The role of social support in conservative treatment for obesity: A qualitative study comparing the experiences of participating in a camp-based weight-loss program with or without a significant other

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PREFACE

This master thesis was performed at the Department of Public Health and General Practice at the Medical Faculty of the Norwegian University of Science and Technology (NTNU) in Trondheim.

It has been interesting to work with this thesis, as it has gained insights into the experiences and everyday life of struggling with obesity, as well as educational in learning how to plan and perform a scientific study.

I would like to thank my supervisors Aslak Steinsbekk and Magnus Strømmen for good ideas, excellent guidance and informative input in order to bring out my own ideas and ability to perform.

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Mari Ellingsbø,

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Table of contents

ABSTRACT

Purpose:

The aim of the study was to investigate the role of social support in conservative treatment for obesity and also in the participants' everyday life, by comparing experiences of those participating in a camp based weight-loss program with or without bringing a significant other.

Material and methods:

This was a comparative qualitative study which was a part of the non-randomized controlled trial "Family & Friends", investigating the effect of having a significant other participating in parts of a camp-based lifestyle treatment program for morbid obesity (BMI>40 kg/m^2 or BMI>35 kg/m^2 with obesity related comorbidities). A purposive sample of participants from the groups with (group A) and without significant others (group B) were separately interviewed and/or in groups. The main question in the interview guide was about the role the participants' family and friends played in the treatment program they were participating in (both at camp and at home). The data was analyzed according to systematic text condensation.

Results:

A total of 20 persons (10 from group A and 10 from group B) were interviewed. The participants consisted of morbidly obese men and women between the age of 27 and 53. Participants from group A, who brought significant others, told that as a result of the program they opened more up to significant others about their problems and felt that the significant others understood more about their situation and helped them out with the lifestyle changes after they had been educated in the program. Moreover, some had brought significant others that they felt were not important to whether they succeeded or not, or not very interested in helping the participants out. Similarities between the groups regarding social support were that in both groups there were found participants who said they were reluctant to open up about personal problems, had experienced positive effect of pep-talks and positive feedback, used self-help groups and had significant others joining them as exercise partners.

Conclusions:

Bringing a significant other made it easier for participants to open up about personal problems and they experienced more social support in everyday life with a positive impact on the household diet and level of physical activity, seen as due to the significant others' education during the treatment program. To achieve this effect, the study indicated that the support partner should be someone with a close relationship to the participant who one thinks might be interested in helping the participant with lifestyle changes.

Relevance:

This study gives knowledge about how the patient's social support network in conservative treatment for obesity might enhance outcomes by including significant others in the treatment. Assessing the patient's level of social support and tailoring the intervention thereafter seems to be important. There is a need for larger studies to confirm this and to look more closely at how to tailor treatments around the patient and the significant other. Further research should focus on the perspectives of the significant other, on selection of support partners and on tailoring the treatment around the participant and support partner.

INTRODUCTION

Obesity and overweight has become a worldwide epidemic. In 2008, approximately 1,5 billion adults were overweight, and app. 500 million were obese. In addition, around 170 million children had an ISO-BMI of 25 or more (1). In Norway 2008, the percentage of men and women with overweight were 74,5 and 60,8, respectively. 22,1 % of men and 23,1% of women were obese (2). Obesity is associated with many health problems, and it involves nearly all organs in the body. Most known are metabolic abnormalities and cardiovascular disease, but among others the musculoskeletal system, the central nervous system and the gastro-intestinal tract are also affected. All in all, obese people have higher risk of dying prematurely than those who are not overweight, and this is especially true for those with morbid obesity (BMI >40 kg/m2) (3). There are also detrimental effects on psychosocial health related to obesity: increased prevalence of psychiatric disorders, suffering from stigmatization, prejudice and discrimination by the society and people close to them. Both physical and psychosocial factors lead to reduced health-related quality of life in obese individuals (4). Obesity also leads to increased costs for the society when it comes to treating obese patients in the health care systems (5).

It is clear that treating obesity is an important measure for reducing the risk for physical and psychological health problems for a large group of the population, as well as reducing the potential costs for society. Much research has been conducted in attempt to find good ways of reducing weight and risk factors for obesity related disease, including hypertension, dyslipidemia and hyperglycemia as examples. It is recommended to loose app. 10% of initial weight in order to reduce these risk factors (6). Weight loss also improves quality of life for obese persons (4). Bariatric surgery seems to give the best results for reducing weight in morbidly obese patients; however, non-surgical/conservative treatment for obesity induces a similar reduction in risk factors and resolution of comorbidities, at least in short term (7). Research supports three main components of conservative treatment: behavioral modification therapy (8), diet and exercise (9), i.e. lifestyle changes. Such conservative treatment can for instance be done in outpatient programs, as residential programs or weight loss camps. Weight loss camps often includes individual and group based behavioral therapy, as well as increasing theoretical and practical knowledge about healthy diet habits and physical activity,

and it is shown that such camps seem to give better short term results compared with hospital outpatient programs with almost double initial weight-loss and better weight maintenance (6, 7, 10-12). However, there is little evidence for the long term effects of this treatment.

The role of social support

In many studies social support has been shown to contribute to better health. It is related to positive health practices in both young and middle aged adults (13, 14) and there is a positive association between having a large social network and improved health outcomes (15). Social support also leads to better health-related quality of life, both physically and mentally, especially in men (16). There are different aspects and definitions of social support. According to Verheijden et al. (17) and Black et al. (18) functional support is the subjective measure of the perception of support, whereas structural support is the availability of significant others, regardless of the actual support received. Instrumental support refers to support given from significant others that provides practical assistance, like taking the subject out exercising or helping out with babysitting so that the subject can exercise. Emotional support (esteem and informational support) on the other hand, refers to support given through for instance encouragement and appreciation of what the subject is doing, and giving advice and guidance.

The role of social support in successfully changing one's lifestyle has been addressed by some research, with results from Kiernan et al. (19) showing that persons with little family support are less likely to lose weight opposed to persons with much family support. After lifestyle intervention programs people reporting low social support were less likely to stick to their diet after 1 year, compared to people with high social support (20). Getting social support from family and friends as well as information and support from health professionals showed better results than from the latter only, in the studies by Verheijden (17) et al. and Hindle et al. (21). Those who had perceived high social support were better able to maintain lifestyle changes over time and they were also more likely to be seeking social support than those who gain weight after weight loss (17, 22, 23). Also, the availability of fruits and vegetables at home and engaging in physical activity were positively associated with social support (24-26).

There are reports of significant others (family, friends and coworkers) socially undermining the patients efforts to change their lifestyle, where the motivation for this could be guilt over their own diets/exercise, not understanding the participants purpose of eating well/exercising, time conflicts and jealousy. Much of this undermining was unintentional (21, 27, 28). It would therefore seem that involving significant others more in the obesity treatment and increasing knowledge about the topic could make them more supportive of the patients' lifestyle changes.

Effect of social support

Integrating social support as an intervention in programs for lifestyle changes in adults has been tried out in a few studies, yielding inconclusive results, saying it may or may not have an effect. An early meta-analysis by Black et al. (18) from 1990 concluded that attending a behavioral treatment program for obesity as couples gave larger weight loss than attending alone. The effect was small, however, and they argued that it was difficult to isolate the effect of the support partners' contributions. Similar conclusions were reached by Glenny et al. (29) in 1997. In 2003 McLean et al. (30) published a literature review where there were no significant conclusions about the involvement of family or spouses, but it could enhance the effectiveness. The literature review by Verheijden et al. (17) from 2005 concluded that there were more effect in support from the patient's natural network than from professionals and that social support can counteract health behavior changes. The review also emphasized the problem with different and unclear definitions of social support within studies and the combination with other interventions that made it difficult to assess the effect of social support. Finally, Levy et al.'s review (31) from 2007 concluded that patients are more successful when they perceive to have more social support and that there are some improvement in weight loss when significant others are included in the intervention, but only if the significant other also is successful in losing weight.

When looking at some of the single studies there are conflicting conclusions regarding the overall effect of the involvement of significant others when making lifestyle changes related to obesity, but many noteworthy findings. Wing and Jeffery (32) found a 33% greater weight loss for people recruited with friends in standard behavioral treatment than for those recruited

alone. More people in this group also maintained weight loss in full. Drop-out rates was lower for the group with friends as well. However, Wing et al. (33) found identical weight loss between groups with and without spouses, but that men did better when treated alone and women when treated together, which may indicate a gender difference in the benefits of social support. Other studies have shown that men benefited more from the partner's emotional and instrumental support than did women (34) and that support from a female partner is more valuable to both men and women when it comes to changing lifestyle and losing weight (34, 35). Gorin et al. (36) couldn't find a difference between the groups regarding weight loss either, but found that having at least one successful partner (i.e. a partner losing more than 10% of initial body weight) made the participant lose significantly more weight than those without a successful partner. There were also a strong relationship between participants and partners when it came to adherence to treatment. The same result was found in a study of African-Americans (37), there were no difference between groups with and without partners regarding weight loss, but the participants' success was related to the partners' weight loss and attendance in personal counseling sessions with the participant. A recent study by Marquez and Wing (38) on Latin-American women could not find any significant difference in weight loss between groups, but also they found an association with better attendance for those who brought a partner. It may therefore seem like the positive effects of social support are linked to the partners' participation and success, rather than just being assigned with a significant other. In addition, studies by Gorin et al. (39) and Golan et al. (40) on untreated spouses of participants receiving treatment showed that also the spouses benefited from the treatment and lost weight themselves, even without treatment. Also, Golan et al. (40) found that if the spouse believed in the other's ability to succeed, it predicted weight loss of the spouse and raised adherence to the treatment.

Qualitative studies on social support

To further understand the patients perception of the role of social support, qualitative studies can offer insights. There are however only some qualitative studies in this area.

Aschbrenner et al. (41) found that bringing a significant other to treatment promoted understanding and enhanced the relationship with the significant other, as they then gained

insight in their illness and their struggle with it. The positive encouragement for life style changes from significant others worked as a facilitator to change, and was emphasized also by participants in the study by Jones and colleagues (42), as well as taking pride in the weight loss they achieved when others commented on it.

Boutin-Foster et al.'s (43) study found that it was easier and more practical to engage in healthy behaviors when one had support partners that helped with preparing and acquiring healthy food, as well as having someone participating in physical activities with them. It also helped relieve stress, as the support partners for instance took care of family members in their absence. However, also negative effects were mentioned: the social network strongly influenced their diet, with problems with family meal habits and the use of food as a social function, results confirmed by Jones et al. (42), Thomas et al. (44) and Gallagher et al. (45), indicating that food is related strongly to family conventions and that involvement of the whole family is important in weight loss programs.

Korkiakangas et al.'s (46), Allender et al. (47) and Gallagher et al.'s (45) studies found that it seemed that social support was most positive related to physical activity, as it offered an opportunity for companionship. However, it was important that the significant others accepted the person's exercise habits and that it was an advantage that the other was on somewhat the same level of physical fitness.

Those who did not live with a significant other found it hard to keep up their lifestyle changes, because of less contact with and reliability of the support persons, as reported by the studies by Aschbrenner et al. (41) and Gallagher et al. (45).

The challenge of isolating the influence of social support

Problems with the presented studies are that social support is often so intertwined with other interventions, that it is difficult to isolate the influence of social support. Social support is ill-defined and varies greatly among the studies, and poses a problem for reaching a conclusion regarding social support in lifestyle treatment for obesity. Previous research has given some directions for further research, including finding out what factors are important for an effective intervention integrating social support (30, 41), which partner and participant characteristics that are important to make treatment successful, including their relationship

(18, 20, 36, 48), and how to involve the patient's natural support groups when trying to make lifestyle changes (49).

Some of these questions can be answered and hypotheses generated by qualitative studies. However, there seem to be a lack of information on the participants' own experiences of participating in treatment programs with social support partners. There is thus still need for more qualitative studies that give knowledge about what the role of social support is, and which factors in social support impacts the effectiveness of the lifestyle changes the patients makes, and how to involve significant others in this treatment for obesity.

As one challenge is to untwine the influence of social support from other interventions, comparative qualitative studies are needed to investigate the experience of those involving family and friends in the intervention and compare this to those who did not. However, no such study has been published.

Family & Friends is an ongoing controlled study looking at the effect of social support during a camp based weight loss program in Central Norway, which provided an opportunity for a comparative qualitative study. In the controlled study half of the participants bring significant others to parts of the treatment at camp while others do not, whereas the rest of the treatment program is identical for both groups (7, 12).

Aim of study/problem to be assessed

The aim of the study was to investigate the role of social support in conservative treatment for obesity and in the participants' everyday life by comparing experiences of those participating in a camp based weight-loss program with or without bringing a significant other.

METHOD

Design and choice of method

This was a comparative qualitative study with semi-structured individual and focus group interviews. Qualitative methods are good for exploring peoples' experiences, thoughts and attitudes (50). It is useful in research on fields that have not previously been thoroughly explored, and where the problem is complex.

Ethical aspects, time frame and resources

The Family & Friends study was approved by the regional ethics committee in Central Norway, Trondheim, Norway. It was conducted by the guidelines of the Declaration of Helsinki. As this present study was a part of the main study's research protocol, there was no need to get new approval from the ethics committee. There were obtained written informed consent from all participants before they were enrolled in the main study. Also, new written information about the interviews was given before this present study, and oral consent was obtained by telephone and/or face-to-face before interviews took place. See attachments 1 and 2.

The work with the master thesis was conducted with starting preparations in June 2012 until submitting it in October 2013. All interviews were conducted one week in October and one week in December.

Setting

The present study is part of a larger study called "Family & friends", which is a non-randomized controlled trial looking at the effect of bringing a significant other to a 2 year intermittent treatment program consisting of five three-week stays at Røros rehabilitation, Norway. The treatment program is group based with 20 obese patients staying at the facilities simultaneously. In model A they were to bring a significant other, as opposed to not bringing a significant other in model B. Primary end points in the controlled study are weight loss after 1 year, maintenance of weight loss after 2 years and change in quality of life (measured by

SF-36) after 2 years. Secondary end points are changes in body composition, risk for disease, appetite hormones, quality of life, experience of one's body, relationships and eating behavior in the patient, as well as changes in weight, activity level and eating behavior in the significant other.

The program takes place at Røros Rehabilitation, where the participants live in apartments two km away from the rehabilitation center, and activities take place at both locations. Participants have a fixed schedule, which is group based with individual follow-up during each of the stays. The focus is on behavioral changes, diet and exercise, and how to manage this when they are on their own at home after the program has ended. Participants have lectures about diet, physical activity and psychological health. They exercise 2-3 times per day, trying out new activities in order to find something that fits each of the participants and which they can continue at home. They also have days dedicated to longer trips biking or walking outside in the nearby surroundings. Weekly they have practical training in making healthy food in the kitchen. Both individual and group meetings with psychologists and psychiatric nurses take place during the three week stay where they discuss challenges in daily life regarding lifestyle changes and how to solve these when they come home.

Participants

Patients enrolled in the main study "Family & friends", who all had been recruited from the Obesity Outpatient Clinic at St. Olavs Hospital in Trondheim, were eligible for this qualitative study. The inclusion and exclusion criteria in the main study:

Inclusion criteria

- BMI > 40 kg/m^2, or BMI > 35 kg/m^2 with comorbidities
- Age 18 – 50 years
- Possibility to participate with a significant other (family or friend)

Exclusion criteria

- Reduced ability to consent
- Pregnancy
- Severely reduced physical ability that limits participation in activities

- Severe psychiatric disorders
- Psychosocial aspects that limits group participation
- Former bariatric surgery
- Severe heart or vessel disease
- Severe overeating behavior

Patients were screened by nurses, endocrinologists, psychiatrists and clinical dietitians by referral. There were patients from both sexes. Both groups were assumed to be equal at time of recruitment, however, the level of social support was not evaluated to a large extent, more than that both groups had someone to bring to as a co-participant, should they be picked out to be in this group.

Significant others were chosen by the participants themselves, and consisted of family members or close friends. There were no specific inclusion criteria for the significant others.

Recruitment for the present study

The interviews were carried out during the participants' last stay at Røros Rehabilitation. At this point, they had been in the program for two years and assumingly had relevant experience from to the program and social support for the life style changes.

Information letters about the study was sent to all the participants in the main study (both the group A with significant others and group B) who were supposed to be at Røros during the periods of data collection. They received this information letter three weeks prior to going to Røros. This letter contained information about the qualitative study including information that they would be contacted by telephone if they were chosen to participate and if so that they would be asked to participate when the interviewer came to Røros. It also informed that they could choose to be interviewed alone or/and in groups

Participants in both group A and B were assigned to the qualitative study by strategic selection, assisted by the staff at Røros rehabilitation that had previously worked with the patient groups and knew the participants well. This guaranteed participants with varying degrees of success in the program, as well as different family and social backgrounds. It was also asked for participants who were most likely give much information during the interviews.

The participants were chosen two weeks prior to their 5th stay, one week after the information letter was received, and contacted at home by telephone to be asked if they were willing to join the study and appointments for the interviews were made. Initially, 10 participants were recruited from each group to be interviewed alone and/or in groups. The intention was to continue the interviews until saturation for each group. Thus there was an opening for recruiting more participants at Røros. This was done by asking them directly during the stay.

The groups were at Røros during different time periods, with group B (without significant others) being there first. The interviews with this group took place in the time period between 16th and 20th of October 2012. The interviews with group A were conducted between 13th and 17th of December 2012.

The recruited participants were informed about the topic and goal of the interview in a common meeting at Røros before they were interviewed, so that their expectations could correspond to what was going to happen in the interview situation.

The interviewer also joined in the daily activities during the interview period (3-4 days), in order to establish a relationship of trust between the participants and the interviewer and to observe how the groups and program functioned.

Data collection

The interviews conducted were semi-structured individual interviews and focus group interviews. Semi-structured interviews were chosen because of the ability to let the interviewees follow some of their own leads, thereby giving room for a broader spectrum of experiences, while the interviewer had a chance to steer the interview towards the research question. Focus group interviews were performed after the individual interviews had been done, in order to confirm and further explore the findings of the first interviews, and to use the group process to help the participants think of new relevant experiences.

Interviews were recorded digitally, and each interview took approximately 30-90 minutes, depending on the amount of information emerging.

An initial interview guide (attachment 3) was prepared before the interviews took place, with the main question being: “Can you tell me about the role your family and friends play in the

treatment program you are participating in (at Røros and at home)?" with subtopics like: instrumental support for changing physical activity and diet, personal changes, perception of social support and attitude changes toward the participants from others during the treatment. The emphasis was on the changes that had occurred during the whole two year treatment period.

The initial interview guide was revised after some new relevant topics and links emerged in the first interviews with group B. General questions about their present and past social situation and social challenges related to their lifestyle changes were added. The revised interview guide was used for group A, with small adjustments like adding questions about the significant other.

Data analysis

The data was analysed according to systematic text condensation (50). The interviews were transcribed, and thereafter read to get a general impression of the main emerging themes. Then meaning units correlating to the main themes was extracted from the text, systematised, coded and sorted within the themes. To elicit the differences between the groups (the comparative aspects of this study), the analysis was first done on interviews from the group participating without significant others (group B). Then group A was analysed by starting to use the themes identified in group B as the main themes. New main themes that emerged were added and the data from group B reanalysed to see if the new themes also were relevant for that data. At last a set of themes that covered both groups were identified and a table over the differences were made. Afterwards an analytical text for each code and subtheme was made. The texts were checked with the original transcript to validate the findings. Citations were chosen and embedded in the results, picking out the ones who best represented the themes that emerged and illustrated what was significant for each group. To preserve anonymity, the citations are only identified by group membership (A with significant other and B).

RESULTS

Participants

A total of 20 participants were interviewed, 10 in group A, who had a significant other who took part in parts of the program, and 10 in group B, who did not get the possibility to bring a significant other. Recruitment is shown in table 1, total attendance in table 2 and descriptives in table 3.

Table 1 Recruitment

	Group A		***Group B***	
	Individual interviews	**Group interview**	**Individual interviews**	**Group interview**
Received information letter	19	19	19	19
Asked to join interviews	10	4	10	5
Agreed to interview	10	4	10	5
Lost informants	2	3	1	1
New recruited informants	0	2	0	1
Total in each setting	8	3	9	5

Table 2 Total attendance

	Group A	***Group B***
Individual interview alone	7	5
Group interview alone	2	1
Both interviews	1	4
Total attendance	10	10

Table 3 Descriptives

	Group A	***Group B***
Age range	32-52 years	27-53 years
Men	4	4
Women	6	6
Marital status		
- *Single*	3	6
- *In a relationship*	0	1
- *Married*	7	3
Signficant other		
- *Spouse*	6	
- *Friend*	2	
- *Family member*	2	

Main findings

The analysis resulted in the following main themes; discussion of personal problems, challenges with support persons, support for sustaining changes, support for changing diet and support for being physically active.

Brief summary of main findings

There were some differences between the groups, especially when it came to involving significant other's in the participants' lifestyle changes. Participants from the group who brought significant others opened more up about their problems to their significant others, they also felt their significant other's understood more about their situation and helped them more out with the lifestyle change. This was seen as being due to the significant other having an enhanced understanding of the patient's problems because of discussions during the treatment program and that the significant others were educated about diet, physical exercise and how to help the patient change lifestyle.

Moreover, some had brought significant others that they felt were of no importance to whether they succeeded or not, or not very interested in helping them out.

There were also many similarities between the groups regarding the role of significant others and social support in their everyday life, like the reluctance to open up about personal problems, the positive effect of pep-talks and positive feedback, the use of self-help groups and significant others joining them as exercise partners.

Discussion of personal problems

In both groups the participants talked about problems with managing to open up to their family and friends about personal problems, especially of more serious nature, even though they said that they would get help if they allowed themselves to open up. It was especially mentioned that it was challenging to make their significant others understand what the reasons for their problems with weight were, and that they feared to be judged for these reasons. Thus, both groups said that they had problems with discussing their personal problems with others, as illustrated by this citation:

> *"(…) I understand that they don't understand, because of (…) the way I have let them get to know me. It isn't at all in harmony with how I've presented myself." (Group B)*

One of the most important findings from the study was that many participants from the group who brought significant others found it was easier to be open to their significant other about their personal problems after they had been at Røros together. They realized they needed to sort out these problems in order to establish the life style changes and felt that the significant other had seen more of what their problem consisted of at Røros, thus making it easier to talk about at home.

> *"He understands it better now. After we've been up here I've opened myself up more about my relationship with food. He saw that I struggled, that this was something I didn't feel comfortable with." (Group A)*

The participants in group A said that it helped that the significant other they brought along got to be a part of the process, rather than being a passive bystander to the program and the changes the participant made. It also made the significant others realize that the treatment

were focused on more than just losing weight, for instance sorting out personal problems and to feel better about oneself. Also, the participants said they felt it was better for the significant others to get information about diet, physical activity and psychological issues from the professionals at Røros than from the participants themselves. They experienced that the significant others took the life style changes of the participant more serious when they got the information from the professionals, as it was seen as more reliable knowledge.

> *"I don't think it would have been good for our marriage if I came home saying that now we are going to do this and that. It was important that he heard it from the professional team here. It is important that he has been a part of the process instead of standing on the sideline when things happened with me." (Group A)*

Challenges with support persons

Some had brought significant others who they felt weren't very important to whether they succeeded or not. They told of little or no contact with the significant others on a regular basis, and could not attribute any of the changes they made to the significant others.

> *"(...) She calls me and is supposed to take her task seriously, checking out how I'm doing and things. I don't believe it has any significance to whether I succeed or not, I'm feeling strongly that it's coming from someplace inside me." (Group A)*

There were also some of the participants from the significant other group reported having partners who wouldn't talk about feelings or personal problems, and refused to accept that the participant had problems or that there were problems between the participant and themselves, which made it difficult for them to get more understanding from the significant other, and thus to get help making lifestyle changes at home.

> *"I don't talk about the things that are difficult, and when you're married to someone who opens up even less it is not easy. (...) My hope is that he will realize that we need help." (Group A)*

A few of the participants with significant others experienced that some of the people around them, including the significant other, were not interested in the life style changes they were trying to make. Some had partners who thought things were fine as they were and would not

make changes. Others said their grown-up children were indifferent to what they did. One participant put it like the partner just contributed with not opposing her, i.e. did not take any action in order to do anything positive or negative for her.

> *"It is more like absence of opposing me. He is not joining in; on rare occasions I can get him to take a walk with me. (…) I make all the food and grocery shopping anyway. (…) When I'm gone he lives of noodles and honey puffs." (Group A)*

Some of those who attended without significant others reported to have no close family or friends that they could rely on for support during this program, even though this was an inclusion criterion for the main study. They had no one to talk to at home when things got tough and felt that no one followed them up. For those living alone without partners or family it was a problem that no one saw if they had been out exercising or eating the wrong food, they missed being held accountable for their own actions.

> *"I've only got myself to think about, and there is no one there to notice if I've been exercising or not. It is sad to make dinner just to myself; it easily becomes something quick and unhealthy. I've only got myself to answer to." (Group B)*

Support for sustaining changes

Both groups said sustaining the life style changes the participants had already made was hard. They mentioned getting pep-talks from friends and family as a help in this. Talking with other people on the phone or face to face when times got though was important for most of the participants. Having someone checking up on them made some of the participants commit more to their original plans.

> *"My sister is coming to check up on me, how I'm doing, what obligations and plans I have to go through with." (Group A)*

Many of the participants in both groups attended self-help groups organized by themselves or larger public support groups. Some had self-help groups prior to joining the program at Røros, while others established groups together with other participants at Røros or people in their local community after starting the program. The participants stated that these groups helped them guide their way during the home periods by getting advice from people in the same

situation regarding what they could do when motivation was low or they struggled maintaining diet and exercise programs. They often felt that the people in their self-help group had a greater understanding of their situation than their family and close friends. Many of them met face to face during the home periods or had frequent contact by telephone or Facebook. They talked about challenges of the lifestyle changes and also met just to be social and have fun.

> *"We've established a self-help group that really works. (...) You get back on track and learn what the others are doing right and find out what we are doing wrong ourselves. It is important to just meet up over a cup of tea and supper; you don't always have to have so much program all the time." (Group B)*

Having support persons who either had or used to have the same problems with weight and weight loss were deemed very valuable by the group without significant others. They also felt that those around them enhanced their understanding of their problems if they encountered some of the same problems themselves.

> *"It is still hard to explain to my husband how I'm feeling, as opposed to talking to someone here or my friend that also is overweight. You don't need to say so much, they understand anyway."(Group B)*

Most of the participants emphasized the importance of positive feedback from those around them. Family, friends and colleagues praised their effort to make changes in their life and gave feedback about how the participants changed in a positive direction. One participant also told that even strangers gave her thumbs up when she was out walking. Getting positive feedback made them want to work even harder with the life style changes.

> *"People come to me all the time and ask me how I'm doing and telling me that I look good and things. It is really nice feedback I get." (Group B)*

On the other hand, participants in both groups also received negative comments about the life style changes they were doing and them attending the program at Røros. This was based on others saying it was their own fault they were overweight and thus they should fix it without

help, while others questioned how they could leave their family for several weeks to focus solely on themselves.

> *"Some think it's my own fault that I've become like this, so that I should fix it myself instead of using the taxpayers' money when I've eaten my way here by myself." (Group B)*

Support for changing diet

One important thing from the group A with significant others was that more people said their significant other helped them eat correctly, related to both meal rhythm and types of food. Spouses went grocery shopping with and without them and bought the same things the participants did themselves. The significant others were reported to keep them from falling back into the old meal habits and told the participants to prioritize the food plan even if they were busy with daily chores. Some had spouses who prepared healthy meals and helped them out with the cooking.

> *"My wife is very eager to go through with the lifestyle changes. She tells me that we have to go exercising and she prepares healthy meals, so she has a great role in looking after our diet." (Group A)*

Some of the significant others were not interested in changing their own or the family's diet or were just ignoring the changes their spouse was trying to do, and some without significant others had family or friends who didn't want to join them in being physically active.

> *"He's just as passive as I am, maybe as big as me too. But he doesn't think the weight is a problem. (...) He hasn't really enlisted for this yet." (Group A)*

The without significant others group reported challenges with having older children and adolescents who ate at different times and wanted other type of meals than the rest of family, which lead to the participants eating dinner twice per day. Some family members also had other nutritional requirements than the participant because of illnesses and activity level. This made it hard for some participants to change the types of food being eaten at home. They also reported that the people around them brought home more unhealthy food and tempted the

participant with it, consciously or not. It could therefore be hard to resist eating this kind of food.

> *"I might already have had dinner earlier in the day (…) when they were not at home, and then it happens that I serve something at night, and that I eat with them just to participate and be with them. It's a part of the comfort and care." (Group B)*

Support for being physically active

Having family and friends as exercise partners were common for both groups. Most had people around them that would take walks or do other exercising with them. In some cases the entire family with spouse and children had started exercising together. Others had their spouse help them with exercise tips and techniques. Most had support persons who wanted to become more physically active themselves who asked if they would like to join them exercising. Significant others were pushing the participants to exercise more and gave them advice about things they could do or try when it came to alternative exercise activities.

> *"I broke my finger playing handball and I thought "Oh no, I can't do that anymore"; it was the automatic negative thoughts. But then my daughter said: "But mom, you can do something else!". (…) It was all about looking at the options one have." (Group A)*

For both groups it was important that the support persons gave them time to be in activity despite a tight family schedule, for instance by taking care of children and house chores.

> *"My husband offers to do the household chores so that I can go out exercising." (Group B)*

DISCUSSION

Summary of main findings

The results showed that bringing a significant other into the treatment program made it easier for the participants to open up about personal problems, thus enhancing the significant others' understanding of the challenges the participants had in changing their lifestyle. The participants also emphasized that it was better for the significant other to get information about diet, physical activity and psychological issues from the professionals at Røros than from the participants themselves. Integrating the significant other in the process of changing life style was from the participants' viewpoint important for the significant other's interest and commitment in helping the participant. The significant others helped them eat correctly and kept them from falling back into old habits. However, participants also mentioned troubles with their significant others: partners weren't willing to talk about feelings or personal problems or were not interested in the lifestyle changes they were making. Some had also brought significant others who they felt weren't very important to whether they succeeded in changing their lifestyle or not.

The group without significant others talked more about having few or no close family and friends they could rely on for support during the program. Problems with following diet and exercise was attributed to tight family schedules, different nutritional requirements for the family members and that they found it boring or sad to cook for themselves only.

It was easier for the participants to sustain the changes of lifestyle when they got positive feedback and pep-talks from their social network. Family and friends acted as exercise partners and gave them time to prioritize being in activity by helping out at home with children and house chores. Common obstacles for social support were problems with opening up about personal problems to family and friends and receiving negative comments about the lifestyle changes and treatment program.

Talking about personal problems

Participants from both groups mentioned how hard it was to talk openly about their problems and to make their significant others understand what their problem consisted of. However, one of the most important findings from the group with significant others was that bringing someone to the treatment made it easier to open up about problems and challenges they had, and that this enhanced the significant others' understanding of the situation the participants were in. The participants also emphasized the value of the significant other getting information about healthy lifestyle from the health professionals at Røros, as they thought the significant others felt it was more reliable information and made them become more involved in the whole treatment plan. This is in accordance with the study on lifestyle changes in mentally ill patients by Aschbrenner et al. (41), where involving support partners increased the understanding of the challenges of the patients and made the relationship between the patient and support partner better, because they learned what the patient was going through. Involving a spouse as support partner has also been found to improve social life and led to positive changes in relationship with the spouse (42). The current study lends strong support to this as it was more clearly expressed in the group that had the significant other participating in the program. Therefore it seems that bringing a significant other to treatment could make it easier to open up about problems, as the significant other enhances his/her understanding of the problems the patient is going through by being a part of the whole lifestyle change process, and that this may improve the relationship between the patient and the significant other. Being involved in the entire process with the participant could make the significant other more informed and ready for helping the participant with the changes.

Positive feedback on the changes the participants made and encouragement to keep on working with their problems was reported to make it easier to sustain the lifestyle changes. There were no differences between the groups regarding this. Earlier studies have also found that positive encouragement, feedback and reinforcement for the efforts the patient makes worked as a facilitator to go through with the changes, as noted by Aschbrenner et al. (41), Jones et al. (42) and Korkiakangas et al.(46). Conversely, negative feedback or significant others not being able to or interested in talking about the changes and problems act as an obstacle to go on with the lifestyle changes. This may indicate that it is important to

emphasize to the significant others the value of focusing on the positive aspects of the changes instead of the negative, and that it is necessary to talk openly with significant others about the problems the patient has.

Dynamics between participant and significant other

Not all overweight or obese persons may benefit from integrating social support from significant others in treatment for their weight problems. This seemed to be true for some of the participants that had joined the study, who openly told that they didn't have anyone to rely on for social support or that they were not especially outgoing and interested in involving other people in their own treatment, or even kept it a secret to those around them that they were in treatment. As noted above, it seems to be important to be open about one's problems in order to benefit from social support, thus requiring the patient to be somehow outgoing and interested in involving others. It may also work better for patients who live with someone on a daily basis, as most of those who lived alone said that it was harder to make lifestyle changes when no one was following them up at home. However, those with no or few significant others to rely on may benefit from organized support groups and help to broaden their social network by for instance professional help.

Some of the participants in the group with significant others had brought partners they didn't feel were important to whether they succeeded or not, and some had brought significant others that did not help them especially much with the lifestyle changes or were not interested in taking part in the program. The relationship between participant and significant other seems to be important with respect to who one should bring as significant other. Previous research has noted that the response from the significant other towards the one changing lifestyle reflects the overall dynamics of the relationship between them. Those who felt they received little support for lifestyle changes also experienced little support generally in the relationship (51). This seemed to be true for some of the participants in the present study who reported having difficulties with talking about problems and making their significant others understand their situation. Also, the group without significant others more often told of having few or no persons to rely on for social support during the treatment. This could indicate that it is important to bring significant others who one thinks could be of help in the process of

changing lifestyle. Levy et al. (31) and Marcoux et al. (48) found that one should identify people who will be supportive of their lifestyle changes and who preferably have health promoting behaviors or/and attitudes, which makes it more likely to be engaging in physical activity and to eat healthy, as the results of Berge et al.(13) and Ashida et al. (25) suggest. It also seems that the success of either the participant or significant other affects the success of the other, as the other also often tries to lose weight. Also, having a significant other that believes you are going to succeed is encouraging and makes it easier to sustain the changes [39, 40]. The significant other should be motivated for lifestyle changes themselves in order for the participant to succeed in changing his/her own lifestyle (36-38).

The results might also indicate a problem with recruitment of significant others, as there seemed to be very varying levels of social support from significant others between the participants, not only inter-group but also intra-group. The significant others most often were spouses, but some also brought more remote friends, siblings and parents. This might have led to larger differences between the participants in one group than between the groups regarding level of social support, and may have affected the results of the study. This raises the question if one should assess level of social support more closely and tailor interventions specifically for the support the participant has on a daily basis, whether this is close family or friends or more remote persons. This is in line with earlier research from McNicholas et al. (14) and McLean et al. (30) that emphasize the need for assessing participants' level of social support in order to improve their healthy behaviors and that one should tailor the social support plan with both the patient and the significant other in order to find out how they will work together; rather than having a general support program to follow, as noted by Aschbrenner et al. (41). Research has also shown that some may benefit from support from family, while others benefit more from support from just friends or both, thus requiring more targeted interventions for each subgroup of social support (19). It would be important to find out what works for the support partner and the patient together, they might work better together when it comes to exercising than diet or vice versa. It could be that the patient needs more support partners for the different parts of the lifestyle changes, if one support partner does not function well in regards to both emotional and instrumental support. It would also be wise to involve support partners that are genuinely interested in helping the patient out. The results also showed that the participants found it easier to talk with people who had the same

experiences related to overweight, than to people with no such experience. Therefore it might be of benefit to have support partners that currently are or have been struggling with the same issues. The use of self-help groups might be of value here.

Support related to diet and physical activity

Results from the group with significant others showed that the significant others helped them to eat correctly and to not fall back into old bad eating habits, this was however not so evident in the group without significant others. This may suggest that significant others that were given education at Røros seem to impact the household's diet more positively than significant others who did not receive education. These findings are partially supported by qualitative research by Boutin-Foster and colleagues (43) that has shown that it was easier to engage in healthy behaviors when patients had significant others that could help them acquire and prepare healthy food. It has also been shown earlier that food was strongly influenced by family traditions and worked as a social function, which may make it difficult to lose weight if the family is not involved in changing dietary habits (42, 45). In the present study some participants said that their significant others tempted them with food they were not supposed to eat, but there were also indicated challenges with other family members wanting /needing other types of food than the participants was supposed to eat and eating at different times, making it harder to stick to their diet. These findings could enhance the importance of engaging the whole family when it comes to changing diet

Participants from both groups had significant others who were interested in physical activity, who took them out exercising, showed them exercise techniques and made it easier for them to get time to exercise and thus to maintain the lifestyle changes, for instance by taking care of household chores and children. This is in accordance with earlier research, showing that it was easier for patients to engage in healthy behaviors when they had someone to participate with them in activities, rather than just saying that they should exercise (24, 42, 43, 46). Also, being held accountable for doing exercise was important for maintaining lifestyle change (41). A possible conclusion could be that it is important that significant others make time for letting the patient exercise, and that joining in on the physical activity themselves could help the patient maintain the habit of exercising.

DISCUSSION OF METHODS

Strengths

The main strength of this study is the comparative design. To the knowledge of the author, this is the first study to be qualitative and comparative between groups with and without support partners taking part in weight loss programs.

The qualitative approach gave the opportunity to look further into the experiences of how integrating social support worked for those participating in the treatment program at Røros Rehabilitation. The interviewer's stay with the participants at Røros by the interviewer is seen as a strength, as it may have served to build the interviewees confidence, making the interview situation more productive. Also, it improved the interviewer's understanding of how the program at Røros worked for the participants.

The strategic selection of interviewees ensured diversity between the participants, with differences between participants regarding demographic values, and a broad spectrum of experiences and aspects related to social support. The study did not aim to provide data that was statistically reliable, but to give in-depth insights into the experiences of individuals.

Limitations

The qualitative study was a part of a larger controlled study. The inclusion criterion for the main study did not seem to be followed accurately, as some patients entered the study without having any available support person, and was thus put in the group without significant others. In the interview situation, this led to some participants having little to say about how they experienced social support. Ideally, to isolate the effect of social support integrated in a treatment program, candidates for the main study should have been matched with respect to having a significant other available, and then allocated by random to the two different treatment groups. From a qualitative point of view (this substudy), however, this would reduce the diversity among patients as the contrast between having a significant other available or not is a valuable contrast

The qualitative design and lack of follow up did not allow for measuring the level of success for the participants, so that the study cannot say whether social support is associated with success in weight loss or not, or if those who are most successful are those with or without significant others. This will be investigated further in the main study. Repeated interviews, e.g. at baseline and towards the end of the treatment, could also have provided more reliable insight into how the nature of social support changed during the treatment program.

The comparative nature of this study and the challenges of doing comparative qualitative analysis pose a possible limitation. Extra care was therefore taken to ensure the validity of the analysis by first analyzing the interviews from group B without significant other and thereafter the group A with main themes from group B. The interviews from group B was then reanalyzed included the new themes that had emerged from group A. Making a table of similarities and differences made it easier to see what distinguished the two groups. However, variations between the participants were great, and there seemed to be some intra-group differences, as well as inter-group differences, which sometimes made it hard to make relevant conclusions from the different groups.

The use of interviews relied on the participants' will to talk about themselves, and some interviews may have suffered from this. The interviews could have been more structured and focused more on solely social support than what was the case for the present interview guide, as it gave much data that was not used directly in this study, but served as supplementary information to understand the participant's experiences and backgrounds.

The experience of the person doing the study could also be a limitation, as she had little experience with conducting interviews and doing qualitative analysis. However, the development of the interview guide and the analysis was conducted with the support of the supervisors, who also read through some of the interviews to validate the analysis.

Lastly there might be a limitation not to have interviewed the significant others, thus just getting the participants' thoughts about the significant others' experiences of the treatment program. However, this perspective was outside the scope of this study.

By using questionnaires with open-ended questions one could have gathered different data regarding the participants' experiences, but it could have been difficult to find out what one

should have asked about. As the aim of the study was to find out more about the experiences of the participants, the use of quantitative methods did not seem to be justified.

CONCLUSION

This explorative study found these main conclusions:

Findings indicated that the support person/persons should be someone who one thinks might be of help. Involving someone with similar problems/experience seemed beneficial. The use of activities that enhance social support, like self-help groups, seems valuable, as both groups in the study had made use of such. And for those not having a large social network to rely on it could be of great importance.

Also, social support interventions might not be for everyone, and that the patient should be interested in involving others in their problems and treatment to take part. Assessing the patient's level of social support and tailor the intervention thereafter seems to be important for a successful social support intervention.

Those bringing a significant other to treatment had some experiences that are different from those not bringing a significant other. This included making it easier for them to open up about personal problems and experiencing more social support in everyday life with a positive impact on the household diet and level of physical activity. This was seen as being due to the significant other having an enhanced understanding of the patient's problems due to the discussions during the treatment program and that the significant others were educated about diet, physical exercise and how to help the patient change lifestyle.

Implications for practice and research

There are some findings from the present study that could be important to focus on when tailoring treatment involving significant other, especially to focus on the selection of significant others. One should find out who might be of best help to the patient and what works for the patient and the significant other together, and then work out a plan which builds on this. After mutual trust have been established, the patients should be encouraged to talk openly about their problems to the support partner. For the education of the support partners, the value of focusing on positive aspects of changes should be emphasized, as well as the importance of engaging the whole family in diet changes, giving the patient time to exercise, and that joining in and giving advice about exercise helps maintain patient's exercise routine.

The treatment program should also encourage the use of activities outside the program that enhance social support.

Further research on the topic of social support in treatment should focus more on the significant others and their perspectives and experiences of being a support partner. The process of selecting significant others and the interaction between them and the patient during the treatment program would be of great interest. The success of the patient and the significant other when it comes to losing weight and changing lifestyle should be assessed. One should also focus on the periods when the patients are at home, not attending a fixed treatment schedule, when social support seems to play a grander part of the help to maintain the lifestyle changes.

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ATTACHMENTS

1 Information about main study and consent form

Family and friends – 8. nov. 2010

Forespørsel om deltakelse i forskningsprosjektet

"Family and friends"

Betydningen av å ha en signifikant annen i behandling av sykelig fedme.
En randomisert studie av livsstilsbehandling ved Røros Rehabiliteringssenter

Bakgrunn og hensikt
Dette er et spørsmål til deg om å delta i en forskningsstudie for å vurdere om familie og nettverk påvirker evnen til å oppnå og opprettholde et vekttap. Du får denne henvendelsen fordi du er henvist til Obesitaspoliklinikken og har ytret interesse for fedmebehandling ved Røros Rehabiliteringssenter. Røros Rehabiliteringssenter er ansvarlig for behandlingen du får under oppholdet. Regionalt senter for sykelig overvekt ved St. Olavs Hospital er ansvarlig for forskningen knyttet til prosjektet.

Hva innebærer studien?
Felles for alle pasientene som inkluderes i studien er en serie undersøkelser og tester. Dette skjer i form av klinisk undersøkelse, blodprøver og utfylling av spørreskjema. (Undersøkelsene er spesifisert i kapittel A.) Noen av pasientene vil også bli intervjuet av en forsker. Studien innebærer fem opphold á tre uker ved Røros Rehabiliteringssenter. En detaljert oversikt over oppholdene er vedlagt.

Et krav for å delta i studien er at du har en nær venn eller familiemedlem som også er villig til å delta. For med-deltakerens del innebærer studien at han eller hun deltar de tre siste dager i hvert opphold. Også med-deltakeren vil måtte avgi opplysninger til forskerne i form av en klinisk undersøkelse, spørreskjema, og i noen tilfeller også et intervju.

Hvorvidt du kommer til å delta alene eller sammen med din med-deltaker avgjøres ved loddtrekning. Du har ikke selv innflytelse på utfallet av dette.

Skulle du bli inkludert i studien, innebærer dette at du forplikter deg til å delta på samtlige fem behandlingsopphold som spesifisert i oversikten. Uteblivelse innebærer at du kan bli ekskludert fra studien. Dette gjelder også din med-deltaker, såfremt du havnet i denne gruppen. Du kan imidlertid når som helst – og uten å oppgi noen grunn – trekke deg fra studien.

Mulige fordeler ved deltakelse
Hensikten med behandlingen er å hjelpe deg å gå ned i vekt, samt opprettholde et vekttap over tid. Dette kan innebære en rekke positive effekter for helsen din, som for eksempel reduserer sykdomsrisiko, øker funksjonsnivå og arbeidsevne, bedrer livskvalitet og så videre.

Mulige ulemper ved deltakelse
Behandlingen ved Røros Rehabiliteringssenter innebærer livsstilsendring i form aktiviteter rettet mot trening, kosthold og motivasjon. Dette er normalt ikke forbundet med risiko for alvorlige komplikasjoner.

Studien innebærer også blodprøver.

En spesiell hormontest gjentaes fire ganger i studien og innebærer en serie med blodprøver tatt med jevne mellomrom etter inntak av et måltid. For å unngå å stikke deg gjentatte ganger, legges inn en venflon.

Hva skjer med prøvene og informasjonen om deg?
Blodprøvene sendes for analyse til St. Olavs Hospital og resultatene vil inngå i din pasientjournal. Prøvesvarene vil sammen med resultater fra kondisjonstest, lungefunksjonstest, blodtrykksmålinger og spørreskjema bearbeides av forskere som er tilknyttet prosjektet. Intervjuet skrives ned, men opplysninger som vil kunne spore tilbake til deg utelates fra utskriften. Lydopptaket oppbevares nedlåst for eventuell kontroll.

Prøvene tatt av deg og informasjonen som registreres om deg skal kun brukes slik som beskrevet i hensikten med studien. Alle opplysningene og prøvene vil bli behandlet uten navn og fødselsnummer eller andre direkte gjenkjennende opplysninger. En kode knytter deg til dine opplysninger og prøver gjennom en navneliste.

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg.

Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Etter hvert opphold sendes en epikrise (sammenfatning) til din egen lege og Obesitaspoliklinikken.

Frivillig deltakelse
Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette innebærer imidlertid at du heller ikke får eventuelle gjenstående opphold ved Team 5 på Røros Rehabiliteringssenter. Det vil imidlertid ikke gi konsekvenser for din videre behandling om du igjen henvises Obesitaspoliklinikken. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte teamleder Vegar Dahl, telefon 72 40 97 56.

Røros Rehabiliteringssenters rolle
Røros Rehabiliteringssenter er ansvarlig for innholdet i de fem behandlingsoppholdene du gjennomgår på Røros. Behandlingsperioden varer i to år og avsluttes etter siste (femte) opphold.

Regionalt senter for sykelig overvekts rolle
Forskere fra *Regionalt senter for sykelig overvekt* ved St. Olavs Hospital er ansvarlige for den vitenskaplige evalueringen (forskningen) som er knyttet til prosjektet. Forskerne får oversendt datamateriale fra Røros Rehabiliteringssenter, men vil også stå for deler av datainnsamlingen selv. De vil kontakte deg også fem år etter behandlingsstart for en siste evaluering (tilsvarende første undersøkelse med tester og spørreskjema).

Ytterligere informasjon om studien finnes i kapittel A
Ytterligere informasjon om personvern og forsikring finnes i kapittel B
Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Følgende kriterier må oppfylles for deltakelse
- BMI > 40 kg/m2, evt BMI > 35 kg/m2 gitt fedmerelatert følgesykdom
- Alder 18-50 år
- Mulighet til å delta sammen med en pårørende (familiemedlem eller nær venn)
- Bekreftelse fra pårørende om mulighet til å delta

Følgende situasjoner vil gjøre at man ikke kan delta i studien
- Mangelfull samtykkekompetanse
- Graviditet
- Vesentlig redusert fysisk funksjonsnivå som hindrer deltakelse i aktiviteter
- Alvorlig psykisk sykdom
- Uttalt overspisingsatferd
- Forhold av psykososial natur som vanskeliggjør gruppedeltakelse
- Tidligere gjennomgått fedmekirurgi
- Alvorlig hjerte-/karsykdom

Bakgrunnsinformasjon om studien
Røros Rehabiliteringssenter har siden 2005 tilbudt prosjektbasert behandling til pasienter med sykelig fedme. Behandlingen har vært utprøvende og har foregått i et samarbeid med Regionalt senter for sykelig overvekt ved St. Olavs Hospital. Røros Rehabiliteringssenter har i denne tiden utviklet kunnskap og erfaring med denne type arbeid. Mange pasienter opplever det utfordrende å opprettholde et vekttap etter man kommer hjem igjen. Venner og familie kan bety mye for den enkelte etter hjemkomst. Denne studien har derfor til hensikt å undersøke effekten av å integrere et familiemedlem eller en nær venn i behandlingen.

For å undersøke effekten av dette forholdet deles deltakerne i to grupper. Innholdet i behandlingsoppholdene til de to gruppene er like bortsett fra at for den ene gruppen er med-deltaker integrert i behandlingen. Det er tilfeldig hvilken gruppe du havner i.

Hva er alternativene om jeg ikke ønsker å delta i studien?
Om du ikke ønsker å delta vil du fortsatt kunne bli utredet Obesitaspoliklinikken. Pr i dag vil Obesitaspoliklinikken utrede deg primært med tanke på egnethet for fedmekirurgi, eventuelt et ikke-kirurgisk tilbud såfremt dette finnes i din kommune.

Undersøkelser, blodprøver og annet den inkluderte må gjennom
Deltakelse innebærer blant annet en rekke spørreskjema. Disse har ulike utgangspunkt, så som kroppsopplevelse, livskvalitet, mental helse, traumer, spiseatferd og personlighet.

Noen av blodprøvene har til hensikt å gi svar på sykdomsrisiko. Andre blodprøver taes spesifikt for å undersøke hormonell appetittregulering. Disse blodprøvene er mer omstendige og taes i en serie i løpet av 3 timer. Du møter da fastende, får lagt inn en venflon (for å unngå å måtte stikke deg gjentatte ganger). Etter en frokost (som du får av forskerne) taes en rekke blodprøver med jevne mellomrom.

En del av pasientene trekkes ut for intervju. I samtalen vil vi fokusere på forventninger til oppholdet og din med-deltaker, og opplevelser under og mellom oppholdene.

Andre undersøkelser du vil gjennomgå er kondisjonstest på tredemølle, undersøkelse av surstoffopptak gjennom natten og blodtrykk.

Tidsskjema – hva skjer og når skjer det?
Se vedlagte tabell.

Mulige fordeler ved å delta
Deltakelse kan innebære at du går ned i vekt, reduserer sykdomsrisiko og bedrer helsen. Du kan oppleve større grad av mestring og et økt funksjonsnivå. Du vil også kunne etablere positive sosiale relasjoner til andre deltakere.

Mulige ubehag/ulemper ved å delta
Deltakelse innebærer systematisk mosjon, noe som kan innebære noe utmattelse og slitasje. Det er også en teoretisk risiko for å skade seg (eksempelvis at man faller), men denne faren er alltid tilstede ved fysisk aktivitet. Det blir videre tatt en serie blodprøver gjennom studien.

Pasientens/studiedeltakerens ansvar
Det er ditt ansvar å påse at du har anledning til å delta på samtlige behandlingsopphold ved Røros Rehabiliteringssenter. Det er også ditt ansvar å påse at din pårørende kan delta i de angitte periodene hvor pårørende integreres i behandlingen.

Egenandel
Du vil under behandlingsoppholdet betale egenandel på kroner 123,- pr døgn (pris pr 17.02.10), begrenset oppad til kroner 2560,- pr år i henhold til egenandelsordning 2.

Med-deltaker har ikke krav på sykmelding etter dagens regler, og må selv ordne med fritak fra arbeid (ferie, avspasering). Med-deltaker må også betale egenandel på kroner 123,- pr døgn. Reisekostnad for med-deltaker dekkes ikke slik det er i dag. Det er viktig at du og din med-deltaker drøfter dette dere imellom opp mot de mulige helseeffektene deltakelse kan innebære.

Kapittel B - Personvern, biobank, økonomi og forsikring

Personvern
Opplysninger som registreres om deg er blodprøveverdier, kliniske funn (kondisjonstest, blodtrykk, surstoffopptak), ulike spørreskjemadata (kroppsopplevelse, livskvalitet, mental helse, traumer, spiseatferd og personlighet), samt relasjonelle forhold.

Deler av datamaterialet kan bli satt bort til andre forskere (eller studenter under veiledning). Slike data vil være avidentifiserte, altså uten personalia.

St. Olavs Hospital ved administrerende direktør er databehandlingsansvarlig.

Av kontrollhensyn blir grunnlagsdata oppbevart forsvarlig nedlåst frem til 1. januar 2018. Deretter vil data anonymiseres. Det er prosjektleder Bård Kulseng som er ansvarlig for datamaterialet i denne perioden. Instanser som kan tenkes å kontrollere grunnlagsmaterialet er f.eks. forskningsansvarlige, Uredelighetsutvalget for forskning og Helsetilsynet.

Utlevering av materiale og opplysninger til andre
Hvis du sier ja til å delta i studien, gir du også ditt samtykke til at prøver og avidentifiserte opplysninger utleveres til forskere ved St. Olavs Hospital. Epikrise (sammendrag) fra oppholdet sendes din fastlege og Obesitaspoliklinikken.

Rett til innsyn og sletting av opplysninger om deg og sletting av prøver
Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Forsikring
Du er dekket av lov om pasientskader under deltakelse i studien.

Informasjon om utfallet av studien
Utfall og publikasjoner fra studien vil bli lagt ut på hjemmesidene til Regionalt senter for sykelig overvekt (www.stolav.no/overvekt).

Samtykke til deltakelse i studien *Family & Friends*

PASIENT
Jeg er villig til å delta i studien og forplikter meg til å delta på samtlige fem opphold.

(Signert av prosjektdeltaker, dato)

Navn med blokkbokstaver

MED-DELTAKER
Jeg er villig til å delta i studien og forplikter meg til å delta sammen med pasienten på 3 dager i hvert av de fem oppholdene.

(Signert av nærstående, dato)

REPRESENTANT FRA PROSJEKTGRUPPEN
Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

2 Letter to the participants

NTNU
Det medisinske fakultet
Institutt for samfunnsmedisin

Intervju i forbindelse med «Family and friends» studien på Røros rehabiliteringssenter

Hei! Det er nå snart tid for ditt femte opphold på Røros i forbindelse med behandlingen i studien «Family and friends». Under dette oppholdet vil det bli utført intervjuer i gruppe og enkeltvis. Tema for intervjuene er:

- *Erfaringer og opplevelser av sosial støtte fra familie og nære venner i forbindelse med behandlingen på Røros*
- *Opplevelser fra deltagelse på behandlingen på Røros*

Intervjuene er en del av studien du er med på, og en viktig del av en masteroppgave ved det medisinske fakultet ved NTNU. Intervjuene utføres av undertegnede, som er mastergradsstudent i klinisk helsevitenskap med fokus på overvekt og helse.

Dette brevet sendes ut til alle deltakere på oppholdet, men ikke alle vil bli plukket ut til å være med på intervjuene. Noen vil være med på gruppeintervju og enkeltintervju, noen bare på en av delene. Intervjuene vil vare om lag 30 – 60 minutter, men dette er avhengig av hvor mye du ønsker å snakke om.

Dersom du blir plukket ut til å bli intervjuet tar jeg kontakt med deg pr. telefon i ukene før det femte oppholdet starter for å avtale tidspunkt for intervjuene. Du kan også få en forespørsel om å delta i intervju etter at du har kommet til Røros.

Med vennlig hilsen

Mari Ellingsbø,mastergradsstudent NTNU

Ved spørsmål ta gjerne kontakt på

Mobil: 97124841

E-post: mari.ellingsboe @gmail.com

3 Initial interview guide

Norwegian:

Kan du fortelle meg om den rollen familie/venner har for det behandlingsopplegget du nå deltar på (på Røros og hjemme)?

- Hvilken rolle har de rundt deg i forhold til det du gjør med endring av kosthold, fysisk aktivitet og mer personlige endringer?
- Hvordan opplever du den sosiale støtten du har mottatt fra de rundt deg gjennom programmet?
- Hvordan reagerte din familie/venner når du bestemte deg for å delta?
    - Hvordan opplevde du reaksjonene?
- Har det skjedd en endring i holdningen til de rundt deg i løpet av tiden du har vært med på opplegget?
    - I så fall, hvordan?
- Hvilke endringer har du gjort?
- Hvordan har pårørende bidratt til dette?
- Integrering av endring i hverdagen
    - Mat, husarbeid, jobb, tid til å gjøre endringer

Kan du si litt om hvordan du har opplevd å delta på dette behandlingsopplegget?

- Hva var hovedgrunnen(e) til at du meldte deg på?
- Hva er de viktigste erfaringene du har fått ved å delta på dette programmet?
    - Hva har vært mest utfordrende?
    - Hva har vært mest positivt/negativt?
- Hva har du oppnådd?
- Hvordan har behandlingen påvirket livskvaliteten din?

Er det noe du vil tilføye som vi ikke har snakket om?

English:

Can you tell me about the role your family and friends play in the treatment program you are participating in (at Røros and at home)?

- What role do those around have in respect to what you do regarding changing diet, physical activity and more personal changes?
- How do you perceive the social support you have received from those around you during the program?
- How did your significant others react others when you decided to participate?
    - How did you experience these reactions?
- Has there been any change in the attitudes towards your treatment from those around you?
    - If there has been, how have their attitude changed?
- What changes have you made?
- In what way have those around you aided in these changes?
- Integrating changes in everyday life
    - Diet, house chores, work, time to make changes

Can you say something about how you have experienced participating in this treatment program?

- What were the main reasons you decided to participate in the program in the first place?
- What are the main experiences you have from participating in this program?
    - What have been challenging?
    - What has been most positive/negative?
- What have you achieved?
- How has this treatment affected your quality of life?

Is there something you would like to add, that we haven't already talked about?