livet drastiskt förbättrat genom den fysiologiska begränsningen över födointag som operationen åstadkom och som i sin tur hade inneburit en stor viktnedgång.

Två år efter operationen rapporterade patienterna fortfarande bra, men något lägre livskvalitet, lite sämre ätbeteende och ett mer ”normalt” vardagsliv jämfört med föregående år. De flesta patienterna upplevde en minskad fysiologisk begränsning vid födointag jämfört med tidigare. De var nu också medvetna om att egen viljestyrka krävdes för att upprätthålla uppnådd viktnedgång med alla dess positiva effekter på hälsa och välbefinnandet som det inneburit. Flera patienter upplevde den ofta beskrivna bi-effekten av kirurgi, ”dumping syndromet” som något positivt, och något man saknade när det försvann. Ett fåtal patienter upplevde förlorad kontroll över födointag, vilket ledde till en negativ självbild och rädsla för framtida viktökning. Många patienter upplevde nu problem med överskottshud, något de önskade få hjälp med genom plastikkirurgi. En hjälp som var svår att få då ett BMI under 30 kg/m² krävs för att bli remitterad, en BMI-gräns som få patienter uppnått trots stora viktnedgångar. På grund av överskottshuden undvek många patienter allmänna platser såsom badhus och stränder, vissa kände sig också oattraktiva och det fanns en ovilja att visa sig inför sin partner.

Jämförelsen mellan tithålskirurgierna Gastric Bypass (GBP) och Duodenal Switch (DS) som behandling för super-obesitas, visade hur DS patienter hade betydligt fler tarmfunktionsproblem (diarré; p=0.002, avföringsläckage; p=0.015 samt fler dagliga avföringar; p=0.007) jämfört med GBP patienter, två år efter operationen. Båda grupperna var signifikant mindre påverkade av

sin fetma i sociala situationer. Deras ätbeteende var bättre och livskvaliteten var högre efter operation, men det fanns inga signifikanta skillnader mellan grupperna.

Patienter som upplevde sig ha en låg kontrollkänsla över sitt ätande två år efter operation skattade signifikant sämre livskvalitet i sju utav åtta hälsodomäner i enkäten SF-36 ($p < 0.05$), hade en högre grad av emotionellt ($p < 0.001$) respektive kognitivt återhållsamt ätande ($p < 0.05$), samt en icke signifikant viktnedgång mellan första och andra året efter operation ($p = 0.15$) jämfört med patienter som upplevde sig ha kontroll över ätandet ($p < 0.001$).

Konklusion: Utifrån patientens perspektiv förefaller känslan av kunna kontrollera ätandet vara av stor betydelse för det kirurgiska utfallet såväl som i individens vardag. Denna kunskap kan användas för att göra patienterna mer delaktiga i sin behandling och stärka deras tro på sin egen förmåga att påverka resultatet, i motsats till att enbart förlita sig på den fysiologiska begränsning som skapas av operationen eftersom denna verkar avta med tiden. Vårdresurser skulle förmodligen utnyttjas mer optimalt genom att identifiera och intervensera gentemot den mindre grupp av patienter med sämre postoperativ kontroll över ätande tidigt efter kirurgi och på så sätt främja ett framgångsrikt långsiktigt resultat.

Nyckelord: Bariatrisk kirurgi, patientperspektiv, kontroll, ätbeteende, hälsorelaterad livskvalitet, välbefinnande, kirurgiskt utfall, patientrapporterat resultat, magtarmfunktion

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LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals.

- I. Engström M, Wiklund M, Fagevik Olsén M, Lönroth H, Forsberg A.
The meaning of awaiting bariatric surgery due to morbid obesity.
The Open Nursing Journal 2011;5:1-8
- II. Engström M and Forsberg A. Wishing for deburdening through a sustainable control after bariatric surgery. International Journal of Qualitative Studies on Health and Well-being 2011,
doi;10.3402/qhw.v6i1.5901
- III. Søvik T, Karlsson J, Aasheim E, Fagerland M, Björkman S,
Engström M, Kristiansson J, Olbers T, Mala T. Gastrointestinal function and eating behavior after gastric bypass and duodenal switch. Surgery for Obesity and Related Diseases 2012,
doi;org/10.1016/j.soard.2012.06.006
- IV. Engström M, Forsberg A, Søvik T, Olbers T, Lönroth H, Karlsson J.
The super-obese patients' sense of control over eating behavior after bariatric surgery – an important factor for outcome. In manuscript

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ABBREVIATIONS

ASMBS	American Society for Metabolic and Bariatric Surgery
ASGARD	Aker Sahlgrenska Gastric bypass and Duodenal Switch study
DS	Duodenal Switch
BMI	Body Mass Index
%EBL	Percent of excess BMI lost
%EWL	Percent of excess weight lost
GBP	Gastric Bypass
GSRS	Gastrointestinal Symptom Rating Scale
HRQoL	Health Related Quality of Life
LCD	Low Calorie Diet
NIH	National Institute of Health
OP scale	Obesity related Problem scale
P	Statistical probability
PCC	Person-centred care
PRO	Patient reported outcomes
SF-36	Short Form-36 Health Survey
SOS study	Swedish Obese Subject Study
TFEQ-R21	Three Factor Eating Questionnaire
VLCD	Very Low Calorie Diet
WHO	World Health Organization

1 INTRODUCTION

Overweight and obesity constitute one of the major challenges to human health worldwide, involving more than 1.4 billion adults and 40 million children. Approximately 500 million people are considered obese with a Body Mass Index (BMI) $> 30 \text{ kg/m}^2$, figure 1. Overweight and obesity are also the fifth leading global death risk, causing at least 2.8 million deaths each year. In addition, obesity represents 44% of the disease burden in diabetes and 23% in ischaemic heart disease¹. In the 2011 national public health survey in Sweden, 43% of the adult male population and 28% of the adult female population reported being overweight, and 13% and 14% respectively were obese². Bariatric surgery is the only effective treatment that leads to sustainable weight loss in morbidly obese individuals³. In Sweden, 8,600 operations were performed in 2011⁴. Although bariatric surgery is a common procedure today, the patient perspective has rarely been investigated. Thus, the present thesis explores the patient perspective.

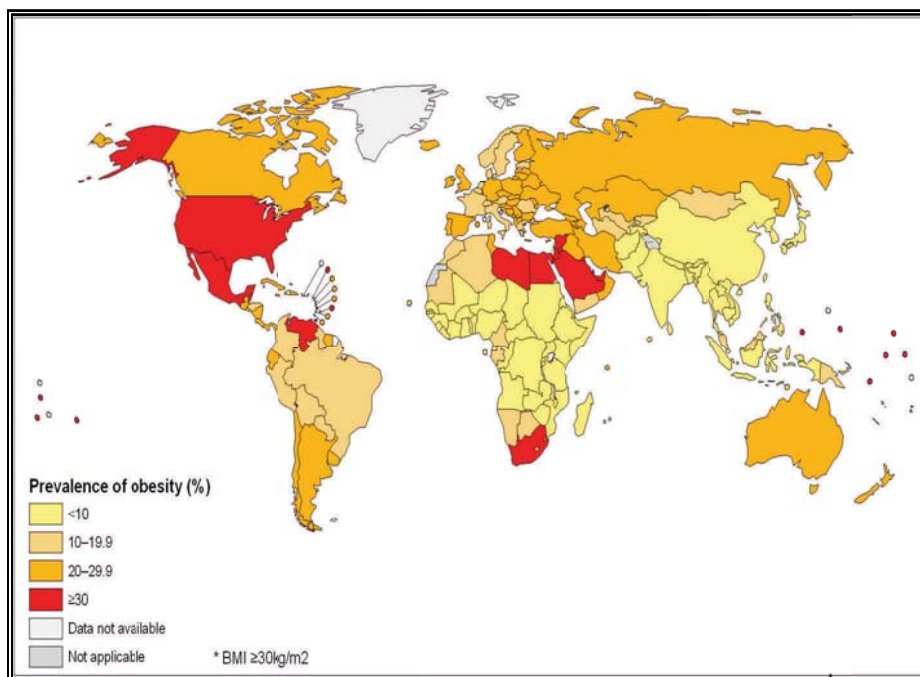


Figure 1. Worldwide prevalence of obesity in 2008 (WHO). Reproduced with permission of the WHO⁵.

1.1 The disease of obesity

Obesity is a chronic medical condition with a complex pathology. Despite extensive research over many years, all mechanisms involved are not fully understood.

Overweight and obesity are based on the BMI and calculated by weight divided by the square of height = kilograms/metre². According to the WHO's definition, overweight starts at BMI 25 kg/m², Obesity class I at BMI 30 kg/m², class II at BMI 35 kg/m² and class III at BMI 40 kg/m²¹.

The unhealthy state caused by obesity has been recognised for centuries; Hippocrates wrote: "*Corpulence is not only a disease itself, but the harbinger of others*"⁶. In the 1950s, Breslow⁷ stated that mortality in cardio-vascular-renal disease was closely related to overweight and that weight control was a major public health issue that needed to be addressed and treated effectively. Today it is acknowledged that obesity is due to the interaction between environment, psychosocial factors and genes acting through the physiological regulation of energy intake and expenditure⁸. The physiological system is designed to protect us from starvation. When a person starts to lose weight, strong signals, e.g. appetite stimulated by ghrelin hormones, are sent out by the gut system, triggering increased food intake⁹. Simultaneously, energy expenditure decreases due to the reduced Leptin hormone level¹⁰. Findings have also revealed how malnutrition early in life increases the risk of obesity in the future. The hypothesis is that energy deficiency triggers metabolic as well as hormonal changes that facilitate accumulation of excess body fat¹¹. There is also a hypothesis termed "the foetal origins of the disease", where an undernourished mother causes the foetal genes to remain at *energy saving* level, leading to an unhealthy accumulation of energy in later life¹².

Obesity negatively affects many organ systems. One example is the metabolic syndrome comprising several interacting risk factors that have a spin-off effect and increase the risk of co-morbidities such as diabetes and cardiovascular diseases. Bray¹³ divided the co-morbidities of obesity into two categories; those attributable to the effects of increased fat mass (stigma, sleep apnoea, osteoarthritis) and those caused by increased release of peptides from enlarged fat cells (diabetes, cardiovascular diseases, cancer). Obesity also increases the risk of mood and anxiety disorders¹⁴. In summary, obesity is a lethal multi-dimensional disease as illustrated in figure 2, leading to ill health and lowering life expectancy by several years¹⁵.

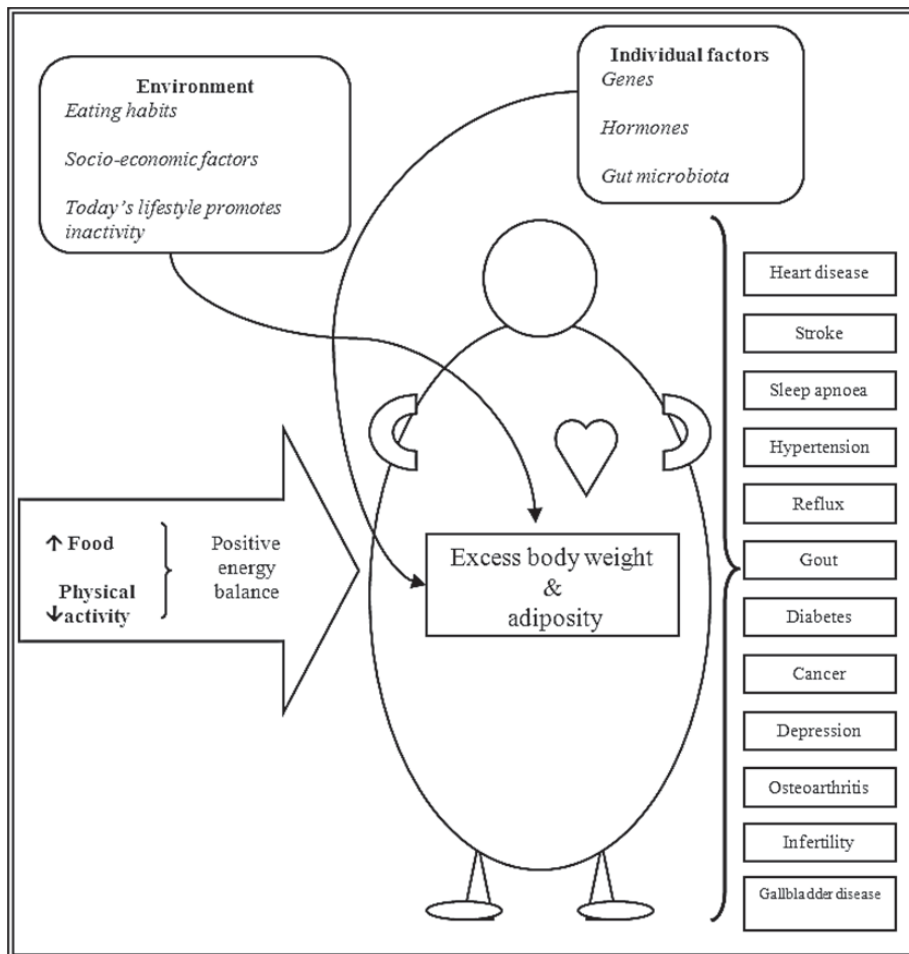


Figure 2. A multi-dimensional explanation of obesity; causes and effects.

1.2 Food

An important factor in the increasing obesity epidemic throughout the world is the shift in eating patterns during recent decades¹⁶. Another explanation is that the financial resources to buy food have increased. Ljungvall and Gerdtham concluded that while the modern economic situation has transformed many people's lives for the better, it has also created new problems, e.g. obesity¹⁷. The pattern of food consumption started to change in the 1950's. Since then, less vegetables, fruit and whole grains are eaten¹⁶ in favour of so-called fast food that comprises large portions of energy-dense food with a high fat content and drinks with a high sugar content¹⁸. This unhealthy behaviour has also emerged in many developing countries where

cheap, high-fat but non-nutritious food is now more available¹². In Sweden, the total amount of calories per capita has increased from 2,823 Kcal/day in 1960 to 3,170 Kcal/day in 2010, a 12% rise according to Swedish Board of Agriculture statistics¹⁹. In the latter year, approximately 15% of the energy intake was derived from food containing a great deal of sugar and low nutrient density such as confectionary, soft drinks, pastries and snacks. In general, young men and women (18-30 years) had the poorest eating habits, although on the whole women were better in this respect than men²⁰.

1.3 The obese person

Several studies^{18,21,22} have found that obesity is more common in lower socio-economic categories. Galobardes et al.²³ revealed that, in general, overweight men and women had a lower educational level and that overweight women also had a lower socio-economic status. However, more recent research on the impact of socio-economic factors and obesity has indicated a shift. For example, in their study of US adults between 1960 and 2008, Ljungvall and Zimmerman²⁴ found that the increased rate of obesity was not linked to race, education or income. They concluded that the obesity epidemic has accelerated and spread to all socio-economic groups, thus everyone would benefit from a healthier lifestyle.

Stigmatization of the obese individual is widespread and it has even been claimed that such persons are the only remaining acceptable target for discrimination. The discriminatory attitudes prevalent in society and the health care services are based on beliefs that obese individuals are lazy, less intelligent and responsible for their obesity, in other words that people get what they deserve and deserve what they get²⁵. Despite new knowledge on the causes of obesity, its increased prevalence and existence in all social classes, being obese is still associated with considerable social stigma. Some researchers have pointed out that stigmatization of obese children has become worse over the past 40 years, even though obesity among children has doubled in the same period²⁶.

1.4 Treatment of obesity

Preventing and treating overweight and obesity represents a tremendous challenge, since losing weight is difficult and maintaining the weight loss even harder, regardless of the type of conventional treatment provided (figure 3)²⁷⁻²⁹. Traditional dieting and pharmacotherapy treatment often fail to achieve a successful long-term outcome³⁰. Nevertheless, even a small weight

reduction (5-10%) in overweight and obese patients has beneficial effects on cardiovascular risk factors and reduces the risk of diabetes³¹. Wadden and Osei³² suggested a conceptual scheme for selecting treatment for overweight and obesity, where those with a BMI of $< 27 \text{ kg/m}^2$ are recommended self-directed lifestyle changes, i.e., diet, exercise and physician counselling. Level 2 in their scheme for persons with a BMI of $27\text{-}29 \text{ kg/m}^2$ comprises activity and an appropriate diet in combination with a behavioural programme. For individuals with a BMI of $30\text{-}39 \text{ kg/m}^2$, Wadden and Osei recommended a portion controlled, low calorie diet and pharmacotherapy.

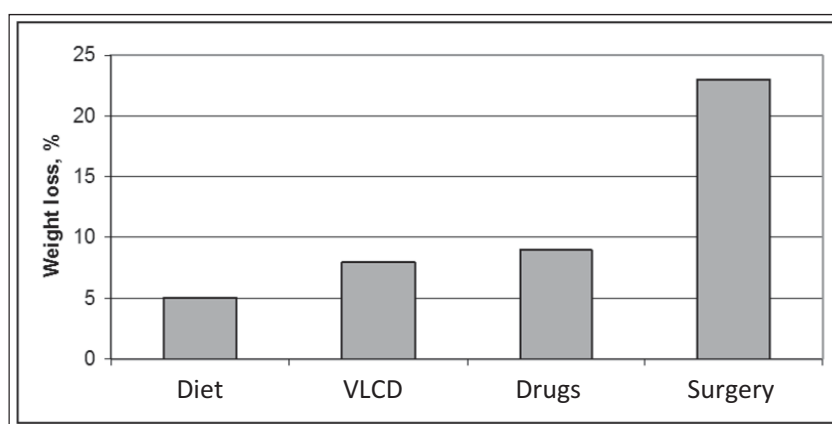


Figure 3. Two-year treatment outcome of different therapeutic strategies. Reproduced with permission of the author³³.

1.5 The evaluation prior to bariatric surgery

In 1992, the US National Institute of Health (NIH)³⁴ presented patient criteria for bariatric surgery in cases of morbid obesity, which in brief are as follows; BMI $\geq 40 \text{ kg/m}^2$ or BMI ≥ 35 and severe comorbidities associated with obesity and aged between 18 and 60 years. Patients should have made several attempts using conventional treatment and be compliant with lifelong follow-up. Finally, potential patients should have no history of substance abuse or major psychiatric disorder³⁴. Morbid obesity is a common classification within the field of bariatric surgery and indicates an individual with a BMI of over 40 kg/m^2 or 45 kg above her/his ideal weight. Further classifications of obesity by the American Society for Bariatric surgery (ASBS) are; severe obesity (BMI $35\text{-}40 \text{ kg/m}^2$), morbid obesity (BMI $40\text{-}50 \text{ kg/m}^2$), super-obesity (BMI $50\text{-}60 \text{ kg/m}^2$) and finally, super-super obesity (BMI $>60 \text{ kg/m}^2$)³⁵.

If a patient meets the above criteria there should be a comprehensive multi-professional assessment prior to bariatric surgery, including obesity history, e.g. weight trends and weight loss attempts, physical examination including cardiovascular and sleep apnoea evaluation, routine laboratory tests such as investigating pre-operative nutritional deficiencies and a mental health evaluation to identify potential psychosocial distress and eating behaviour as well as the patient's perceptions about weight loss to avoid unrealistic expectations³⁶. Two to three weeks before surgery, patients could be advised to start a very low calorie diet (VLCD), primarily to improve the conditions for laparoscopic surgery by reducing liver size and abdominal adiposity³⁷.

1.6 The surgical procedures

The first surgical attempt to cure obesity took place in Sweden in 1952 when Doctor Viktor Hendrikson performed an irreversible, extensive small bowel resection on a morbidly obese female patient, which led to a malabsorptive weight loss. In a follow-up 30 years after the procedure, it was reported that the patient was alive, well and no longer obese^{38,39}. In the 1960's, Jejunum shunt surgery⁴⁰ and Gastric Bypass surgery⁴¹ were introduced for surgically treating morbid obesity. Twenty years later, two additional techniques were introduced; Gastric Banding⁴² and Biliopancreatic Diversion by Scopinaro⁴³ as well as a modification of the latter; Biliopancreatic Diversion with Duodenal Switch surgery⁴⁴. In 2010 the American Society for Metabolic and Bariatric surgery recognizes Sleeve Gastrectomy as an acceptable options as a primary choice of bariatric procedure⁴⁵. These surgical techniques are divided into two groups; malabsorptive and restrictive. The former limits absorption of calories and the latter restricts food intake due to reduced gastric volume. Some procedures employ one of these mechanisms (Gastric Banding), while others combine the two (Gastric Bypass)⁴⁶. Figure 4 presents the most common bariatric surgery techniques.

The transition from an open to a laparoscopic procedure began in the 1990's⁴⁷⁻⁴⁹. Today, 90% of first time bariatric surgery, unlike revision or re-operation, is performed by means of the laparoscopic technique⁵⁰. In 2008, approximately 344,221 bariatric operations were performed around the world. The most common techniques were Laparoscopic Adjustable Gastric Banding (42.3%) and Laparoscopic Gastric Bypass (39.7%). Total Sleeve Gastrectomy was used in 4.5% of cases and Biliopancreatic Diversion with or without Duodenal Switch in 1.7%⁵⁰.

According to the Scandinavian Obesity Surgery Register (SOReg), Laparoscopic Gastric Bypass is the most frequently employed technique in Sweden, constituting 97% of all operations⁴.

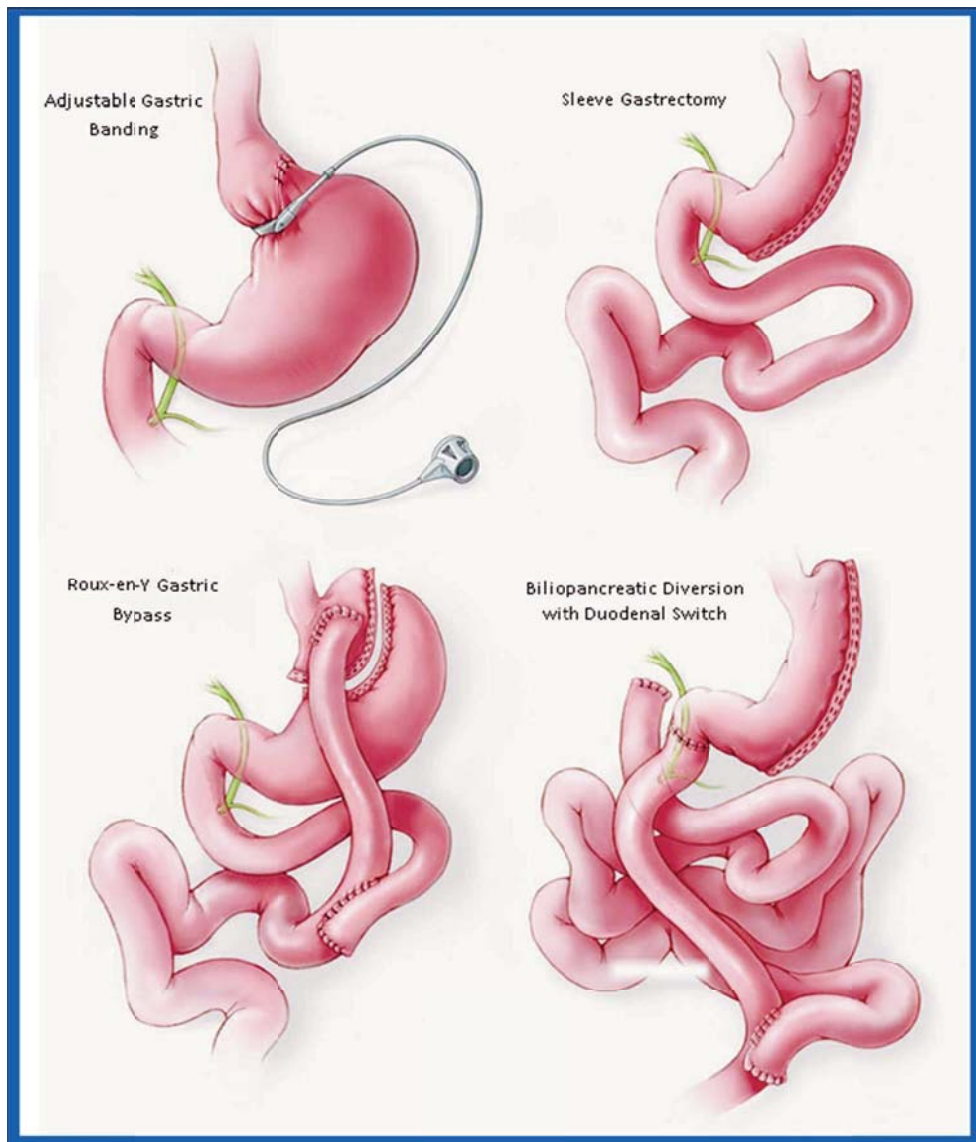


Figure 4. The most common bariatric surgery techniques. Reproduced with permission of the author⁵¹, Copyright Massachusetts Medical society⁵².

1.7 Mortality and possible surgical complications

Both the early (≤ 30 days) and the late (< 2 years post-surgery) mortality rate after bariatric surgery is low, approximately 0.3-0.35%^{53,54}. The mortality rate in Sweden from 2007 to 2011 during which period 26,162 operations were performed was 0.05% within 30 days and 0.09% up to 90 days after surgery⁴. Differences in mortality rates between surgical techniques vary, where Laparoscopic Banding has the lowest risk compared to open Biliopancreatic Diversion and revisions that have the highest. Open surgery involves a higher risk of death compared to laparoscopic procedures. Patient characteristics such as super-obesity, male gender, elderly and significant comorbidities appear to result in higher mortality⁵³.

The complications, e.g., thromboembolism, anastomotic leaks, bleeding and internal hernias, as well as quantity of complications after bariatric surgery differ between techniques and are also related to the surgeon's experience⁵¹. In the SOS study³, early post-operative complications occurred in 13% of the participants, almost half of which (6.1%) were pulmonary. In the SOReg 2011 annual report it was stated that the risk of the patient experiencing some type of complication was 10%, with significant variation between clinics⁴. Nausea and vomiting are common complications after restrictive surgery, often due to overeating or rapid eating, but sometimes caused by mechanisms triggered by the surgery⁵¹. One adverse event following Gastric Bypass is the dumping syndrome, which includes symptoms such as nausea, vomiting, diarrhoea and tiredness caused by calorie dense food, mainly carbohydrates^{55,56}. In the study by Laurenius et al.⁵⁷ in 2013, the prevalence of dumping 2 years after Gastric Bypass surgery was only reported by a small number of participants (between 6-12%) who had symptoms such as post prandial fatigue, nausea and fainting etc. Nutritional deficiencies are a late complication that can occur after surgery, for example, anaemia as well as low iron, calcium and vitamin levels. These deficiencies are most common following operations containing components of malabsorption such as Gastric Bypass and Biliopancreatic surgery but very rare after Banding procedures⁵¹.

1.8 Follow-up, medication and dietary treatment after bariatric surgery

In Sweden, the average length of hospital stay after surgery is 2.1 days⁴. Postoperative out-patient follow-up is recommended at 1 month, six months

and one year after surgery and thereafter once a year by a surgeon, dietician or nurse with knowledge of bariatric surgery³⁶. However, after the first year many patients are referred to primary health care for annual follow-up visits⁴, mainly for blood sampling to detect any deficiency.

A recommendation after discharge is the prescription of daily nutritional supplements; multivitamin mineral tablets including folic acid, vitamin B₁₂, calcium citrate with vitamin D and iron for fertile women, all of which should be taken on a lifelong basis after bariatric surgery³⁶.

Dietary recommendations usually comprise one week of liquid food including a protein drink. Thereafter, semi-solid or soft food with a protein drink is prescribed up to day 30. Solid food is recommended from day 31-60, with the exception of food that is difficult to digest (e.g. raw carrots, asparagus) and finally, from day 61 onwards, all solid food is allowed. Patients also receive advice about meal sizes, food choices that have good nutritional value and eating behaviour such as eating slowly and not drinking during meals^{36,58,59}.

1.9 Previous research in the area of bariatric surgery

Various aspects of bariatric surgery have been investigated and some of them are presented under the following themes:

- Bariatric surgery as an accepted treatment for morbid obesity
- Weight loss after surgery
- Improvement of co-morbidities
- Health related quality of life (HRQoL)
- Eating behaviour
- Outcome predictors
- Patients' experiences

1.9.1 Bariatric surgery; a recognised treatment for morbid obesity

In their 2004 review, Buchwald et al.⁶⁰ stated on page 1,736 that; *“All therapeutic interventions need to have efficacy balanced against risk. In such*

assessment, bariatric surgery does well". The statement in this well-cited review (according to Scopus, 2,128 times up to January, 2013) was based on low mortality rates, effective weight loss and full or partial recovery from co-morbidities. In 2002, the Swedish Council on Technology Assessment in Health Care (SBU) published a report; Obesity – Problems and Interventions, which had a major impact on the Swedish health care system and which stated that bariatric surgery is the only evidence-based treatment for patients with morbid obesity⁶¹. Two Swedish articles from the prospective, controlled Swedish Obese Subject Study (SOS study) published in 2004 and 2007 compared bariatric surgery with conventional treatment for morbid obesity. The 10-year follow-up data revealed that the surgery group exhibited greater weight loss, lower energy intake, more physically active participants, higher rates of recovery from co-morbidities and decreased overall mortality compared to the control group^{3,62}.

1.9.2 Weight loss

The primary end-point for many studies of bariatric surgery is weight loss, commonly termed percentage of excess body weight loss (%EWL). Similar to many of the outcome measurements after surgery, the amount of weight loss also differs between surgical techniques. Please see Table 1 for a summary. Weight loss stabilizes between 18 and 24 months after surgery, often with a small regain during the third year⁶³. A successful outcome is often defined as EWL > 50%^{36,64,65}. Studies have revealed that between 5 and 30% of patients fail to achieve long-term successful weight loss after surgery, where the variation was partially due to different surgical methods^{36,66-69}.

Table 1. Weight loss \geq 2 years after surgery⁷⁰⁻⁷².

Type of surgery	Gastric Banding	Gastric Bypass	Duodenal Switch	Sleeve Gastrectomy
Weight loss (kg)	38.3	41.4	49.8	41.7
%EBL	49.0	63.3	73.7	64.3

1.9.3 Co-morbidities

Given that many obese individuals suffer from co-morbidities, recovery or improvement is an important factor when evaluating obesity surgery. Today, 'metabolic surgery' is sometimes used as a complementary term or instead of bariatric surgery. In recent years, great focus has been placed on the improvement of diabetes after surgery. Gastric Banding procedures cure this condition in 58% of cases, Gastric Bypass in 71% and Biliopancreatic

Diversion/Duodenal Switch in 96%⁷⁰, while Sleeve Gastrectomy is effective in this respect in 85%⁷³. Bariatric surgery has also been found to significantly improve glycaemic control in obese patients with uncontrolled type 2 diabetes compared with intensive medical therapy⁷⁴. In the SOS study, the surgery group had a more favourable recovery at the 10 year follow up compared to the control group in all of the risk factors studied, with the sole exception of hypercholesterolemia. The incidence rates of hypertriglyceridemia, diabetes and hyperuricemia were also better in the surgery group³.

1.9.4 Health related quality of life (HRQoL)

As the aim of the various forms of bariatric surgery is not only to improve the physical health status, but to restore function and well-being, HRQoL must be one of the endpoints when evaluating the treatment⁷⁵. Quality of life surveys were not continuously used within the field until the end of the 1990's; thus the two-year follow-up in the SOS study was one of the first to evaluate HRQoL as well as eating behaviour⁷⁶ in bariatric surgery research.

Obese individuals report poorer HRQoL than those who are non-obese⁷⁷ and also compared to patients with other chronic conditions⁷⁸. Furthermore, obese individuals who seek surgery report lower HRQoL than those who consider other treatment options⁷⁶. According to van Hout et al.⁷⁸, obesity is nowadays associated with higher morbidity and poorer HRQoL than smoking, problem drinking and poverty. In the SOS study, it was reported that HRQoL was generally related to weight loss, weight regain and weight stability. The surgery group experienced a significantly better outcome in terms of current health status, social interaction and psychosocial function as well as being less depressed compared to the conventionally treated group. Furthermore, it was found that the 10% weight loss achieved by approximately two-thirds of the surgery group was sufficient to ensure a positive long-term outcome in terms of HRQoL⁷⁹.

1.9.5 Eating behaviour

Several studies have demonstrated that bariatric patients have poorer eating behaviour before than after surgery^{3,80-82}. Other studies have revealed the differences between obese and non-obese persons, where the former tend to have a higher disinhibition scale score (inability to resist food stimuli or social and emotional eating situations)⁸³, stronger feelings of hunger⁸⁴, more cognitive restraint eating⁸⁵ and a higher mean calorie intake⁸³ compared to the latter. In the SOS study, mean calorie intake before surgery was 2,882 kcal/day, which decreased by 20% at ten years after surgery³. There have also

been reports of differences in dietary intake and food choice associated with the surgical technique employed^{86,87}. Olbers et al.⁸⁸ found that Gastric Bypass patients consumed less fat than Vertical Banded Gastroplasty patients, who in turn consumed more sweets and avoided whole meat and vegetables.

1.9.6 Outcome predictors

As the weight loss achieved after surgery is not maintained in the long-term in approximately 5 to 30% of patients^{36,66-69}, there is an interest in finding pre-operative predictors of weight loss and weight stability. Several research papers have been published on Binge Eating Syndrome (BED) and its possible impact on post-operative weight loss⁸⁹⁻⁹². BED is characterized by repeated binge eating, i.e., an individual consumes very large portions of food within a limited period and has the feeling of being incapable of restricting her/himself. The prevalence of BED among persons seeking treatment for obesity is 30% compared to the 2-5% in the general population⁹³. In Livhitt's 2012⁶⁷ review, three studies reported that pre-operative BED patients lost more weight after surgery, while 13 found no such association. Finally, four studies concluded that there was a negative association between pre-operative BED and weight loss after surgery.

The review by Livhitts⁶⁷ found no strong pre-operative predictor of surgery outcome. Nevertheless, the findings revealed that some factors probably contribute to poorer weight loss after surgery, such as super-obesity and a personality disorder, i.e., hysteria and paranoia, while prescribed pre-operative weight loss had a positive effect on weight loss after surgery.

Some recent studies have illustrated how early post-operative factors can play an important role in long-term outcome compared to pre-operative factors. For example, post-operative loss of control over eating had a negative impact on weight reduction but was not correlated if identified before surgery^{94,95}. In conclusion, patients' ability to adjust their lifestyle and eating habits *after* surgery also plays an important role in long-term outcome.

1.9.7 Patients' experiences

Only a small part of previous research on bariatric surgery attempted to grasp the patient perspective by means of qualitative research methods, i.e., interviews and focus groups. To the best of our knowledge, only 26 qualitative articles were published up to 2013, describing the patients' experiences of the procedure as well as nurses' accounts of caring for this patient group. The main conclusion from these studies was the shift in patients' sense of control over eating from before to after surgery. Please see

Table 2 for a summary of the results from these studies. The 26 articles can be compared to a Pubmed search using the terms; bariatric surgery AND weight loss, which resulted in 4,835 hits. Thus qualitative research constitutes a very small percentage in this area.

Table 2. Summary of the results of qualitative bariatric surgery studies published between 2002 and 2013.

Overall findings	References	No of references
Absence or presence of control over food intake before and after surgery and its consequences.	96-105	10
Stigmatization before surgery due to the obese body and afterwards because bariatric surgery is viewed by others as “the easy way out”.	97, 98, 100, 106-111	9
Improved physical and mental well-being after surgery.	96, 97, 100, 101, 108, 111-114	9
Focus on food and eating; emotional eating, food addiction and food as ever present.	96-98, 100, 102, 103, 111, 112, 115	9
Surgery as a last resort after a number of unsuccessful weight loss attempts.	97-99, 103, 105, 116	7
Re-entry into family and society after bariatric surgery.	97, 100, 112, 113, 116, 117	6
Problems with surplus skin after surgery.	97, 100, 112, 117	4
Patients’ explanation of their obesity; genetic factors, stressful life situations, pregnancy.	96, 101, 110, 118	4
Lack of patient involvement in their treatment.	96-98, 118	4
Nurses’ experiences of caring for obese patients; ambivalence towards treatment, fear of injury	119, 120	2
Patients’ reasons for substance abuse after surgery, e.g. unresolved psychosocial problems, faster and stronger effects	121	1
Grazing, a risk factor after surgery.	122	1
Differences and similarities between patients’ and health care professionals’ views on bariatric surgery	123	1

1.10 Main concepts in research on outcome

This thesis focused on understanding and explaining potential factors of importance for the outcome of bariatric surgery. Two important concepts will be described and explained in the following.

1.10.1 Health and well-being

Health has been an important issue for many centuries, stretching back to philosophers such as Plato, Decartes and Kant. The issue is just as important today and many health authorities are required to maintain and promote health in the population in addition to treating diseases¹²⁴. There is no single consensus on health, but in 1946 the WHO formulated its constitution, which includes the quotation: *Health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity*¹²⁵. Katie Eriksson¹²⁶ described health and the human being in a holistic way as a multidimensional wholeness strongly connected to body, mind and spirit. People can promote health by eating nutritious food, exercising and resting. Unfortunately many individuals do not fully appreciate their health until it is gone. The definition of health differs and depends on a person's present situation, culture, competence etc.¹²⁶.

1.10.2 Health Related Quality of Life (HRQoL)

Evaluating HRQoL in health care and clinical research provides knowledge of patients' opinions of their treatment. The information thus obtained often differs from the health care professionals' impression, but if properly utilised can lead to more holistic care. Investigating HRQoL involves collecting knowledge that will reduce problems and increase the well-being of the individuals concerned, in this case the bariatric patient. In the bariatric surgery context, HRQoL can be viewed as the functional effect of obesity and subsequent therapy, as perceived by the patient¹²⁷. Cohen¹²⁸ suggested 30 years ago that it would be useful if prior to surgery, patients were to state what changes they hoped for and to ascertain, by means of follow up, the extent to which their expectations were realized.

It is believed that the term Quality of Life (QoL) was introduced by two American economists, Samuel Ordway and Fairfield Osborn. They were concerned that only quantitative factors, such as BNP/capita, cars and phones were used to measure social development and that environmental degradation was not taken into account¹²⁹. Some years later, Gailbraith wrote "*What counts is not the quantity of our goods but the quality of life*"¹³⁰. However, it was not until 1976 that the concept of QoL was included in the Index

Medicus¹²⁹. QoL is defined as a person's overall satisfaction with daily life, including general health, family situation, employment and standard of living¹³¹. Although there is no consensus on the meaning of the concepts of QoL and HRQoL, the definition proposed by Ware in 1987 has been widely used. He suggested that HRQoL measurements should relate to an individual's experience of physical and mental health, social and role function, as well as her/his perception of general health. Furthermore, all measurements should include the full range of health indicators, covering both function/dysfunction and well-being/distress¹³¹.

There are two different types of questionnaire for HRQoL measurement; generic- and disease-specific instruments. Generic questionnaires, such as the Short Form-36 Health Survey, were developed for measuring health from a general perspective and can be used when comparing patient groups with different diseases. These types of questionnaire can contain items that are irrelevant for certain patient groups. It is therefore recommended to include a disease-specific instrument comprising health issues that affect the study population¹²⁹, for example the Obesity-related Problems scale¹³².

In general, there has been a strong increase in the number of QoL measurements within medical science during recent decades¹³³, partially because traditional measures are no longer sufficient as health care assessments today are more patient-centred¹³⁴. New treatment methods, e.g. for incurable diseases, have led to a shift in many individuals' medical condition, which requires improved evaluation options as a complement to traditional measurements⁷⁵. Nowadays many patients are well informed about their health status and want to be involved in and influence their treatment, thus by using HRQoL questionnaires, patients' subjective perceptions are integrated in the care. Finally, when new medications are developed and tested, both questionnaires and interviews with patients have to be included in the testing process in order for the new drug to be approved¹³⁵.

1.11 Summary of the introduction

The increasing prevalence of obesity is a major public health concern around the world, as it leads to several forms of physical and mental ill health. For the vast majority of morbidly obese patients, conventional treatment, such as dieting, pharmacotherapy and behavioural counselling, often fails in the long-term. Bariatric surgery is currently the only effective treatment, although recent research has revealed that weight loss, weight stability and HRQoL vary both within and between different surgical techniques. Furthermore, there is a lack of knowledge of the patient perspective on treatment, a factor that could affect the outcome of surgery. This formed the background for the present thesis.

2 FRAMEWORK

The basic assumption in this thesis is that the patient perspective is an important cornerstone within research as well as when caring for the bariatric surgery patient.

2.1 Research perspective

The lived experiences of bariatric surgery patients can be studied by obtaining their inside perspective through interviews. Thorne & Paterson described the outside and the inside perspective. The former represents the symptoms of the disease, in this case obesity, based on pathophysiology, while the latter involves the patient's view of the disease and its consequences for her/his daily life, the so-called illness perspective. When taking the inside perspective into consideration, the focus changes from the client as a patient to the client as a partner in the caring process^{136,137}. According to Toombs¹³⁸, the outside and the inside perspective can also be termed the professional and personal understanding of the disease. Both perspectives are important and valid, with no contradiction between them. However, they differ from each other in four respects:

- **Focus on the current situation**
- **Attitude**
- **Relevance** – (i.e., what is important)
- **Perception of time**

2.2 Care perspective

2.2.1 Patient-centred care

The 1982 Swedish Health Care Act states that health care “*should be built on the patients’ autonomy and integrity*”, if possible “*be designed and implemented in consultation with the patient*” and finally, that “*patients should receive individually customized information about their health and the methods of diagnosis, care and treatment available*”¹³⁹. This piece of legislation corresponds well with the foundations of person-centred care, which in turn are derived from patient-centred care. According to Mead and Bowers¹⁴⁰, patient-centred care is an alternative to the positivist biomedical framework where the patient's accounts of her/his illness are only viewed from a sickness perspective and her/his illness experience is reduced to signs

and symptoms. Patient-centred care should be based on the following five assumptions:

- 1) Bio-psychosocial perspective; understanding the patient's disease in a broader framework, in which a description of symptoms is added to the potential social and psychological impact. This leads to the understanding that the medical approach to a disease is more than just biology.
- 2) Patient-as-person; every individual has a unique experience of illness. People experience the same disease in different ways, which also affect various aspects of their lives.
- 3) Sharing power and responsibility; it is important to involve the patient in her/his treatment, for example in the choice of treatment options thus ensuring compliance with treatment agreements.
- 4) Therapeutic alliance; grounded in an empathetic relationship based on a common understanding between health care professionals and care recipient.
- 5) The doctor-as-person; the physician's personality can affect the outcome as well as patient satisfaction. If the doctor has a positive attitude towards the patient, there is a greater chance of a satisfied patient and a favourable outcome¹⁴⁰.

2.2.2 Person-centred care (PCC)

During the past decade, person-centred care (PCC) has become more widely acknowledged and should be considered a further development of patient-centred care. The Committee on quality of health care in America¹⁴¹ stated in 2001 that it is necessary *"to customize care to the specific needs and circumstances of each individual, that is, to modify the care to respond to the person, not the person to the care"*, which implies a partnership between health care professionals and patients. The WHO described PCC as a target and key aspect of good quality health care that considers the patient's entire health situation and not only her/his illness¹⁴².

Carlström and Ekman¹⁴³ stated that the major challenge in Swedish health care today is rethinking and reorganizing clinical practice in order to meet the increasing demand. This challenge might be met by the implementation of PCC, as several studies have demonstrated that compared to "usual care", PCC reduces the length of hospital stay, leads to better maintenance of ADL activities, improves pain relief and results in fewer medical complications¹⁴⁴.

PCC involves three major components¹⁴⁷:

- 1) Initiating the partnership
- 2) Working the partnership
- 3) Safeguarding the partnership by means of documentation

Initiating the partnership means creating a good dialogue between the health care professionals and the patient, in which there is a mutual respect for each other's knowledge. While it is the care provider's responsibility to initiate this partnership, both parties must participate equally; the patient based on her/his treatment goals, experience and knowledge of the disease and the health care professionals with their knowledge of health care from a medical perspective. This approach facilitates the collection of important information, which is the cornerstone of an individually tailored care plan that is approved by both parties, in which tests and examinations, treatment, goals and hospitalization are documented and patients encouraged to participate in their treatment.

Furthermore, both health care professionals and the patient actively work together to achieve the goal of the PCC plan, which is evaluated on a regular basis to strengthen the interaction between patient and caregivers, monitor the treatment and ascertain whether any changes are required. To ensure safe care, the treatment and goals are routinely documented, thus the care plan can be seen as a contract between the patient and health care professionals¹⁴⁷.

2.2.3 Self-efficacy

Understanding the concept of self-efficacy might be important for the provision of PCC to patients. Self-efficacy is a social cognitive learning theory that concerns a person's confidence in her/his ability to cope with a specific task or challenging situation. The more a person believes her/himself capable of a task, the greater the chance that she/he will be successful. Individuals with high self-efficacy more often choose challenging missions and have a greater endurance than those with low self-efficacy¹⁴⁸. Research has revealed that self-efficacy plays an important role in successful outcome in several different areas; addictive behaviours such as alcohol consumption and tobacco smoking¹⁴⁹, conventional obesity treatment¹⁴⁸, exercise¹⁵⁰ and cardiac rehabilitation¹⁵¹. A study on bariatric patients and self-efficacy found a correlation between self-efficacy and HRQoL as well as a relationship between self-efficacy and weight loss¹⁵².

3 RATIONALES

Knowledge of bariatric patients' expectations on the surgical procedure as well as their long-term strategies for managing their life post-surgery was almost non-existent when this thesis began, although there were numerous studies that reported objective indicators. At the start of this research project, we only found six studies with an inside perspective^{101, 103, 105, 110, 112, 114}, thus understanding of the relationship between the objective conditions of life after bariatric surgery and the patients' subjective perceptions might be poor. Objective indicators alone could produce results unrelated to the patients' feelings and experiences. From a clinical perspective, knowledge of patients' perceptions is a necessary foundation for individual quality care. Surgical and caring interventions should be tailored in order to increase patients' ability to deal constructively with various concerns, thereby enabling them to experience HRQoL and satisfactory long-term weight loss. The basic idea behind this project was therefore to search for knowledge in the area of bariatric surgery, mainly from the perspective of patients. The aim of the thesis was to provide new knowledge about expectations before as well as experiences and consequences after bariatric surgery.

The first rationale of this thesis was to explore expectations and experiences on surgery as well as the main concerns among bariatric patients, how they dealt with them and whether such concerns affected the long-term outcome.

Due to the fact that improved HRQoL and eating behaviour are important goals of bariatric surgery as well as assessing potential side effects that can occur after surgery, self-reported outcomes play a vital role when evaluating the treatment, especially as patients and health care professionals often view success differently. Therefore, the second rationale was to explore how factors such as self-reported HRQoL, eating behaviour and gastrointestinal side-effects changed over time.

The issue of control in relation to food seems to be of importance before as well as after bariatric surgery. However, the different aspects of control after bariatric surgery are not well described and there is a lack of knowledge about whether this could be of significance for the outcome. Therefore, the third rationale was to test the hypothesis that a sense of control over eating two years after surgery improves long-term weight loss, eating behaviour and HRQoL.

In conclusion, this thesis:

- was conducted in the light of multi-professional surgical care, where one basic assumption was that knowledge of the patients' perceptions before and after bariatric surgery is necessary for quality care
- explores and illuminates the inside perspective, i.e., that of the bariatric patient, in order to understand underlying dimensions that might affect long-term outcomes after bariatric surgery and hinder the realization of stable weight loss and health
- employs both inductive and deductive reasoning to capture the complexity of outcomes after bariatric surgery.

4 AIM

The general aim of this thesis was to explore patients' expectations, experiences and self-reported outcomes in connection with bariatric surgery in order to determine whether or not and how these aspects affect HRQoL, everyday life, weight loss, eating behaviour and gastrointestinal side-effects.

4.1 Specific aims

- I. To investigate the meaning of awaiting bariatric surgery for morbid obesity.
- II. To examine in depth the change process experienced by patients undergoing bariatric surgery.
- III. To evaluate gastrointestinal side-effects, eating behaviour and changes in obesity-specific quality of life two years after Gastric Bypass and Duodenal Switch.
- IV. To explore how sense of control over eating behaviour changes after bariatric surgery and whether it affects outcome in super-obese patients.

5 METHODS

The efforts to acquire scientific knowledge included seeking the unique in each individual case (papers I and II) as well as group correlations and differences (papers III and IV). For this reason, the data collection methods were both inductive and deductive comprising interviews and questionnaires. Table 3 presents an overview of the research designs.

Table 3. Overview of research designs.

Paper	Aim	Study design	Participants	Analysis
I	To investigate the meaning of awaiting bariatric surgery for morbid obesity.	Interviews	23 patients	Phenomenological hermeneutics
II	To examine in-depth the change process experienced by patients undergoing bariatric surgery.	Prospective longitudinal. Interviews.	16 patients	Grounded theory
III	To evaluate gastrointestinal side effects, eating behaviour and changes in obesity-specific quality of life two years after Gastric Bypass and Duodenal Switch.	Prospective longitudinal randomized clinical trial. Questionnaires	60 patients	Statistical analysis
IV	To explore how control over eating behaviour changes after bariatric surgery and whether it affects outcome in super-obese patients.	Retrospective design. Questionnaires	49 patients	Statistical analysis

Induction can be defined as a type of reasoning that begins by studying a range of individual cases and using them as a basis for constructing a conceptual category, as in paper II¹⁵³. Humans differ as to how they experience the world, but these differences can be described, communicated and understood by others¹⁵⁴. The main purpose was to gain new conceptual insights based on hands-on research¹⁵⁵. An inductive approach was chosen in the first two studies because the area in focus had been poorly investigated from an inside perspective, thus there was a lack of knowledge about expectations on bariatric surgery and post-surgery experiences.

The epistemological assumption also involved a belief that knowledge about the outcome of bariatric surgery can be gained by observing patient by employing measurement instruments. The numerical data collected in the randomized trial allowed comparison and enabled statistically significant relationships. The deductive approach in paper III was motivated by the wish to confirm and empirically establish the differences between two surgical methods for super-obesity in terms of gastrointestinal symptoms, eating behaviour and obesity-specific QoL over time. In the fourth paper the deductive approach was chosen as it enabled the use of a hypothesis for testing the data that emerged from papers I and II.

5.1 Participants

In total, 70 patients participated in the studies in this thesis. Some were included in one of the papers and others in several. All were morbidly or super obese and on the waiting list for bariatric surgery. The first 10 patients in paper I came from Sahlgrenska University Hospital in Gothenburg, Sweden, and were morbidly obese (mean BMI 47.8 kg/m², mean age 49 years, 3 men and 7 women). The remaining 60 patients came from Sahlgrenska University Hospital (n=30) and Akers University Hospital, Oslo, Norway (n=30). They participated in a randomized clinical trial; ASGARD – the Aker Sahlgrenska Gastric Bypass and Duodenal Switch study. Baseline values for the whole group were mean BMI 55 kg/m², age 35.5 years, 18 men and 42 women. Figure 5 presents a detailed description of the patients who participated in the four studies. The interview studies (papers I and II) were sub-studies of the ASGARD trial and only involved the Swedish patients.

In the ASGARD trial, patients were randomised to Laparoscopic Gastric Bypass (GBP) or Laparoscopic Duodenal Switch (DS) as treatment for their super-obesity. The patients' BMI (50-55 or 56-60), age (20-35 or 36-50), sex and surgical centre were used as stratifiers in the randomisation. Detailed descriptions of the two surgical techniques are available in Søvik et al.^{156,157}. However, in brief; in GBP the stomach was divided proximally to create a 25 ml pouch and in DS a Sleeve Gastrectomy was performed using a 30-32 Fr nasogastric tube. The alimentary limb was 150 cm and the biliopancreatic limb 50 cm in GBP, while in DS the alimentary limb was 200 cm and the common channel 100 cm. According to Korenkov et al.¹⁵⁸, the aim of GBP surgery is to restrict the stomach and induce malabsorption by dividing the small intestine into an alimentary limb and a biliopancreatic segment. The aim of the DS procedure is to restrict the size of the stomach by means of a vertical gastric resection to remove the whole fundus for the purpose of

inhibiting ghrelin production and dividing the small intestine into an alimentary limb and a biliopancreatic segment to induce malabsorption¹⁵⁹.

The sample size for the ASGARD trial was based on weight loss two years post surgery, as that was the primary end-point. A retrospective analysis¹⁵⁶ of super-obese patients who had undergone GBP or DS at Sahlgrenska University hospital¹⁶⁰ was conducted. Patients who underwent GBP surgery had a mean BMI reduction of 18 kg/m² (SD, 6.7) compared to DS patients who had lost an average of 24.9 kg/m² (SD, 5.0). By applying these data to the power calculation it was found that 26 patients were required in order to achieve the 80% power necessary to detect significant differences between the groups. However, 60 patients were included in order to strengthen the analyses of secondary end-points and allow for possible drop-out. The sample size was calculated using Sample Power, version 2.0 (SPSS, Chichago, IL)¹⁵⁶.

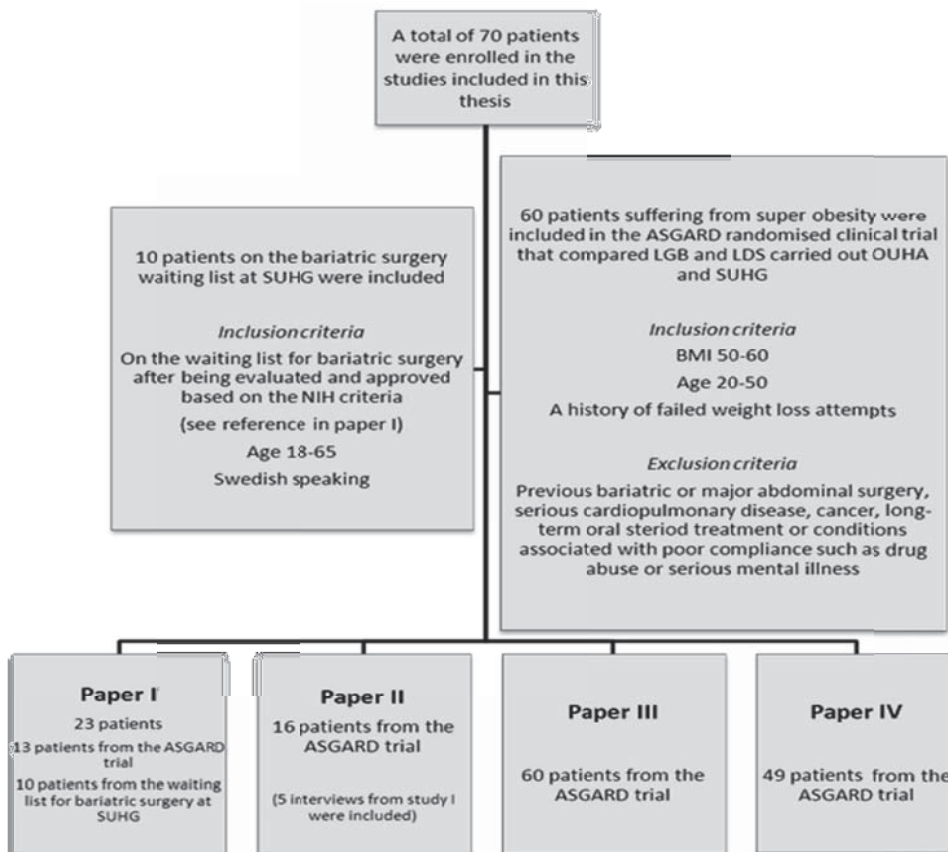


Figure 5. Flowchart of the patients in the four papers.

5.2 Paper I

As the aim was to study the obese patients' lived experiences of awaiting bariatric surgery, a phenomenological hermeneutic approach was chosen. This text interpretation method was developed in the late 1990's and early 2000's by Anders Lindseth and Astrid Norberg inspired by the philosophy of Paul Ricoeur¹⁶¹. According to Ricoeur¹⁶², phenomenology has its foundation in the lived experience of being in the world, which can only be understood by others through language. The text is interpreted to establish the meaning of lived experience, i.e., to find out what the text "talks about" concerning the studied phenomenon¹⁶³. Phenomenological hermeneutics is based on both the hermeneutic method, i.e., text interpretation, and the phenomenological method, since the researcher wants to understand the meaning contained in the text¹⁶¹. Phenomenological hermeneutics is neither a "pure" phenomenological nor a "pure" hermeneutic method. The text is interpreted by the researcher and not read intuitively as in phenomenology. Likewise, the interpretation reveals essential meanings of the life world that transcend the text, which does not occur with the hermeneutic method¹⁶¹.

The reason for choosing phenomenological hermeneutics was the possibility to explore the meaning of the lived experience of the poorly understood phenomenon of being morbidly obese and awaiting bariatric surgery. It provided an opportunity to gain knowledge about what these patients experience, which can be used by other health care professionals in the care of other bariatric patients.

5.2.1 Data collection and data analysis

What is experienced by one person cannot directly become another person's experience. However, collecting the patients' narratives by means of interviews and then interpreting the text makes the meaning of the experience visible to others¹⁶².

In paper I, data were collected through audio-taped interviews that were transcribed verbatim and checked for accuracy by comparing the transcripts with the tapes. A total of 23 patients were interviewed prior to surgery on topics such as their reason for choosing bariatric surgery, expectations on surgery and eating behaviour. These interviews took the form of an open dialogue between the interviewer and patient. During the interviews the patients were encouraged to narrate as freely as possible about their lived experiences of the studied phenomenon.

The data analysis followed the three steps developed by Lindseth and Norberg¹⁶¹; naïve reading, structural analysis and comprehensive understanding. In the first step, the text was read through several times to ‘get to know’ it and gain an initial understanding. The first impression of its content emerged. The naïve understanding and first impression were examined and validated in the second step, the structural analysis, sometimes termed the thematic structural analysis. In this step the text is interpreted and divided into meaning units that capture the meaning of the lived experience described in the narratives. The meaning units were then reflected on in the light of the naïve understanding, after which they were condensed and sorted into themes and sub-themes. In the final step, the themes were summarized and reflected on as a “whole” text in relation to the research question. A comprehensive understanding of the studied phenomenon was based on the naïve reading, the validated themes and the authors’ pre-understanding¹⁶¹.

In phenomenological hermeneutics, there are some important aspects that should be considered¹⁶¹:

- Being aware of and critically reflecting on one’s pre-understanding. It may be necessary to study relevant literature to broaden understanding.
- The result describing the lived experience should be formulated in everyday language and the category labels using the gerund form of the verb.
- Within this research method one cannot expect to find one single truth, since the whole truth can never be fully understood.
- There are always several probable interpretations of a text, as a text has more than one meaning.

Finally, Lindseth and Norberg who developed this method stated (page 152)¹⁶¹:

“Phenomenological hermeneutics lies between art and science. We use our artistic talents to formulate the naïve understanding, our scientific talents to perform the structural analysis and our critical talents to arrive at a comprehensive understanding”.

5.3 Paper II

In paper II the aim was to study the process of change that patients undergo from before to after surgery. The Grounded theory method was chosen to investigate this transformation.

Grounded theory was developed in the United States in the 1960's when two sociologists, Barney Glaser and Anselm Strauss, studied the process of dying in a hospital setting. The two researchers developed this strategic, constant comparative method of conducting qualitative research and in 1967 published a book: *The discovery of grounded theory: strategies for qualitative research*¹⁶⁴. Since then, a number of different guidelines on conducting Grounded theory have emerged, making it important for the researcher to state which guidelines she/he has used¹⁶⁵. In paper II, the guidelines developed by Kathy Charmaz¹⁵³ as described in her book: *Constructing grounded theory – a practical guide through qualitative analysis*, were employed. Figure 6 presents an overview of the data analysis based on the Charmaz approach. The reason for choosing Charmaz' guidelines on Grounded theory (sometimes called constructivist Grounded theory), as opposed to the classical Grounded theory by Glaser and Strauss, is because the classic method is based on positivist/objective assumptions, i.e., presupposes the absence of pre-understanding and that the researcher conducts an objective collection and analysis of data. This is in contrast to constructivist Grounded theory, where the researcher acts as an interpreter in the data collection and analysis¹⁶⁶.

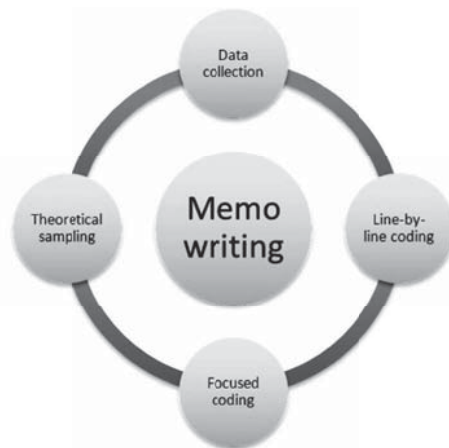


Figure 6. The Grounded theory method is a constant comparative process that compares data with data, codes and categories and finally the core category to confirm that they are grounded in the text.

5.3.1 Data collection and data analysis

In this longitudinal prospective interview paper, 16 patients were interviewed before as well as one year after surgery and 11 of them two years after surgery. To ensure a broad range of experiences, selection of the subjects was based on sex, age and BMI. Five of the pre-operative interviews from paper I were included as they contained rich narratives and formed the basis of the on-going data collection.

All interviews were audio-taped, transcribed verbatim and checked for accuracy by comparing the tapes and the written narratives, which amounted to 300 pages of text. Both before and one year after surgery, the interview guide covered areas such as the reason for choosing bariatric surgery, expectations and everyday life. Two years after surgery the interviews contained additional questions concerning the relationship to food as well as the role in the family and society, as the analysis of the earlier interviews revealed that these issues were important for the informants.

Data collection and analysis took place simultaneously in a continuous “back and forth” process. Analyzing the text during the data collection distinguishes Grounded theory from most other qualitative research methods. The initial coding of data started immediately after the first interviews when the text had been read through to obtain an impression of its content. The first step involved line-by-line coding, where relevant words and phrases were highlighted. This was followed by focused coding, which is more efficient and based on the codes that emerged from the line-by-line coding, making it possible to examine whether they are an accurate representation of the data. The codes were based on events and processes (verbs) instead of concepts and topics (nouns). During this stage, questions are put to the text: What is the patients’ main concern? What are the consequences? and How do the patients deal with these concerns? Codes with a similar content were grouped together into summarized categories and sub-categories, with more abstract labels compared to the initial codes. A core category that was central to all the data was identified from the codes, categories and sub-categories¹⁵³.

Memos, which are an important element in Grounded theory, were written during the entire study. Initially, they included impressions gained during the interviews (e.g. the patient’s mood and any interruptions) as well as the researchers’ thoughts at the time. Later, these memos contained information such as the code content, how codes might be connected, choice of theoretical sampling, written abstractions from the text, thoughts about the emerging categories as well as the connection between categories and

possible sub-categories. Finally, the core category and future research questions were formulated. According to Charmaz¹⁵³, the memos constitute an essential intermediate step between the data and the drafting of the research report. Memos also play an important role by helping the researcher when many on-going processes are running simultaneously (data collection, coding, analysis, drafting of article, etc.). By writing memos an overall picture of the research process emerges¹⁵³.

5.4 Paper III

The aim of this paper was to evaluate secondary end-points; gastrointestinal side-effects, eating habits and obese-specific QoL two years after surgery. This was achieved by the use of the questionnaires described below and presented in Table 4.

Gastrointestinal symptom rating scale (GSRS)

GSRS was presented in the late 1980's by Svedlund et al.¹⁶⁷ in the form of an interview-based scale to measure changes in the physiological state of patients suffering from irritable bowel syndrome (IBS) and ulcer disease. The scale was later modified by Dimenäs et al.¹⁶⁸⁻¹⁷⁰ to a self-administered questionnaire that they validated and tested for reliability, after which it was further validated by Talley et al.¹⁷¹. The GSRS measures the perceived severity of gastrointestinal symptoms (diarrhoea, indigestion, constipation, abdominal pain and reflux) on a 7-point, 15-item Lickert scale, where 1 represents the absence of symptoms and 7 indicates severe symptoms¹⁶⁸.

Bowel function questionnaire

In the mid-1990's Österberg and co-researchers developed and validated the bowel function self-report questionnaire that evaluates faecal incontinence and constipation. Reliability, validity, discrimination and sensitivity testing was conducted on three groups; controls, patients with faecal incontinence and patients with constipation problems, and deemed satisfactory¹⁷². This questionnaire was later modified at Sahlgrenska University Hospital, where for example, questions about urinary incontinence were removed. In the modified questionnaire, patients are asked about the frequency and texture of stool, awareness in relation to stool ability to discriminate between gas and stool, deferring time, involuntary leakage of gas, anal leakage of stool, physical and social impact of bowel function and use of pads as well as medications.

The Three Factor Eating questionnaire (TFEQ-R21)

The original version of the TFEQ was constructed in the 1980's by Albert Stunkard and Samuel Messick. The 51-item questionnaire, which was validated on obese and non-obese individuals, was designed to measure cognitive restraint eating, disinhibition and hunger¹⁷³. The original version was later translated, validated and adapted for Swedish conditions, resulting in a 21-item questionnaire^{85,174,175} comprising three eating domains; cognitive restraint eating, emotional eating and uncontrolled eating. The domain scores range from 0-100, where a higher score indicates greater restraint, emotional or uncontrolled eating⁸⁵.

4-day food record

This method is commonly used to evaluate food habits, energy intake and nutrients in various settings. Subjects are asked to keep a record of food intake for four consecutive days (3 week days and 1 weekend day) while eating in their usual way. They are instructed that all quantities should be stated in standard household measures and information provided about how the food was prepared and cooked. Energy intake and nutrients are then calculated with the help of the National Food Administration nutrient database computer program¹⁷⁶.

Obesity related Problem scale (OP-scale)

This scale was constructed in the late 1990's for the SOS-study in order to measure the impact of obesity on psychosocial function and comprehensively tested on large samples of obese and non-obese subjects. The questionnaire consists of eight items that determine how bothered the patient is by her/his obesity in an everyday setting, e.g., community activities or private gatherings. The item results are summarized into one scale score, ranging from 0-100 and where a higher score indicates a higher level of psychosocial dysfunction¹³².

Table 4. Measurement instruments in paper III.

Name	Abbreviation	Measurement domains	Reference
The Gastrointestinal Symptom Rating Scale	GSRS	Diarrhoea Indigestion Constipation Abdominal pain Reflux	^{167, 168}
Bowel function questionnaire	-----	Frequency and consistency of stool Awareness of stool Discrimination between stool and gas Deferring time Involuntary leakage of gas Anal leakage of stool Use of pads Physical and social effects of bowel function Medications	¹⁷²
Three-Factor Eating Questionnaire-R21	TFEQ-R21	Uncontrolled eating Emotional eating Cognitive restraint eating	^{85, 174}
4-day Food Record	-----	Total calorie intake Fat Protein Carbohydrate	¹⁷⁶ Diet32 software (Aivo, Solna, Sweden).
Obesity-related Problem scale	OP-scale	Effect of obesity on psychosocial function	¹³²

5.4.1 Data collection and analysis

The 60 patients in Paper III were randomized to Laparoscopic Gastric Bypass (n=31) or Laparoscopic Duodenal Switch (n=29). All patients were asked to complete self-administered questionnaires at three time points; before as well as 1 and 2 years after surgery.

The data analysis was performed by a statistician, who fitted linear mixed models to all continuous variables to permit analysis of change over time. These linear models included fixed effects of treatment, time and time ^x treatment. Time was modelled by a piecewise linear spline with a knot at 1 year measurements. The time point for each patient was based on weeks since inclusion. All models included a random intercept and random time effect, with the exception of the TFEQ-R21, which only had a random intercept. An unstructured covariance matrix was used in all models with the exception of

the diarrhoea dimension in the GSRS, which had an independent covariance matrix structure. The Pearson chi-square test was used for comparison of binominal proportions. Group comparison in the Bowel function questionnaire was conducted using the exact Wilcoxon-Mann-Whitney test. A 2-sided P value <0.05 was considered statistically significant¹⁷⁷.

5.5 Paper IV

In the final paper of this thesis, the aim was to test a hypothesis mainly generated from paper II. The hypothesis was that uncontrolled eating two years after bariatric surgery affects weight loss, eating behaviour and HRQoL. For this purpose a retrospective design was employed.

Eating behaviour was evaluated by means of the TFEQ-R21, disease specific HRQoL with the OP-scale and the generic HRQoL with the SF-36. Please see below for a detailed description of the SF-36 and Table 5 for a summary. In paper IV, data from some of the questionnaires used in the ASGARD trial were re-analysed by grouping patients according to their perceived sense of control over eating as opposed to surgical technique as in paper III and in Søvik et al.¹⁵⁶ where the SF-36 result was included.

Short-Form 36 Health Survey (SF-36)

The SF-36 was developed in the early 1990's for evaluating health status in the Medical Outcome study as well as for use in clinical practice, research and general health population surveys¹⁷⁸. In Sweden, the translation, reliability and construct validity were tested in large population studies^{179,180}. The impact of overweight and obesity on HRQoL measured by the SF-36 has also been studied in a large population in Sweden¹⁸¹. The instrument contains 36 items that measure eight domains, representing different concepts of health. Four domains measure physical function and well-being while the other four evaluate mental health aspects. Response alternatives are summarized through algorithms for all scale scores, which range from 0-100, where 0 indicates worst and 100 best health¹⁷⁹.

Table 5. Domains in the SF-36.

Name	Abbreviation	Domains	Reference
The Short-Form 36 Health Survey	SF-36	Physical Function Role-Physical Bodily Pain General Health Vitality Social Function Role-Emotional Mental-Health	179

Role-Physical and Role-Emotional refer to physical or emotional limitations in everyday life, i.e., at work or in the family.

5.5.1 Data collection and analysis

Of the 60 patients in the ASGARD trial, 49 were included in paper IV based on completed questionnaires at all three time points. Group A comprised 29 patients who reported control over eating as evidenced by a score ≤ 28.7 , which was the mean Uncontrolled Eating score for the whole group at the 2-year follow-up. Group B consisted of 20 patients who reported poor control over eating as evidenced by an Uncontrolled Eating score > 28.7 .

The statistical analyses were conducted between as well as within the groups using the Wilcoxon Signed Rank Test to compare changes in continuous variables over time and the Mann-Whitney U test for comparisons of non-normally distributed data between two unrelated groups. Student's t-test was employed for the normally distributed values between the groups and the paired t-test within groups. Correlation coefficients were calculated by means of Pearson's or Spearman's rho, as appropriate. Binary logistic regression was performed where applicable. Statistical significance was set at a p value (two sided) of < 0.05 . Effect sizes (ESs) were also calculated, making it possible to judge the significance of group differences and facilitating comparisons across measures. This was done by calculating the mean difference divided by the pooled standard deviation. The between group differences were then evaluated based on Cohen's criteria: trivial (0 to <0.20), small (0.20 to <0.50), moderate (0.50 to <0.80) and large (>0.80)¹⁸².

5.6 Ethical considerations

Approval for the studies was granted by the regional ethical review board in Gothenburg, Sweden. Papers III and IV were also approved by the regional committee for medical and health research ethics in south-eastern Norway. The ASGARD trial was registered at ClinicalTrials.gov (reg. no: NCT00327912).

Each patient was given written and verbal information about the study designs, voluntariness, confidentiality and the fact that they could withdraw at any time without consequences for their future care. Signed informed consent was obtained from all participants. In paper II, the information about voluntariness and the possibility to withdraw consent was repeated verbally before the patients were interviewed 1 and 2 years after surgery. An ethical consideration in paper II was the potential risk that distressing memories or difficult feelings could surface during the interviews. Therefore, before conducting these interviews, arrangements were made for further care by a counsellor if required. After the second interview occasion two years after surgery, two patients were referred to the counsellor at the surgical clinic. Both patients used food as consolation, one due to being dissatisfied with the weight loss, while the second felt anxious and depressed. In the case of the first patient, this led to sadness and a fear of a return to unhealthy eating habits, while the second had a small weight gain that made her even more concerned about her situation.

6 RESULTS

The overall result of this thesis suggests that the patients' sense of control over eating plays an important role in surgery outcome as well as in their everyday life. An overview of the findings can be found in figure 7. The results will be presented in two sections, the qualitative data from papers I and II in the first. In both of these papers the aim was to gain a deeper understanding of being obese, waiting for and undergoing bariatric surgery.

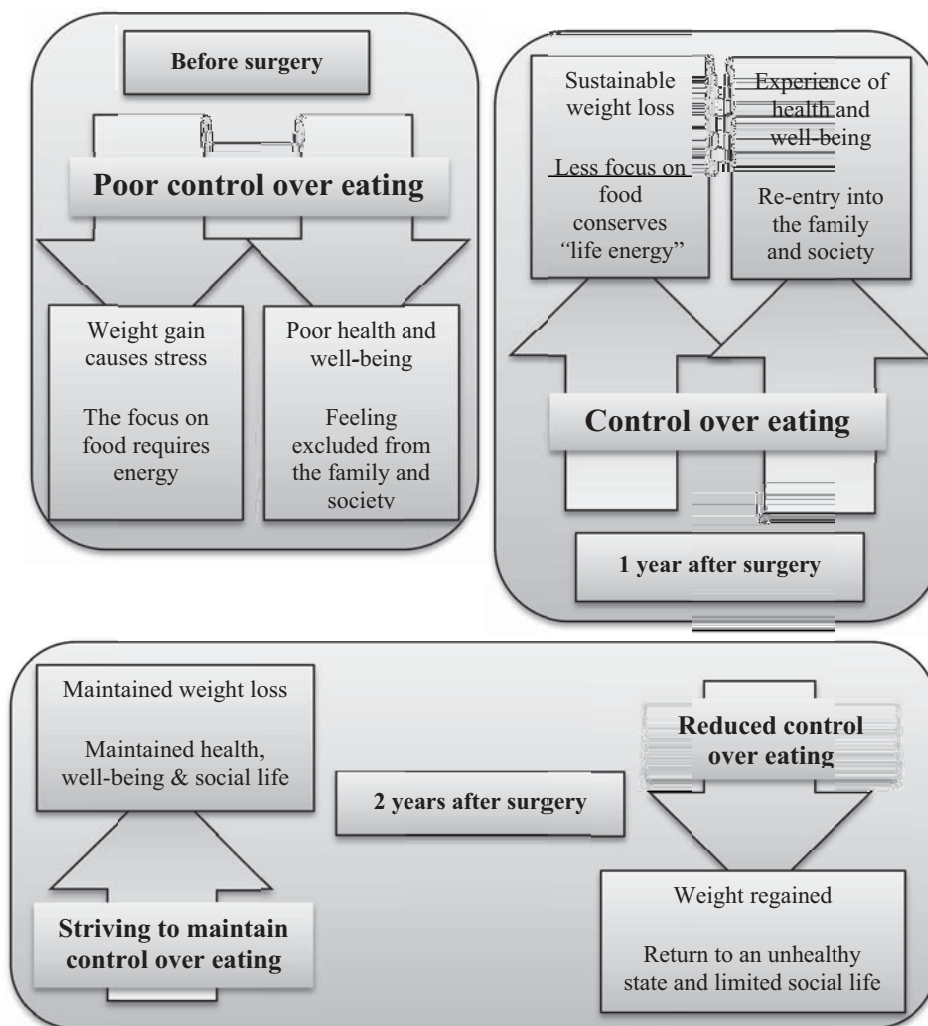


Figure 7. Summary of the findings from the papers in this thesis.

6.1 Understanding the inside perspective (Papers I and II)

Before surgery, many patients viewed their eating as based on a complex relationship to food, which they described as a time-consuming and negative focus that drained a great deal of their already reduced energy. The most commonly reported cause of obesity was inability to control eating behaviour. Hardly any of the patients mentioned genetic, environmental or childhood factors and instead had a very negative attitude towards themselves, blaming the obesity on their own personality. As they had all made numerous conventional dieting attempts (i.e., low-energy diets and pharmacotherapy) in the past with a non-sustainable outcome, they depended on the surgery as a last resort. The greatest expectation on surgery was that it would provide external control over eating and thus lead to sustainable weight loss. Virtually all patients underestimated their own role in the treatment, believing that surgery per se was sufficient for a positive long-term outcome. One common explanation for seeking bariatric surgery was the hope and expectation of being able to live a *normal* life in the future, where their body size and illness did not prevent them from playing with their kids, becoming pregnant, buying desirable clothes or just having the energy to socialize with friends. They also wished to improve their overall health as well as to reduce future co-morbidities and the risk of premature death.

One year after surgery, the patients experienced control over their unhealthy eating habits, resulting in great weight loss and a very positive spin-off effect in many areas of life – just as they had hoped for. Feelings of self-esteem and empowerment gave them strength to improve their life situation within the family and society by becoming more active, something they had been unable to manage before surgery, due to lack of energy and the physical restriction caused by their body size. For the first time in many years, patients felt that they were in charge of their total life situation instead of being restricted because of their obesity.

Two years after surgery the overall feeling of many patients was that their “new” life had now become normal, in contrast to the first year when they perceived themselves as being in a major process of positive life change. An overarching concern for the patients was that the physiological control system created by the surgery began to decline in the second year. This made them aware that their own willpower and commitment were necessary to maintain healthy eating behaviour in order to preserve what they had achieved. Nearly all patients were concerned about the reduced physiological restriction and many reminded themselves of what life had been like before

surgery as a means of empowering themselves to maintain control over eating. A minority of the participants felt that they had once again lost control of their food consumption, which had led to a small weight gain. These patients felt very anxious about this situation and feared further weight gain. They were afraid that surgery would also become another failed attempt to lose weight, leading to poorer physical and mental health. Figure 8 is an overview from paper II of how the patients strived to maintain control over their eating and weight.

One interesting finding is that some participants in paper II viewed the dumping syndrome, often described as an adverse effect of surgery, as something positive. When the episodes of dumping and its impact on food restriction decreased in the second year after surgery, several patients wanted it to return, as it helped them maintain their healthier eating habits.

Another issue that patients often narrated about and that caused a great deal of distress two years after surgery was surplus skin. Several had a large amount of excess skin, which became both a health problem (due to itching, fungus and rash) and a mental problem as many felt ashamed of their appearance. This made them avoid certain public situations, such as going to the beach with their family, which they had previously avoided due to their obesity. Another dimension of this problem was that the patients felt dependent on health care (in the same way as when seeking bariatric surgery) for obtaining plastic surgery. It is difficult to be accepted for such surgery due to insufficient resources within the area, as well as the requirement of a BMI below 30kg/m^2 to be even referred to a plastic surgeon. Few patients were able to achieve such a BMI, partly because they had been super-obese before bariatric surgery.

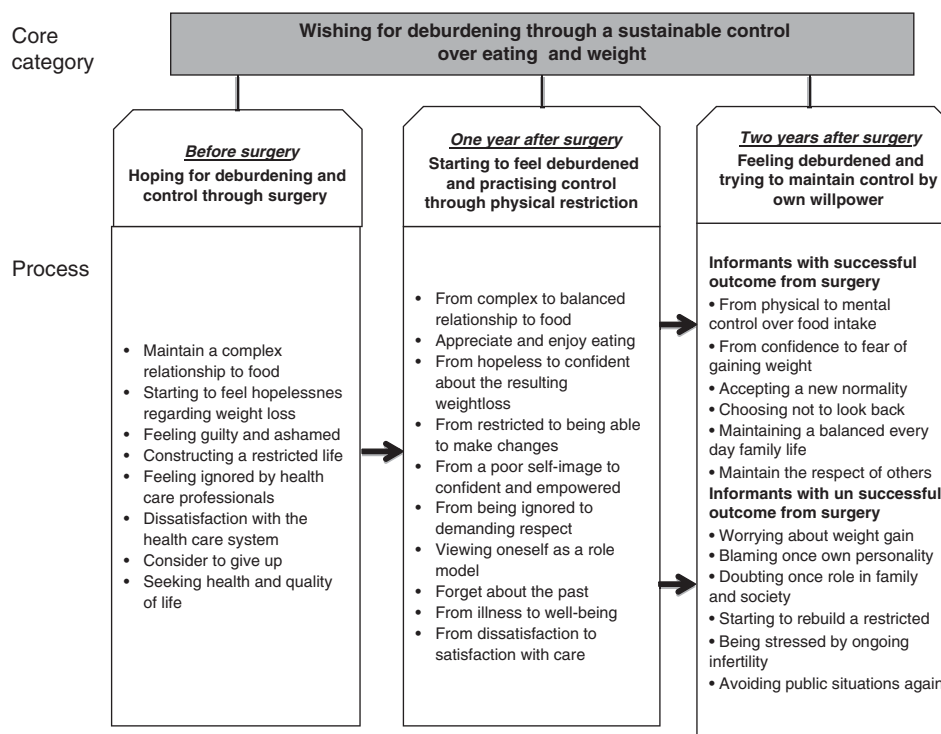


Figure 8. Patients' experiences of the change process before and after bariatric surgery

6.2 Self-reported outcome after surgery (Papers III and IV)

The main findings in paper III revealed significantly worse bowel function in the Duodenal Switch (DS) group compared to the Gastric Bypass (GBP) group. The DS patients had more diarrhoea ($p = 0.002$) and anal leakage of stool, which were experienced by 50% of the DS patients compared to 18% of the GBP patients ($p = 0.015$), see Table 9. DS patients also had a greater mean number of daytime defecations ($p = 0.007$). Despite the fact that the DS group reported more adverse effects regarding bowel function, there were no differences in the physical and social impact between the groups.

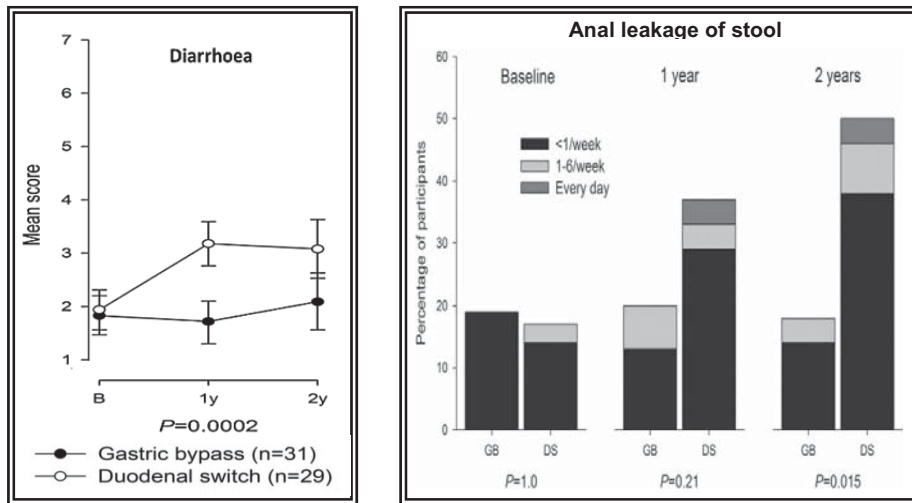


Figure 9. Group differences in bowel function between Gastric Bypass (GB) and Duodenal Switch (DS) patients in paper III, in terms of diarrhoea and anal leakage of stool.

Another significant difference at two years after surgery was protein intake in grams per day. GBP patients consumed less protein (72.9 grams/day) compared to the DS group (87.6 grams/day, $p = 0.008$), see figure 10. Another finding regarding food was that both GBP and DS patients had a significantly reduced total calorie intake per day from baseline to two years after surgery; from 2,691 to 1,670 kcal/day in the GBP group and from 2,470 to 1,953 kcal/day in DS patients ($p=0.26$). Intake of fat and carbohydrates was also significantly reduced over time, but did not differ significantly between the groups.

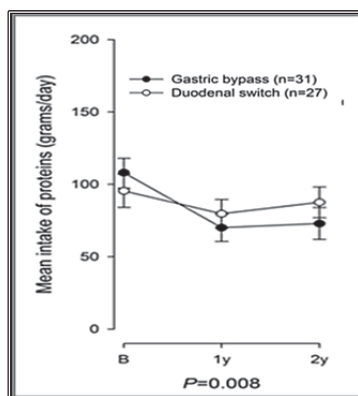


Figure 10. Group differences between GBP and DS in mean protein intake (grams/day) two years after surgery.

There were no significant differences between the GBP and the DS group in terms of psychosocial function measured by the OP-scale. Both groups had a similar significant improvement between baseline and the second year after surgery. Nor were there any group differences between Uncontrolled, Emotional and Cognitive Restraint eating, as illustrated in figure 11. At group level both procedures led to a significant improvement in Uncontrolled and Emotional eating one and two years after surgery. However, there was no improvement in the Cognitive Restraint eating score in either group.

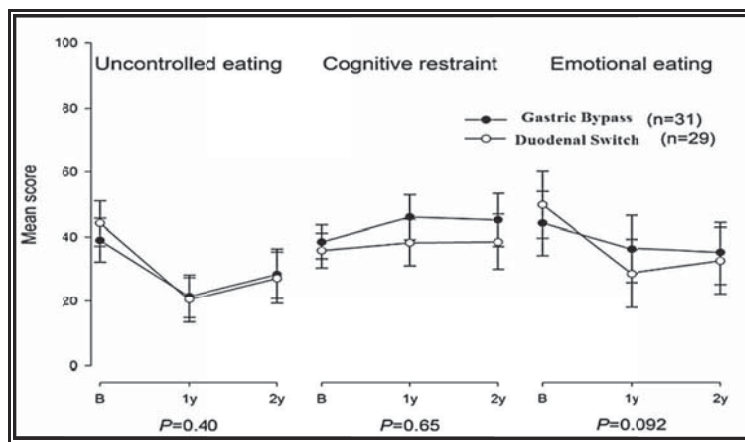


Figure 11. A comparison of eating behaviour before and after surgery.

In paper IV there were several differences in HRQoL as well as in eating behaviour after surgery between the group who experienced control over eating (Group A) and the group that experienced poor control over eating (Group B). Patients who experienced control over eating 2 years after surgery reported significantly better HRQoL in seven out of eight SF-36 domains (Table 6). It was only in the Bodily Pain domain that the scores did not differ significantly between the groups, with a mean score of 75.1 in the group with control over eating (Group A) and 62.5 in the group with poor control (Group B) ($p = 0.11$). Another difference concerned the improvement over time, where Group A exhibited a significant improvement in seven out of eight SF-36 domains between baseline and two years after surgery. Group B, on the other hand, exhibited no improvement whatsoever in three out of the four SF-36 mental health domains; Social Function, Role-Emotional and Mental Health at any time-point. However, between baseline and two years after surgery, Group B improved in the four SF-36 physical domains; Physical Function ($p < 0.05$), Role-Physical ($p = 0.02$), Bodily Pain ($p = 0.03$), General Health ($p < 0.05$) as well as in the Vitality domain ($p = 0.01$).

Table 6. SF-36 health profiles of patients with control over eating versus poor control over eating after surgery based on the Uncontrolled Eating scores two years after surgery.

	BASELINE				1 YEAR POST OP				2 YEARS POST OP			
	Group A with Control	Group B with Poor control	*	Effect size ^	Group A with Control	Group B with Poor control	*	Effect size ^	Group A with Control	Group B with Poor control	*	Effect size ^
	Mean±SD				Mean±SD				Mean±SD			
Physical Function	50.9 ±27.6	52.8 ±17.8	n.s	-0.08	88.1 ±18.2	82.3 ±15.3	n.s	0.35	92.9 ±7.5	84.8 ±15.8	*	0.70
Role - Physical	55.2 ±34.2	47.5 ±35.7	n.s	0.22	84.3 ±27.0	80.0 ±27.0	n.s	0.16	86.9 ±24.9	78.4 ±28.6	*	0.31
Bodily Pain	48.4 ±28.6	45.9 ±29.4	n.s	0.09	74.8 ±28.4	63.9 ±29.2	n.s	0.38	75.1 ±30.2	62.5 ±28.0	n.s	0.43
General Health	48.9 ±19.2	45.3 ±21.6	n.s	0.18	80.4 ±20.3	72.4 ±17.9	n.s	0.42	83.2 ±17.8	64.3 ±24.7	*	0.89
Vitality	38.8 ±23.8	35.6 ±22.6	n.s	0.14	62.9 ±26.2	51.6 ±25.8	n.s	0.44	67.0 ±25.0	46.6 ±20.0	*	0.91
Social Function	56.5 ±35.5	68.1 ±28.8	n.s	-0.36	90.5 ±17.6	73.1 ±27.0	*	0.78	87.9 ±21.3	71.3 ±26.6	*	0.70
Role - Emotional	70.1 ±34.4	61.7 ±37.0	n.s	0.24	91.1 ±19.9	77.1 ±30.1	n.s	0.56	88.8 ±19.5	72.5 ±30.2	*	0.66
Mental Health	66.6 ±20.9	60.5 ±21.9	n.s	0.28	80.2 ±14.0	67.8 ±20.3	*	0.72	76.7 ±20.6	64.3 ±19.4	*	0.62

< 28.7= Group with control over eating and > 28.7 = Group with poor control over eating. ^ Effect size criteria: trivial (0 to <0.20), small (0.20 to <0.50), moderate (0.50 to <0.80) and large (0.80+). * = p <0.05.

There were large differences in eating behaviour between the two groups two years after surgery. The domain score for Uncontrolled Eating was 12.5 ± 7.2 in group A and 52.2 ± 16.3 ($p < 0.001$) in group B, i.e., a four times poorer result in group B. In the Emotional Eating domain, the score of the group with poor control was approximately three times worse than the group with control, mean score 58.1 ± 16.3 (group B) and 18.0 ± 19.5 (group A), $p < 0.001$. In the domain of Uncontrolled Eating, the patients with poor control exhibited a significant deterioration between the first (33.5 ± 16.1) and second year (52.2 ± 16.3), $p < 0.001$. These patients also had a higher level of Restraint Eating two years after surgery compared to group A ($p = 0.04$).

Both groups had significant weight loss between baseline and two years after surgery. The only weight loss parameter that differed was the significant continuing weight loss between the first and second year after surgery in group A. Thus, group A had an excess BMI loss (%EBL) of $63.7\% \pm 15.6$ in the first year and a total loss of $71.2 \pm 17.8\%$ ($p < 0.001$) in contrast to group B (62.9 ± 16.7 after one year and 65.4 ± 17.4 after two years), $p = 0.15$.

7 DISCUSSION

7.1 Methodological considerations

Rigour and trustworthiness in the phenomenological hermeneutic study (paper I) were based on Lincoln and Guba's¹⁸³ four criteria; credibility, dependability, confirmability and transferability. These criteria can be compared with validity and reliability in quantitative research¹⁸³. Follow-up questions were posed to enhance credibility and prevent retrospective distortion or misinterpretation of participants' statements. Quotations were included to illustrate the participants' views, as well as to enable the reader to decide whether the chosen interpretations of the data are reasonable and transferable to other groups of bariatric patients. Several findings in this paper were subsequently confirmed by other studies, which also strengthens credibility. As all patients were interviewed at the hospital, we endeavoured to overcome their sense of dependence by creating a tolerant and open environment in which the patients could feel free to narrate and be assured of confidentiality as outlined by Lindseth and Norberg¹⁶¹. Confirmability was achieved by describing the different steps in the analysis process and how the various themes in the structural analysis were created based on the statements.

The full text of the interviews was read by all the authors and only statements relevant to the aim of the study were included in the final analysis. Transferability was ensured by the fact that the interviews were performed at about the same time interval before admission to the hospital ward for surgery, which makes it possible to transfer the findings to other patients awaiting bariatric surgery¹⁸³.

In phenomenological hermeneutics, a text never has only one meaning. It can be approached from different research perspectives and even if several interpretations are possible, one of them is more probable than the others^{161,162}. In paper I, the interpretation was guided by the authors' pre-understanding based on their experience of working with bariatric patients, teaching in surgical nursing as well as knowledge of previous research. This pre-understanding was constantly reflected upon and reconsidered during the data analysis and interpretation process. The authors agreed that the presented interpretation was the most reliable, although alternative interpretations were considered.

Twenty three participants were included in this paper, which is considered an acceptable number in a phenomenological hermeneutic study.

In paper II, the Grounded theory paper with a constructivist approach was performed in line with the four quality criteria described by Charmaz, i.e., originality, trustworthiness, resonance and usefulness¹⁵³. How these four criteria were applied is illustrated in Table 7.

Table 7. Evaluation criteria for Grounded theory studies presented by Charmaz¹⁵³.

Originality	Trustworthiness	Resonance	Usefulness
The study contributes new data describing the patients' experiences of their disease, its consequences in everyday life and their expectations on the treatment.	The material was sufficient to answer the research question. In the paper the constant comparison between data, codes and categories and how the core category emerged is clearly described. This allows the reader to form her/his own opinion of the findings.	The study allowed the development of categories that explained the participants' perception of their illness and its impact as well as their expectations on surgery. We believe that the results can be understood by the study participants and provide a deeper understanding of their life-world.	The overall findings of this paper contribute new knowledge of these patients' experiences of their treatment, a perspective that was previously less known. These new findings might improve the care of this patient group.

Charmaz described how a researcher's pre-understanding can be utilized in a positive way as long as it is reflected on and the researcher does not force her/his pre-understanding on the data¹⁵³.

Within the Grounded theory the aim is to achieve saturation of data by theoretical sampling, which means that additional interviews do not contribute new information¹⁵³. In paper II, the theoretical sampling did not take place until the interviews two years after surgery. As the evaluation concerned an intervention, i.e., surgery, it was believed that the study would benefit from late theoretical sampling by ensuring more variation in the data. However, at the two year interviews the narratives provided rich data, thus it was believed that the main research question had been answered, which was

subsequently confirmed by later studies. Concerning saturation within Grounded theory in general there is no guarantee that additional interviews would not provide new information.

Another methodological consideration in paper II was the re-inclusion of five interviews from paper I. These interviews were chosen because of their rich narratives and the quotations are those that best illustrate the studied phenomenon. However, if paper II was to be conducted today, we would select a different approach with no overlapping interview text, which could have led to greater divergence in the results based on the pre-operative data.

The most important criteria when selecting surveys for a study is to identify well-validated patient reported outcomes (PROs) that have been tested for reliability, where:

- Validity is the degree to which an instrument measures what it is supposed to measure regarding the studied population, aim and health domains.
- Reliability is the degree of consistency with which an instrument measures the target attributes.

How these two criteria were applied in the questionnaires used in papers III and IV is outlined in Table 8.

Table 8. Validity and reliability testing of the questionnaires in this thesis.

	Validity	Reliability	Reference
GSRs	Validated on a population other than obese individuals. Initially on Irritable Bowel Syndrome (IBS) and Ulcer disease, later on a general population and reflux.	Test-retest ranged from 0.53-0.69 using the Intraclass Correlation Coefficient.	167 168, 170 171
Bowel function questionnaire	Validated on a population other than obese individuals (faecal incontinence, constipation, healthy controls).	Test-retest by means of kappa [k], demonstrated; k=0.57 (faecal incontinence), k=0.60 (constipation) k=0.95 (controls)	172
TFEQ-R21	Validated on overweight, obese and non-obese individuals.	The reliability estimated using Internal consistency with Chronbach's alpha was above the 0.70 standard	85, 174, 184
OP-scale	Validated on overweight, obese and non-obese individuals.	The reliability estimated by means of Internal consistency with Chronbach's α ranged from 0.89-0.92	132
SF-36	Validated on a general population as well as overweight and obese individuals.	The reliability estimated by means of Internal consistency with Chronbach's α , ranged from 0.79-0.93	179, 181

The test-retest using the Intraclass correlation is considered acceptable if 0.50-0.60. When using the test-retest measured by kappa, a value of >0.60 is defined as good reliability. For internal consistency, reliability is deemed adequate for group data if the Chronbach α is at least 0.70^{185, 186}.

The choice of the GSRs questionnaire can be criticized due to lack of validity, as this PRO has not been specifically validated on an obese population. The Bowel function questionnaire is perhaps even more debatable, as the modified version has not been validated at all, despite the fact that it is widely used in several specialist colorectal clinical settings in Sweden. However, as there are no other questionnaires that in our opinion better address the research questions, these two PROs were appropriate.

The 4-day food record of dietary intake cannot be included in the above criteria as it is not a questionnaire. However, it is an acknowledged fact that patients often underestimate their habitual intake, which is a limitation of most dietary reporting methods^{83,176}. Nevertheless, the use of dietary reporting in an obese population is as valid and reproducible as for individuals of a normal weight¹⁸⁷

In papers III and IV, one issue that requires consideration is the power calculation based on the differences in BMI two years after surgery between patients who underwent a Laparoscopic Gastric Bypass and those who had a Laparoscopic Duodenal Switch. Due to the small sample size, there is a risk that differences between the groups measured by e.g. questionnaires, are not sufficiently large to be statistically significant and thereby not identified, i.e., a type II error¹⁸⁸.

In paper IV, the use of the Uncontrolled Eating domain two years after surgery as a group variable could be a weakness. However, as there are no general guidelines for measuring control over eating in a bariatric population, it can be argued that it was appropriate to employ the well validated and widely used TFEQ-R21 instrument to test the hypothesis.

An overall methodological consideration is that, with the exception of most patients in paper I, all participants were super-obese, thus the results may not be transferable to less obese bariatric surgery patients. Although the aim of qualitative research is usually not for the results to be generalizable, qualitative results and understanding can be useful in other groups and settings¹⁸⁹. In papers I and II, a detailed description of the research process was provided to strengthen the transferability, which is in line with Lincoln and Guba's guidelines for transferability of qualitative data¹⁸³, page 316;

“Thus the naturalist cannot specify the external validity of an inquiry; he or she can provide only the thick description necessary to enable someone interested in making a transfer to reach a conclusion about whether transfer can be contemplated as a possibility.”

However, the morbidly obese patients' narratives in paper I did not differ to any great extent from those of the super-obese patients and therefore the results might be transferable to less heavy patient groups. The findings of papers I and II were later confirmed by other studies, in which the data were based on morbidly as opposed to super-obese patients^{96,100}. Nevertheless, it should be borne in mind that no specific group comparisons were conducted in paper I to detect any differences and further research is needed in order to draw more generalizable conclusions.

The negative impact on outcome (weight loss and psychological distress) of feelings of loss of control after surgery has also been reported in morbidly obese patients⁹⁵, but further research is needed in this area.

7.2 Reflections on the findings

7.2.1 Eating and control

It is well-known that bariatric surgery has achieved great results in morbidly obese patients because it restricts food intake in various ways. The underlying mechanisms are not fully understood but involve physical restriction¹⁹⁰, malabsorption¹⁵⁸ and changes in the hormonal regulation system^{191,192}. This thesis has contributed knowledge of the patient perspective on the restriction and control mechanisms related to eating and demonstrated that an individual's perceived control or lack of control in relation to food is important for the long-term outcome after bariatric surgery. The surgery is considered an external control that will compensate for one's own lack of self-control. Patients put their trust in the physiological restriction and not their own behaviour. This is dangerous because when the physiological restriction decreases, they need willpower. This phenomenon is illustrated in paper II, which was the first longitudinal prospective study with an inductive approach in this research area. The findings in papers I and II have been recently confirmed by other qualitative studies^{96,100}. The pre-operative patients in the study by Da Silva et al.⁹⁶ reported food as ever-present and found it difficult to change and control their eating behaviour. Knutsen et al.¹⁰⁰ supported our finding that food was an important part of life and that the obese individuals were unable to change their eating behaviour by themselves. One of their informants also drew parallels between uncontrolled eating with an alcoholic that cannot drink; they on the other hand, could not stay away from the fridge. One year after surgery patients felt relieved by their rapid weight loss due to "stomach control". They also experienced being

in control of their life and viewed themselves as healthy. Two years after surgery the control mechanism became weaker, leading to fear of weight gain¹⁰⁰.

In paper II the participants described a lack of physiological and mental control before surgery, a physiological control (restriction, satiety, dumping) one year after surgery, followed by decreasing physiological restriction that in most cases was compensated for by mental control two years after surgery. A majority of patients were able to change their eating behaviour after surgery thanks to the new intestinal restriction and their own willpower. These findings were statistically confirmed by the quantitative papers in the thesis, where paper III demonstrated that the poor eating habits prior to surgery were replaced by a much healthier eating pattern after the procedure, which has also been confirmed by other studies^{3,80-82}. Eating behaviour assessed by the TFEQ-R21 in paper III revealed that Uncontrolled Eating and Emotional Eating dramatically improved up to one year, followed by a slight regression to baseline values at the two-year follow-up. Cognitive Restraint eating did not improve significantly between baseline and the second year after surgery. These findings are in line with the Laurenus et al.'s⁵⁹ study on morbidly obese patients undergoing Gastric Bypass surgery. Both Gastric Bypass and Duodenal Switch patients exhibited similar improvements over time with no significant differences in Emotional eating, Uncontrolled eating or Cognitive Restraint eating scores between the groups at any point of measurement. The 4-day food record in paper III that measured mean energy intake (Kcal/day) revealed a significant reduction between baseline and 2 years postoperatively, without any group differences. Although the type of surgical technique might not play the main role in the bariatric patient's ability to change her/his eating behaviour, surgery per se is undoubtedly the necessary tool for improving destructive eating behaviour.

Many patients were surprised and worried when the external control declined after surgery, which raises the question of the quality and amount of information provided by healthcare professionals to such patients. It is possible that healthcare professionals lack knowledge concerning long-term post-surgery eating patterns as described by Marino et al.¹⁹³. These authors highlighted the importance of making healthcare professionals aware of potential unhealthy eating patterns that can occur after surgery as, for example, loss of control or grazing could lead to a less beneficial outcome¹⁹³. Moreover, it may be that healthcare professionals underestimate patients' ability to influence the outcome and believe that surgery alone will lead to satisfactory long-term results. As in the present thesis, patients' overconfidence in the effectiveness of surgery has also been described by

others^{100,194}. Boeka et al.¹⁹⁵ concluded that much is still unknown about how to motivate patients to follow post-operative guidelines regarding eating behaviour. They also stated that bariatric treatment would benefit from new findings to enhance the patient's ability to comply with post-surgical recommendations, which in turn will further increase the effectiveness of bariatric surgery, i.e., sustained weight loss.

It is understandable that bariatric patients underestimate their role in the treatment as they appear too confident in the surgery itself. Unfortunately, this often leads to an unpleasant surprise between one and two years after surgery when the physiological restriction begins to weaken. One possible way of addressing this issue is to implement PCC (person-centred care) to empower patients and increase their self-efficacy, as both self-efficacy and PCC are based on supporting and motivating patients to play an active part in their treatment. Strengthening the patients' self-efficacy and supporting them to believe in their own ability to cope with the challenges that occur after surgery might result in fewer negative outcomes after bariatric surgery from both an inside and an outside perspective. A study on the value of perceived self-control and outcome by Karlsson et al.¹⁷⁵ revealed that moderately obese women's perception of their chances of success with conventional weight loss treatment was a predictor of outcome. More optimistic participants changed their eating behaviour to a greater extent and achieved higher weight loss. The authors concluded that self-control over eating was a clinically useful predictor of weight loss.

In the future, research on patients' self-efficacy and its effect on outcome should be conducted and validated in prospective longitudinal studies.

7.2.2 Food

Almost all patients in papers I and II narrated that their obesity was a result of overeating. The cause and effect of high calorie intake are acknowledged and empirically established facts^{16,18,83}. Interesting findings from the qualitative papers with an inductive approach that are not often described in the literature are why, how and what patients ate as well as the degree of difference in this respect between individuals. Some explained their overeating as due to physical factors, such as an unusually large stomach or the absence of a stop mechanism. Others saw food as a consolation when exposed to difficult situations or when they felt anxious. Several viewed their relationship to eating as an addiction and compared it to alcoholism, although there were also a few who reported that they had absolutely no interest in food. Furthermore, the unhealthy eating pattern involved what the patient ate

and the number of meals per day, which could be too many or too few and comprise large portion sizes of nutrient poor food. Overall, the participants described that they often thought about food, which had an impact on their everyday lives. It seems important to identify the individual's relationship to food in the pre-operative assessment, as some forms of overeating have a more negative influence on post-operative weight loss and weight stability than others. Emotional eating, for example, has been reported to have a negative correlation with weight loss after surgery^{89,102,196}.

7.2.3 Dumping

Patients' positive experience of dumping was a surprising finding, as in the literature it is often described as a complication or adverse effect of surgery with symptoms such as abdominal pain, nausea and tachycardia¹⁹⁷. The dumping syndrome mainly occurs after Gastric Bypass surgery. Although there have been some reports of dumping among Laparoscopic Sleeve Gastrectomy^{198, 199} and Duodenal Switch patients²⁰⁰, its extent is relatively unexplored.

In paper II, patients viewed dumping as a help mechanism for avoiding unhealthy food and as early as one year after surgery some wished for more or stronger dumping. Knutsen et al.¹⁰⁰ described patients' fear of weaker physiological signals, i.e., dumping and "stomach control", as well as their sense and fear of being unable to trust themselves to control their food intake.

Banerjee et al.²⁰¹ reported that dumping occurred in 42% of their Gastric Bypass patients and that in most cases the syndrome ended completely within 18 to 24 months after surgery. They found no differences in weight loss between "dumping" and "non-dumping" patients, which is supported by Mallory et al.²⁰². The primary assumption in these studies was that dumping leads to a positive outcome. While dumping was found not to correlate with weight loss, it seems to work as a control mechanism that prevents unhealthy eating, as reported by our patients and described by Laurenus et al.⁵⁷. Thus further research within this area would be valuable. According to Banerjee et al.²⁰¹, some patients pre-operatively fear dumping, which raises the question of how these beliefs about dumping as a negative but common side-effect of surgery should be addressed when caring for bariatric patients. For example, should pre-operative information state that only a small number of patients have problems with dumping after surgery⁵⁷ and that some view it as positive? (paper II).

7.2.4 Surplus skin

Almost all patients mentioned that one side-effect of surgery was the excess skin after weight loss, a finding that is in line with other studies^{100,117,203}. The surplus skin caused medical issues (i.e., dermatitis), problems with hygiene, difficulties with physical activities, feelings of being unattractive to their partner and avoidance of public settings such as going for a swim. It had a very negative impact on their lives and many patients were frustrated about not receiving a referral for plastic surgery, as despite their great weight loss, their BMI was still over 30 kg/m², which is a requirement for surgery. These problems have recently been addressed by Kitzinger et al.,^{204,205}, who reported that 96% of their study population complained about the development of surplus skin after surgery and that approximately 70% wished for body contouring surgery. Their studies also contained two interesting findings that are similar to ours. Firstly, the discrepancy between the number of patients who request plastic surgery and those who actually receive it and secondly, many patients were surprised when surplus skin development occurred despite being informed about the risk prior to surgery. Kitzinger et al. highlighted the importance of pre-operative information to ensure that patients have realistic expectations in terms of both the development of surplus skin after surgery and the possibility of obtaining body contouring surgery^{204,205}.

7.2.5 Health and well-being

The extent to which the patients' inability to control their food intake and weight affected their well-being before surgery (social life, physical and mental health) was somewhat surprising, despite the fact that several reports on poor HRQoL have been published^{181,206-208}.

Papers I and II contributed a deeper understanding of this issue. The patients described that prior to surgery, their obesity had negatively influenced almost all areas of life. They were unable to play with their children, buy desirable clothes, find a partner or obtain employment. Feelings of guilt and shame were common and their self-esteem and vitality were low. They felt isolated, partly by choice but largely due to the widespread stigma attached to obesity by society and healthcare professionals. These everyday experiences together with their inability to control their eating and weight were the main reasons they wanted surgery. Surprisingly, co-morbidities and mental health problems were seldom reported as an important reason for wanting bariatric surgery.

One year after the procedure, life had become easier for the participants. The focus was now on re-building self-esteem, feeling empowered, experiencing vitality and being an active member of the family as well as the community. Food and weight were under control, leading to overall satisfaction with life. In the second year after surgery, life was still much better than before, something that the patients often reminded themselves of as an encouragement to restrict their food intake by willpower to compensate for the decreasing physiological control.

Feelings of being unable to control food intake after surgery had a very negative impact on patients' health and well-being. In paper II the patients described how the feeling of loss of control led to reduced life satisfaction, which was exacerbated by the fear that surgery would become just another failed dieting attempt. Once again they started to develop a negative self-image and blamed their own personality for overeating and becoming obese. Their lives became restricted once more and they questioned their role in the family and society. The negative effect of Uncontrolled Eating on HRQoL was significantly confirmed in paper IV, where patients who experienced poor control over eating had a lower HRQoL two years after surgery compared to those who experienced control.

The goal of bariatric surgery is to improve physical, mental and social well-being⁷⁸ by weight loss as a result of reduced nutritional intake. This goal was achieved by the vast majority of our patients, measured by different methodological approaches. Studies on the impact of bariatric surgery on HRQoL have confirmed that in a majority of patients, HRQoL before surgery is poor but gradually improves and peaks at one year after surgery, followed by a slight to moderate decrease at the two-year follow up^{76, 156, 209}. This trend was also observed in the OP-scale in papers III and IV and the SF-36 scale in paper IV with the exception of the group with poor control over eating.

One interesting difference in the ASGARD trial is the generic HRQoL result (SF-36) where findings from previous report revealed similar improvement in HRQoL, irrespective of surgery technique and large weight loss differences, two years after surgery¹⁵⁶. This in contrast to the findings in paper IV, where there were several significant differences in HRQoL between the groups based on the sense of control or lack of control over food intake. Perhaps, as in the case of eating behaviour, it is not the type of surgical technique that matters the most but the degree to which the patients are able to respond to the physiological signals, thereby experiencing control that is important for HRQoL.

Another interesting finding from paper IV was that group A had an on-going significant weight loss in the course of the first and second year after surgery, while group B did not, although there were no significant differences between them. Insufficient weight reduction after surgery leads to lower HRQoL and decreased patient satisfaction^{79,210}. Furthermore, most weight loss occurs during the first two years after surgery²¹¹. As the differences between the groups might continue to increase after 2 years, long-term studies are needed to assess whether weight control over time is inferior in patients with poor control over eating, who thus require support to maintain their weight loss and HRQoL.

8 CONCLUSIONS

The following are the main conclusions from the papers:

- ❖ Patients feel dependent on bariatric surgery to regain control over their eating behaviour, weight and overall health situation.
- ❖ The inside perspective of the morbidly obese person awaiting bariatric surgery comprises being restricted in daily life due to body size, low self-esteem, lack of energy and stigmatization from others including healthcare professionals.
- ❖ The relationship to food demands a thorough assessment before surgery as it is often complex and unhealthy.
- ❖ Bariatric patients seem to underestimate their own role in a successful outcome, solely relying on the surgical treatment.
- ❖ When the physiological restriction becomes weaker between one and two years after surgery, there is a risk of breaking the positive trajectory, as many patients feel unprepared and doubt their own ability to maintain control over food intake and weight loss.
- ❖ Duodenal Switch patients reported significantly worse bowel function compared to the Gastric Bypass group.

- ❖ Both eating behaviour and HRQoL improved significantly after the intervention irrespective of the type of surgery, peaking in the first year followed by a slight regression in the second year.
- ❖ HRQoL improved after bariatric surgery. The extent of the improvement may be partly explained by the patient's perceived sense of control over eating.
- ❖ Sense of control over eating may be associated with more favourable weight loss two years after surgery compared to poor control over eating.

9 CLINICAL IMPLICATIONS

It is important that patients are aware that surgery is not the only key to a successful outcome. Healthcare professionals should encourage and support the patient to play a more active role in her/his treatment and have realistic expectations of the surgery. This information should be provided both before and after surgery.

In order to provide individual care, it is essential that healthcare professionals listen to the patients' own experiences. This could be achieved by implementing PCC in the clinical bariatric setting, as one of the foundations of this approach is a therapeutic relationship based on respect and a positive attitude. In such a relationship the patients are more likely to share their experiences and expectations with the healthcare professionals. If the latter understand the patients' preoperative experiences and expectations of surgery, risk factors can be identified, e.g., too much reliance on the surgery per se, lack of empowerment during treatment and "emotional eaters", all of which can hinder optimal pre- and post-surgery care and weight loss.

Many of the participants were surprised and worried when the physiological control over food intake started to fade between the first and second year post surgery. This could be viewed as a result of too little information and preparation from the healthcare professionals. However, clinicians might have insufficient knowledge about such a reaction a long time after surgery. In many cases, the follow-up programme only lasts for one year and then patients are expected to manage by themselves or seek help from primary health care where knowledge of bariatric treatment is often sparse. At this stage of the process, supportive and educational interventions seem essential in order to put those at risk of weight gain back on the right track. To ensure a satisfactory long-term outcome, the present fairly short follow-up programmes should be extended to at least two years after surgery and involve mandatory long-term participation in support groups as well as individual consultations when necessary. This would be valuable, as a number of patients were unable to maintain the restricted food intake and started to regain weight two years post-surgery. These participants blamed themselves for not having a sufficiently strong character to control the situation. Long-term clinical support can help the bariatric patient to understand that several aspects are involved in the process of losing weight after surgery.

Surplus skin was a major concern for many participants in paper II, which highlights the importance of information on this issue, both before and after surgery. Such information would make them aware of the fact that surplus skin can become a problem, of the criteria for plastic surgery and that the waiting list can be long.

Patients need not fear dumping as a negative side-effect of surgery. On the contrary, it can be used as a tool to help them listen to their bodies and make healthier food choices, leading to an improved eating pattern that will hopefully be maintained when the physiological restraint decreases.

I believe that the clinical follow-up of bariatric patients would benefit from using HRQoL and eating behaviour patient reported outcomes (PROs) (i.e., the SF-36 and TFEQ-R21), as the latter can help healthcare professionals to detect concealed problems that otherwise might easily be missed. These measurements would contribute the patients' experience of the treatment as a complement to biomedical factors and make them more involved in the care. It is also fairly simple to compare PRO data over time, thus facilitating the detection of unhealthy changes that could contribute to a less favourable outcome. This would also mean that resources can be allocated to patients in need of extra interventions. The use of PRO has been validated by others and the findings indicate that if properly applied, it can improve the healthcare professionals' awareness of patient problems²¹², thus enhancing the care as well as the outcome²¹³.

10 FUTURE RESEARCH

Many areas in the field of bariatric surgery are still relatively unexplored. In Sweden, the healthcare professionals' role has been overlooked and to the best of my knowledge, no published studies have investigated their experience of caring for the morbidly obese patient. One unpublished essay²¹⁴ that investigated nurses' experiences of caring for bariatric surgery patients found that nurses were ambivalent towards surgery as a weight loss alternative. There is certainly a great deal that remains unknown and not reflected upon in this area, which might be of importance to investigate in view of the goal of improving patient care in hospital and primary care settings.

The hypothesis that a more involved patient with a greater degree of self-care has a more favourable outcome needs to be tested, as does the influence on outcome of patients' general self-efficacy and self-efficacy in relation to control over eating. Such knowledge could help us determine how these factors might contribute to an even better success rate in bariatric patients. To enable this, a new instrument specifically designed to measure bariatric surgery patients' self-efficacy in relation to control over eating and general self-efficacy needs to be developed. Prospective, longitudinal studies that compare PCC with today's standard clinical care and evaluate HRQoL, weight loss, eating behaviour and patient satisfaction after bariatric surgery are required.

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