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## Using concept maps to describe the evolution in obese patients' knowledge and expectations following bariatric surgery

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**Abstract** – **Objectives:** This study describes how the obese patient's initial mental states evolved two years after surgery and their perception of therapeutic education. **Methods:** Twenty-four patients reviewed during telephone interviews the concept map they had fulfilled before surgery. Patients' comments were analysed on the basis of their trend to confirm or refute their initial representations. **Results:** Twenty-three patients confirm most of their initial representations. Eight over twenty negative initial representations, often related to diet field, became positive; 21% positive initial mental states became negative in differents fields. Most of the added comments had negative tendency (17 over 23) and 6 were related to the patient's difficulties to cope with diet. Psychological and health consequences constitute the most important issues for 1/3 patients. Fourteen patients consider they have been well educated before intervention, 7 patients stress the importance of meeting other operated patients before surgery. Patients' recommendations for therapeutic education before surgery. The difficulties related to nutrition and weight regain stress the importance of long term therapeutic education promoting patients group discussion. The use of concept maps develops the patient self evaluation skill.

Key words: morbid obesity / bariatric surgery / concept mapping / patient education

**Résumé – Exploration, par le moyen des cartes conceptuelles, de l'évolution des représentations des patients obèses après une intervention de chirurgie bariatrique. Objectif :** Cette étude décrit l'évolution des états mentaux de patients 2 ans après une intervention chirurgicale de l'obésité et leur perception de l'éducation thérapeutique. **Mé-thode :** Vingt-quatre patients ont commenté au cours d'un entretien téléphonique leur carte conceptuelle élaborée avant l'intervention et leur perception de l'éducation. Les commentaires des patients ont été analysés selon leur tendance à confirmer ou infirmer leurs états mentaux initiaux. **Résultats :** Vingt-trois patients confirment la majorité de leurs représentations initiales. Huit des 20 représentations dans le domaine de l'alimentation initialement négatives deviennent positives. Inversement, 21 % des représentations positives deviennent négatives dans différents domaines. La plupart des commentaires ajoutés ont une tendance négative (7/20), 6 concernent les difficultés rencontrées avec l'alimentation. Les conséquences psychologiques et sur la santé sont les plus importantes pour 1/3 des patients. Quatorze patients estiment avoir été bien éduqués, 7 soulignent l'importance des rencontres avec des patients opérés avant l'intervention. Ils proposent d'améliorer l'éducation sur la douleur, les difficultés alimentaires et les risques de reprise de poids. **Conclusion :** Cette étude souligne la qualité de l'éducation thérapeutique réalisée avant l'intervention. Les difficultés relatives à l'alimentation et à la reprise de poids incitent à assurer un suivi éducatif dans le long terme en favorisant les échangent entre patients. L'utilisation des cartes conceptuelles a fait appel aux compétences d'auto évaluation des patients.

Mots clés : obésité / chirurgie bariatrique / carte conceptuelle / éducation thérapeutique

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#### 1 Introduction

Patients suffering from morbid obesity are resorting to surgery more and more often. Long before their decision, candidates for this type of surgery are placed in the care of a multidisciplinary team that not only prepares them for the intervention itself and its probable consequences, but also for the changes in behavior that this kind of surgery requires. This preparation takes the form of a therapeutic educational program, which may be more or less formal [1, 2]. In the therapeutic education of patients suffering from a chronic disease. a new mode of evaluation utilizing concept maps has been developed. The concept map is a means of describing the cognitive structure of patients before and after a course of therapeutic education, and recognizing any evolution therein [3-5]. In a previous study, we used the concept mapping technique to describe the mental states (knowledge and affects) comprising the cognitive structures of 30 patients before a bariatric surgery (RYGBP or gastric banding) [6]. These concept maps, created over the course of individual interviews with patients, were used to analyze how the patients envisage the surgical intervention and its consequences. The results of that study showed that the patients' representations of the consequences were mainly linked to positive affects, revealing their hope for improvements in health, psychological state, and quality of life. Their knowledge of the intervention, its consequences, and the nutritional behaviors to adopt was for the most part correct.

This new study is designed to learn how the mental states of the same patients evolved about two years after their intervention, as well as to reveal their perceptions of the pre-surgery education program.

#### 2 Methods

Among the 30 patients included in the previous study, 29 actually underwent a surgical intervention. Letters were sent asking them to participate in this new study. After granting consent, the patients participated in a telephone interview lasting between 15 and 45 min (depending on the patient). Beforehand, each patient received by e-mail or post a copy of the concept map realized during their original interview, reproduced using the "Inspiration" software. During the interview, we went over this map with the patient. He or she was invited to confirm, modify, or complete the information in the map on the basis of what they had learned or experienced since the intervention. The patient's comments were then transcribed onto the concept map (Fig. 1).

Next, we asked the patients three complementary questions: (1) Among all the things you have told me, which is the most important to you today? (2) Among all the information given you before the intervention, what has been the most important to you? (3) With respect to your intervention and its aftereffects, what information do you feel was missing and what would you recommend we do to better prepare patients? The interviews were recorded to verify the validity and completeness of changes made to the concept maps as well as their responses to the three complementary questions. The comments collected during our discussion of the initial concept map were transcribed and analyzed according to the following grid.

A. Total number of comments made by the patients.

- Number of comments confirming initial mental states, distinguishing those drawing on personal experience from those with no apparent basis in their life (the patient is more precise, or had a different experience).
- Number of comments refuting or changing the sense of initial mental states, again distinguishing those which draw on personal experience from other types (questioning their initial impressions).
- Number of comments added by the patient with no immediate link to their initial mental states.

B. The comments were then analyzed with respect to the 10 knowledge domains identified in our previous study: nutrition and diet, surgical intervention, health, self-image, social and professional, weight loss, physical activity, psychology or well-being, follow-up care, and immediate side effects [6]. A "trend" was then attributed to each category to describe whether its comments were more often positive or negative.

Responses to the complementary questions were subjected to content analysis.

#### 3 Results

#### 3.1 Population

Among the 29 patients contacted, 24 (20 women and 4 men) agreed to participate in this study. Twenty-two patients received an "RYGBP" gastric bypass, and 2 were fitted with a gastric band. The patients were contacted about 2 years after their intervention (mean 24 months,  $\pm 5$ ). They lost on average 30% of their pre-surgery weight (an average of 39.8 kg). Nine had gained back a little weight at the time of the study compared to their weight one year following the intervention (3.2 kg on average). Three patients experienced complications immediately following the operation (less than one month): one gastric leak with abscess, one anastomosis stenosis, and one nosocomial pneumopathy. Three patients experienced a delayed complication: one anastomotic ulcer, one cholecystitis, and one anastomosis stenosis. Table I describes the evolution of comorbidities identified before the interventions.

#### 3.2 Limitations of the study

Keeping in mind the limited number of patients (N = 24), this analysis is mainly qualitative. It was not possible to demonstrate a statistical correlation between changes observed in the patients' concept maps and certain clinical data. Fourty-seven pourcent of mental states identified in the previous study



Figure 1. Exemple of concept mapping.

Table I. Evolution of comorbidities at t	the moment of the study.
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	No. of patients concerned	Disappearance	Improvement	Stabilization	Aggravation
Diabetes	7	4	3	0	0
Dyslipidemia	14	10	3	1	0
AHT*	16	7	4	5	0
SAS*	11	6	4	1	0
Gonalgia	17	7	5	3	2
	65	34	19	10	2

\* AHT: Arterial hypertension. SAS: Sleep Apnea Syndrome.



Figure 2. Distribution of comments per domain of knowledge (N = 351).

were the subject of at least one comment from the patients. Given that we went over the whole map with the patient during the interview, domain by domain, the absence of comments may signify either tacit acceptance or simply that the prior representation did not elicit any response at the moment of the interview. However, the conditions and duration of the telephone interview may not have always given the patients' time to express themselves fully. For this reason only, the explicit comments of the patients were analyzed, since they at least are known to have made sense to the patient at the time of the interview.

#### 3.3 Analysis of comments and questions

A total of 351 comments were verbalized by the 24 subjects of the study (Tab. II). Each patient expressed an average of 10.6 comments (95% C.I. = [8.9, 12.3]) confirming their initial mental states, 83% of which drew on their lived experience. On average 3.04 comments (95% C.I. = [2.2, 3.9]) per patient refuted an initial mental state. Again, the majority of these cases (89%) were based on their personal experience of the intervention. Twenty-three of 24 patients confirmed most of their initial mental states. Only one patient expressed more comments questioning the validity of initial mental states.

Table II.	Classification	of comments	bv	orientation.
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All comments $(N = 351)$				
	Number	%		
Comments confirming initial mental states	255	73		
Comments refuting initial mental states	73	21		
Comments not corresponding to an initial	23	7		
mental state (added comments)				
Comments confirming initial mental sta	ites $(N = 25)$	5)		
	Number	%		
Confirmation by personal experience	212	83		
Confirmation with additional information	25	10		
Confirmation, but personal experience was	18	7		
different				
<b>Comments refuting initial mental states</b> $(N = 73)$				
	Number	%		
Refutation by personal experience	65	89		
Initial statements now in doubt	8	11		

The distribution of comments (between confirmation and refutation) is linked to the concerned domain (Fig. 2). The "nutrition and diet" domain received the most comments (84), and also has a large percentage (32%) of comments invalidating initial mental states (Chi Square test: p < 0.002).

Table III. Analysis of responses to complementary questions.

	No. patients $N = 24$
What is most important to the patient at the moment of the interview	
Psychological consequences	7
Health consequences	6
Resumption of physical activity	5
Weight (loss or fear of regaining)	4
The effects of the intervention (miracle, medicines)	3
Long-term care before and after	2
Self-image consequences	2
Controlling diet	2
Social and professional changes	1
What is most important in preparing for an intervention	
The quality of general and technical information provided	14
Meeting with patients who have had the operation	7
Psychological preparation, "having decided"	5
Supervision, long-term care before and after	4
Fairly representing the expected level of weight loss	4
Lacks felt and recommendations for improvement*	
The education program lacked nothing	11
Information on pain (post-surgery, joint, weight loss)	4
More emphasis on the risk of regaining weight	4
Difficulties with respecting dietary instructions	3
Given bad information on weight loss at the beginning of the program	2
Difficulties with follow-up care and communication	2

\* Several comments related to the patients' individual life experiences are not reported in this table. We only list comments offered by more than one patient.

In our previous study, the mental states of patients were also classified according to their nature: knowledge (e.g. "the intervention consists of reducing the stomach"), positive affects (e.g. "no more frustration"), and negative affects (e.g., "fear of death"). Fourty percent (8 of 20) of comments related to initially negative affects substitute a rather positive outlook. Most of these modifications concern the "nutrition and diet" domain (6 comments), but one relates to psychological aspects and one is linked to the risk of death. Some examples: "I'm less afraid of cravings", "Today, I'm not frustrated at all", "I was afraid of a change in personality, but it's not at all the case."

At the same time, 21% of comments related to initially positive affects testify to a negative trend in the following domains:

- Social and professional (9 times): "my life changed with my husband, because I left him", "I have no more desire to go out than before";
- Nutrition and diet (6 times): "my body is no longer my ally, I'm still greedy, I eat everything";
- Self-image (5 times): "I have difficulty with my family... they don't see me in what I am today... I don't see myself completely either...", "I still hate my body";
- Psychology (4 times): "it's harder than I thought because there is a disconnect between my physique, my self-image, and reality", "not at all, I'm better physically but I have more internal suffering";

- Physical activity (2 times): "no, especially with joint problems, the desire is there but I still hurt";
- Weight loss (1 time): "I lost 30 kg, but it's not a lot".

Twenty-three comments without direct links to the initial mental states were expressed by 13 of the patients. The vast majority (17 of 23) was negative. Nine of these (from 5 patients) concern nutrition, of which 6 emphasize difficulties with managing diet on a daily basis. Four of the 23 comments were related to the intervention and short- or medium-term complications, and three were linked to physical activity (loss of muscle, tendonitis). For 3 patients, accepting their new appearance was still difficult. Two comments concerned weight loss (disappointment or satisfaction), one comment evoked the resumption of social activity around food, and one spoke of difficulties in follow up care.

An analysis of the information collected in response to the three questions posed after reviewing the concept map is presented in Table III.

#### 4 Discussion

# 4.1 What do the patients have to say about mental states they expressed before the intervention? How have their initial representations evolved since the intervention?

Generally speaking, the experiences of the patients following their interventions correspond to their representations before the intervention. Only one patient expressed more comments going against his initial mental states than supporting them. This woman received a gastric bypass and experienced no post-surgery complications. She lost 30 kg (25% of her initial weight). Her negative comments concerned expectations related to weight loss, her psychological state, and self-image.

Given that the patients' representations prior to intervention reveal high hopes [6], the results of this study seem to indicate that the patients are generally satisfied and were well educated about the intervention before undergoing surgery. Indeed, many of them claim to have been sufficiently well informed before the intervention. The patients offered few recommendations for improving the therapeutic education program for obesity surgery candidates (Tab. III).

Nonetheless, certain of the patients' experiences contrasted with their initial mental states (21% of comments). These invalidations concern all three types of mental states: knowledge, positive affects, and negative affects. Negative affects, rather uncommon before the intervention (12% of all mental states), were transformed in 40% of cases into positive affects. This result testifies to a rather positive experience. For example, during the first study a patient expressed their "fear of cravings, of needing to feel full" (a negative affect related to nutrition and diet). After the intervention, their comment on this topic was "this fear has really diminished because I feel satiated" (the initial representation has transformed into a rather positive affect). It is in the Nutrition and Diet domain that patients most often refuted their initial mental states. Six of these modifications are related to initially positive affects revealing unfulfilled expectations. For example, two patients said they "still have cravings" (one received a gastric band, the other a bypass) and one patient reported "no change in [their] relationship with food" (after a gastric bypass). Also, 5 patients offered supplementary remarks (added comments) and two-thirds of these (6/9) were negative. For example, we find comments such as "I still feel ill at ease when I can't clean my plate", "...we ask what we're allowed to eat, but the starting point is a bit vague. We're told 'eat what you want, what you can', but it's a bit vague." Recall that before the intervention, the percentages of positive and negative affects in the Nutrition and Diet domain were equivalent – the patients were hopeful, but also held realistic views of the dietary constraints they would face [6]. The comments of patients in this domain confirm that the changes were difficult, but also that following the surgery the patients had more or less adapted.

Concerning the domain of complications surrounding the surgical intervention, half (4/8) of the comments offered by 7 patients (Fig. 2) call into question certain initial mental states. This may be explained in part by the interval that had passed since the surgery, as the fear of death or complications abates with time. Four patients thought that the information provided on post-surgery pain and the suffering provoked by weight loss could be improved.

Consequences of the intervention related to psychology and/or health were most often cited as "the most important today" by the patients. These results agree with the conclusions of other studies [7, 8]. Moreover, objectively the health problems associated with obesity improved or even disappeared in 82% of cases (Tab. I). Over the course of the first study, no negative affects were expressed concerning the health consequences of the intervention. On this level, we find very few invalidations of the initial mental states. The reality experienced by patients after the intervention therefore seems to have lived up to their hopes. On the other hand, their hopes for social changes (resumption of a professional activity, improvement in romantic, familial, and platonic relationships) are often disappointed. In this domain we find the largest number of comments refuting initially positive mental states. These results are again in line with other studies, which have emphasized the absence of change in romantic relationships and social status following obesity surgery [8].

Most of the changes anticipated by obesity surgery candidates are directly linked to weight loss; 22 out of 24 patients expressed comments in this domain. Most of the initial mental states on this subject were later confirmed by the patients (72%). This result indicates that the subjects had reasonable initial representations of their possible weight loss, contrary to the results of other studies [2,7]. At the time of their interview, however, 9 of 24 patients had regained some weight compared to their state one year after the intervention. This result corresponds to the post-surgery evolution described elsewhere [9]. These clinical data partly explain the fact that weight (the fear of continuing to lose weight, as well as the fear of gaining it back) is still the greatest worry of 4 patients at the time of the interview. Four others emphasized the importance of holding reasonable expectations of weight loss before the intervention, including the delay before obtaining results and the risk of regaining weight.

Certain authors have emphasized the difficulties encountered by patients in controlling and stabilizing their weight after the intervention, as well as maintaining appropriate dietary habits [10]. According to some [11, 12], long-term care is essential to prevent the patient from regaining weight or suffering a nutritional deficiency. This follow-up care should not only focus on medical, nutritional and psychological aspects of the patient's health, but also encourage encounters between patients. Indeed, 7 of the patients in this study highlighted the importance of such meetings. For other chronic health problems (asthma, for example), sharing experiences among patients contributes to the acquisition of knowledge and constitutes an important source of support for people coping with their illness [13]. Moreover, patients suffering from a chronic illness are more and more often sharing their experiences by participating in Internet forums. A recent study has shown that this type of exchange permits diabetic patients to help each other and reinforce their self-treatment skills [14].

## 4.2 Using concept maps to support patient evaluations

Several studies have examined the evolution of obese patients' knowledge and expectations, or analyzed the results obtained following surgical intervention. Most of the time, they take the form of questionnaires administered after the intervention; sometimes they compare the results of tests administered before and after the intervention [2, 7, 8, 15, 16]. These questionnaires may explore just one dimension, or several simultaneously. Examples include true/false tests of knowledge [15]; questionnaires exploring different facets of psychological function such as self-image, depression, and selfesteem; or even questionnaires evaluating dietary behavior and physical activity [17].

Concept maps realized from candidates for obesity surgery have been used to quantify the extent of these patients' mental states with respect to the various aspects of obesity management. Their analysis also permits us to show how cognitive, dietary, psychological and social aspects of their cognitive structure were linked [6].

In the present study, concept maps realized with the patients before their operation were used as a way of inviting patients (about two years after the intervention) to look back on their own initial representations. Their comments depend on their unique personal experiences of the surgical intervention. Beyond permitting us to evaluate the quality of therapeutic education, this new way of using concept maps brings a complementary and innovative dimension to the post-surgical evaluation process. It permits the patients to take an active role in their own evaluation, through the judgments they pass on their own representations. Looking back on their initial representation in this manner helps the patients distance themselves from their knowledge and experience, and develops their capacity for self-evaluation. The process thereby reinforces self-care skills and helps the patient adapt to their illness [18].

#### 5 Conclusion

This study testifies to the quality of therapeutic education offered to patients about to receive a surgical intervention for obesity. The vast majority of their initial representations correspond to their personal experiences following the operation. But the success of this type of treatment relies heavily on the patient's ability to stabilize their weight and thus maintain adequate dietary behavior over time. Even if the patients are aware of and have accepted the changes in dietary behavior that must be implemented following the intervention, the complications associated with this type of surgery can make it difficult to follow instructions [12]. This qualitative study, centered on the patient, highlights the importance of therapeutic education and long-term care of obese patients treated by surgery. Both pre- and post-surgery education programs should strongly encourage meetings between patients, either by organizing group sessions, arranging informal meetings, and/or sharing their experiences on an appropriate discussion forum.

The concept maps used here to explore and evaluate patients' representations before and after the obesity surgery are just as pertinent for other medical interventions. They permit caregiver teams to center their therapeutic education more on the patients, considering each person's specific learning needs in turn.

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