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“I’m only numbers on paper” – A qualitative evaluation of the Internalized Weight Bias Scale in a Swedish sample

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Abstract

Weight-based stigma includes negative stereotypes and negative attitudes directed toward people with obesity or overweight. When internalized, a process also referred to as self-stigmatization, it can have detrimental effects on health. There is currently no instrument to measure internalized weight bias in a Swedish context. Developing such an instrument could be a vital step in improving obesity treatment. The purpose of this study was to perform a qualitative evaluation of the Swedish version of the Internalized Weight Bias Scale as well as to explore its utility. Twelve participants, who have or have had obesity or overweight, were interviewed about their experience of filling out the questionnaire. After transcribing interview recordings, a thematic analysis was conducted, and themes were identified. The findings show that overall, the questionnaire was received positively and perceived as relevant by the participants, with some minor changes. This indicates that self-stigma as conceptualized in the questionnaire is applicable in a Swedish context. A prominent theme was previous negative health care experiences where participants expressed a fear that if the questionnaire were to be used carelessly it could be experienced as part of weight stigma. However, when used mindfully, it was believed to have the potential to provide insight on the experience of self-stigma as well as improve treatment for people with obesity. Based on the findings, suggestions on changes of the questionnaire and recommendations for utility are proposed.

Keywords: obesity, overweight, self-stigma, internalized weight bias

Sammanfattning

Viktstigma inbegriper negativa stereotyper och negativa attityder riktade mot individer med obesitas eller övervikt. Internalisering av viktstigma, en process som också kallas självstigmatisering, kan ha negativa konsekvenser för hälsan. Det finns för närvarande inget instrument för att mäta självstigmatisering i en svensk kontext. Att utveckla ett sådant instrument skulle kunna vara avgörande för att förbättra behandling för obesitas. Syftet med denna studie var att genomföra en kvalitativ utvärdering av den svenska versionen av the Internalized Weight Bias Scale samt utforska dess användbarhet. Tolv deltagare, som har eller har haft obesitas eller övervikt, intervjuades om sin upplevelse av att fylla i formuläret. Efter att ha transkriberat inspelningar av intervjuerna genomfördes en tematisk analys och teman identifierades. Överlag visar fynden att formuläret mottogs positivt och uppfattades som relevant, bortsett från mindre justeringar. Detta tyder på att formulärets konceptualisering av självstigma är applicerbart i en svensk kontext. Ett utmärkande tema var tidigare negativa vårdupplevelser där deltagare uttryckte en rädsla att om formuläret skulle användas vårdslöst riskerar det att upplevas som en del av den pågående viktstigmatiseringen. Skulle det däremot användas eftertänksamt skulle det kunna ge insikt i upplevelsen av självstigma och förbättra vården för individer med obesitas. Med utgångspunkt i dessa fynd föreslås justeringar av formuläret och rekommendationer för användning.

Nyckelord: obesitas, övervikt, självstigma, internaliserad viktstigma

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“I’m only numbers on paper” – A qualitative evaluation of the Internalized Weight Bias Scale in a Swedish sample

Obesity and overweight

Obesity is a complex disease that affects more than 650 million people around the world (World Health Organization [WHO], 2019). In Sweden alone, more than half of the adult population reported a body mass index (BMI) indicating obesity or overweight in 2021 (Folkhälsomyndigheten, 2022a). BMI is calculated for an individual as the ratio between height and weight (WHO, 2019), where $25 \leq$ BMI < 30 is classified as *overweight*, while a BMI ≤ 30 is classified as *obesity* (WHO, 2019). Obesity is classified as a disease because it puts one at risk for developing other diseases (Jannesdotter, 2022). Overweight is not classified as a disease, but it does, however, increase the risk of developing obesity (Jannesdotter, 2022). Common comorbidities of obesity are cardiovascular diseases, type 2 diabetes, and asthma (Guh et al., 2009; WHO, 2019).

WHO (2019) states that obesity, and overweight, are fundamentally caused by an energy imbalance: more calories are gained by consumption than used up. This imbalance leads to the accumulation of fat. There is an increasing prevalence of obesity that can, on a societal level, be explained by the fact that we have higher access to food than ever before (WHO, 2019). Our food is unhealthier than it has been, and unhealthy food is generally cheaper (WHO, 2019). Moreover, an increasing proportion of our waking hours is allocated to sedentary activities such as transport, desk jobs, and long working hours (WHO, 2019). A simplistic explanation of obesity, which emphasizes individual responsibility and downplays systemic and biological factors, is one commonly held by the general public (Kite et al., 2022). The same explanation has also been reported among medical practitioners, who erroneously rated physical inactivity as the main cause of obesity (Foster et al., 2003). This explanation fails to consider the complexity (and multifactorial aspect) of the disease. While the principal causative component of obesity *can* be a caloric imbalance, more factors are often involved (Huang et al., 2009). These factors include genetics, stress, lack of sleep, age, mental health issues and various medications (e.g., antidepressants) (Jannesdotter, 2022).

There are several ways of treating obesity with the most common approach being lifestyle treatment, such as receiving personalized dietic advice and learning to manage sleep and stress. There are also various prescription drugs meant to decrease one’s appetite. When other treatments

do not lead to enough weight loss, there are surgical options such as gastric sleeve, gastric bypass, and duodenal switch (Jannesdotter, 2022). Surgery in conjunction with knowledge and lifestyle changes has been shown to be the most effective treatment in terms of weight loss (Jannesdotter, 2019). People who have had weight loss surgery report an overall positive effect (Alegría & Larsen, 2015). However, there are potential negative effects such as body distortion, body image dissatisfaction due to excessive skin, as well as a remaining perception that one is still the subject of weight stigmatization (Alegría & Larsen, 2015).

Obesity and overweight in society

Obesity is not only a medical condition in Western culture, but also has social implications in the sense of it being a stigmatized condition (Puhl & Heuer, 2009). Living with obesity or overweight in Western society today is considered negative not only because it puts you at risk for developing other diseases (Jannesdotter, 2022), but because it leads to people perceiving and treating you differently (Puhl & Heuer, 2009). However, obesity and overweight are not considered negative in all cultures. In Niger, for example, having a high percentage of fat is a beauty ideal and highly desired (Popenoe, 2005). This difference, compared to Western cultures, highlights the influence of cultural context on how obesity is perceived. Additionally, considering obesity from a historical perspective highlights how excess body fat has been perceived differently throughout history. By viewing art from different time periods, it becomes evident that heavy bodies used to be a beauty ideal also in Western cultures, and commonly an outward display of affluence (Bonafini & Pozzilli, 2011). At different points in history, obesity has been a marker of health, social status, and wealth, and it is only recently that obesity is considered a global epidemic and threat to public health (Sumińska et al., 2022). One must therefore keep in mind that the meaning and implications of obesity and overweight are contextually bound.

Weight-based stereotypes and prejudice

Some of the prejudice and stereotypes directed at people with obesity in Western society include negative characteristics and personality traits such as laziness, lacking self-discipline, low competence, unattractiveness, sloppiness, and bad hygiene (Puhl & Brownell, 2001; Puhl & Heuer, 2009). The same negative stereotypes can be seen in a Swedish context. For example, Sandberg (2007) found that Swedish daily newspapers report on obesity in a stigmatizing manner, where people with obesity or overweight are described as lazy, stupid, ugly, and greedy.

One way to better understand how people perceive others is to use the Stereotype Content Model (SCM), proposed by Fiske et al. (2002). In this model, individuals are evaluated on two different dimensions: competence and warmth. Evidence from recent research using the SCM suggests that people with obesity and overweight are perceived as warm but incompetent, compared to people with thin bodies. One possible explanation is that thinness signals self-control whereas a heavy body signals impulsive behavior (Bryksina et al., 2021). In addition to these results, Sim et al. (2022) found that people with higher weights are seen by others to lack mental agency, meaning that they lack higher order cognitive and intentional abilities. With these results in mind, it becomes evident that living with obesity in a Western society today has implications for how others perceive you. Instead of obesity being a sign of wealth and beauty, in Western culture it is a sign of incompetence and impulsivity.

Weight and beauty ideals

Most are aware of the thin beauty ideal in Western society where a widely held norm regarding beauty is that obesity is considered unattractive (Puhl & Heuer, 2009). While large bodies historically have been regarded as beautiful, the ideal body today has a BMI of 18 to 20 or even lower (Bonafini & Pozzilli, 2011). To put these figures in context: a BMI below 18.5 is classified as medically underweight (Folkhälsomyndigheten, 2022b). People who view underweight bodies as ideal even tend to categorize these bodies within a normal weight range (Aniulis et al., 2022). Internalization of the thin beauty ideal starts at a young age: girls as young as three to five years old have been shown to attribute positive adjectives to “thin targets” and negative adjectives to “fat targets” (Harriger et al., 2010). Children aged five have also been shown to prefer thin bodies over heavy bodies and to hold the belief that thinness predicts happiness (Lipowska et al., 2022). The thin ideal seems to be pervasive in society as well as unavoidable from a young age.

Media perpetuate the thin beauty ideal by portraying thin characters in movies and on TV positively and people with obesity or overweight negatively (Himes & Thompson, 2007). Characters with obesity or overweight are often disliked by others, given negative traits such as unattractiveness, and are presented in a negative light (Ata & Thompson, 2010). Additionally, the majority of main roles in films are portrayed by thin people (Greenberg et al., 2003). An implication of the media’s role in perpetuating the thinness ideal is that it may affect attitudes toward people with larger bodies. For example, people watching a Victoria’s Secret advertisement

showed greater dislike toward people with overweight, compared to people watching body accepting advertisements, and control groups (Selensky & Carels, 2021). Similarly, in a recent review, Kite et al. (2022) reported that exposure to stigmatizing media content has a negative effect on attitudes toward people with overweight. An implication for women is that mass media has been shown to be a strong influence in women's drive for thinness (Chou, 2018). There is, however, an ongoing reaction to the current ideal in the form of body positivity, with the purpose of counteracting the thin ideal (Vandenbosch et al., 2022).

In summary, in the context of Western society today, thinness is something desirable and positive whereas obesity or overweight is associated with negative traits. These views are learned from an early age and are then perpetuated and reinforced in society, for example through media. Cultural norms are, nonetheless, constantly changing and movements such as body positivity could be a step toward changing the thinness ideal.

The stigma of obesity

Definition of stigma and weight bias

Stigma happens when an individual is singled out for possessing a characteristic that in some respect deviates from what is considered the norm (Andersen et al., 2022). The principal component of stigma is labeling, where a negative stereotype is applied to an individual. The connotations of that stereotype are subjectively deemed to be undesirable in line with presiding societal norms and beliefs (Andersen et al., 2022). When stigma occurs, there is power asymmetry between the one who stigmatizes and the person subject to the stigmatization as well as linguistic separation, e.g., using "us" versus "them" language (Andersen et al., 2022). In a recent conceptualization of stigma, Andersen et al. (2022) suggest that "it is groups that are the target of stigma, but it is individuals who pay the price" (p. 852). Concisely put, stigma is built *on* groups but directed *towards* individuals.

People with obesity and overweight are a highly stigmatized group (Puhl & Heuer, 2009). Weight stigma, or weight bias, occurs in various life domains such as employment settings (Roehling et al., 2007), health care settings (Foster et al., 2003), and interpersonal relationships (Puhl & Brownell, 2006). Stigma often, but not ubiquitously, leads to negative individual emotional reactions and discrimination (Andersen et al., 2022). Weight-based discrimination is one of few types of discrimination that are still socially acceptable (Puhl & Heuer, 2009).

Experienced weight stigma and weight-based discrimination

People with obesity often face discrimination due to weight-based stigma (Puhl & Heuer, 2009) with women being three times more likely to report experiences of weight-based discrimination in comparison to men (Puhl et al., 2008). It is worth noting that in this thesis we are not referring to discrimination in the legal sense, but discrimination as unfair treatment due to weight. According to Swedish anti-discrimination laws, one cannot be discriminated against based on weight (Diskrimineringslag, 2008). However, this does not mean that people with obesity and overweight are not unfairly treated because of their weight and may, because of unfair treatment and perceived weight stigma, suffer negative consequences.

Overt and covert discrimination have been shown to be negatively linked with subjective well-being (Magallares, et al., 2014) and researchers have found an association between perceived weight discrimination and anxiety and mood disorders (Hatzenbuehler et al., 2009). Additionally, weight stigma has been suggested to affect eating; research indicates an association between experienced weight stigma and maladaptive eating patterns, such as binge eating or skipping meals (Vartanian & Porter, 2016). Weight-based stigma is for many people an occurrence in their everyday lives. Situations experienced as problematic are, for example, difficulty finding clothes that fit (Laitala et al., 2011) and insulting comments at the gym (Argüelles et al., 2022). Other domains where discrimination and weight stigma are common include workplace and health care settings.

Workplace discrimination. Examples of work-related discrimination that have been reported include wrongful termination, being overlooked for promotion, and not being hired for a specific job (Puhl & Heuer, 2009). BMI has been found to be positively linked with chronic job discrimination, where people with obesity reported experiencing it to a greater extent compared to people within a normal weight range (Kungu et al., 2019). In addition to perceived discrimination, people with obesity suffer a wage penalty (i.e., earn less) overall, with women with obesity being more affected than men with obesity (Baum & Ford, 2004).

Health care discrimination. Health care settings is another domain where people with obesity may experience weight-based stigma and discrimination, such as doctors commenting inappropriately on patients' weights (Puhl & Heuer, 2009). One study found that a fifth of patients with obesity and overweight reported feeling judged by their primary care providers, and that these patients had lower trust in health care providers (Gudzune et al., 2014). Additionally, negative

encounters with health care professionals appear to make individuals with obesity less likely to seek treatment (Mold & Forbes, 2011). Compared to normal weight patients, primary care physicians also seem to spend less time building emotional rapport with individuals with obesity and overweight. In other words, health care providers are less likely to communicate empathy, understanding, reassurance and concern to patients with obesity or overweight (Gudzune et al., 2013).

Self-stigma and weight bias internalization

Self-stigma refers to a process where an individual takes the stigma of the public at "face value" and internalizes it (Corrigan & Watson, 2002). Self-stigma should be considered separately from perceived stigma and stereotype awareness, where an individual is aware of being stereotyped but can separate themselves from it. These individuals are not necessarily affected by the stigma and may even as a result respond to stigma by getting energized and expressing righteous anger (Corrigan & Watson, 2022). An individual who self-stigmatizes, however, not only agrees with the stereotype they are labeled with but also applies it to themselves, which could affect their self-esteem and self-efficacy negatively (Corrigan et al., 2006). In general, women are more likely to internalize weight stigma compared to men (Himmelstein et al., 2017). There are many ways of referring to self-stigma among people who have obesity or overweight, such as weight bias internalization (WBI; Durso & Latner, 2008), internalized weight bias (IWB), and weight self-stigma (WSS; Lillis et al., 2010).

The effects of self-stigma

In a recent review of the literature on self-stigma and WBI, self-stigma was found to correlate negatively with the mental health of individuals who seek treatment for obesity (Pearl & Puhl, 2018). Internalizing stigma has a more negative impact on psychological wellbeing in comparison to simply perceiving it (Pudney et al., 2020). WBI does not only affect mental wellbeing, but also self-esteem and level of concern regarding body image (Durso & Latner, 2008). In addition, internalizing weight bias can predict overall quality of life, both mentally and physically (Hilbert et al., 2014; Pearl & Puhl, 2016; Walsh et al., 2018). For example, a recent systematic literature review reported consistent evidence of a relationship between WBI and eating disordered outcomes such as emotional eating, loss of control, and purging (Bidstrup et al., 2022). Moreover, it can affect interpersonal relationships negatively; level of internalized weight bias has been shown to impact various aspects of marriage quality and individual psychological wellbeing

(Carels et al., 2020). It occurs even in younger populations where children with obesity or overweight are likely to internalize weight stigma if they have experienced teasing from their peers or suffer from low self-esteem (Fields et al., 2021).

An important and central aspect of internalized weight stigma is *shame*. Ueland (2019) investigated the relationship between stigma and shame. Internalizing the stigma of the public is reported to cause feelings of shame, which in turn can affect self-image and self-perception (Ueland, 2019). This observation was corroborated by Bidstrup et al. (2022), where they found evidence for internalized weight stigma acting as a mediating variable between stigma and body shame.

Measuring self-stigma

Questionnaires and scales are commonly used tools by psychologists in clinical settings and research. There are several scales designed to measure self-stigma, with a widely used scale being Durso and Latner's (2008) Weight Bias Internalization Scale (WBIS). The WBIS is an 11-item measure developed to assess an individual's weight bias internalization. Pearl and Puhl (2014) modified this scale to make it applicable for people in any weight category by replacing "overweight" with "weight", thereby creating the Modified Weight Bias Internalization Scale (WBIS-M).

The development of approaches to measure psychological constructs in a health care setting demands high reliability and validity of those measures. A recent review assessed the psychometric properties of different self-reported measures of self-stigma and found limited reporting on aspects such as content validity, reliability, cross-cultural validity, and responsiveness (Papadopoulos et al., 2021). It is for this reason crucial to consider psychometric properties and rigorously assess scales before they are used in research and clinical settings.

Our study

This thesis is part of a larger research project, which intends to develop a Swedish self-report questionnaire for self-stigma. The questionnaire was originally created by Canadian researchers led by Dr. Ximena Ramos and is a merge of one of the most widely used questionnaires to measure self-stigma, namely WBIS-M (Pearl & Puhl, 2014), as well as a subscale from The Objectified Body Consciousness Scale that measures body shame (McKinley & Hide, 1996). The merged questionnaire is called the Internalized Weight Bias Scale (IWBS). The English version, which is in the process of being published, has been translated to Swedish under supervision by

the principal investigator of the research project, Dr. Kajsa Järvholm. It is now undergoing a ten-step "translation-back translation" process to ensure cultural adaptation according to guidelines provided by Wild et al. (2005). Details of the full translation process will be published separately by Dr. Järvholm. There is currently no Swedish instrument to measure self-stigma among people with obesity and overweight. Therefore, the overarching purpose of this project is to develop an instrument making it possible to measure self-stigma in a Swedish context.

Purpose

Within the scope of this thesis, the aim is to conduct a cognitive debriefing as outlined by Wild et al. (2005) as part of a larger translation and cultural adaptation process. The purpose of the questionnaire is to provide insight on the experience of self-stigma, and ultimately improve the care of people with obesity and overweight. Therefore, it is important to include people from the target population because their unique experience can provide meaningful insight and feedback on the IWBS. Furthermore, it is important to examine the use of language in the questionnaire in terms of respectfulness and understandability as well as whether this conceptualization of self-stigma is culturally relevant. In this thesis we will attempt to answer the following research question: how is the translated questionnaire on self-stigma received and perceived by individuals from the target population? To explore whether the questionnaire could be experienced as helpful, useful, or problematic for the participants in a potential health care context, we also investigated the following question: how do the participants view the potential use of the IWBS questionnaire in its current form with respect to their previous health care experiences?

Methodology

Theoretical approach

The wider project of translating a self-stigma scale to Swedish involves several theoretical approaches. Whereas the research project itself has a realist approach with the aim of developing an instrument to *measure* self-stigma, our thesis strove to examine how the conceptualization of self-stigma in the questionnaire was received in a Swedish context. Our thesis was therefore a qualitative study. Throughout this project we have moved between different philosophical perspectives, namely realism and pragmatism. A realist approach assumes that social and psychological processes and phenomena exist independently of the researcher and the participant and can be identified. On the one hand we worked from a realist perspective, where we were trying to find a reliable and valid way to measure self-stigma, implying that there is such a thing as self-

stigma and that we could measure it. Specifically, we worked from a critical realist perspective since we acknowledge our role in interpreting the data. On the other hand, from a pragmatic perspective, we wanted to investigate whether self-stigma as a concept is experienced as useful on an individual level. In pragmatism, a theory or claim is true if it has practical utility (Alvesson & Sköldberg, 2017). Instead of being solely concerned with whether self-stigma is an objective truth, we examined how useful the concept was. If self-stigma as conceptualized in the questionnaire was found to be useful by people with obesity, then it does not necessarily matter if self-stigma is objectively real. By looking at how useful the concept of self-stigma was, we were working with what Alvesson and Sköldberg (1994) call *application* in their trilateral concept of truth. The knowledge we aim to produce in our thesis therefore not only deals with how the questionnaire is received but also whether self-stigma, as conceptualized in the questionnaire, is experienced as useful by the participants.

Reflexivity

The process of reflexivity includes an awareness that we, as researchers, contribute to the construction of knowledge and that we cannot entirely distance ourselves from the research. (Willig, 2013). Willig (2013) describes two types of reflexivity: personal reflexivity relates to how one's own interests, identity, opinions, values, and experiences could shape the research, whereas epistemological reflexivity deals with the researcher's wider assumptions about the world and about knowledge during the research process.

In relation to personal reflexivity, there are many aspects that could have contributed to the construction of knowledge. For example, the participants were aware of us interviewers being future health care professionals (future licensed psychologists). Many individuals with obesity or overweight have a negative experience of health care, which could have affected how the participants responded to our questions. We also have experience in talk therapies (psychotherapy), which could have affected how we responded to participants' emotions and experiences as well as what questions we asked. In addition, we have no history of seeking or receiving treatment for obesity and therefore lack the lived experience of the patient perspective.

Procedure

Cognitive debriefing

In this thesis we conducted the seventh step in the translation and adaption process, described as *cognitive debriefing* (Wild et al., 2005). The purpose of cognitive debriefing is to test

the translated instrument on people from the target population. It aims to assess to what degree the translation resonates with people who have relevant experience in the matter, and to give those people the opportunity to express potential confusion, ambiguity or triggering aspects of the questionnaire (Wild et al., 2005). The debrief should include five to eight people in the target country (Sweden), who are native speakers of the target language (Swedish), and who adequately represent the target population (people with obesity or overweight). To fully capture the varying views of our participants, we decided that a thematic analysis was the most appropriate method for analysis. Since our analysis extends beyond what is expected of a cognitive debriefing, we chose to recruit more than eight participants.

To ensure flexibility in real-world situations, Wild et al. (2005) do not provide specific guidelines on how to conduct the cognitive debrief. We decided to conduct semi-structured individual interviews as this was deemed most suitable to evaluate cultural appropriateness and to answer our research questions. We developed an interview guide (see Appendix A) with the purpose of examining understandability, interpretation, and cultural relevance by exploring emotions evoked and associations activated when participants answer the questionnaire. In addition to questions regarding the self-stigma questionnaire, we gathered the following information about our participants: age, gender, Swedish proficiency, current and highest BMI. For us to better understand each individual's unique experience, we also asked questions about their weight history, their experience of the health care system, previous and ongoing weight treatments as well as their understanding of the questionnaires' items on self-stigma. After filling out the translated version of the questionnaire (see Appendix B), we proceeded to interview the participants about their experience.

Participants and recruitment

Inclusion criteria for participating in this study were that the individual has or has had obesity or overweight, was over the age of 16 and spoke fluent Swedish. Individuals were recruited through various treatment centers and patient organizations for obesity in Sweden. Information about the study was distributed in a manner suitable to the medical staff assisting in the recruitment process (email, flyers, verbally or digitally), and is detailed in Appendix C. We also personally visited some treatment groups for recruitment purposes. Potential participants were explicitly informed that their participation would not in any way be connected to their usual treatment.

Individuals showed interest in participating by filling out an online form. They were then contacted by the authors of this study via medium of their choice (phone call, text message or email). Irrespective of preferred contact medium, each potential participant received an extensive written summary of the project, detailing the implications of participating via email (see Appendix D). If the participant was still interested in taking part in the study after having been informed of its potential risks and implications, they were contacted to set up an interview via Zoom or at the Department of Psychology at Lund University. Informed written consent was given in conjunction with the interview or beforehand through mail or email (see Appendix E). The form was posted, or scanned and emailed, when participation took place over Zoom. Interviews were recorded using a Dictaphone or the record function on Zoom.

Considering the thesis was time constricted, the number of participants included in the analysis of this thesis was determined based on how many interviews had been conducted by October 21, 2022. If participants showed interest after that point in time, we interviewed them and handed the recordings to the principal investigator of the research project who will use them for the final publication.

Data processing

Transcribing the interviews. To process the data, we transcribed the interview material using the method of orthographic transcription as described by Braun and Clarke (2013). Orthographic transcription means giving a verbatim account of what is being said in the interview. To immerse ourselves in each other's material, we transcribed each other's recordings.

Analyzing the transcripts. With the purpose of identifying, analyzing, and presenting patterns in our collected data we conducted a thematic analysis as outlined by Braun and Clarke (2021). We initially immersed ourselves in the data when we transcribed the material. We further immersed ourselves in the entire data set by reading through each transcript. Meanwhile we took notes to keep record of our initial reflections and assumptions. Before coding, which entails highlighting significant content in the data, we had a meeting during which we exchanged ideas and impressions. We created a mind map of what we, at that stage, considered to be the most central aspects of the data.

The coding process began by us coding the material separately. Due to the mixed epistemological approaches, we decided that a bottom-up approach to coding the data was best suited to investigate the primary research question as well as to be open to unexpected findings.

We coded everything of interest, both on a semantic and latent level (Braun & Clarke, 2021). After having completed the systematic coding process, we compared our codes. We assessed where our codes overlapped and came to find similar top-level codes, which we categorized to create an overview of the data. We then used a top-down approach to sort our top-level codes with the purpose of identifying which codes were relevant to answer our research questions. We also evaluated and identified important aspects that had emerged; top-level codes that appeared frequently or which held importance to the stories of the participants were added to a new mind map to be considered further.

After assessing the mind map and interpreting the data behind our top-level codes, we generated initial themes. Codes were re-allocated to respective themes, and themes were considered in relation to each other and the data set as a whole. The initial themes were presented to and discussed with the principal investigator of the research project to evaluate viability and relevance. After a general discussion we decided to keep the themes in their current form and started reviewing them by going back to the entirety of the data set. The themes were once again considered in relation to coded extracts, in relation to each other, the data set as a whole and the research questions (Braun & Clarke, 2021). In this process some subthemes were merged into one and new ones were created, and we further defined and named our themes. Since we have been working with Swedish transcripts while writing in English, we conferred with a native English speaker to ensure that the translated themes were comprehensible and made sense. We finalized the analysis by going back to the transcripts to find quotes that highlighted and illustrated our themes.

Ethics

Ethics approval application

The current study involved investigating and potentially evoking psychological discomfort in participants and was therefore subject to a formal evaluation in line with Swedish laws regulating ethics within research (Lag om etikprövning av forskning som avser människor, 2003). An ethics approval application was submitted on May 12, 2022, and approved on June 21, 2022, with the following registration number: 2022-02800-01.

Microethics

Microethics refers to ethical aspects of how we treat our participants (Brinkmann & Kvale, 2005). Informed consent was ensured by providing our participants with detailed information

about the research project and collecting their written agreement. Confidentiality was secured by pseudonymizing the data when transcribing the interviews. We kept a keycode that links each participant to a number, which was stored separate from recordings and transcripts. All participant material was, and will be, kept in accordance with university guidelines (detailed in Appendix D). Participants were informed that their participation was voluntary, and that they had the right to withdraw at any time.

In all interview situations there is an asymmetrical power relation which needs to be considered (Brinkmann & Kvale, 2005). We are aware of us being in a researcher role, which entails control of the interview situation as well as monopoly of interpretation (Brinkmann & Kvale, 2005). Another aspect of the dynamic between the interviewer and interviewee is that we do not have the physical characteristics of a person with obesity. This made it apparent that we are not part of the societal category subject to weight stigmatization.

There was a risk of the questionnaire evoking negative emotional reactions. To avoid harmful consequences, participants were informed to contact the principal investigator of the research project should there be a need for professional help. Temporary discomfort was possible, but the likelihood was deemed low that it would cause long-lasting harm. Any potential negative effects were considered to be outweighed by the potential benefits. One such benefit is that these interviews could offer a space for the participants to make their voices heard. They could feel empowered by contributing to the development of an instrument that aims to measure an experience that is often neglected in obesity care.

Macroethics

Macroethics refers to “how the knowledge produced will circulate in the wider culture and affect humans and society” (Brinkmann & Kvale, 2005, p. 167). The instrument we are developing might evoke emotions. If these are negative, it is important that the instrument is used in a careful manner. We know from research (see Mold & Forbes, 2011 for an overview of the literature) that health care often is a negative experience for people with obesity and overweight. From a wider ethical perspective, it is therefore important to consider the fact that the instrument may be used carelessly. If so, the harm may outweigh the benefits. However, if the instrument is accepted as well as used correctly, the target population is expected to gain from such a questionnaire.

Results

After analyzing the interviews, we identified four main themes. Translated quotes from the participants have been included to support each theme. To ensure confidentiality, the participants have been assigned a number. We included data from twelve participants, all women, and aged 21 to 62 years old.

Table 1

Overview of themes and subthemes

Themes	***Subthemes***
Theme 1. Accessibility	Instructions
	Structure
	Language
Theme 2. Extent of identification	Conscious recognition
	Implicit exhibition
	Lack of consensus
Theme 3. Ambivalence	Confronting difficult feelings
	Verbalization and validation
Theme 4. Treating the weight versus seeing the person	The weight as the patient
	Not another number

Theme 1. Accessibility

The theme *accessibility* highlights the direct feedback given by our participants regarding the composition of the questionnaire. This is pertinent given that unclear or inappropriate language, sentiment, and structure, would present a barrier to wider adoption of the IWBS. For example, poor structuring of the questionnaire could lead to miscomprehension of the task involved, as well as obfuscation of intent. Moreover, if the language used is not clear and respectful it will decrease the accessibility and usability of the questionnaire.

Instructions

It was noted by a few participants that the form did not clearly state the timeframe in which the patients did or did not experience stigma, for example “the last 6 months” or “the last 10 years”. This is a potential shortfall of the questionnaire, as level of self-stigma can vary over time.

Structure

Generally, the questionnaire was not perceived as overly complicated, and was considered brief and precise. Consequently, the structure of the questionnaire did not distract from the focus of the study, and the participants were able to consider each item carefully. Nonetheless, two of our participants reacted strongly to the first item in the questionnaire regarding feeling less attractive because of one’s weight: “I reacted to the first question I thought it was a very tough question to have come first” (Participant 2). Consequently, it set a negative tone for answering the remainder of the form.

Language

The participants described the questionnaire as well formulated, straightforward, and easy to understand. Overall, it was reported that the language used was neutral enough to feel respectful, and left room open for individual interpretation. The use of the word “should” in the item regarding physical activity (item 17) was, however, triggering for two participants, who felt that it could be interpreted as stigmatizing. There was some issue in interpreting the item regarding interpersonal relationships (item 10), which was deemed ambiguous. Participant 2 brought attention to that one can consider romantic relationships or friendships, which could have different responses. Further, “weight” and “overweight” are used interchangeably, which can affect how the questionnaire is interpreted, especially for people who have lost weight. For Participant 6, for instance, “overweight” was interpreted as the past, and “weight” as the present.

Summary

Overall, no major barriers to comprehensibility were identified by participants. The questionnaire would, however, benefit from a clear set of instructions. Additionally, clarifying some items and being more consistent with use of words could further increase the understandability of the questionnaire.

Theme 2. Extent of identification

The theme *extent of identification* dealt with to what degree the participants could identify with the items in the questionnaire. In other words, this theme captures how much their experience

overlapped with the way self-stigma is conceptualized in the questionnaire. We found that participants explicitly and implicitly expressed identification with the items, as well as disagreed with some. Hence, the following subthemes were identified: *conscious recognition*, *implicit exhibition*, and *lack of consensus*.

Conscious recognition

Participants reported a high level of recognition and identified with the items in the questionnaire. Many gave several examples of similar experiences to the ones described in the questionnaire and expressed explicitly that they agreed with the items. Very often memories and associations were evoked in relation to the items in the questionnaire. Another way of expressing recognition with the items was by disclosing to us that they had rated an item with a high number, indicating that they strongly agreed with the item, or expressing that an item was easy to rate because it felt true. Participant 4 described identification with the items in the questionnaire by revealing that she had had the same thoughts: "I could rate myself very highly on like most of the questions (…) because (…) this is what it feels like this is what it's like I think they [the items] capture (…) the thoughts that I have".

Participants not only expressed recognition with the questionnaire in its entirety; they also expressed identification with individual items. In relation to the items regarding appearance and weight (item 1 and item 13), Participant 4 stated the following:

> One thing that I always react to is that er take any movie almost any movie at all (…) and it is (…) the fat child that is also the mean child (…) and that makes appearance very strongly associated also with qualities (…) that are viewed very negatively and that is one of those things that eventually become a truth about myself.

In relation to item 2, which describes a worry about what other people think of you, Participant 9 communicated the following: "yes I do er and it's this thing that people think you're lazy and indolent and er er that I am less er er yes less intelligent almost (…) because you have overweight". In relation to item 3, which is about a wishing to be able to drastically change one's weight, Participant 12 expressed the following: "yes that is definitely a dream oh my god yes (...) but unfortunately you're well-educated enough to know that it doesn't exist". Participant 7 described a similar feeling of wishing for a drastic change: "if there was a miracle cure I would definitely take it (…) if there was some magical pill I would easily take that pill".

Some participants did not currently identify with the items but had done so in the past. In relation to item 7, about whether one feels worthy of having a rewarding social life, Participant 9 responded the following about whether the item is relevant in the questionnaire: “yes I do think so because er had it been three years ago then I would have agreed then it would’ve been higher [rated]”.

Some participants did not find certain items relevant to their own experience but could see that others might identify with the thoughts and emotions described. They could also see that some items may be relevant to the experience of self-stigma, even if they themselves did not identify with these items. Regarding item 17, which asks about shame related to physical activity, Participant 7 said the following when asked about the item’s relevance: “but it is still a relevant part of like the issues you’re having yes so it is a good question”, even though they did not experience any shame themselves.

Implicit exhibition

Apart from explicitly sharing their own experiences of self-stigma, participants also seemed to implicitly self-stigmatize during the interview. We noticed that the way the participants talked about themselves, others and their experiences was in line with how self-stigma is conceptualized in the questionnaire and in research. We interpret this as another example of recognition, but on an implicit level. What is important to bear in mind is that we did not see this pattern in all participants.

In many instances, what was interpreted as the participants’ implicit self-stigma was about weight controllability beliefs. For example, Participant 9 said the following about item 11, an item that assesses weight controllability beliefs:

> There are lots of people that can eat right and and like eat regularly and work out and go to the gym er but I can’t do that so yes it it feels like there is something wrong er because I can’t control it and can’t stay with it you know and that’s also why I’m in this treatment because I feel like I really need to be reprogrammed.

In this quote, Participant 9 expressed how she feels unable to follow diets and exercise regularly. With this, she was implicitly expressing a belief that her weight is her responsibility. By stating that she needs to be reprogrammed, she is attributing her overweight solely to cognitive factors, and entirely disregarding societal, biochemical, physiological, and genetic factors. Participant 8 said the following about the same item: “I can think that I’m stupid because I

understand (...) I know why you gain weight I know what I'm doing wrong but I don't do anything about it instead I just continue".

Similar to Participant 9, Participant 8 blamed herself for her weight gain and attributed it to lacking mental capabilities and weak character. She said that she understands how weight gain works, but that she does not do anything about it, implying that she has the power to control her weight. Participant 7 also appeared to self-stigmatize by expressing weight controllability beliefs. In talking about sadness in relation to her life she essentially blamed herself for not being able to control herself and her weight. In relation to item 7, which is about being worthy of a rewarding social life, she expressed the following:

> You're a little sad like what the hell have I been doing with my life like this far well at least the past few years like what the hell have I been doing (…) with all the social [aspects] and yes the overweight and not being able to control myself and my overweight in some way.

Implicit self-stigma was also exhibited as negative self-talk as well as participants' belittling themselves and their experiences. Participant 9 described an experience of traveling to Denmark to be prescribed dieting pills, to explain how she takes the "easy way out". She talked about herself in a belittling manner, implying that she has a weak character because she cannot adhere to proper diet and exercise behaviors. A similar exhibition of possible self-stigma, regarding appearance, was made by Participant 5 who said the following: "if I had just pulled myself up by the bootstraps I could have lost weight (…) I could have been really attractive". In other words, Participant 5 believed that she is unattractive due to her weight and that she is to blame because she does not have a strong character. Believing that one is to blame for their weight and feeling unattractive due to overweight are common forms of self-stigma.

Lack of consensus

The subtheme *lack of consensus* encapsulates participants' disagreement with items in the questionnaire. Two aspects of self-stigma in the questionnaire were repeatedly commented on by several participants, namely physical activity, and interpersonal relationships. One aspect of self-stigma that seems to be missing from the questionnaire is an item about eating or food.

Physical activity. Among the participants who commented on the item about physical activity (item 17), many agreed that it was relevant to the experience of self-stigma, even if they themselves did not agree with it. Some participants, however, did not agree whatsoever with the item and expressed that it could be removed completely from the questionnaire.

Some participants highlighted that the item was difficult to answer due to their inability to work out. Participant 2 said, regarding item 17, that “it was difficult to answer since I can’t work out anyway”. Participant 1 reflected on the fact that she does feel shame connected to physical activity, but not in relation to working out too little. For her, the shame was instead connected to disappointing others, such as health care professionals, who have expectations on physical exercise. She expressed the following:

> They don’t get that I can’t do it I can’t bend my legs enough to be able to bicycle so sure you do feel a negative emotion or yes a little shame basically because you can’t do what they [health care professionals] want you to do.

Participants 11 and 3 said that they do not see the connection between physical activity and obesity, and that the item therefore feels less relevant. Participant 11 stated “no it’s not always true that you’re overweight just because you don’t take care of your physical self”. Similarly, Participant 3 expressed that “it doesn’t have to go hand in hand (…) it doesn’t have to be connected at all you can work out a lot and still be overweight”. Participant 4 agreed and believed item 17 to be more detached from the questionnaire compared to the other items and said that “I don’t personally see that physical activity matters that much”. Overall, however, many participants believe item 17 to be relevant for the experience of self-stigma even if they did not agree with it themselves.

Interpersonal relationships. Two additional items were frequently commented on, regarding interpersonal relationships. Item 7 asks whether respondents feel worthy of a rewarding social life and item 10 asks whether the respondents think others would want to spend time with them. Many participants did not necessarily believe the items should be removed but expressed that they disagreed with the assumption of not being worthy of interpersonal relationships. For example, Participant 8 said that “it’s actually only the items about how others saw me that I didn’t rate with a high number” as well as “I think I deserve (…) the same life as anyone else”. Even though they personally disagreed with the items, some participants could see that other respondents might agree. For example, Participant 12 disagreed with the item about being unworthy of rewarding interpersonal relationships but understands that others might not feel the same way: “the weight shouldn’t matter that much but I can understand that people might feel that way”.

Eating and food. Many participants highlighted that there is no item about food or eating. In regard to self-stigma, some people found eating just as relevant as working out, if not more

relevant. For example, Participant 9 said, regarding physical activity, that “in direct relation to weight I’m not sure it [physical activity] is very relevant because I believe nutrition is more important since not everyone can work out”. Also, in regard to item 17, Participant 4 said that “I can imagine that for many people with overweight it is more about what we eat and how we eat and patterns regarding that”.

Without remarking on the absence of an item about food, many talked about food and eating habits during the interviews. Some participants described food as something wrong or forbidden, while other participants described it as something pleasurable as well as a means of emotional regulation. For example, Participant 10 said that her eating had been a way to regulate her emotions: “I’m thinking that I can find comfort I mean (…) my eating has been comfort-eating”. For Participant 9, on the other hand, food and eating brought up negative emotions: “I think about food daily and what you cannot eat and what you should eat and what you shouldn’t eat and some things [foods] bring shame”. For one participant, eating had become so important that she developed an eating disorder and must now follow a food schedule as part of her treatment. To summarize, nutrition and eating habits seem to be relevant to the experience of self-stigma, perhaps even more relevant than physical activity.

Summary

To conclude, participants identified with the items in the questionnaire, and in addition to explicitly talking about how they identified with the items, several repeatedly self-stigmatized on an implicit level. There were, however, some aspects of the questionnaire with which participants disagreed, namely physical activity and interpersonal relationships. A central part of self-stigma that might be missing from the questionnaire is an item about eating and food.

Theme 3. Ambivalence

Answering the IWBS questionnaire appears to have been an ambivalent experience for the participants. Many participants reported having to confront feelings and thoughts they might otherwise avoid but also a range of positive reactions (primarily validation) in response to the questionnaire. This resulted in the theme *ambivalence* which consists of the subthemes *confronting difficult feelings* and *verbalization and validation*.

Confronting difficult feelings

The thoughts and feelings described in the questionnaire seemed to be something that several participants usually avoid. Therefore, having to answer it meant having to face inner

experiences they otherwise would prefer not to engage with. Participant 1 commented: “well you have to really think about it usually you just push it aside (…) sure you know you’re overweight but (…) the more you can avoid thinking about it the better”.

The content of the questionnaire was experienced as deeply personal, and “hit close to home” as described by Participant 10. The items entailed thoughts that the participants are not used to verbalizing, even though these thoughts were described as very common by many of our participants. Having to verbalize thoughts they might otherwise avoid was, in many ways, described as a confrontation. Participant 1 felt as if it forced her to “face the truth”, whereas Participant 12 commented that “it was very much like ripping off a band-aid you very quickly felt very naked”. This evoked several negative feelings since it for most participants meant having to think back and re-experience previous instances of self-stigma.

On participant retrospection, myriad insights were attained with regard to what role self-stigma has played in their lives. A common shared experience was having been inhibited by their own self-perception. For example, Participant 9 described feelings of shame and disappointment, as well as grief over “not allowing oneself to participate in the daily world”. Furthermore, Participant 2 was reminded of how she would like to be her true self and felt sad that she was not. Realizing the implications of self-stigma thus contributed to the difficulty in answering the questionnaire.

The experience of answering the questionnaire was also described by many as difficult. There was a sense of vulnerability in discussing one’s situation and sadness in realizing that one belongs to a stigmatized group. Participant 2 comments: “yeah, I thought of the fact that it’s extremely sad that I evaluate myself based on how much fat there is or isn’t on my body”. When reflecting on their own internalization of stigma, many participants were able to take a step back and think about where their thoughts stem from. In those reflections, they expressed grief and powerlessness about how they are viewed and treated differently by society. Participant 9 stated that “it’s kind of sad that er (…) partly that you end up here but mostly that (...) you’re viewed in a different way because you have an overweight (…) you’re basically viewed differently that’s how I feel”.

Many felt a deep sadness over how society’s stigma has made them feel. Participant 6 described feeling sorrow regarding identifying with the items in the questionnaire. The process of agreeing with the items, in other words experiencing self-stigma, was described by her as

something she lacked control over and that she does not want: “sorrow that (…) it’s like this that I have to feel this way (…) because really I don’t really want to [feel like that]”. Participant 11 expressed a similar sentiment: “I myself have thought that you’re not worthy of certain things or that I am not worthy of certain things because of my weight absolutely and (…) I think it's sad that it has to be that way”.

Verbalization and validation

For most participants the emotional difficulty of answering the questionnaire was outweighed by the opportunity of putting words to and verbalizing self-stigma. Describing the role of self-stigma in her life, Participant 3 said that it happens “subconsciously sometimes and consciously sometimes (…) but mostly it sadly happens subconsciously and then you realize when talking about it here that oh god I compared myself to this and this”. The questionnaire made self-stigma more concrete for some, which caused them to realize how much time they had spent self-stigmatizing. Even though the questionnaire presented participants with the harsh language sometimes used to describe obesity and overweight, they believed this to be necessary. Participant 3 stated that those words “are needed because it might not be possible to describe it [self-stigma] any other way”.

For many participants, this study was their first encounter with the concept of self-stigma. Consequently, they had not made the connection between stigma and their own thoughts and feelings. Many described self-stigma as (prior to this study) a core part of their self-perception. Participant 5 was shocked over her degree of recognition and commented that “it’s not something I’ve reflected upon (…) you assume it is true and you kind of feel ashamed”. Consequently, answering the questionnaire was a meaningful experience that offered a new perspective. A coincidental component of this study was an educational effect, where an understanding of the self-stigmatization construct empowered many of them. Participant 4 said:

> [I’ve] mostly thought that yeah it’s been more about self-contempt (…) but I think I can kind of move it outside of myself and connect it more to stigmatization that happens in society by health care for example or by family and friends in school (…) it makes it more nuanced.

Verbalizing self-stigma both created a better understanding for the participants’ own thoughts and feelings and made them feel validated. They described a sense of joy and relief in feeling seen, and in having their reality recognized. For many of the participants, seeing their

reality mirrored in items on a questionnaire made them feel less alone. Participant 3 commented that "apparently other people can feel the same way and that's good (…) knowing you're not alone". Participant 4 said "putting words to it gives me a feeling that I may not be as different as I fear", revealing a sense of shared experience and community.

For some of the participants, realizing where self-stigma stems from gave rise to anger. It made them see the injustice more clearly and some felt provoked by the questionnaire for that reason. Participant 1 started questioning how she has been affected by stigma and her own self-stigmatizing behavior: "you start to think about how (...) maybe you deserve more than what you actually think (…) maybe you back away a little too much because you think that others don't think you're deserving".

Because of the questionnaire Participant 1 started questioning opinions she otherwise had taken for granted and began to re-evaluate her own worth. In this sense, anger arising from thinking stigma is deserved or justified, while in fact it is not, is considered a positive aspect that brings purpose to the questionnaire. A similar sentiment was displayed by participants when not agreeing with self-stigmatizing items. Several participants expressed that previously they would have agreed fully with the self-stigmatizing component of the items in the questionnaire and felt happy over not doing so today. Participant 12 said "it was a good eye-opener that 'no I actually don't agree with that' (…) I don't consider myself a victim either so it was kind of like I felt as if I was standing up for myself in the questionnaire".

Summary

While the experience of answering the questionnaire may have been difficult, it appears to have been outweighed by the catharsis of verbalizing personal experience, making the questionnaire an overall meaningful experience. In a sense, it led to the realization that others feel the same way, making participants feel less alone. Additionally, it made them aware of where self-stigma comes from, making it possible, to some extent, to separate it from their own self-image, sense of self, and self-worth.

Theme 4. Treating the weight versus seeing the person

Most participants described negative experiences with the health care system, where the weight had been the focus of treatment. The negative experiences were brought up both in association to items in the questionnaire, and when imagining filling it out in a health care setting. Patients with obesity are at higher risk for a range of diseases, and obesity is a frequent

comorbidity, which highlights the importance of treatment. However, the participants felt stigmatized by the extent to which medical practitioners documented and commented on their weight, especially under circumstances that they did not perceive weight to be directly relevant. These experiences were described by participants to have affected their views on future use of this scale and highlighted possible consequences.

The weight as the patient

Most of the participants repeatedly described negative health care experiences. Many stated that their weight had been pointed out in circumstances where it wasn't directly relevant. Participant 2 commented "I mean any medical worker can all of a sudden start talking about weight without it being obviously relevant". If not mentioned in person, several participants stated that every medical note, regardless of why they sought medical attention in the first place, includes a description of their weight. Participant 8 commented that "sometimes it probably has a significance but sometimes it feels (...) like it's just supposed to be there (…) 'overweight woman' and 'severely overweight'(…) as if it explains some things". This has left the participants feeling negatively labeled and categorized.

What compounds the experience of stigma is the manner in which weight is discussed. Descriptions of previous interactions with health care professionals indicate insensitivity and judging attitudes, making participants feel ashamed and vulnerable. Participant 11 revealed that she has tried to share her experience of not being listened to in medical settings with medical practitioners, but in vain. Consequently, she no longer feels that she can trust the health care system:

> I've tried to leave my- to tell my story and how I've experienced it [the health care system] but it hasn't been met when I've communicated it to the health care system, so it feels like (…) it doesn't matter I don't think there's anyone who wants to listen to me or at least that's what it feels like.

The participants shared an experience of their weight being the focus of treatment. In many ways they felt as if the weight was the patient, not them. Participant 11 described feeling as if she was expected to "fix" her weight, and that there was this illusion of the weight being the cause of all her problems:

> 'Okay we've got to fix this [the weight] (...) this is your problem and now we have to fix it' and I felt a lot like when I was there that it wasn't about me as a person instead

everything revolved around my overweight and how we were going to take care of it but not how we were going to take care of me.

When weight is the principal focus, the individual behind the weight tends to be forgotten. This suggests a lacking mental perspective, as described by Participant 11:

There was such a large focus on my overweight that it felt like I'm just numbers on paper and it's those that matter it's not how I- how I am like it doesn't matter how I feel in all of this or what I think or how I feel.

The weight-centric approach, and the absence of mental consideration, indicates a shortfall in the current practices adopted by the Swedish health care system. Participant 4 described experiencing a simplistic view of obesity and overweight within the health care system, which likely contributes to how people with obesity and overweight are treated:

I feel that I meet a lot of prejudice a lot of myths and a whole lot of ignorance when it comes to people with overweight (…) like it's all about caloric intake like balance in caloric intake or physical activity.

The lacking cognizance of the multi-faceted nature of obesity seems to result in people with obesity and overweight being treated in a way that makes them feel stigmatized by the health care system. Participant 1 recalled a time when her doctor instructed her to bicycle more, not understanding and considering the physical obstacles she faced, leaving her feeling ashamed ultimately contradicting the intended purpose of the physician.

On the other hand, some participants described positive experiences of health care. These have been at expert institutions and centers, and the key to a good experience appears to have been a holistic approach where the individual is treated, rather than the weight. In describing her current treatment, Participant 8 said "they look at the big picture (…) and don't make you feel like a 'fatty' (…) it's one of few places I've been treated for the person I am and not for having a bunch of excess weight".

Not another number

The subtheme *not another number* reflects a pattern in how participants wanted the questionnaire to be used and how they did not want it to be used. Overall, the participants asked for a clear purpose of the questionnaire if it was to be used, for the answers to be handled by competent health care professionals that they trust, as well as there being some form of action taken after the questionnaire had been completed. Some feedback from the participants highlighted

that the questionnaire can be perceived as shallow – not capturing the full extent of self-stigma – while still arousing negative affect. For this reason, the questionnaire needs to be dealt with in a careful manner where the individual's needs are in focus. If not, the experience of filling out the questionnaire could become a stigmatizing experience on its own where the participants once again are reduced to a number on a paper. Hence the name of the subtheme: *not another number*.

Participants provided feedback on how to use the questionnaire in order for it to become a meaningful and helpful experience. They emphasized the importance of trust in the health care professional who uses it. Before health care professionals use the form, consent should be given. For example, Participant 2 said that it would be helpful if health care professionals first prepared the patient and that they could even ask permission before introducing the questionnaire. Participant 6 reminisced on her previous health care experiences and realized that she was probably not open to help the way she is now, and it therefore is important that "one raises that question [of self-stigma] in a careful way". Furthermore, Participants 2 and 11 stressed the importance of trust in one's health care providers. Participant 2 remarked that "you don't want to have to open up to a person you're never seeing again", while participant 11 said "there has to be some kind of (…) trust you know in the person you're er doing this with". Participant 9 did not necessarily care about who reads her answers but pointed out that "there needs to be some significance to my doing it [completing the form]".

Additionally, participants pointed out that after having used the questionnaire, health care professionals need to do something meaningful with the responses in the form. Many asked that some form of action is taken to improve their treatment. To illustrate, Participant 4 said the following: "in the health care process or during individual medical appointments I feel that it is important to connect it [the questionnaire] to some form of action or measure". Similarly, Participant 12 suggested that "the ones who give honest answers would want something to happen afterward".

Lastly, participants highlighted how not using the questionnaire in an appropriate way could lead to a negative experience of the health care system, which on its own could contribute to stigma and self-stigma. Participant 3 highlighted the risks of using the questionnaire carelessly:

> If it's a place where you can trust or you feel that you can get the help you need or that they're kind or if it's just nervous and stressful and you only get five minutes and then they say 'just lose weight' then it's not great.

Participant 2 explained how the questionnaire could become a stigmatizing experience by pointing out that "if any doctor or nurse (…) would just throw it [the questionnaire] out there for me to fill out then it would become a part of the stigma". She also highlighted how disrespectful and hurtful the experience would be: "I would get angry actually I would be furious because I think it would be a violation of my integrity".

Summary

To conclude, participants described previous stigmatizing experiences of the health care system and from these provided opinions on how the form should be used. In the past, participants' weights have been commented on in a careless manner by health care professionals as well as documented in their charts without there being an obvious reason to do so. In other words, health care professionals treated the weight, not the person. To rectify previous stigmatizing experiences, the participants provided feedback on how a form such as the IWBS should be used. Used incorrectly, there is a possibility of the questionnaire becoming part of the stigma directed at people with obesity and overweight.

Discussion

The overarching purpose of this project is to develop a reliable and valid instrument to measure self-stigma in a Swedish context. In this thesis, the aim has been to perform a qualitative evaluation of the translated questionnaire, as outlined by Wild et al. (2005), and to examine participants' views on its potential use. Therefore, the following research question has been investigated: how is the translated questionnaire on self-stigma received and perceived by individuals from the target population? Working from a pragmatic theoretical approach, our ambition was also to investigate participants' views on the potential use of the questionnaire with regard to their previous health care experiences.

Reception and perception of the questionnaire

Overall, the questionnaire was received well by the participants. They felt that the language used was appropriate, clear, and respectful. On a technical level there were some aspects that presented as barriers to understanding, and consequently answering, the questionnaire. Some participants experienced lack of clarity in the instructions, some reacted to the chronology of items, some noted inconsistency of words used and some considered items ambiguous. These aspects are discussed in further detail under "Suggested changes" and followed by concrete recommendations

for improvement. Generally, however, the questionnaire was not perceived as overly complicated. Accessibility could be further enhanced if barriers identified are rectified.

Explicit and implicit self-stigma

In relation to the content of the questionnaire, participants seem to have received and perceived the questionnaire well. *Extent of identification* with the items in the questionnaire, which was one prominent theme, indicates that the content is relevant and appropriate to describe the participants' experiences of self-stigma. Self-stigma thus seems to be an occurring phenomenon also in Sweden.

Implicit exhibition of self-stigma, another identified subtheme, suggests that the items are relevant for describing a recurring behavioral pattern of self-stigmatization among the participants that they may not be aware of themselves. Repeatedly, some participants alluded to themselves as being unattractive and lacking self-discipline (Puhl & Brownell, 2001; Puhl & Heuer, 2009), which suggests that they applied negative stereotypes to themselves and believed these to be true. Some participants also implied that they lacked mental ability, for example by calling themselves stupid. In line with research from Bryksina et al. (2021) and Sim et al. (2022), these participants seem to have internalized the negative stereotype of low competence and lacking mental agency. The application and internalization of negative stereotypes indicate that self-stigma is a useful and relevant concept in a Swedish context.

In contrast to previous self- stigma instruments, this questionnaire includes a subscale regarding body shame (McKinley & Hide, 1996). Considering participants identified with the body shame items (item 12-17), we deem these to be relevant to the concept of self-stigma in a Swedish context. This is in line with previous research which found shame to be associated with weight-based self-stigma (Bidstrup et al., 2022; Ueland, 2019).

Disagreement with the questionnaire

Not all items in the questionnaire were seen as relevant and helpful, highlighted by the subtheme *lack of consensus*. Items about physical activity and interpersonal relationships were not always relevant to the participants' own experiences, which may suggest that these items are not applicable in a Swedish context. There could be several reasons why.

One reason why items in the questionnaire were not experienced as relevant could be a difference in understanding of the causes of obesity. In a Swedish context, the explanatory model of overweight and weight-loss could differ from Anglo-Saxon contexts (where the original scales

were developed). The common model, reported by WHO (2019) for example, is that obesity is caused by an energy imbalance, where physical activity is seen as a way to decrease overweight. It is possible that the understanding of obesity is changing in Swedish culture, and that obesity and overweight is now seen as a more complex condition (Huang et al., 2009). If this is the case, it makes sense that feeling shame in relation to physical activity (item 17) is not seen as relevant. Increasing awareness about the complexity of the disease can, in combination with the constant changing of beauty ideals (Bonafini & Pozzilli, 2011) and body positivity movements (Vandenbosch et al., 2022), affect how the public views people with obesity and overweight. One can imagine this having a positive effect on stigma as such and consequently self-stigma, as noticed among our participants.

Another possible reason why items are not seen as relevant could be an ability to separate one's own thoughts and feelings from society's stigma, meaning that participants may have been able to perceive weight-based stigma without internalizing it. For example, participants who found the items relevant for the experience of self-stigma but did not agree themselves might have been able to recognize that their thoughts and feelings were a result of society's stigma. Instead of displaying self-stigma, these individuals might have been able to identify perceived stigma and show stereotype awareness (Corrigan et al., 2006).

Many participants also brought awareness to the fact that there were no items about food or eating. Considering that food is a major aspect of the common explanatory model of obesity (WHO, 2019) it makes sense that participants highlighted that there is no item about food or eating. Due to the fact that there was an explicit call for an item about food and it being a recurring topic during the interviews, it seems that food and eating is relevant to the experience of self-stigma in a Swedish context. Vartanian and Porter (2016) identified an association between experienced weight stigma and maladaptive eating patterns, and Bidstrup et al. (2022) found a relationship between WBI and disordered eating. Based on previous research demonstrating that food and eating is a relevant aspect to stigma and self-stigma, as well as feedback from our participants, we believe that an item about this aspect should be considered for inclusion in the questionnaire.

To summarize, the subtheme *lack of consensus* points toward the fact that not all aspects of the questionnaire were perceived as helpful and that important aspects (food and eating) have not been included. Without determining whether physical activity, interpersonal relationships, and food and eating are relevant or irrelevant to the conceptualization of self-stigma on a theoretical

level, we emphasize that these aspects may be more and less, respectively, helpful in the questionnaire.

Reactions to the questionnaire

Although there was, overall, a high degree of recognition of the questionnaire's conceptualization of self-stigma among the participants, their experience of answering it was two-sided, as highlighted by the theme *ambivalence*. On the one hand, facing their feelings and thoughts was an emotionally demanding experience. This is not surprising considering the vast amount of research reporting a strong association between internalized weight stigma and mental health issues (Bidstrup et al., 2022; Carels et al., 2020; Durso & Latner, 2008; Pearl & Puhl, 2016; Pearl & Puhl, 2018; Walsh et al., 2018). Reflecting on one's own experiences of self-stigma for many participants thus meant re-experiencing these events, along with the feelings associated with them.

The emotional difficulty of answering the questionnaire could possibly be outweighed by the opportunity of putting words to one's experience and feeling seen, resulting in the subtheme *verbalization and validation*. Seeing their experience described in words, realizing that they were not alone in it, appeared to be validating. Further, realizing that self-stigma stemmed from something outside them (i.e., stigma) led, for some, to a redirection of negative feelings from themselves to the public, resulting in a conversion of self-hatred to anger. Reacting with anger is not an uncommon response to stigma (Corrigan & Watson, 2002) and the questionnaire seems to have made it possible for some participants to identify their own self-stigma and perceive the stigma of the public. Previous research shows that perceiving stigma without internalizing it can have a positive effect on mental wellbeing (Pearl & Puhl, 2016). Thus, the questionnaire can be seen as a tool for achieving mental separation of perceived and internalized stigma.

In summary, the IWBS was received well and positively in a Swedish sample. There were no major obstacles to taking part of the items in terms of language and structure, and the items were perceived as relevant and helpful. The items might evoke negative emotions, but these appear to be manageable and acceptable due to the positive effects of validation and verbalization. Some minor adjustments to language and instructions are recommended (see under "Suggested changes"). Evaluating items relating to physical activity and interpersonal relationships might be necessary as well as considering the inclusion of an item relating to food and eating. Overall, however, the questionnaire was perceived as accessible and relevant.

Helpfulness and usefulness

To investigate the subjective helpfulness and usefulness of the questionnaire was not originally part of this study's objective. However, during interviews, aspects on how to use the questionnaire in a health care context was identified as a pronounced theme which, out of respect for our participants' stories, we did not want to dismiss. Thus, the theme *treating the weight versus seeing the patient* was identified. This theme highlights valuable information on how filling out the questionnaire may become a helpful and meaningful experience to the patient. The questionnaire is designed with the intention to be used by health care professionals and researchers, but ultimately, it is the patient group who will receive it and hopefully be helped by it. Thus, usefulness relates to both patients and the health care professionals who will use it.

Negative health care experiences

Differing and often negative health care experiences were a prominent and recurring pattern in our interview material, resulting in the subtheme *the weight as the patient*. The participants' negative experiences are in line with previous research showing that it is common for people with obesity and overweight to experience weight-based stigma in health care settings (Puhl & Heuer, 2009). They told stories of instances where their weight had been mentioned in irrelevant situations, of having been described, and consequently categorized, as "overweight" or "obese". Additionally, participants in general perceived health care professionals as insensitive and as having judging attitudes when addressing weight, leaving them feeling shameful. These findings are also in line with previous research showing that many patients with obesity and overweight report feeling judged by health care professionals (Gudzune et al., 2014).

Obesity is a complex disease, with many comorbidities that pose physical risks to the individual (Guh et al., 2009; WHO, 2019), and this somatic perspective is a reality that needs to be considered in weight treatment. However, based on our participants' experiences of weight-centric treatment, it is important that this is not the only perspective. Treatment of obesity in the current Swedish health care system, based on our participants' experiences, fails to see beyond the weight. Additionally, participants described medical practitioners adopting a view of obesity being as simple as "calories in, calories out", further reinforcing obsolete views held by the public as reported by Kite et al. (2022). This indicates a lack of knowledge regarding the complexity of the disease in line with previous research demonstrating lacking knowledge among health care professionals (Foster et al., 2003). Participants even explicitly stated that they believe obesity

treatment is not up to date with current research. Instead of health care professionals seeing all needs, including emotional and psychological, their focus lies on the body and on the weight. By not asking about experiences of stigma and self-stigma, one risks treating only one part of the patient's problem, namely the weight. Only treating obesity as a medical condition means that the social and cultural aspects of obesity, which include stigma and self-stigma, may be lost. Furthermore, only treating the weight often results in obesity treatment becoming a stigmatizing experience on its own, where the patient is reduced to a number.

Participants' feedback on how to use the questionnaire

Based on their previous experiences, the participants in our study emphasized the importance of using the questionnaire in a respectful and considerate manner. When used correctly, they believed the questionnaire could become a helpful instrument for both health care professionals and patients to raise awareness of potential self-stigma, and thereby enable the treatment of more than just the number on the scale. Another positive use of the form is that it could help health care professionals communicate a consideration for the patient's needs. Previous research has shown that health care providers may spend less time building rapport with patients with obesity (Gudzune et al., 2013). Used correctly, this questionnaire could potentially be a tool to communicate understanding and empathy by raising awareness of more than the individual's weight.

Were the questionnaire to be used carelessly, however, participants believed it could become another stigmatizing experience where the patient once again is reduced to a number, highlighted by the subtheme *not another number*. Participants highlighted the need for consent to use the questionnaire as well as for the questionnaire to be handled by competent health care professionals whom the patients trust. Self-stigma was described as something personal and sensitive, and as indicated in the theme *ambivalence*, something that could evoke negative affect when disclosed or openly discussed. Were the form not to be handled in a thoughtful manner, it could potentially leave the patient vulnerable and exposed, and at risk of having a negative health care experience. An implication of negative health care experiences is reduced help-seeking, as seen in research by Mold and Forbes (2011).

Additionally, participants asked for some sort of measure or action to be taken in relation to filling out the questionnaire and for there to be a clear intention with answering it. Participants expressed an expectation on health care professionals to do something meaningful with the

responses. This means that filling it out alone is not enough for good treatment; the responses must be handled thoughtfully. Otherwise, using the questionnaire risks becoming another stigmatizing experience.

Our recommendations for using the Internalized Weight Bias Scale

Based on the feedback provided by the participants, we have compiled a set of recommendations on how to use the questionnaire in an appropriate way. First, if the questionnaire is to be used, there needs to be a clear intention with using it. If health care professionals do not have a clear intention with the form or are not able to make it a meaningful experience for treatment in some way, it is better not to use the form. For example, participants do not wish for the form to be handed out as a standardized questionnaire together with other health-related forms. Second, before handing out the form, it is important to ask for consent and introduce the concept of self-stigma. Third, the form should only be used if health care professionals can handle the responses in a considerate way and if possible, take some sort of measure afterward. Lastly, there needs to be a foundation of trust in order to use the form – only health care professionals who already have an established relationship with the patient and have the right competence should use it.

Suggested changes

When summarizing and evaluating the findings of this study we attempted to respond to the questions outlined in Wild et al. (2005). This resulted in practical suggestions on what changes should be considered moving forward in the validation process.

As the results show, confusion can arise if a timeframe is not provided since level of self-stigma can vary over time. One can, however, imagine using the questionnaire several times during treatment to assess how self-stigma has changed throughout a person's life. Therefore, we suggest that there are clear instructions for the medical practitioner on how to instruct the responder depending on what one aims to assess. The structure of the questionnaire may also affect the experience of participants. However, items will always be experienced differently and changing the order of the items would not necessarily improve the overall structure. What one can do is keep in mind that items will affect participants differently and perhaps take note of and discuss this with them.

In terms of language, the use of "weight" and "overweight" should be reviewed. Durso and Latner (2008) used "overweight" to address specifically a population with obesity and overweight, whereas Pearl and Puhl (2014) used "weight" to be able to use the weight bias questionnaire in

any weight population. As the results show, using both can cause confusion and have implications for the time framing of answers, with "overweight" being interpreted as the past and "weight" being interpreted as the present. Therefore, we suggest using either word exclusively.

On an item level, some considerations should be made. There was confusion regarding item 10, that asks about interpersonal relationships, on whether it concerned romantic relationships or friendships. Further, the word "should" in item 17, regarding physical activity, was perceived as triggering by some participants. Without saying anything about whether these items should be changed, we want to address that they are potentially problematic and should be taken into consideration before the final publication of the questionnaire. We do suggest adding an item regarding participants' relationship to food. As several participants noted, food related aspects can be central to one's experience of self-stigma, which has also been seen in previous research (Bidstrup et al., 2022). Seeing as caloric intake plays a greater role than physical activity in obesity (Huang et al., 2009), it would be reasonable to include both.

Ethical considerations

Microethics

In relation to the research context, we have considered several ethical aspects, not least the asymmetrical power relation between interviewer and interviewee (Brinkmann & Kvale, 2005). Even though participants were given the opportunity to disagree with aspects of the questionnaire and to give their point of view, one must take into account that we as interviewers ultimately had control over the interview situation, and subsequently, the interpretation of the data (Brinkmann & Kvale, 2005). As the primary objective of this study was to investigate to what extent the questionnaire was culturally appropriate and to what degree the questionnaire resonated with the participants, we had no other option but to invite people from the target population to participate. In other words, there was no way for us to avoid the power dynamic. To compensate, we strove toward asking open-ended questions, to be aware of the participants' well-being during the interview and offered a professional contact for emotional support should it be necessary after the interview was completed.

Macroethics

Using the questionnaire is tightly intertwined with ethics. As mentioned above, when used incorrectly the form can risk further stigmatization of an already vulnerable group of people. On a larger scale we need to consider the macroethics of developing the IWBS (Brinkmann & Kvale,

2005). There is a risk that the questionnaire could be used as an instrument of power. In this context, the power dynamics described by Andersen et al. (2022) are relevant, where the stigmatized individual holds little power in counteracting any stigmatizing processes. If the form were to be used carelessly, resulting in perceived stigmatization for the patient, then the creation of the form could be considered unethical. The pre-existing power dynamic where the medical professional is a figure of authority already puts the patient in a vulnerable position. When creating this type of questionnaire, we need to be aware that it may put the patient in an even more vulnerable position. However, when used by the right person in the right context, with the right intentions, the questionnaire has the potential to be a meaningful experience, and an improvement to obesity treatment. The questionnaire could potentially call attention to self-stigma in health care settings and thus enrich current treatment options. Both patient and health care provider are then expected to benefit from the development of such a form.

Methodological strengths and limitations

Applicability and transferability

From an ethical perspective, we did not see a reason for reporting participants' weight history. We did, however, include the participants' gender and age to give the reader an understanding of who the participants were. Additionally, in our results we disclosed their previous experiences with the Swedish health care system, which further contextualized the participants' situation. Participant information that was gathered, but not reported, was previous weight treatment, first-time seeking weight care and current respective highest measured BMI. This information was used to contextualize responses during interviews and when interpreting the data. With these aspects in mind, we have situated the participants to the extent we deem necessary for our readers to assess the relevance and applicability of our findings. Since we have shared relevant participant and context information, we have given readers the necessary means to determine degree of transferability (Willig, 2013).

Credibility

Our results were presented with adjoining examples to illustrate our findings. We have repeatedly returned to the transcripts, assessing the fit between the data and our interpretations, as well as assessed the fit between the data and how we chose to present the findings. Having done so, we consider this to be a strength of our methodological work. Furthermore, while the main purpose of the quotes is to support our interpretations, it also gives the reader an opportunity to

create their own understanding. However, a limitation is that we have translated our quotes, potentially risking valuable information to be lost in translation.

To ensure credibility we have coded transcripts separately, which we consider to be a methodological strength. To further ensure the legitimacy of our claims, we have conferred and discussed our findings with the principal investigator of the research project who is an expert in the field. In our study we have included thoughts on reflexivity, however, we have consciously made the decision not to disclose our own assumptions regarding obesity and overweight, nor the stigma surrounding it. Firstly, we are respecting our right to privacy. Secondly, from a realist perspective, it is assumed that knowledge (in this case self-stigma) exists in the world regardless of the person exploring it (Willig, 2013). Therefore, we consider the disclosure of our personal assumptions theoretically redundant and believe that there is no added benefit to including private information.

Procedure

Another strength is how comprehensively the research questions have been studied. Wild et al. (2005) recommends five to eight people in order to carry out a cognitive debrief. We, however, interviewed twelve participants in our study, which gave us the possibility to include a variety of viewpoints and opinions. The method of choice to analyze our interview data was a thematic analysis (Braun & Clarke, 2021), which also extends beyond the recommendations presented by Wild et al. (2005). Furthermore, when analyzing the transcripts we adopted a bottom-up approach, making sure we were open to any unexpected findings. Regarding the procedure, we were two people who conducted the interviews and analyses, resulting in a wide range of perspectives and continuous learning from one another. Taken together, we believe that we have studied the topic comprehensively and systematically.

Nonetheless, we are aware of limitations in regard to the procedure. For example, one potential limitation to our study is related to the difficulty in conducting a thematic analysis when following recommendations by Wild et al. (2005). Since the procedure of cognitive debriefing is less extensive than that of a thematic analysis, we occasionally felt limited by an interview guide that was adapted for cognitive debriefing. Another possible limitation is that only women participated. However, we see the value in researching self-stigma among female participants since previous research indicates that women are more prone to internalizing weight stigma

(Himmelstein et al., 2017). Despite these considerations, we still believe that our findings are trustworthy since any limitations have been compensated for to the best of our ability.

Future research

This thesis has conducted the cognitive debriefing process of Wild et al.'s (2005) guide for translating and culturally adapting questionnaires. The remaining steps of this process are to be carried out following the integration of the findings (and proposed changes) of this thesis. Additionally, the questionnaire should go through a quantitative validation process in order to ensure psychometric properties such as reliability and validity.

With the validity and reliability of the IWBS questionnaire established, future research should investigate the prevalence of weight-based self-stigma in a Swedish population since previous findings indicate that weight-based self-stigma can have a negative effect on well-being. As indicated by the results in this thesis, filling out the IWBS questionnaire was commonly experienced as validating, therefore it is likely that patients would benefit from using the questionnaire in concert with further weight treatments. It is therefore pertinent to investigate whether identifying and targeting self-stigma, with the help of the IWBS questionnaire, could improve patients' experience of treatment as well as treatment outcomes.

When using the IWBS questionnaire in a medical context, it is crucial to investigate patients' experiences of the questionnaire in practice. Particularly relevant since this thesis only explored participants' views on the potential use of the questionnaire. Broadly speaking, it is of interest to gain feedback on using the IWBS questionnaire from more than just the patients. Perspectives on using the questionnaire from health care professionals could further provide insight on the utility of the questionnaire in practice.

Conclusion

To conclude, the questionnaire was overall received well and perceived as relevant by the participants. The language was seen as correct and respectful, the questionnaire was considered culturally appropriate and no major triggering aspects were reported. However, some changes to language and instructions as well as review of some items are recommended. In terms of using the questionnaire, our findings emphasize the importance of using it mindfully with respect for the individual and their past experiences. If used carelessly, the participants highlight the risk of the questionnaire potentially becoming part of the stigma that many people with obesity already experience. We believe that when using the form correctly, it can provide insight on the experience

of self-stigma and improve treatment for people with obesity, ultimately resulting in a holistic approach to weight care.

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Appendix A

Interview guide

Inledande

- Hur gammal var du när du fick din övervikt?
- När kom du först i kontakt med vården angående din övervikt?
- Vad för behandling har du fått i samband med din övervikt?
- Vet du vad självstigma handlar om?
- Har någon inom vården pratat med dig om självstigma?
- Vad har du för tankar kring självstigma?
    - Är du insatt i vad självstigma innebär?
    - Väcktes nya tankar kring självstigma i samband med att du fyllde i formuläret?
    - Vad har det för betydelse i ditt liv?

Allmänt

- Hur tyckte du att det var att fylla i formuläret?
    - Var det något som var förvirrande eller otydligt?
    - Hur upplevde du instruktionerna?
- Hur upplevde du antalet svarsalternativ på varje fråga?

Språk, begriplighet och kulturell lämplighet

- Väcktes några känslor när du fyllde i formuläret?
    - Var det något ord du reagerade särskilt på?
    - Var det något påstående som du reagerade särskilt på?
- Hur uppfattade du de olika känsloorden som användes? (”besviken”, “skäms”)
    - Kan du relatera till de orden?

Upplevelse

- Fångar formuläret in dina tankar och känslor kring din vikt?
    - Om ja, på vilket sätt?
    - Om nej, hur skiljer de sig?

- Finns det aspekter du tycker hänger ihop med dina känslor och tankar, som saknas i formuläret?
- Hur tänker du kring frågorna (fråga 1, 13) om utseende och hur de hänger ihop med vikt?
- Hur tänker du kring frågan (fråga 17) om träning och hur den hänger ihop med vikt?
- Om du föreställer dig att du fyller i detta formulär när du är på [setting i vilken formuläret kommer användas], hur känns det?
    - Skulle det kännas jobbigt?
    - Skulle det påverka vem det var som läste svaren, eller var du fyllde i? Något annat?
- Hur känns det att vi utvecklar ett formulär för att mäta detta?

Genomgång av samtliga frågor i skalan

- Hur upplevde du den här frågan?
    - Var något otydligt?
    - Väcktes några associationer?
    - Upplevdes något triggande? Väcktes tankar som du inte haft om dig själv tidigare?

Avslutande

- Finns det något mer du vill ta upp som vi inte frågat om?

Appendix B

The Internalized Weight Bias Scale

Nedan följer ett antal påståenden. Läs varje påstående och ringa in den siffra som bäst stämmer in på dig, där **1** = ”Håller inte alls med” och **7** = ”Håller helt med”.

1. **På grund av min vikt så är jag mindre attraktiv än andra.**

1 2 3 4 5 6 7

Håller inte alls med Håller helt med

2. **På grund av min vikt känner jag mig orolig för vad andra ska tänka om mig.**

1 2 3 4 5 6 7

Håller inte alls med Håller helt med

3. **Jag önskar att jag drastiskt kunde förändra min vikt.**

1 2 3 4 5 6 7

Håller inte alls med Håller helt med

4. **När jag tänker på min övervikt, känner jag mig nedstämd.**

1 2 3 4 5 6 7

Håller inte alls med Håller helt med

5. **På grund av min övervikt är jag besviken på mig själv.**

1 2 3 4 5 6 7

Håller inte alls med Håller helt med

6. **Min vikt är en stor del av hur jag bedömer mitt värde som person.**

1 2 3 4 5 6 7

Håller inte alls med Håller helt med

7. **På grund av min övervikt så känner jag inte att jag förtjänar ett givande socialt liv.**

1 2 3 4 5 6 7

Håller inte alls med Håller helt med

8. **Jag är bekväm med min nuvarande vikt.**

1	2	3	4	5	6	7
Håller inte alls med						Håller helt med

9. **På grund av min vikt känner jag mig inte som mitt sanna jag.**

1	2	3	4	5	6	7
Håller inte alls med						Håller helt med

10. **På grund av min vikt, förstår jag inte hur någon skulle vilja umgås med mig.**

1	2	3	4	5	6	7
Håller inte alls med						Håller helt med

11. **Det känns som att det är något fel på mig, eftersom jag inte kan kontrollera min vikt.**

1	2	3	4	5	6	7
Håller inte alls med						Håller helt med

12. **Jag skäms över mig själv när jag tänker på min vikt.**

1	2	3	4	5	6	7
Håller inte alls med						Håller helt med

13. **På grund av min vikt tycker jag att jag inte ser lika bra ut som jag skulle kunna.**

1	2	3	4	5	6	7
Håller inte alls med						Håller helt med

14. **Min vikt gör att jag känner mig besviken på mig själv.**

1	2	3	4	5	6	7
Håller inte alls med						Håller helt med

15. **Jag skulle skämmas om folk visste vad jag verkligen väger.**

1	2	3	4	5	6	7
Håller inte alls med						Håller helt med

16. Jag skäms för att min vikt inte är som den borde vara.

1	**2**	**3**	**4**	**5**	**6**	**7**
Håller inte alls med						Håller helt med

17. Jag skäms för att jag inte motionerar tillräckligt mycket.

1	**2**	**3**	**4**	**5**	**6**	**7**
Håller inte alls med						Håller helt med

Appendix C

Recruitment information for participants

SAMHÄLLS-
VETENSKAPLIGA
FAKULTETEN

Utveckling av ett frågeformulär för att mäta självstigma hos personer med obesitas

Obesitas (fetma) är en stigmatiserad sjukdom, där personer med obesitas ibland bemöts på ett nedvärderande sätt av sin omgivning. Personer, som utsätts för fördomar, tar ibland till sig dessa och börjar tänka negativt kring sig själva i linje med fördomarna. Detta fenomen kallas självstigmatisering. För psykologer och andra inom sjukvården är det viktigt att kunna mäta om en person med obesitas stigmatiserar sig själv och i så fall hur mycket för att kunna hjälpa dessa individer så bra som möjligt.

Vi vill därför undersöka hur personer med obesitas uppfattar ett frågeformulär kring självstigmatisering som vi har översatt och utvärdera om det översatta formuläret kan fungera för personer i Sverige. Vi vill tillfråga dig som har eller har haft obesitas, talar flytande svenska samt är 16 år eller äldre att delta. Studien kommer genomföras under höstterminen 2022 och involvera en intervju som tar max 1 timme. Den äger rum på Institutionen för psykologi eller över Zoom. Insamlad data avidentifieras. Deltagande är frivilligt och kan avbrytas när du vill.

Om du är intresserad av att delta vänligen scanna QR-koden och följ anvisningarna.

Om du har frågor är du välkommen att kontakta ansvarig forskare Kajsa Järvholm.

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Appendix D

Research information to participants

Information till forskningspersoner

Vi vill fråga dig om du vill delta i ett forskningsprojekt. I det här dokumentet får du information om projektet och om vad det innebär att delta.

Vad är det för ett projekt och varför vill ni att jag ska delta?

Obesitas (fetma) är en stigmatiserad sjukdom, där personer med obesitas ibland bemöts på ett nedvärderande sätt av sin omgivning. Personer, som utsätts för fördomar, tar ibland till sig dessa och börjar tänka negativt kring sig själva i linje med fördomarna. Detta fenomen kallas självstigmatisering. För psykologer och andra inom sjukvården är det viktigt att på ett tillförlitligt sätt kunna mäta om en person med obesitas stigmatiserar sig själv och i så fall hur mycket i syfte att kunna hjälpa dessa individer.

I det här projektet vill vi undersöka hur personer med obesitas uppfattar ett frågeformulär kring självstigmatisering som vi har översatt. Vi utvärderar om det översatta formuläret kan fungera för personer i Sverige.

Vi vill tillfråga dig som har eller har haft obesitas att delta i studien.

Forskningshuvudman för projektet är Lunds universitet. Med forskningshuvudman menas den organisation som är ansvarig för projektet. Ansökan är godkänd av Etikprövningsmyndigheten. Diarienummer för prövningen hos Etikprövningsmyndigheten är 2022-02800-01.

Hur går projektet till?

Projektet syftar till att utveckla ett frågeformulär på svenska för att mäta självstigmatisering hos personer med obesitas, som ett led i detta är det viktigt att personer i målgruppen får komma till tals kring hur de uppfattar formuläret. Ansvarig forskare är psykolog Kajsa Järvholm, som har mångårig erfarenhet av att behandla patienter med obesitas.

Du som vill delta kommer bli inbjuden till en intervju som kommer att pågå i max 1 timme. Intervjun äger rum på Institutionen för psykologi eller över Zoom. Du kommer utöver intervjun få fylla i det aktuella frågeformuläret som mäter självstigmatisering. Intervjun kommer utgå från upplevelsen av frågeformuläret och kommer att spelas in (endast ljud). Intervjumaterialet

kommer sedan transkriberas (skrivas ut ord för ord) och analyseras på gruppnivå. När intervjun skrivs ut kommer den att avidentifieras, vilket innebär att det inte går att koppla intervjun till dig som individ. Resultaten kommer att ligga till grund för en psykologexamensuppsats och en vetenskaplig artikel. Du kan i samband med avslutat projekt ta del av examensuppsatsen och artikeln genom att kontakta projektansvarig.

Deltagande i projektet är helt oberoende av den eventuella vård du får för din obesitas.

Möjliga följder och risker med att delta i projektet
Deltagandet medför inga uppenbara risker och medverkan innebär en möjlighet att få vara med att påverka ett formulär som kan komma att användas i vården i framtiden. Formuläret finns redan på engelska och där har personer med obesitas också varit med i framtagandet av frågorna. Under intervju kommer du som deltar få ta del av frågeformuläret och besvara frågor. Möjligen kan dessa ha en känslomässig påverkan.

Om deltagande leder till obehag får du hjälp. Ansvarig forskare är legitimerad psykolog med mångårig erfarenhet av behandling av obesitas och psykisk ohälsa. Om någon forskningsperson skulle påverkas negativt av sin medverkan i studien föreligger därför kompetens att samtala om detta och ge adekvata råd kring vart personen bör vända sig med denna problematik.

Vad händer med mina uppgifter?
Projektet kommer att samla in intervjudata om din upplevelse av frågeformuläret. Dina svar kommer att behandlas så att obehöriga inte kan ta del av dem. Resultaten kommer att presenteras på gruppnivå så att det inte går att knyta någon information till en viss person. Insamlad forskningsdata kommer att arkiveras och gallras (rensas ut) enligt Lunds universitets regler, vilket innebär att data kommer att sparas i 10 år efter att resultaten har publicerats.
Ansvarig för dina personuppgifter är Lunds universitet (kontaktperson Kajsa Järvholm). Enligt EU:s dataskyddsförordning har du rätt att kostnadsfritt få ta del av de uppgifter om dig som hanteras i projektet, och vid behov få eventuella fel rättade. Du kan också begära att uppgifter om dig raderas samt att behandlingen av dina personuppgifter begränsas. Rätten till radering och till begränsning av behandling av personuppgifter gäller dock inte när uppgifterna är nödvändiga för den aktuella forskningen. Om du vill ta del av uppgifterna ska du kontakta huvudansvarig forskare Kajsa Järvholm. Dataskyddsombud nås på dataskyddsombud@lu.se. Om du är missnöjd med hur dina personuppgifter behandlas har du rätt att framföra klagomål till Integritetsskyddsmyndigheten, som är tillsynsmyndighet.

Hur får jag information om resultatet av projektet?
Som deltagare kan du välja att inte ta del av resultatet efter att ditt deltagande är avslutat. Skulle du som deltagare dock vilja ta del av projektets resultat kan du göra detta genom att kontakta huvudansvarig Kajsa Järvholm. Din individuella data kommer transkriberas och analyseras.

Detta kommer sedan användas i samband med det slutgiltiga analysresultatet som baseras på samtliga deltagares data och presenteras i en skriftlig sammanställning. Din individuella rådata kommer således inte vara del av projektets slutprodukt, men kan delas med dig om du så önskar. Projektet kommer vara del av en examensuppsats vid Institution för psykologi och publiceras på Lunds universitets portal (lup.lub.lu.se/student-papers/search). Det ingår även i ett större forskningsprojekt som ämnar publiceras i en vetenskaplig tidskrift.

Försäkring och ersättning

Forskningspersonerna är via forskningshuvudmannen återförsäkrade genom kammarkollegiet. Det finns möjlighet för deltagaren att bli ekonomiskt kompenserad för eventuella resekostnader. Denna är icke skattepliktig. Ingen ersättning utöver reseersättning kommer att utgå.

Deltagandet är frivilligt

Ditt deltagande är frivilligt och du kan när som helst välja att avbryta deltagandet. Om du väljer att inte delta eller vill avbryta ditt deltagande behöver du inte uppge varför, och det kommer inte heller att påverka din framtida vård eller behandling.

Om du vill avbryta ditt deltagande ska du kontakta den ansvarige för projektet (se nedan).

Ansvariga för projektet

Ansvarig för projektet är:

Leg. psykolog, docent Kajsa Järvholm

Adress:	Institutionen för psykologi, Lunds universitet
	Box 213, 221 00, Lund
Mailadress:	kajsa.jarvholm@psy.lu.se
Telefonnummer:	046 - 222 37 35

Appendix E

Consent form

SAMHÄLLS-
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Samtycke till att delta i projektet

Jag har fått muntlig och/eller skriftlig information om studien och har haft möjlighet att ställa frågor. Jag får behålla den skriftliga informationen.

- Jag samtycker till att delta i projektet *Utveckling av ett frågeformulär för att mäta självstigma hos personer som har obesitas*.

Plats och datum	Underskrift
	Namnförtydligande