TACKLING OBESITY WITH ADVOCACY: **BEYOND FOOD & EXERCISE**

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Abstract

Obesity has become a global crisis. Since 1980, the obesity rate has doubled in 73 countries and increased in 113 others. Currently, 650 million adults and 340 million children (and adolescents) have obesity. This worldwide crisis has profound social, economic and health implications for individuals, their families and their communities. What actions are currently being taken to bend the curve on obesity around the globe? Who are the key actors in this debate and how they are approaching this international crisis? And more relevant, are these actions creating an effective, meaningful, ethical, innovative, and sustainable impact on people with obesity and their communities? These are some of the questions this study research tries to answer from a social and socio-psychological perspective.

The paper at hand explores and reflects upon diverse narratives constructed by main actors involved in the obesity debate to understand how and why they have adopted a patient-centric narrative to contribute to the (re)construction of obesity as a global epidemic. Therefore, the configuration of this study develops a qualitative perspective that creates awareness on the narratives among selected stakeholders and the patient role within the obesity debate in a global context. Hence, the investigation (1) address the increasing prevalence of the global obesity debate since the mid-twentieth century with a focus on social and socio-psychological approaches; (2) point out the prominent patient advocate movements that contribute to such debate from a global scope; and finally, (3) crystallise the growth of patient engagement narratives used by different stakeholders involved in this new paradigm of obesity as a chronic disease narrative.

Abstract på Dansk

Overvægt er et kritisk globalt problem. Siden 1980 er overvægtsfremvensen fordoblet i 73 lande og steget i 113 andre. I øjeblikket lider 650 millioner voksne og 340 millioner børn (og unge) af overvægt i verden. Denne verdensomspændende krise har dybtgående sociale, økonomiske og sundhedsmæssige konsekvenser for enkeltpersoner, deres familier og samfundet. Hvilke foranstaltninger er der i taget for at bøje kurven for overvægt over hele kloden? Hvem er nøgleaktørerne i denne debat og hvordan tilgår de denne internationale krise? Videre, er disse handlinger skabt en effektiv, meningsfuld, etisk, innovativ og bæredygtig indvirkning på personer med overvægt og deres samfund? Dette er nogle af de spørgsmål, som denne undersøgelse forsøger at svare på ud fra et socialt og socio-psykologisk perspektiv.

Dette speciale undersøger og reflekterer over forskellige fortællinger opbygget af hovedaktører involveret i overvægts-debatten for at forstå, hvordan og hvorfor de har vedtaget en patient-centreret fortælling til at bidrage til (re) kunstruktion af forståelsen for overvægt som en global epidemi. Denne undersøgelse udvikler søger at skabe et kvalitativt perspektiv, der fremmer bevidsthed om fortællingerne blandt udvalgte interessenter og patientrollen inden for forhandlingen af den nye overvægtsdiskurs i en global sammenhæng. Derfor undersøger undersøgelsen (1) den stigende udvikling af den globale fedmedebat siden midten af det tyvende århundrede med fokus på sociale og socio-psykologiske tilgange; (2) påpege de fremtrædende advocacy-bevægelser fra patienter, der bidrager til en sådan debat fra et globalt omfang og slutteligt (3) krystalliserer væksten i patientinddragelsesfortællinger, der anvendes af forskellige interessenter, der er involveret i dette nye paradigme for overvægt som en kronisk sygdomshistorie.

Introduction

The introductory chapter elaborates on the motivation behind the research at hand placing it in the current global discussion about the obesity pandemic and its subsequent social and psycho-sociological implications related to patient advocacy. Following this outline, the ensuing focus of this master thesis and the associated research questions will be illustrated.

Motivation and problem area

The research study was originally inspired by my personal interest in the way in which different key stakeholders involved in the global obesity debate define obesity and perpetuate its causes and consequences. More specifically, how such actors are seeking to find solutions to the exponential growth of this public health issue through patient-centric narratives. Since 2012, multiple stakeholders such as academia, healthcare professionals, policy makers, influencers, pharmaceutical industries and food companies have been slowly joining forces to develop more knowledge about obesity and/or its complications. While some say, obesity is a lifestyle condition, others argue it is a disease. Obesity and overweight have been continuously framed in many distinguish ways: As a normal physical healthy state, a financial problem related mostly with low incomes, a social stigma, a consequence of new trends in civilisations and technology innovations, among others. These frames evoke different ideas and ways of understanding obesity from numerous and diverse perspectives (Sandberg, 2007, p. 459). In fact, while the debate tries to move forward and make some progress, there are more and more discrepancies within the same study fields: Physicians do not agree with each other, scientific studies contradict other scientists, and policymakers debate upon whether or not their local healthcare systems should take

a major role into ensuring people to have (more) access to obesity treatments and comprehensive care. The World Health Organisation (WHO) and the International Association for the Study of Obesity have been working with national obesity associations in various countries to help implement programmes for the prevention and management of obesity and mostly to persuade health policymakers and key health professional organisations to recognise that obesity requires urgent actions (Lau, 1999, p. 503).

Nevertheless, there is certainly common ground when discussing this issue of obesity which is that this condition is indeed a gateway to a multitude of further diseases and health risks threaten not only global healthcare systems but also with the potential to cripple national economies and global development (Frühbeck et al., 2016, p. 297). There is no doubt that obesity should have turned off all alarms across governments at this point on time; as there is a need of a multi-stakeholder strategy that favours an increased commitment for concerted, coordinated and specific actions that yield to tangible results (Ibid.). To effectively tackle the obesity epidemic a more proactive approach is urgently needed. While this study does not intend to define obesity - a controversial challenge that has been going on-and-on for decades - there is a need to explain the different definitions and perspectives from main actors involved in the global debate and find common ground.

Obesity classification

Cambridge Dictionary defines obesity as “the fact of being extremely fat, in a way that is dangerous for health” (“Obesity”, 2019, para. 1). Nonetheless, what does ‘extremely fat’ really mean and when/how does it become dangerous for health? While there are various ways to measure obesity, the most widespread international used method of measuring and identifying obesity is Body Mass Index (BMI) (“Obesity

Classification", 2018, para. 1). BMI is a standardised measure of body fat that - together with its fat distribution and its classification of obesity - allows for more accurate estimates of prevalence rates of obesity in the population, the identification of individuals or groups at increased health risks, identification of priorities for intervention at an individual and community level and, more important, the evaluation of intervention and treatment strategies (Lau, 1999, p. 504). The World Health Organization (WHO), the specialized agency of the United Nations, defines obesity as "[...] abnormal or excessive fat accumulation that presents a risk to health" ("Obesity", 2019, para. 1). WHO categorises obesity only when such a condition presents health risks: "Obesity can be defined simply as the disease in which excess body fat has accumulated to such an extent that health may be adversely affected" (Consultation, W. H. O., 2000, p. 6). The WHO standardised the BMI by providing a more detailed population-level measurement of obesity. This means that the way the majority of individuals are measured of obesity today is based on the BMI ("Obesity Classification", 2018, para. 2).

Classification	BMI kg/m²
Underweight	<18.5
Normal range	≥18.5 and <25.0
Overweight	≥25.0 and <30.0
Obesity	≥30.00
Obesity, class I	≥30.0 and <35.0
Obesity, class II	≥35.0 and <40.0
Obesity, class III	≥40.0

Table 1: Obesity Classification in adults (WHO, 2018).

Problem formulation and research questions

In order to create common ground and enrich the debate and literature on the obesity and advocacy subject, the aim of this research is to explore and reflect upon the narratives constructed by community groups and non-profit organisations; health providers, private sector (pharmaceutical industries); researchers and academia; patient organisations and people with obesity to understand how and why these actors have adopted a patient-centric narrative to contribute to the (re)construction of obesity as a global epidemic. With no intention of generalisation or fully closed explanations of these positions, the configuration of this study will aim at a qualitative perspective that will benefit the discussion and awareness on the narratives among selected stakeholders and the patient role within the obesity debate in a global context. The above will be attempted by conducting nine interviews with diverse representatives from different anchors that collaborate and have an active role and participation inside the debate. Hence, the investigation aims to (1) address the increasing prevalence of the global obesity debate since the mid-twentieth century with a focus on social and socio-psychological approaches; (2) point out the prominent patient advocate movements that contribute to such debate from a global scope; and finally, (3) crystallise the growth of patient engagement narratives used by different stakeholders involved. Therefore, and based on specific theories and its discussions presented in the theoretical framework, the analysis and discussions produced in this research study should help to explore and discuss the following problem formulation:

How has the patient perspective voice been used by key actors inside the obesity global debate, and what narratives have they constructed around the obesity global crisis during the last seven years?

Consequently, with the view to examine the above problem formulation the following research questions are presented:

1. *How do key actors understand obesity and the patient-centric role in the global debate?*
2. *Do stakeholders involved share the same understanding of obesity than patients who advocate inside the global debate?*
3. *How and why some of the actors have adopted a patient-centric narrative to contribute to the global debate?*
4. *How do patients and patient associations advocate for a more patient-centric perspective?*

To understand the relevance of the problem formulation and the research questions one must first understand the obesity debate landscape and its development. Thus, the following section will provide an overview of all relevant events during the last seven years in relation to the persistent social disparities in obesity, its worldwide debate and the four schools of thought analyse the literature.

Literature Review

This following section explains the current state of knowledge on the obesity global debate, its evolution and the four different scientific explanations that define the studied subject for this which I will summarise as follow. These chosen four schools of thoughts will be disseminated in order to provide an overall framework of the problem, highlight the key findings and set up a point of departure to then explain the theoretical choices made.

Obesity in 2019

Several facts have shown that obesity is becoming a global crisis. Since 1980, the obesity rate has doubled in 73 countries and increased in 113 others (Hobbes, 2018, para. 55). Currently, 650 million adults and 340 million children (and adolescents) have obesity (Addicted brain, para. 8). Such condition contributes to an estimated 2.8 million deaths per year worldwide and a staggering $850 billions of direct healthcare costs globally (¨It's Poverty, Not Individual Choice¨, para. 1). Lau (1999), head of the division of endocrinology and metabolism in Ottawa University and the Ottawa Hospital, argues that there is a realistic estimate of the cost of obesity ranging from 2% - 10% of the total health care budgets of different countries. In Canada, she alludes, the direct cost of obesity is about $2 billion per annum or 2.4% of the total health care budget (p. 503). In addition, the World Obesity Federation (2018) estimates that obesity is expected to climb to $1.2 trillion by 2025 (¨The Narrative Around Obesity¨, para. 3). In the United States - one of the few countries with reliable data about obesity within their own populations - nearly 80% adults and about one-third of children now meet the clinical definition of overweight or obesity according to the Centres for Disease Control and Prevention (CDCP) (as cited in Hobbes, 2018,

para. 6). Nowadays, more Americans live with “extreme obesity” than with breast cancer, Parkinson’s, Alzheimer's and HIV put together” (Hobbes, 2018, para. 6).

This worldwide crisis has profound social, economic and health implications for individuals, their families and their communities. In addition, there are significant scientific shreds of evidence proving that obesity can develop cardiovascular diseases, diabetes, cancer, joint pain, among many other complications; putting people's lives in risk and increasing healthcare treatment costs. What actions are currently being taken to bend the curve on obesity around the globe? Who are the key actors in this debate and how they are approaching this crisis? And more relevant for this study, are these actions creating an effective, meaningful, ethical, innovative, and sustainable impact on people with obesity and their communities?

The global obesity debate: A short version

Obesity has become a significant public health issue that has spread further in the past seven years (McAllister et al., 2009, para 1). The ‘obesity epidemic’ is in urgent need of more serious attention than it has been getting so far. It is, after all, thought to be killing nearly 3 million people per year worldwide (Cohen, 2018, para. 1). There is an outstanding demand for urgent debate from a more global perspective. The prevalence rate of obesity has increased in both developed and undeveloped countries, especially over the past decade. Canada, France, Mexico, Switzerland and the United States have had an exponentially increased of people with obesity (OECD, 2017, p. 2). However, countries with a major percentage of the population with obesity are not necessarily the richest. In fact, places with smaller economies, such as the Marshall Islands, Kuwait, Samoa, Palau, and Nauru have made it to the top 10 during the last decades (¨The Narrative Around Obesity¨, para. 6). This could potentially

indicate that even when there are indeed relationships between obesity and a country's economic status, there are not clear - nor extraordinary - correlations between obesity and social inequality. In sum, what once was considered a problem only in high-income countries, has now dramatically risen in low and middle-income countries, particularly in urban settings (WHO, 2019, para. 2).

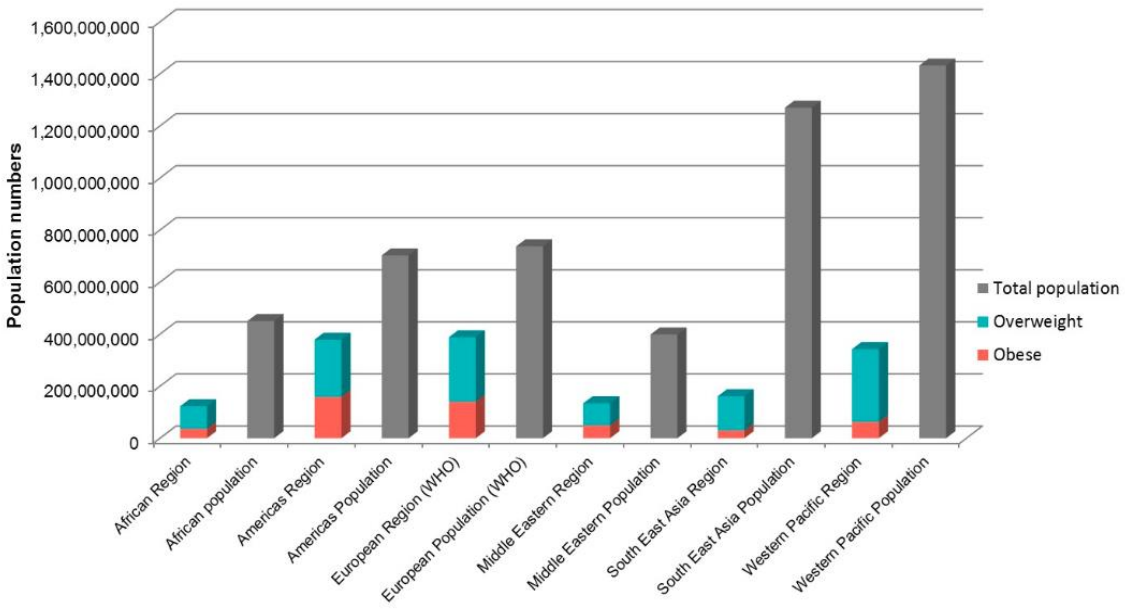

Figure 1: Number of Overweight & Obesity by Region for Individuals ≥15 years (World Obesity, September 2016).

The shift in obesity

In 1949, a small group of doctors created the National Obesity Society, the first of many professional associations meant to take obesity treatment to another level (Obesity Society, 2019, para. 5). Through annual conferences, like the first International Congress on Obesity, held in United States in 1973, doctors from different fields started helping to propagate the idea that dealing with weight and obesity was a job not only for patients but also for "highly trained experts" (Brown, 2015, para. 5) including health care professionals and providers (HCPs). This attitude inspired a number of new obesity treatments where HCPs, from public and private

anchors, helped to focus not only on treatment but also on prevention efforts. International congresses, regional and local conferences and a few patient organisations (POs) emerged in order to focus on weight management and obesity. It does not come to a surprise why the United States is the country with the major number of obesity POs worldwide (21st Global Obesity Meeting, 2019, para. 9). In 1999, the European Association for the Study of Obesity (EASO) called for recognition, support and national action to combat the obesity epidemic (Frühbeck et al., 2016, p. 296). EASO decided to prove leadership, guidance and support to governments as part of its own mission of "facilitating and engaging in actions to reduce the burden of unhealthy excess weight in Europe" (Ibid., p. 297). From here, organisations such as The American Medical Association (AMA) - the largest professional organisation of physicians in the United States with over 215,000 members in 2010 (Topol, 2015, p. 21) - designated obesity a disease in June 2013[1]. AMA's new policy was a step that aimed to focus more attention to the condition and spur more insurers to pay for treatments and prevention efforts, and it did. The headlines "AMA Recognizes Obesity as a Disease" were catapulted across both academic and mainstream media worldwide. From TED Talks and The New York Times to The Clinical Advisor, obesity specialists were interviewed providing diverse - and clashing - opinions on this ground-breaking and somewhat controversial topic and to answer the question, "is obesity a disease?". At this point on time obesity "was no longer a conversation topic tucked away in a dusty corner but was instead sprinkled across national news for the public to scrutinize" (Obesity Medicine Association, n.d., para. 1). The idea that obesity was

[1] It is important to note that AMA decisions do not have recognized legal implications. However, these policy decisions are often referenced by federal and state legislators and other decision-makers when setting medical policy and health regulations (Obesity Medicine Association, 2013, para. 5).

caused by insufficient willpower, lack of discipline and bad choices from the people living with obesity began to transform.

Nevertheless, some contradictors suggested this new paradigm on obesity may have led to greater acceptance by insurance providers to cover treatment, a move that could induce physicians to pay more attention to the condition and spur more insurers to pay for treatments. In other words, “follow the money” as Brown (2015) eludes to:

> Doctors want to be paid for delivering weight-loss treatments to patients [...]. If Medicare goes along with the AMA and designates obesity as a disease, doctors who even mention weight to their patients could charge more for the same visit than doctors who don’t. (para. 14)

In addition, there are also financial conflicts of interest defended in the field. “It’s rare to find an obesity researcher who hasn’t taken money from industry, whether it’s pharmaceutical companies, medical-device manufacturers, bariatric-surgery practices, or weight-loss programs” (Brown, 2015, para. 15). Now, four years later, the debate continues.

Four schools of thoughts

Throughout the literature review, I have found four schools of thought when discussing obesity among the studied stakeholders from a social and psycho-sociological perspective: 1) Obesity as a cause of poverty and low education; 2) Obesity as a consequence of the Modern Age; 3) Obesity as a disease; and finally, 4) Obesity as a risk factor. These predominant four positions show - from different perspectives - the narratives expressed when debating obesity and, most importantly, when discussing effective solutions to the problem. The research at hand will focus on

these four scientific explanations to further analyse and discuss the problem formulation.

Obesity as a cause of poverty and low education

Cohen (2018), specialised in interdisciplinary research in Social Sciences in Hertfordshire University, states that there is a clear and extraordinary correlation between obesity and social inequality: “Obesity is not just a matter for nutritionists: rather, it is a product of social inequality and requires a collective social response” (para. 2). The Health and Social Care Information Centre in the United Kingdom, NHS Digital[2], echoes this by illustrating the link between children with obesity and income, where the ten worst areas in terms of overweight or obese children, half are also in the worst ten for child poverty (NHS Digital, 2016, para. 7). Caraher (2016), professor of food and health policy at the Centre for Food Policy in London University, explains that food choices are massively influenced by factors such as income, knowledge and skills (p. 35). In addition, research on obesity in four countries - Australia, Canada, England and Korea - found that higher rates of obesity were associated with fewer years of education. In fact, each additional year of education resulted in a lower chance of obesity (OECD, 2014, p. 1). Such study also suggested that “youth who struggle with obesity are less likely to achieve higher education” (Ibid.).

In sum, studies have shown that overweight and obesity - instead of being treated as a direct problem and responsibility of individuals and/or their families - are a social problem that involves more core issues such as poverty and low-educational environments. Here education can play a key role in reversing the obesity trend especially among children and young populations.

[2] NHS Digital is a British national provider of information, data and IT systems for commissioners, analysts and clinicians in health and social care in England, particularly those involved with the National Health Service.

Obesity reinforces inequality

As education and socio-economic background affect obesity, reciprocally, obesity damages labour market outcomes that - in turn - contribute to reinforcing existing social inequalities, “Obesity has clear negative labour market impacts, reducing employment prospects, wages and labour productivity (Devaux & Sassi, 2015, p.10). Research consistently finds that people with obesity - especially women - earn lower salaries and are less likely to be hired and promoted (Hobbes, 2018, para. 41). In addition, people with obesity seem to be less productive at work due to more sick days and fewer worked hours and earn about 10% less than non-obese people (OECD, 2017, p. 7). Additional research indicates that employers rather “normal weight” over candidates with obesity, partly due to perceived risks of lower productivity due to poor health (OECD, 2014, p. 7).

	Employment	Wages	Absenteeism
Obesity	Lower probability of employment	Larger wage penalties	More sickness absences

Table 2: Labour market outcomes of main behavioural risk factors in obesity (Devaux & Sassi, 2015, p. 9).

In other words, people with obesity have poorer job prospects compared to normal-weight people, they are less likely to be employed and have more difficulty re-entering the labour market (Devaux & Sassi, 2015, p.10). For the European Association for the Study of Obesity (OECD) addressing obesity and the associated negative labour market outcomes could help “break the vicious circle of social and health inequalities” (OECD, 2017, p. 7).

Obesity as a consequence of the Modern Age

McAllister et al. (2009) define what they call “the two most commonly advanced reasons for the increase in the prevalence of obesity” (p. 869): 1) The food marketing practices and 2) the institutionally-driven reductions in physical activity. The elements of the big two include - but are not limited to - the “built environment”: The increase of portion sizes in commercially marketed food items, inexpensive food sources such as fast food, increased availability of vending machines with energy-dense items and less physical education. Based on the above, the reason why social disparities in obesity persist and have increased is because of accessible and inexpensive “unhealthy” food items and the adoption of multiple technological innovations that reduce daily physical activity (Benjamin, 2010, p. 514).

Furthermore, stress, a “modern life symptom” that tends to be mostly present in developed environments, i.e. cities and urban areas, may limit people’s motivation and ability to adopt positive weight-related behaviours (Björntorp, 2001, p. 73). “Studies have shown chronic stress adversely affects blood pressure and cholesterol and may lead persons to increase their caloric intake” (Ibid.). Similarly, obesity can produce long-term adverse psychological and physical outcomes as people with obesity are more likely to suffer from poor self-esteem, anxiety and depression (OECD, 2014, p. 7).

Obesity as a disease

The Obesity Medicine Association (OMA), the largest organisation of physicians, nurse practitioners and physician assistants located in Boulevard Nazarene University, works to improve education and provide support to HCPs in the field of obesity medicine including treatments. OMA defines obesity as a chronic

disease (Obesity Medicine Association, n.d., para. 3). The association states that individuals with obesity that have increased the accumulation of fat not always attributable to eating too many calories or lacking physical activity, as this condition can be correlated with disorders of hunger, satiety (the feeling of fullness) or fullness (the state of fullness) (Ibid., para. 4). The European Association for the Study of Obesity (EASO) also defines it as a progressive disease, impacting severely on individuals and society (Frühbeck et al., 2016, p. 297). Not surprising, more organisations have followed this statement including the Obesity Society (TOS) and the British World Obesity Federation (WOF), the last affirming that obesity is a "Chronic, relapsing, progressive disease process that emphasises the need for intermediate action and the prevention and control of this global epidemic" (Bray et al., 2017, p. 720). The Royal College of Physicians (RCP), a British based professional membership body for physicians with presence over 80 countries worldwide, has been the latest organisations calling for obesity to be recognised as a disease in January 2019: "[Obesity] is not a lifestyle choice caused by individual greed but a disease caused by health inequalities, genetic influences and social factors" (RCP, 2019, para. 5).

Advocacy in Obesity

Professor Andrew Goddard, RCP president, affirms that it is governments - not individuals - which can have an impact on the food environment through regulation and taxation, and by controlling availability and affordability (RCP, 2019, para. 10). Currently, Portugal is the only country in Europe that officially classifies obesity as a disease (McCall, 2017, para. 3). In addition, this condition has been also recognised as a disease in the United States (by the American Medical Association in 2013), Canada (by the Canadian Medical Association, 2015) and Israel (by the Israel Medical

Association, IMA, 2018); followed, as mentioned before, by the international organisation WHO and WOF (Ibid., para. 4). Speakers at the European Congress of Endocrinology (ECE) 2017 and the recent European Congress on Obesity (ECO) 2017 called for more countries to formally recognize obesity as a disease in order to strengthen the fight against this epidemic. John Wass, MD, professor of endocrinology at the University of Oxford, United Kingdom, expresses: “One of the ways in which obesity can receive more attention from politicians, the general public, and healthcare professionals caring for obese patients is for obesity to become formally recognized as a disease” (as cited in McCall, 2017, para. 4).

Lau (1999) echoes this by explaining the need for enhancing the knowledge and attitudes of health care professionals and provider for the acceptance of obesity as a medical disease “with increased morbidity and mortality that supplant the previous perception of obesity as a cosmetic concern” (p. 505). However, there are many discrepancies among the statements above.

Obesity as a risk factor

Stoner and Cornwall (2014) express that, undeniably, obesity is indeed a risk factor associated with several health complications. However, they believe that obesity is exactly that - a risk factor:

> Being obese does not necessarily equate to poor health [or having a disease]. Strong evidence has emerged suggesting that an adult may be “fat but fit”, and that being fat and fit is actually better than being lean and unfit. Moreover, if we do accept this risk factor as a disease, should we also consider cigarette smoking a disease? (p. 462)

Several scientific and medical publications argue that labelling obesity as a disease may foster a culture of personal irresponsibility, where “individuals are absolved from practising healthy lifestyle behaviours” (Stoner & Cornwall, 2014, p. 462). Some also address that the notion of understanding obesity as a disease may benefit especially industries - in the form of pharmaceutical companies - who make billions of dollars from this potential shift within the medical landscape (Kyle, Dhurandhar & Allison, 2016, p. 519).

In sum, healthcare professionals, academia, policymakers, public organisations, pharmaceutical and food companies are divided: Some say obesity is a social problem that involves more core issues such as poverty and low-educational environments. Others, on the other hand, state that such condition is the result of a modern built environment where access to inexpensive food and no-physical activities are the major contributors. Others may argue that obesity is indeed a disease with causes beyond eating too much and exercising too little and consequences that harm the body like any medical condition. In addition, they claim that referring to obesity as a disease would potentially improve care for patients and ensure covered treatments by insurance plans. In contrast, some others disagree by saying that obesity is a risk factor for health problems, but not a disease itself. They express that calling obesity a disease would stigmatise a huge population and categorize some people as "sick" who actually may be healthy.

Theory

The following section reflects on the theoretical approaches applied to this study. It will be elucidated by describing the narrative theory focused on sociological and psycho-sociological approaches in order to understand the content strategy of each one of the analysed stakeholders. Moreover, the theory of advocacy will be introduced to examine how main factors among the debate influence and motivate people with obesity to increasingly engage and participate in the mentioned healthcare discussion. Finally, the theory of patient-centricity will be outlined in order to explain the interest of actors involved in the debate to establish meaningful relationships among each other, including people with obesity seeking to be positioned at the same level as all the other stakeholders involved.

Narrative theory

Narratives can be seen as an instrument that helps to construct a reality of social life where communities come to know, understand and make sense of their social world and, therefore, constitute cultural social identities (Bruner, 1991, p. 6; Somers, 1994, p. 606; Krebs, 2015, p. 136). Thus, the following theory description can help to understand the stakeholders' diversity and their contradictory perspectives based on the same studied subject from a more delimited social and psychological frame of reference in the analysis section.

The narrative construction of reality

Scientists have documented the urgent of human minds to constantly seek coherence and meaning, “We have a need to tell ourselves stories that explain it all” (Krebs, 2015, p. 137). Bruner (1991) corroborates this idea by describing how human

beings organise their own experience and memory of happenings mainly in the form of narrative through stories told by others, excuses, myths, reasons for doing and not doing, experiences, and so on (p. 4). By defining reality, narratives make rational decision-making possible: “[Narratives] are the vehicle through which human beings formulate and articulate understandings about self and other and about what self and other want” (Krebs, 2015, p. 137). This is the main reason why the debate regarding a definition of obesity among all actors involved in the global discussion has increasingly emerged. The dominant narrative about obesity - “obesity seen as a lifestyle chosen condition” - has been challenged by others and new versions of reality whose acceptability is governed by conventions and "narrative necessity" have been rather shown by empirical verification especially during the last decade. Most of the knowledge about human reality, including obesity, is drawn from studies of how people come to know the natural or physical world (Bruner, 1991, p. 4). The interesting part of this view is that every study or told conception is linked to personal knowledge-gaining and knowledge-using capabilities to the symbolic system of a culture of which he/she is an active member (Ibid., p. 20), meaning that the conceptions of obesity vary depending on the person(s) background, education, knowledge and development.

Types of narratives

There are two types of narratives that can potentially correlate to the research study problem formulation: 1) Public narratives and 2) conceptual narrativity. *Public narratives* are those that have attached cultural and institutional formations such as family, workplaces (organisational myths), churches, study organisations, public or private companies, governments and nations. These constructed stories have selective criteria related mostly with what communities define as good or bad (Somers,

1994, p. 619). *Conceptual narrativity*, on the other hand, conveys concepts and explanations constructed by social researchers. Its challenge is to produce texts that can be used to (re)construct - over time and space - the public and cultural narratives between historical actors, their relationships and their lives (Ibid., p. 620). Within the academic world, one of the stakeholders further analysed for this paper, narratives are seen as public distributed intelligence which is domain by certain actors (Bruner, 1991, pp. 3-4). The above implies that knowledge (or narrative producer) is used by certain ways allowing people to grow in certain spheres and remain incompetent in others, all based on personal knowledge that has been acquired by others either in the present or transferred in the past (Bruner, 1991, p. 2). Somers (1994) adds that domain narratives are (re)constructed mostly by those who 'owned' a status in academia (p. 606).

In sum, narratives constitute versions of realities whose acceptability depends on what happens to people and the meaning they make of events or conditions such as obesity, throughout a bunch of relationships embedded in time and space formed by selective and historical events that fit their own identities and fit their own stories (Mouton, Kjærbeck & Rasmussen, 2017, p. 4; Somers, 1994, p. 618).

The politics of narrative identity

The construction and appropriation of narratives have historical constructed and legitimate features of identity that limited new available representations and stories (Bruner, 1991, pp. 4-5). Hence, it is difficult for new narratives to establish within societies. Such narrative structures retain socially dominant where alternative narratives are not in wide circulation (Krebs, 2015, p. 140), and those who give voice to alternatives are rudely received, ignored or treated. As actors involved in these structures do not freely construct their own narratives, new social movements rise to

influence and challenge social norms. These expressions of new “politics of identity” shared common ground: Being created and supported by people who have experienced marginalisation from dominant political, theoretical and social narratives cover especially by social norms and accounts (Somers, 1994, p. 608). The aim here is to reintroduce excluded narratives into theories of action. Different theories, such as patient-centric theories, advocate for the importance of constructing new public narratives and symbolic representations that do not continue the long tradition of exclusion so characteristic of dominant ones (Somers, 1994, p. 630). Hence, debates regarding obesity and new effective obesity treatments have increased. Narratives that once were a seeming unquestioned common sense are subject to widespread public challenge (Krebs, 2015, p. 140).

Here narratives are crucial as they help to underpin the political, economic and cultural commonplaces among societies and the ways the universe is intrinsically defined (Krebs, 2015, p. 137). In addition, narratives expose what Burke (1978) defines as *the five elements of the pentad*: 1) Act, what is happening?; 2) scene, what is the background to action?; 3) agent, who is acting?; 4) agency, what means or instruments do agents employ?; and 5) purpose, why action? what are agents’ motivations? (p. 332). Burke’s pentad is a very useful framework to identify the core features of narratives among the obesity global debate on which this paper focuses. Furthermore, Krebs (2015) highlights four useful dynamics when settled narratives become relatively unsettled within a specific scene (pp. 144-145):

- *The Dominant Narrative:* It usually happens at the beginning of the debate when there is a relatively dominant and stable public narrative about obesity and a few limited ranges of contradictory arguments.

- *The Emergence of Dominant Narrative:* Alternative narratives emerged and the narrative situation becomes unsettled. Different actors begin to express themselves confronting events, people or objects that are “confusing or troubling” the dominant narrative.
- *Competing Narratives:* Unsettle narratives present an opportunity to fix meanings - not only fitting it to established expressive conventions but also to challenge political and elite contestants.
- *Contestation within Dominant Narratives:* During relatively unsettled times, speakers may engage in storytelling to challenge the dominant narrative, their efforts help keep alive an alternative whose main objective is that the dominant narrative collapses.

Strategic narratives

Strategic narratives help to directly address the formation, projection, diffusion and reception of ideas finding the best methods of persuasion to influence targeted international audiences (Roselle, Miskimmon & O’Loughlin, 2014, p. 71-74). Miskimmon, O’Loughlin, and Roselle (2015) define strategic narratives as means for actors to construct a shared meaning of the past, present and future especially in international concepts and politics to shape the behaviour of domestic and/or international actors (p. 341). In the long term, manage to make others see the world in your own terms (or strategic narratives) can shape people’s interests, identities and understandings of how international conceptions and relations work and develop (Miskimmon et al., 2015, p. 341). When diverse narratives compete with each other, “skilful leaders” can work to find the points of narrative alignment to foster cooperation and a sense of shared destiny. Often, they do the opposite, taking narratives as weapons to ‘win’ the final battle (Miskimmon et al., 2015, p. 341). To analyse a

narrative one must identify the narrator and what within the story belongs to his/her perspective; distinguish between the action itself and the narrative perspective on that action (Culler, 1980, pp. 27-28); and finally, contrast what the narrative includes and what it is excluding within certain periods of time. That is why strategic narratives are often directed at external stakeholders such as customer or citizens, suppliers or shareholders, investors or industry groups, governmental agencies, or non-governmental activists (Mouton et al., 2017, p. 1). To analyse a narrative one must identify the narrator and what within the story belongs to his/her perspective; distinguish between the action itself and the narrative perspective on that action (Culler, 1980, pp. 27-28); and finally, contrast what the narrative includes and what it is excluding within certain periods of time. That is why strategic narratives are often directed at external stakeholders such as customer or citizens, suppliers or shareholders, investors or industry groups, governmental agencies, or non-governmental activists (Mouton et al., 2017, p. 1). Therefore, in order to analyse narratives within the obesity debate, different answers to the following questions offer narratives to the global debate about obesity:

- *Agents:* Who are the key actors in the global debate? How unified are they? What resources do they possess?
- *Purpose:* What are the character and interests of the agents involved in the debate? What is the resulting relationship between the protagonists with respect to obesity as a disease/lifestyle condition?
- *Act and Agency:* What evidence supports this characterisation of the relationship? What have the actors do in the past?
- *Scene:* Are obesity and the global debate of obesity a real urgency, or do they position obesity as such?

In sum, the narrative theory helps to understand how strategies are narratively constructed from actors involved in the discussion. In addition, it crystallises how narratives re-construct realities by deconstructing or delegitimising others: “Narratives not only serve as ways of world-making; they also function as ways of world breaking” (Mouton et al., 2017, p. 7).

Advocacy theory

For Carragee and Roefs (2004) the interactions and abilities of social movements to challenge dominance - especially over social groups - are tied directly to their effectiveness in influencing new and alternative narratives (p. 224). For the aim of this study, social movements will be understood as networks of interactions between individuals, groups and/or organisations engaged in political, economic, social or cultural conflicts on the basis of shared collective factors (Stammers & Echle, 2005, p. 53). Hence, the theory of advocacy has been chosen to examine in the further analysis section how main factors among the debate influence and motivate people with obesity to increasingly engage and participate in the mentioned healthcare discussion.

The growing integration and liberalisation of worldwide markets, along with the development of communications and transport technologies and the rapid growth of global governance institutions above and beyond the state, have opened new opportunities for social international movement and their explanations of what Stammers and Echle (2005) called *Transnationalisation of activism* (p. 55). These interactions are networks which often reach beyond policy change to advocate changes in international levels multiplying opportunities for dialogue and, more importantly, exchange (Keck & Sikkink, 1999, p. 89). Therefore, *Transnational advocacy networks* are increasingly visible in the obesity debate. Some of them are

constituted by scientists and experts, others are networks by activists. In sum, the dynamics of these transnational advocacy network relationships within social movements can be crucial for the potential shift towards a more democratic and alternative narrative(s) where advocates - patients, researchers, etc. - become key actors of such shift (Stammers & Echle, 2005, p. 63).

Advocacy: Pointer to democratisation

Motivated by pressing problems that threaten the wellbeing of the communities - the global obesity epidemic - advocates are making themselves heard using a variety of means. They are holding governments accountable for their most vulnerable populations and strengthening the rights of people with obesity - usually (but not only) low-income populations - and increasingly the environment and its other inhabitants (Gardner & Brindis, 2017, p. 44). Savvy about the policymaking process and navigating political and social arena, these network actors bring innovative ideas, new narratives and creative norms into global debates serving as sources of information and testimony. They do so by three main strategies: 1) To expose the issues; 2) attract attention, and 3) encourage action (Keck & Sikkink, 1999, p. 90). Gardner and Brindis (2017) define an advocate as someone who actively tries to argue for or supports a cause by persuading others to act, affiliated with an organization or group with the same intent of working for the same cause (p. 33). Lately, advocacy has been considered by many as a way of expanding democracy (Stammers & Echle, 2005, p. 28). These political and social actors bring their influence prior to and/or during the policymaking process and social debates. Based on Gardner and Brindis (2017) the advocates' strategies and tactics have been increasingly recognised for their "potential to achieve lasting systems change" (p. 28): "Foundations, public agencies, and

nongovernmental organizations have marshalled significant resources to ensure that advocates' voices are heard and that they are able to navigate the policy arena" (Gardner & Brindis, 2017, p. 28).

Evidence shows that despite narratives spread by advocacy movements are often ignored (Carragee & Roefs, 2004, p. 225), policy decisions are mostly and greatly affected by the way issues are understood collectively by policymakers, advocates and the public in general. Naturally, advocates attempt to affect these dynamics by drawing attention to specific matters (Baumgartner & Mahoney, 2008, p. 435). Nonetheless, advocacy strategies not always result in positive mobilisation or change. Such an impact depends on how effective is the penetration to the target (Gardner & Brindis, 2017, p. 28). In sum, it seems potential advocates have the capacity (though not necessarily the freedom) to make their wishes known, from the person with obesity who seeks funding for his or her treatment, towards a community that is opposed to certain food marketing practices within their surroundings (Gardner & Brindis, 2017, p. 33).

Advocacy theory in public health

Public health advocacy is intended to reduce death or disability in targeted groups, such as people with obesity (Christoffel, 2000, p. 723) where advocates can be represented not only by individuals but also by organisations and groups:

- *Individuals:* Individual advocates can provide information about a particular problem, such as the obesity epidemic, and participate on committees to develop frameworks, standardised rules and/or regulations within policy making, explain network or conduct research. Individual advocates are likely to be part of an advocacy community within policy issues; specifically, citizens,

policymakers, directors, entrepreneurs, appointed officials, patients, among many others. In addition, they can potentially be more than one type of advocate at the same time (citizen, director and patient) where mobilization efforts make them formidable advocates alone and together (Gardner & Brindis, 2017, p. 34).

- *Organisations:* While organisations are the easiest type of advocate to discern in a crowded debate, “they may or may not be the most potent voice” (Gardner & Brindis, 2017, p. 39). Their role can be from influencing public opinion forming a long-term policy agenda (obesity as an international health priority) to public awareness and support for a particular issue, policy, or regulation (obesity as a disease or not). The key organisations include in this research within the advocacy are government agencies, universities, non-profits and nongovernmental organisations including patient organisations (Ibid., pp. 39-40).
- *Groups:* The public, organised communities or informal coalitions, networks, interest groups, associations, communities and social movements are considered the most potent forces for change in policy and social processes (Gardner & Brindis, 2017, pp. 43-44). These groups work as networks that share values and frequently exchange information and services where the flow of information among advocate actors in the network expand both formal and informal (Keck & Sikkink, 1999, p. 92).

Advocating in health from all levels (individuals, organisations and independent groups) have been challenging many corporate and government behaviours. In the obesity world, for example, advocates have been participating in international debates strengthening their role in the promotion of better food supplies, higher standards of

nutrition and even reduce the risk of diet-related ill health (Lobstein et al., 3013, p. 154). Here, health problems - factors that reduce the quality of life and life duration - become public problems when they affect a substantial portion of people. Thus, advocacy plays a key role in public health as it can direct systemic changes that shape the way people live (Christoffel, 2000, p. 722). As one of the main objectives of public health advocacy is to reduce morbidity and mortality, intermediate deliverables are to bring together forces to work for common goals and changes in the conduct of individual and community life (Ibid., p. 723). In efforts to reduce obesity in certain communities, intermediate goals could include new understandable schemes of food labelling, mass media campaigns to increase public awareness and reinforced regulation of marketing of potentially unhealthy products, especially when directed to children (OECD, 2014, p. 2).

Public health advocacy activities

Christoffel (2000) suggests a conceptual framework for the process of public health advocacy that includes three stages: Information, strategy, and action (p. 723). The framework identifies sets of different activities and logical sequence (Christoffel, 2000, p. 724). The roles of the various participants in public health advocacy in these stages are outlined in *Table 3*. Thus, processes of public health advocacy include: 1) problem identification; 2) research and data gathering; 3) professional and clinical education, as well as education of those involved in the creation of public policy (including media coverage); 4) development and promotion of regulations and legislation; 5) endorsement of regulations and legislation via elections and government action; 6) enforcement of effective policies; and finally, 7) policy process and outcome evaluations. These activities occur in a context in which many groups and individuals are involved, often from diverse functional perspectives, including governmental,

geographic, religious, racial or ethnic, family, professional, and/or personal (Christoffel, 2000, p. 723).

Actor	Information	Strategy	Action
Community groups	Request data Knowledge	Public education Work with legislators Join coalitions Mobilise groups	Testify Promotion
Health provider organisations	Identify needed data Research	Public education Join/support coalitions Policy statement Clinical guidelines	Testify Promotion
Legislators	Request data Authorise data work Fund data work	Hold hearings Draft legislation Draft regulations	Pass laws Fund enforcement
Private sector (pharmaceutical industries)	Fund data work Fund research	Fund public education Funding priorities Fund coalitions	Apply safety standards
Researchers & academia	Conduct research & evaluation	Develop data/based and theoretical concepts to guide prevention planning; educational curricula for medical students	Testify Write editorials Publish papers A determinate course of the debate Vote
Patients	Identify needed data Request data Bear witness Participate in research	Public education Work with legislators Patient perspective Build a coalition Join/support coalitions Coordinate group efforts Mobilise groups	Testify Promotion An active voice in the debate Vote

Table 3: Public Health Advocacy Participant Roles (based on Christoffel, 2000, p. 724).

The model above highlights common problems in public health advocacy as well as in suggesting solutions. Several studies on public health campaigns have

shown that it is rather common for involved actors to work at all stages of the public health advocacy process, often simultaneously. However, real-world efforts rarely meet these expectations (Christoffel, 2000, p. 725).

Patient-centric theory

The term *patient* originally meant “one who suffers” - derived from the Greek verb “to suffer” (Topol, 2015, p. 27). As a noun, it is defined as a “person receiving or registered to receive medical treatment”, which implies a passive role. It is not easy to think about a definition of such term; as many other terms such as consumer, customer or client refer more to a business relationship than to a medical perspective. However, the research at hand will adopt Topol’s definition (2015) of *the patient* as an individual who can be “an active participant in his or her care, who commands the same level of respect as the doctor, and who is privy to all data and medical information that is about that person” (pp. 27-28). When referring to the patient(s), the paper intends to reference a person/people with obesity. The patient-centric theory explains as follow can collaborate to determinate in the analysis section the motivations behind integrating patients’ insights and desires into the advocate activities created by stakeholders involved in the obesity debate and their social, economic and psychological impact.

Topol (2015) affirms that societies are experienced a “medical revolution with little mobile devices” (p. 50) where the flow of information - mostly through the Internet - has been radically shifted. In the last decade, communications between doctors, HCPs and patients have shifted from a unidirectional power relationship - where physicians dictate what they think is the best diagnosis/treatment for their passive patients - to a more “participatory” and equal dynamic. A movement focus on

consumers within healthcare has been taken predominance aiming to promote patient centricity and truly establish partnerships among patients and HCPs moving away from *medical paternalism*. Such advocate movement seeks to emphasise the capabilities of patients as engaged consumers instead of passive recipients of medical instructions (Jutel & Lupton, 2015, p.129). For Hoos et al (2015), patient centricity and active patient participation can potentially develop initiatives and innovative medicines that generate relevant and impactful life-changing for people (p. 929). In addition, the International Alliance of Patients' Organizations, IAPO (2019), a global organisation representing patients of all nations across all disease areas, emphasises that a patient is the only directly affected by the actions and decisions that influence and affect the course of his or her treatment (para. 2). In sum, the patient-centric theory can prioritise public debates and public-private funds focus on real needs for the patients. Progress towards adopting patient participation within processes of decision-making requires an effort from all stakeholders to work in true partnership to identify gaps and develop knowledge where the needs and desires of patients, in this case, people with obesity, can be met.

The three previous theories represent the major original concepts of the research study and will be later used to analyse the different advocate narratives from the studied stakeholders during the data collection.

Methodology

The following section reflects the underlying position this research study takes within social science in the context of qualitative research. Furthermore, the research strategy will be presented to allude to the philosophy of science and the social constructionist position. Moreover, the research design will be described through framing theory and data collection both aiming to be applied effectively in the study at hand. Finally, bias and limitations will be outlined in order to expose transparency during the sequence of analysis and further discussion in the research paper.

Research strategy

The research study at hand is qualified as qualitative research. This distinctive research strategy implies a philosophy of science making use of a range of concepts that intend to expose the purpose of social science as informing and contributing to the ongoing debates and to praxis around the obesity discussion (Flyvbjerg, 2001, p. 451). Rather than identifying objective truths, qualitative research will be applied in the study paper in order to 1) stress an understanding of the obesity world through an inductive, epistemological and ontological examination of the interpretation of that world by its participants (Bryman, 2008, p. 366); and 2) employ the findings in to test the theories explained in the section above (Ibid., p. 373). Furthermore, the research's position on what novel knowledge is and how such new knowledge can be created throughout research design processes will be presented as following in order to understand qualitative research from a heterogeneous perspective.

Situating the project in qualitative research

Qualitative research specifically stresses the socially constructed nature of reality seeking for answers to questions focus on *how* social experiences are created

and *what* narratives are followed to give meaning to such reality (Denzin & Lincoln, 2008, p. 13). Qualitative research helps then to properly locate the researcher in the studied world, providing a set of useful interpretative material and practices that make such world visible. In addition, it also helps to crystallise the studied world into series of representations such as case studies, interviews, conversations, productions, personal experiences and/or events (Ibid., p. 4). In other words, it involves an interpretative approach to the world in its natural setting attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to it (Denzin & Lincoln, 2008, p. 5).

Lastly, qualitative research tends to view social life in terms of processes. Here the concept of processes is defined as a sequence of individual and collective events, actions and activities that unfold time in contexts (Bryman, 2008, p. 388). Moreover, less structured approaches to interviewing become more common among qualitative research as it opens the opportunity for a more open-ended and hence less structured approach (Ibid., p. 389). Therefore, qualitative research can be enlisted as an aid to implementing social change for people with obesity. Miner-Rubio et al. (2007) suggest that knowledge about the distribution of attitudes and behaviour in a sample can be used to establish the most appropriate course of action for social change (as cited in Bryman, 2008, p. 397).

Social constructionism position

As mentioned before, qualitative research is built in a profound concern with understanding what humans beings are doing or saying in order to make the world visible in different ways. Social constructionism provides different ways to address such concerns highlighting every day's interactions between people and how they use language and narratives to construct their common realities (Andrews, 2012, p. 44;

Denzin & Lincoln, 2008, p. 311). Moreover, social constructionism can be seen as an ontological position which usually is used to refer to constructivism or as a synonym of an interpretive point of view (Bryman, 2012, p. 33) that generates real debate and lead to potential changes among relevant discussion that involves a considerable range of actors (Andrews, 2012, p. 44). In addition, one of the mains of social constructionism focuses on how knowledge is constructed and understood among individual within communities. This epistemological perspective has a social rather than a humanistic focus (Ibid., pp. 39-44). The social world is a world of experiences as it is being continuously re-signified and re-narrated: "The social science must begin with the stories that people tell of their experiences, experiences about themselves and about each other, about their lives, led and spoken about, in all their variation and difference" (Pickering, 2002, p. 392).

Thus, the theory of narrative, as mentioned in the section above, affirms that concepts and definitions are constructed rather than discovered. Hence, reality - or the understanding of it - is socially defined by the subjective experience of everyday life: How the world is understood rather than to the objective reality of the natural world. This can be defined as constructionism (Andrews, 2012, p. 40). Such term also tends to accept the view of language as embedded within broader forms of life. Therefore, the use of narratives - as conventions for communication - is key as human motivation linked to certain activities, objectives and settings specially assess between a group of people (Given & Gale Group, 2008, p. 818). The notion that obesity is or not a disease can and does exist as independent realities are compatible with the social constructionist view. Andrews (2012) affirms that the naming of disease and indeed what constitutes disease is arguably a different matter and has the potential to be socially constructed (p. 42). As mentioned before, continued empirical investigations

have argued that obesity can be defined as a disease. Therefore, as knowledge increases about the condition, attitudes to it and how it is constructed change dramatically creating new paradigms among the domain narratives (Andrews, 2012, p. 42). In sum, it is in the sense that disease is socially constructed.

To conclude, the research strategy was introduced as a broad orientation to social research and qualitative research. Therefore, this research study will be carried in consideration of knowledge created from the analysis and meaningful collective data for this research study specifically. All theories, findings and conclusions will be constructed by the key actors involved, situated in specific historical and social contexts recognising the potential existence of several meanings in the data collection. Hence, the novel knowledge express in this paper will be a co-creation process between the researcher and all participants implying social properties such as qualitative methods based on interviews and language narrative analysis as outcomes of the interactions with them within the global debate of obesity.

Research design

The research design will be introduced as following in order to provide a framework for the collection and analysis of data collected in this research at hand. First, a description of the process and type of research will be examined through the use of a case study. Moreover, the methods applied in the study will be presented following by a brief introduction of the participants involved in the research and further analysis.

Case & theory

Understanding that the research at hand has the overall goal of investigating how the patient perspective voice has been used by key actors inside the obesity

global debate and what narratives have been constructed around the obesity epidemic, the research uses a case study - the global obesity debate - in order to analyse a specific reality in a specific context and period of time - from 2012 until the present. For the aim of this research, case study will be adopted as an approach to helps portray particular events, circumstances and people advocating - and advocated - in the global obesity debate (Simons, 2009, p. 3). The case study in this research can provide a unique wealth of information once obtain various perspectives and conclusions according to how it is viewed and interpreted whether one or another definition of obesity (Flyvbjerg, 2006, p. 233). In addition, detailed exploitation of the specific chosen case helped to select the research methods needed to collect data which are semi-structured interviews (Simons, 2009, p. 3) which will be explained below.

The consonant of how the study will be disseminated is by choosing to understand the subject matters through the way in which participants construct their narratives about the obesity debate and how they interpret and frame them (Simons, 2009, p. 4). Such findings will be analysed in order to test the theories and concepts explained in the section above. Different actors from HCPs (doctors and pharmaceutical employees); academia (university representatives) and independent researchers; regulators involved in obesity consensus; obesity patient organisations; and people with obesity will be interviewed in order to get a ‘close in’ on real-life situations and “test views directly in relation to the phenomena as they unfold in practice” (Flyvbjerg, 2006, p. 235). The above will be executed with the aim of offering concrete, context-dependent knowledge (Ibid., p. 224) to the theoretical framework used as an important consideration to better understand the reality of obesity.

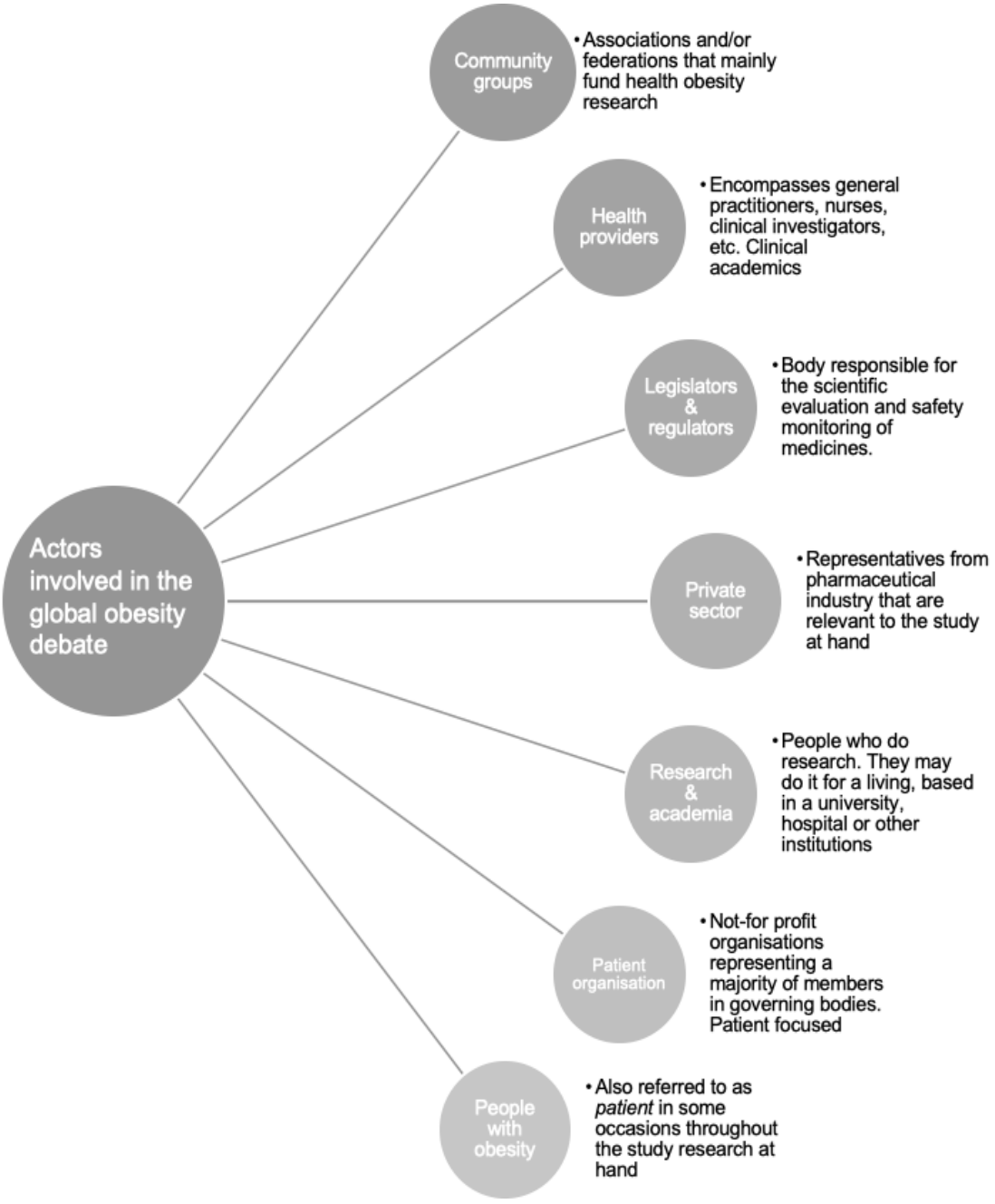

Figure 2: Overview of stakeholders involved in the study to the data collection.

In conclusion, the case study of the research at hand intends to explore the uniqueness of the global obesity debate and the variety of framed narratives around the same object by different actors involved. The life experience of the particular participants will be carefully evidenced and validated in order to find insights into the specific subject of study. Hence, qualitative case study aims to value multiple

perspectives of stakeholders and participants, observations in naturally occurring circumstances and interpretations in context (Simons, 2009, p. 4). Therefore, it is through analysis and interpretation of how people think, feel and act that many of the insights and understandings of the case will be gained (Ibid.).

Lastly, in order to produce clear and tested knowledge, I participated in the European Congress on Obesity (ECO), the biggest obesity congress held this year in Glasgow, Scotland, whose objective is to bring together stakeholders from every area of obesity research, prevention and management (EASO, n.d., para. 1). The congress is EASO's annual scientific congress where clinicians, practitioners, physicians, nutritionists, surgeons, researchers and advocates - all experts and key opinion leaders in the field of obesity and its related conditions - actively participate and discuss relevant medical and technological advances around obesity. The congress will allow the research to have direct contact with actors involved, follow the discussion around the obesity debate, and therefore, avoid great distance to the object of the study and lack of feedback easily lead to obstruction of learning processes (Flyvbjerg, 2006, p. 223).

Framing

I will use framing theory in order to understand how the stakeholders, involved in the discussion, participate in the debate and advocate for people with obesity. The aim is to elaborate a data analysis of frames in order to identify the specific arguments or ways of framing opposition to or support for calling obesity a disease used by proponents and opponents. The research paper - based on existing analyses of legislative and related proceedings on obesity as a disease - aims to produce initial frames such as those involving causes and consequences of obesity, the role of the people with obesity within the discussion and allowed additional themes to emerge

from the data. As narratives enquire descriptions and interpretations of the phenomenon from the perspective of participants (Flyvbjerg, 2006, p. 240), frames then help to angle differently the same phenomenon. This is one of the premises of framing theory on how an issue can be viewed from a variety of perspectives and be constructed for multiple values or considerations (Chong & Druckman, 2007, p. 104). Therefore, framing perspective will be described as following to understand how alternative narrative actors - including people with obesity involved in the debate - construct and interpret the messages received, develop a particular conceptualisation of the issue, reorient their thinking, and, lastly, create new narratives using particular framing structures in order to contribute to the global debate of obesity.

For Entman (1993) to frame is to select some aspects of a perceived reality and make them more salient in a communicating text to promote a "particular problem definition, causal interpretation, moral evaluation, and/or treatment recommendation for the item described" (p. 52). Nonetheless, Sandberg (2007) argues that frames increase the probability of certain interpretations of a text (p. 250). Framing then stimulates a "collective identity" to bridge the gap between each individual and a group. This helps to build a "[...] shared movement community through the construction and representation of common beliefs, values, and commitments to change" (Olsen, 2014, p. 250). In other words, the diverse and particular meanings to an issue such as obesity are not only about a physical objectively measurable phenomenon in kilos. It has also considerable social constructions, and thus, it is a result of a social process. In sum, the way social constructions make us understand and make sense of obesity, how we construct obesity in our minds and how we deal with it (in our actions and measures) is negotiated while exchanging ideas and communicating with others such as alternative or traditional actors involved in the obesity debate, relatives, colleagues,

and so on (Sandberg, 2007, p. 450). Thus, framing processes could occur at different levels: In the culture; in the minds of elites and professional political communicators; in the texts of communications; and in the minds of individuals (Entman, Matthes & Pellicano, 2009, p. 176).

Research method & data collection

The research at hand will use mixed method approaches taking advantages of technological developments such as the internet and teleconferences. Thus, the decisions underlying methodological choice are not restricted by epistemological commitment, but rather because of selecting the best methods for the task in hand (Vogt & Williams, 2011, p. 6). Hence, the research study encompasses different types of methodological integration such as document analyses, semi-structured interviews and observations - all qualitative focused - in a specific case study: The global debate about obesity. The above will bring more fruitful thinking of knowledge creation by which the research at hand will collect data. The techniques for collecting data will be described as follow.

Content analysis

The collection and qualitative analysis of texts and documents form part of the qualitative research strategy in the research study at hand. Thus, this qualitative content analysis refers to a set of techniques for the systematic analysis of texts of many kinds addressing not only manifest content but also themes and core ideas found (Drisko & Maschi, 2015, p. 82). Contextual information and latent content will be included in the analysis based especially in the conducted semi-structured interviews and the presentations during the obesity congress. Such method will be used to focus on identifying categories (or themes) that both summarise the content found in the full

data set and highlight key content (Ibid., p. 89). Some of the analysed texts and documents have been already mentioned in the Literature Review Section and can also be found in the Reference list. In addition, five more research sources, presented during ECO in Glasgow, will be added to the Analysis Section: 1) *The paradox of undernutrition and obesity in South Africa: A contextual overview of food quality, access and availability,* by Muzigaba et al (2016); 2) *From simplicity towards complexity: the Italian multidimensional approach to obesity,* by Donini et al (2014); 3) *The weight gain response to stress during adulthood is conditioned by both sex,* by García-Cáceres et al (2010); 4) *A cognitive profile of obesity and its translation into new interventions. Frontiers in psychology,* by Jansen et al (2015); and finally, 5) *Addressing weight bias and discrimination: moving beyond raising awareness to create change,* by Ramos Salas et al (2017).

Narrative analysis

A narrative analysis approach, grounded in the epistemology of constructionism (Frey, 2018, p. 1342), will be applied to the elicitation and analysis of the qualitative collected data to emphasise the stories employed and the sense of temporal sequence that people detect in their surroundings episodes (Bryman, 2008, p. 560). The above will help to build up story-cases and patterns from collected interviews, field work and available texts. The focus of attention will be how do people make sense of what is happening in the obesity global debate, and how many narratives there are (Boje, 2010, p. 593). Therefore, narrative analysis will represent how the author involved and others value the obesity events, characters and elements differently (Ibid., p. 592).

Interviews

In order to obtain empirical data, different interviews have been conducted with nine representatives from community groups, health provider organisations, private

sector, researchers, patient organisations and people with obesity. As there is a preference for seeing through the eyes of the research participants (Bryman, 2008, p. 398), qualitative research will employ a substantial amount of qualitative interviewing activities (Ibid., p. 369). The purpose of the qualitative research interview is to understand the themes inside the debate's own perspectives and the dynamics/interactions from each of the participants in the debate. Hence, the structure of the interview comes close to a conversation involving specific approaches and techniques of questioning (Kvale & Brinkmann, 2009, p. 27). Technically, the qualitative research interview is semi-structured: Neither an open conversation nor a highly structured questionnaire. Prior to each interview, interview guides have been elaborated in order to indicate the focus on specific themes and topics of the interview and relevant sequence points for the research at hand and the problem formulation. The interviews will be face-to-face, by telephone or Skype. All will be recorded and transcribed, both, the audio and the written text are materials for the subsequence interpretation of meaning (Ibid.). Transcriptions can be found in the appendix section. Following, a presentation of the participants interviewed for this research study will be explained.

Participants

The participants interviewed do not mean to be representative of a population as the study emphasise the limitations of finding more or less impossible to enumerate the population in any precise manner (Bryman, 2008, p. 391). Rather, the aiming of the collected data is to analyse the different perspective of individuals involved in the global obesity debate. As follow *Table 4* shows the specific actor's field and the actors interviewed. In addition, the nine participants interviewed will be presented.

Actor's field	Actor	Name	Country
Community group	European Association for the Study of Obesity (EASO)	Paul Chesworth	United Kingdom
Health provider	Professional Health Psychologist	Michael Vallis	Canada
Private sector	Pharmaceutical industry Novo Nordisk S/A	Amy Peters	United Kingdom
		Douglas Ordonez	United States, based in Denmark
Researcher & academia	Researcher in Clinical Trials	Flavia C. Ladwig Robles	Brazil, based in Denmark
Patient Organisations	WLSinfo	Ken Clare	United Kingdom
	Obesity Action Coalition (OAC)	Pamela Davis	United States
People with obesity	Kesha Calicutt		United States
	Marty Robert Enokson		Canada

Table 4: Overview of the categorisation of the actors interviewed (based on Christoffel, 2000, p. 724).

Bias & limitations

Bias allocate case studies at a disadvantage within most disciplines (Flyvbjerg, 2006, p. 242). Therefore, in order to critically and independently review the data collection a thorough understanding of bias and how it can potentially affect the study results is essential for the practice of research (Pannucci & Wilkins, 2010, p. 7). The study at hand could be biased by various factors such as familiarity and socially constructed meaning systems given for granted. More specifically, the researcher is currently employed in one of the studied organisations (Novo Nordisk A/S). However, and even though this is used as an advantage by giving easier and faster access to potential participants, it can also have significant repercussions regarding what needs to be considered to analyse. The researcher's strategy from the beginning was to be transparent and awarded of the reasons behind the choices that are made in relation

to the organisations, interviewees and events analysed in the research study. In addition, the researcher finds as the main limitation for the study the latest exponential growth regarding obesity and the notorious new engagement with people with obesity. Thus, psychological and social studies on obesity, as well as advocacy in obesity studies are surprisingly recent and currently in processes of change. Such reformulation based on the participation of people with obesity in the global debate could create misinterpretations and shift changes throughout a short period of time.

In conclusion, the case study of the research study at hand will be told in its diversity, allowing the global debate to unfold from the many-sided, complex and conflicting narratives that the actors in the case will share (Flyvbjerg, 2006, p. 238). The analysis section that follows is a result of the strategy proceeding in the following: 1) a coding process attempted to create meaning from the collected empirical data, 2) an effort to connect these separate conducted codes in categories, and finally, 3) an explanation of the themes found by the researcher to better conceptualise and organise the findings related to the problem formulations and research questions.

Analysis

Taking into account the above methodological section, this chapter will highlight the collected empirical data in the context of the theoretical framework. The reflections as follow aim to shed lights on the problem formulation initially described for this research study which is how has the patient perspective voice been used by key actors inside the obesity global debate, and what narratives have they constructed around the obesity global crisis during the last seven years. Therefore, three main categories will be presented in terms of advocacy in obesity understanding in relation to 1) obesity as a chronic disease and its construction as a new public competing narrative among people with obesity advocates and all participants interviewed; 2) weight bias and stigma as the main obstacle when advocating for obesity, especially among doctors and patients; and finally, 3) storytelling as one of the most effective advocacy strategies to involve and motivate people with obesity to actively participate in the discussion. Moreover, the references mentioned here are referenced to appendix in the form of (actor's last name, actor's field, time[3]).

Obesity as a chronic disease narrative

According to the empirical data, it was noticed that new social movements have started to rise to influence and challenge the social norms around obesity. All interviewees, from their own perspectives, defined obesity as a chronic disease and the importance of advocating for its biological, social, but mostly, psycho-sociological implications. This resonates with what the Council of the Obesity Society has stated in 2008 (see Theory Section): ''Considering obesity a disease is likely to have far more positive than negative consequences and benefit the greater good by soliciting more

[3] In *minutes:seconds* format.

resources into research, prevention, and treatment of obesity''. Some participants even mentioned the great implication that the American Medical Association (AMA) had inside the global debate since they categorised obesity as a disease back in 2003 with their argument that obesity was not caused only by insufficient willpower, lack of discipline and bad choices from the people living with obesity (see Literature Review Section). In this sense, some of the stakeholders reflected on the importance of keep constructing new public narratives and meaningful symbolic representations that do not continue the long tradition of exclusion (see Theory Section). Vallis, PhD and Health psychologist Founding-Member and President of the Canadian Obesity Network and Associate Professor in Family Medicine at Dalhousie University, Canada, explained that "One of the challenges that we face right now is that we must look at obesity as a chronic condition that has an innumerable number of reasons" (Vallis, Health Provider, 19:09). His focus on training healthcare providers to develop competencies to help patients' behaviour change, help him also to promote this competing narrative at the same time that he challenges the provider's understanding of obesity. Calicutt, former patient advocate member of the biggest obesity patient organisation in the US, the Obesity Action Coalition (OAC), dealing with obesity since her first and only pregnancy, expressed that obesity is truly a chronic disease because her "obesity is in remission, and something that is in remission It doesn't mean that it's cured, it means that it needs constant vigilance, constant monitoring" (Calicutt, Person with Obesity, 10:18). This emphasises what Jansen et al (see Methodology Section) indicated when defining obesity, as they argued that the traditional narrative "Eat less, eat better, exercise more: change your lifestyle" is not always applicable to people who experience dramatical weight gain without changing their behaviour. For instance, Calicutt added that "People look at obesity as 'how fat you are', not realising that there

are psychological, social, emotional and metabolic processes that go under" (Calicutt, Person with Obesity, 12:39).

Moreover, Ramos Salas et al (see Methodology Section) corroborated the above by arguing that people involved "should address not only weight loss but also quality of weight loss, medical and psychiatric comorbidity, psychosocial problems, and physical disability. Such management of obesity requires an effective multi-professional team". Clare - a Registered Nurse and the Chairman of WLSinfo, UK, member of the committee of the Association for the Study of Obesity (ASO) and is now an Allied Health Professional (AHP) member of The British Obesity and Metabolic Surgery Society (BOMSS) - reinforced this by saying: "I think there are lots of different types of obesity [...] We see people with environmental problems, people with things about the way they were brought up by their families, things about the food needs and even trauma" (Clare, Patient Organisation, 31:33). Lastly, García-Cáceres et al (see Methodology Section) ratify the above - from a medical perspective - by exposing in how the tendency to have obesity, and to develop associated comorbidities, depends on numerous factors including genetics, dietary habits, physical activity, psychological matters and the interaction between these factors, "the sex of the individual also affects the propensity of having obesity".

Furthermore, the majority of the interviewees agreed that one of the main focus that should be included, but not limited to, in the advocacy agenda for obesity is the psychological stage and social conditions of each patient. For example, the Molecular Biologist, Peters, Public Affairs and External Relations Manager in Novo Nordisk, working mostly on Obesity Patient Access and Public Affairs in London, UK, addressed the importance of psycho-sociological implications when describing obesity as a disease as "There's a massive reason and a massive link between mental health

and many other factors with obesity. That's why obesity should be recognised as a disease" (Peters, Private Sector, 11:13). Chesworth - living with obesity since the age of five and diagnosed with type two diabetes in 2005, well-known in the advocacy obesity world for his impassioned plea as an NHS service user to Secretary of State for Health in the UK, Matt Hancock, to acknowledge obesity as a disease and trustee and committee member of WLSINFO, the EASO Patient Council, the Obesity Empowerment Network (OEN), the Novo Nordisk Disease Experience Expert Panel (DEEP) and the new European Coalition for People Living with Obesity (ECPO), formally launched in April 2019 - also mentioned the importance of psychological factor when treating people with obesity: "I do think the psychological side is the biggest element that needs more focus on obesity research throughout the doubt" (Chesworth, Community Group, 00:31). And lastly, Enokson, patient advocate and Chairperson of the Canadian Obesity Network - Public Engagement Committee, the EASO Patient Council and the European Coalition for People Living with Obesity (ECPO), diagnosed with type two diabetes, high blood pressure (experienced a mini-stroke at the age of thirty-eight) and living with obesity since the age of twelve - stated that "Mental health and obesity are very tied together" (Enokson, Person with Obesity, 41:28). Sandberg (see Theory Section) stressed this by affirming that overweight and obesity are not only a physical objectively measurable phenomenon but also a social construction, and as such it is the result of a social process. Thus, people do not only suffer medically from obesity but also physiologically and socially.

Furthermore, the majority of the advocates interviewed believe that even though there have been remarkable changes within this active worldwide movement, it will take time until there is a consensus among all the stakeholders to agree that obesity is much more complex than the traditional 'eating less and exercising more'

narrative as Ordonez, Associate Global Director for Global Patient Relation (GPR) in Novo Nordisk heart quarters, Denmark, leading the integration of patient engagement practices in obesity projects, highlighted, "I've seen a change in regard to a movement within the healthcare professionals who are really pushing obesity as a disease narrative. The change is coming" (Ordonez, Private Sector, 18:12). The above could be supported by Brown (see Theory Section) when referring that dealing with weight and obesity is a job not only for patients but also for "highly trained experts including health care professionals and providers (HCPs). Ladwig, a pharmacist by training working with people with obesity as a Global Project Manager in clinical trials and research also at Novo Nordisk heart quarters, Denmark, added that for her obesity is also a disease: "the problem is that there is no consensus, yet. It's becoming an awareness but you see is a long way to go still" (Ladwig, Researcher, 17:18). Ladwig efforts have been recognised for her contribution for better and effective drug treatments for losing weight and advocates for the cause of defeating obesity together with her scientific background. She was born in Brazil and has been living with obesity since she got pregnant at the age of 16 years old. As mentioned by Stammers and Echle (see Theory Section), the dynamics between these transnational advocacy network relationships among different stakeholders could be crucial for a potential shift towards a more democratic and alternative narrative(s) where advocates among patients, physicians, researchers, etc. become key actors of such shift as Chesworth also mentioned: "[Stakeholders] need to come closer, together, to understand each other's world a little bit because there is plenty of stuff in the background which has to be done to ensure that whatever that anybody's doing is correct and that will benefit people with obesity and that is why things are taking so long" (Chesworth, Community Group, 15:32). The above resonates with Donini et al (see Methodology Section) and

their call for having scientific and academic institutions dealing with obesity as a priority from a multidimensional, multi-professional, and multidisciplinary integrated approach to obesity as this is the result of a complex interplay among many risk factors.

Finally, there was also an evident and considerable level of frustration among the stakeholders, especially those who live with obesity, and their efforts when advocating for a common understanding of why obesity is a disease. For instance, what it seems to happen inside the debate is that there is still a rather dominant narrative (see Theory Section) which is, as mentioned before, “obesity is a lifestyle condition” and “people have obesity because they want to”. Regarding this some of the participants expressed: “I do struggle sometimes thinking about obesity as a disease but I also think it's because my entire life people have said that it's a lifestyle choice, and when something is so ingrained within society you can't help but believe that it's like if everyone said” (Peters, Private Sector, 10:02); “People that live with obesity will do just anything not to be obese. No one wants to live this life, nobody! And it hurts because people generally think that you do this to yourself, that you have no self-control and it's so much more than that” (Enokson, Person with Obesity, 09:11). In addition, the clinical trial researcher echoed this by adding:

> For me, it is a disease and has to be addressed as such. I cannot accept why you cannot get a drug If you are above BMI 25, I cannot accept that! We're not getting anything! So, from BMI 25 to 27, the only thing that is recommended is diet and exercise. This is something that we hear since always and it's not really helping or changing anything! (Ladwig, Researcher, 17:21)

To support the above, Muzigaba et al (see Methodology Section) eluded that the nutritional and environmental status of the population ('eat less, move more') are influenced by both multiple modifiable and non-modifiable risks factors and determinants that provide sufficient support to a considerable number of people with obesity. Non-modifiable risk factors of obesity - gender, age, race, culture, ethnic and genetic makeup - are comprised in an individual-level that together with other modifiable risk factors - behavioural, social and structural determinants associated mostly with urbanisation - should be analysed in order to elaborate better plans for efficient and effective treatments for people living with obesity.

Weight bias & stigma: The main obstacle when advocating for obesity

The empirical data sheds on how stakeholders advocate for obesity and what their biggest challenges are. It was noticed that the main obstacle among all interviewees when advocating for obesity is weight bias and stigma. For instance, the lack of trust and empathy towards people with obesity, especially in the doctor's offices, was the main concern: "The healthcare professionals do not trust their patients! When I say to my doctor, "But I have tried! I have controlled my diet, and I always have been, I always keep track of my exercising: there is no trust!" (Ladwig, Researcher,18:32). Paradoxically, as the number of people with obesity has risen, it seems the biases against them have become more severe. For example, during Enokson's opening workshop on stigma at ECO, Glasgow, last April, he expressed:

> I asked the medical professionals: 'How many of you have ever made fun of a fat person? How many of you have ever treated a person who suffers

from obesity with disrespect?' And the hands went up. I was warmed by the fact that they were so honest but sad in my heart at the same time because a medical professional should know better. (Enokson, Person with Obesity, 33:51)

In addition, the interviews provided examples of contradictory opinions and instances of discriminatory treatment experienced by members of the disadvantaged group (people with obesity) soliciting sympathy and support from power holders, usually, healthcare providers as mentioned by Vallis, psychologist focused mainly in obesity research: "What I expect here is that doctors say 'I have a role to play in Obesity', and gives them the opportunity to assess it and to support the patient" (Vallis, Health Provider, 36:33). Ramos Salas et al (see Methodology Section) echoed this by mentioning that best practices in the treatment and management of obesity need to make meaningful space to address weight bias and stigma as more implementation research is needed to assess the impact of HCP's attitudes on individuals as well as on health care practices and policy changes. Enokson endorsed the above by arguing that "You have to understand that you have the bias yourself and that you can set that bias aside and treat people for the disease that they have and help them" (Enokson, Person with Obesity, 37:17).

Moreover, in a similar position, Ladwig added that people with obesity need to go through periods of probation by losing weight in order to get access to treatment: "I have to prove that I have worth the help, that's the reality! Today for any person living with obesity, doesn't matter the BMI, once you start telling your story to the HCP, you have to go on probation for a period of time. Meanwhile, you have a patient that is suffering" (Ladwig, Researcher, 18:53), referring to the significant scientific shreds of

evidence proving that obesity can develop cardiovascular diseases, diabetes, cancer, joint pain, among many other complications; putting people's lives in risk and increasing healthcare treatment costs (see Literature Review Section). Nevertheless, all participants who have had bariatric surgery needed to wait between two up to five years to be able to have access to surgery regardless of the country they are from. For instance, Clare declared: "There are 1.5 million people in the UK who need or qualify for bariatric surgery but NHS carries out only 5000 operations a year" (Clare, Patient Organisation, 16:05). Davis, a Registered Nurse and one of the Directors of the Obesity Action Coalition (OAC) National Board and part of the Eating Disorders Coalition, Tennessee, together with other several committees on the American Society for metabolic and bariatric surgery - living with obesity since she was a child - also expressed the challenges that people with obesity have in her country: "Less than 1% of the people that are appropriate for treatment are actually accessing the appropriate treatment in the US" (Davis, Patient Organisation, 06:47). This also falls within Enokson's experience when asking for his experience when asking for treatment: "It was two years that I waited to get in [to bariatric surgery program] and it was another two years in the program before I got surgery. You can wait up to five years to get into a program in Toronto" (Enokson, Person with Obesity, 07:33). Krebs (see Theory Section) highlighted the direct impact that advocacy narratives can have especially on access to effective and timely obesity treatments, "narratives that once were a seeming unquestioned common sense are subject to widespread public challenge". He emphasised the importance of having people addressing such complications in access to treatment in order to have better tools when framing the new competing narrative.

On the other hand, the interviews showed that a great number of people with obesity internalised weight bias and self-stigma as mentioned by Vallis: "Obesity is this unique condition in which there's self-bias or stigma and as a result, the individual feels that it is their fault" (Vallis, Health Provider, 31:06). Calicutt, living with obesity since her pregnancy, added: "I was really desperate! At that point [after her child was born], I didn't go anywhere, I didn't do anything. I was ashamed, embarrassed by the way that I looked" (Calicutt, Person with Obesity, 06:09). Hence, people suffering from obesity have a tendency to not bring up the situation with their doctors because of fear and embarrassment: "I wasn't dealing with my type 2 diabetes. I was very sick obviously, but I didn't want to talk to my doctor about my weight or what are the complications of being overweight. I was ashamed" (Enokson, Person with Obesity,10:12). As Davis also added, "People with obesity are often afraid if they speak up or speak out that they're going to be ridiculed, belittled" (Davis, Patient Organisation, 10:33). The above could bring lights in regards to why people who feel discriminated against because of their weight have shorter life expectancies than those who don't (see Theory Section) - having into account the many health complications that obesity brings to a person - as Enokson described, "You beat down a patient, they blame themselves and, then, they never get out of obesity" (Enokson, Person with Obesity,10:02).

Finally, it is also relevant to mention the different perspectives the interviewees showed regarding how obesity is still a socially acceptable form of discrimination particularly on workplaces and the media, "There are no laws really protecting people with obesity against discrimination in regards to losing their jobs or hiring practices or anything like that" (Ordonez, Private Sector, 06:24). The above is also reinforced by OECD (see Literature Section) as the institution has highlighted the adverse effects

that obesity brings into future career opportunities and earning potential, “Research indicates that employers prefer normal weight over obese candidates, partly due to perceived risks of lower productivity due to poor health”. Sandberg (see Theory Section) mentioned how the media portrayed people with obesity. In her study, she mentioned how overweight and people with obesity are presented as: ‘stupid’, ‘ugly’, ‘naive’, ‘lazy’, ‘irresponsible’, ‘greedy’, ‘without manners’, and ‘repugnant’. Thus, negative stereotypes are still reproduced both among experts and laymen, “Overweight is associated with garbage, and people who are too heavy are seen as a burden to public medical service, at times referred to as parasites”. The TOS Obesity as a Disease Writing Group (see Literature Review Section) also mentioned how the current weight stigma attached to having obesity is portrayed by the media, often including headless, faceless overweight bodies that keep adding to the mental burden and stigma faced by people with obesity: “Policymakers, the media and indeed the medical profession are consciously biased against people who have obesity, which is thought to be a lifestyle choice and continues to exacerbate the stigma and discrimination”. In sum, the majority of the interviewees argued that advocacy must fight back against obesity and not against those who are living with obesity. Therefore, some participants agreed that people with obesity must be framed as a vulnerable population: “Individuals that are living with obesity have to be appreciated as a vulnerable population” (Vallis, Health Provider, 31:26); “We shouldn't be dying, we shouldn't be treating people with such disrespect” (Enokson, Person with Obesity, 33:44).

Storytelling: Bringing people with obesity in the discussion

According to the interviews that have been made, it seems that the emergence of patient-centric advocate movements has contributed to a shift towards a more resilient public competing narrative among key actors involved in the global debate. All participants coincided that hearing the experiences and struggles of people with obesity is crucial to educate and engage not only with all stakeholders - including people with obesity - but also with the public in general. For instance, Peters pointed out that "What's really missing, and what the government and the department of Health really needs to be aware of, is that patient voice. Without that sort of knowledge and real understanding of the everyday struggles that people with obesity face, nothing will change" (Peters, Private Sector, 18:04). Such advocate movements can emphasise the capabilities of patients as engaged consumers instead of passive recipients of medical instructions. (see Theory Section). In addition, Sandberg (see Theory Section) addressed that the way society understand and make sense of obesity, how they construct obesity in their minds and deal with it in actions and measures, is negotiated and change while communicating and discussing with others: "This means that our knowledge about the world we live in is not predetermined or fixed. It is constantly constructed, deconstructed and reconstructed".

Moreover, Ladwig and Vallis, both health providers and researchers, stressed the importance of including patient-centric practices in the discussion in order to improve medicines and treatments:

> We live in an environment where regulators, companies, doctors and scientists decide what is good for a patient. We do not ask the patient: "What do you expect with a new drug?" - "Yes, I expect to lose weight, but also I expect

that I don't lose too much weight, and also improve other parameters like my cholesterol". (Ladwig, Researcher, 09:10)

In addition, Vallis claimed that "We need to start realising that we're not there to convince patients that one pathway is the right pathway. As in any chronic disease, we're there to understand the patient and find from all of the various effective treatment what is best for the patient" (Vallis, Health Provider, 20:25). For this reason, one of the most common advocacy strategies in obesity among the participants was storytelling (see Theory Section). By using a combination of different approaches - such as daily basis struggles, access to treatment, weight bias and stigma - diverse messages are portrayed with the objective of achieving common advocacy goals. This could be an example of what Krebs (see Theory Section) defined as *Contestation within Dominant Narratives*, which is when actors engage in storytelling to challenge the dominant and traditional narrative and their efforts help keep alive an alternative whose main objective is that the dominant narrative collapses: "I shared my story for the first time and spoke to the Deputy Minister of Health and realised the power of the story, the power of a patient telling what they've lived through" (Enokson, Person with Obesity, 16:23). Hence, as common tools to (re)construct meanings and educate stakeholders among the participants, storytelling seems to be the more effective; "There is an element of education that needs to happen in order for people to really understand obesity and its daily-to-day struggle" (Peters, Private Sector, 11:38). Here storytelling is crucial to the experience-sharing that promotes common understanding and contributes to the development of (new) obesity networks, health debates and social movement. In other words, by framing the narrative through real stories of people living with obesity, advocates can stimulate a *Collective Identity* (see Methodology Section)

in order to bridge the gap between each individual and the group. This helps to build a shared movement through the construction and representation of common beliefs, values, and commitments to change (see Methodology Section):

> In my advocacy, I build through the relationships that I have with people by getting down to a level that people can easily understand exactly what it is that I'm talking about. So, I go in and visit members of the parliament. I talked to them and go through the story of obesity [...] I can give them fully peer-reviewed references and then I can say, "This is why we have a problem. So, what are we going to do together to change that?" It's sort of that real relationship where you are speaking a language that they understand. (Peters, Private Sector, 21:17)

Hence, when asking the participants what were the stories they have heard/shared the most, the majority consider that 1) the struggles of maintaining a 'healthy' weight, and 2) bias and stigma were the main themes inserted in the narrative. Among the struggle for maintaining weight, some of the participants living with obesity shared the stories they usually mention when discussing with other stakeholders: "three years ago, I probably would have thought that I had it all figured out, but even though I'm doing all of the same things that I've done since the surgery, it's not working anymore" (Calicutt, Person with Obesity, 10:02); "I can see that I have increased my body weight despite the fact that I have not changed my diet or my physical activity. It's not known how the body come up with a new strategy to actually gain more weight" (Ladwig, Researcher, 03:18); "Whatever seem to do, I'd go on a diet, and I stick to the diet, and I'd lose weight but then gain weight again" (Chesworth,

Community Group, 01:06). In addition, the empirical data also showed that patients are the only directly affected by the actions and decisions that influence and affect the course of their treatments (see Theory Section) as Clare and Chesworth indicated respectively, "This is all about patient's lives, it's not about what a doctor wants or surgeons think is good" (Clare, Patient Organisation, 20:05); "We see obviously a very big organisation of people with obesity, and I hope that our efforts are recognised and that gained momentum to get the change and to go to the European Parliament to lobby the government" (Chesworth, Community Group, 38:59).

Lastly, Ordonez and Peters, both from the pharmaceutical side, emphasises the main objective when advocating at a governmental and corporate level: "We are the people who are living with the disease, of course, we should be talking about ourselves and advocating for our rights and for how we're being treated and what kind of drugs were being given" (Ordonez, Private Sector, 22:27); "For me to be able to advocate at a very high level - governmental, ministerial or member of parliament level - have a huge appeal because, ultimately, they are the final decision makers" (Peters, Private Sector, 06:44). Thus, while storytelling frames make new narratives coherent by linking personal accounts to dominant political and legal narratives, the use of personal experiences of injustice or ignorance help to draw empathy and stress similarities between a marginal group and authorities (see Theory Section). Entman et al (see Methodology Section) resonates with this by describing how framing - through new narrative processes - could occur at four different levels at the same time: In the culture, within communities and surroundings; in the minds of elites and government, medical professionals; in the media, within scientific researchers; and in the minds of individuals, people with obesity and general public.

Finally, the importance of educating people with obesity is another relevant element to take into consideration. Overall, participants expressed the need for better education towards patients. By providing emotional and psychological support, patients can potentially receive help throughout the process of managing obesity. The above can not only motivate patient to address their concerns regarding obesity with their physicians, but also promote motivational tools to advocate for themselves and become more knowledgeable about their rights and needs when discussing obesity, "The beauty of advocating and speaking up is that not everybody is in that place. Not everybody has built up enough of a skin to stand up and say, "enough is enough, and I'm going to tell you my story" (Enokson, Person with Obesity, 24:04). In fact, most of the interviewees that advocate for obesity shared common personal motivations from their own areas of expertise, "I wanted to be part of the obesity team because it is a way to work for something that is personal to me and, at the same time, use all my professional knowledge" (Ladwig, Researcher, 05:23), In contrast, Davis' and Chesworth's experiences with their own healthcare system motivated them to become advocates: "I had bariatric surgery in 2001. That really solidified that I wanted to work with people affected by obesity, that I wanted everyone to have the opportunity that I have had to get treatment" (Davis, Patient Organisation, 02:59); "The motivation came from going through a process which I did with the NHS system. It took me probably about two and a half years to get the surgery" (Chesworth, Community Group, 09:03). In summary, advocating for obesity can help to build up ownership and interest for building up strong communities where people with obesity feel represented and "[are] able to share [their] experience to benefit others" (Chesworth, Community Group, 13:57).

In conclusion, this chapter highlights the empirical data providing different ways of understanding how these actors have adopted a patient-centric narrative to contribute to the (re)construction of obesity as a global epidemic. 1) All stakeholders have as common objective to advocate for a very definable way of describing obesity as a disease and getting it recognised as a disease among all stakeholder involved in the global debate focusing more on the physiological factors of obesity and on each individual. In this sense, some of the stakeholders reflected on the remarkable changes within the active obesity worldwide movement. However, all acknowledged that it will take some time until there is a consensus that obesity is much more complex than 'eating less and exercising more' as there is a clear traditional narrative even within the healthcare providers, especially physicians, who work with patients living with obesity. 2) The majority of the interviewees recognised the need for addressing the burden of weight bias and stigma when assessing the root causes of obesity. Based on the collected data, fear, shame and self-blame contribute to mortality and complication developed by obesity as patients avoid the discussion about their health and weight with their healthcare providers. The above highlighted potential causes of why patients do not receive early support nor treatment, including medicine and/or considering surgery. Conclusively, 3) the empirical data provided different ways of understanding and including patients and patient insights inside the global debate. Storytelling practices are the most common strategies among advocates to facilitate different phases of movement involvement, including awareness, encourage, action, and commitment to build up strong communities that can influence high-level of decision-making.

Discussion

Through the analysis and empirical data, this section seeks to reflect upon the problem formulation of how and why the nine actors interviewed have adopted a patient-centric narrative to contribute to the (re)construction of obesity as chronic disease through three main discussions exposed as follow. The first approach reflects on the need for more scientific research that helps to ratify and endorse obesity as a chronic disease narrative. Furthermore, a self-made model approach on how obesity research could be potentially developed in order to advocate for categorisation of obesity as a chronic disease will be presented. The second approach aims to discuss the urgency for finding common ground among stakeholder, explaining that a clear definition of 'chronic disease' seems to be missing as this concept is perceived slightly different among all the participants throughout the emergence of this new obesity paradigm where an Obesity Advocacy Priorities, based on the collected empirical data exposed in the Analysis Section, will also be presented. Ultimately, the last reflection exposes the importance of acknowledging the current lack of diversity among people with obesity inside the global debate where most of the advocates representing patients in these discussions have had bariatric surgery, being rather challenging to find voices of people who are trying to manage obesity without treatment nor access to medicine.

Scientific research: A key component when advocating for obesity

The analysis demonstrates that there is a need for resources that alleviate the categorisation of obesity as a chronic disease through scientific evidence, both the problem and potential solutions, to elevate obesity to a level where it can be

categorised as a disease narrative. In other words, by using only psychological factors and elements of society, the arguments - such as weight bias and self-stigma - that further discriminate against people with obesity do not seem enough justifications for refraining obesity as a disease. Research based on 1) the evolution of genetics and biological causes of obesity, 2) behaviour and culture, and 3) why or how the body manages to gain weight even though patients have had access to weight-loss treatments, dietarian plans, psychological support and/or physical activities, in conjunction with other external causes such as the environment, the economic factors and urban areas, are needed to support the advocate's work. The above can actively contribute to the construction of obesity as a chronic disease not only from a causality point of view but also from an effective and more available access to treatment and prevention efforts. Ladwig, Obesity Clinical Trials researcher, and Vallis, Health Behaviour Change psychologist, emphasised the need for more less-invasive obesity treatment options that move away from weight to look more into functions and quality of life. One of the main potential challenges is that medical doctors have none or limited education in obesity management, mainly because of the poor obesity research inside health institutions. In addition, as current medical education pays minimal attention to the problem of obesity, the lack of obesity training and obesity specialists made it difficult for doctors to discuss weight management and health obesity complications with their patients living with obesity. Thus, if physicians are not getting trained - or educated enough - about obesity and weight management, the chances of knowing about available drugs or treatments are rather limited. No mention the capacity to be aware of their own bias and stigma compromise the life of their patients who can develop different comorbidities such as type two diabetes, infertility, cardiovascular disease, liver disease, cancer, mental health, along with many other

complications. In other words, a categorisation of obesity as a chronic disease narrative by governments and medical authorities could have ultimately profound effects on obesity treatments as such categorisation would allow patients to ask for treatment and get access to physicians better instructed on how to support and provide the best treatment plans, especially drug treatment.

Further development in obesity research

Moreover, when the narratives and their frames are rather varied, patients can determine what factors need to be addressed as first and, more importantly, what narratives need to be critically flagged or consider. Thus, to recognise and strength then plural and socially embedded identities of people with obesity *Figure 3* represents a self-made model approach on how obesity research could be developed in order to advocate for categorisation of obesity as a chronic disease. Three main advocacy pillars have been integrated in order to contribute to the (re)construction of obesity as a global crisis. These pillars are 1) The patient's' voice and the importance of involving people with obesity in research, asking them what are the main needs, fears, challenges and interests when treating overweight or obesity. Their first-hand experience on how obesity impacts their day-to-day lives could bring novel ways of defining and treating obesity; 2) medical management and the importance of integrating obesity education inside medical schools, training to general physicians and specialists, etc.; and, finally, 3) the psychological aspects of obesity factor to treat patients individually being aware that obesity cannot be tackle from one-size-fits-all treatment but rather focus on the patient's health behaviours and behaviour change through the lens of psychological experience(s).

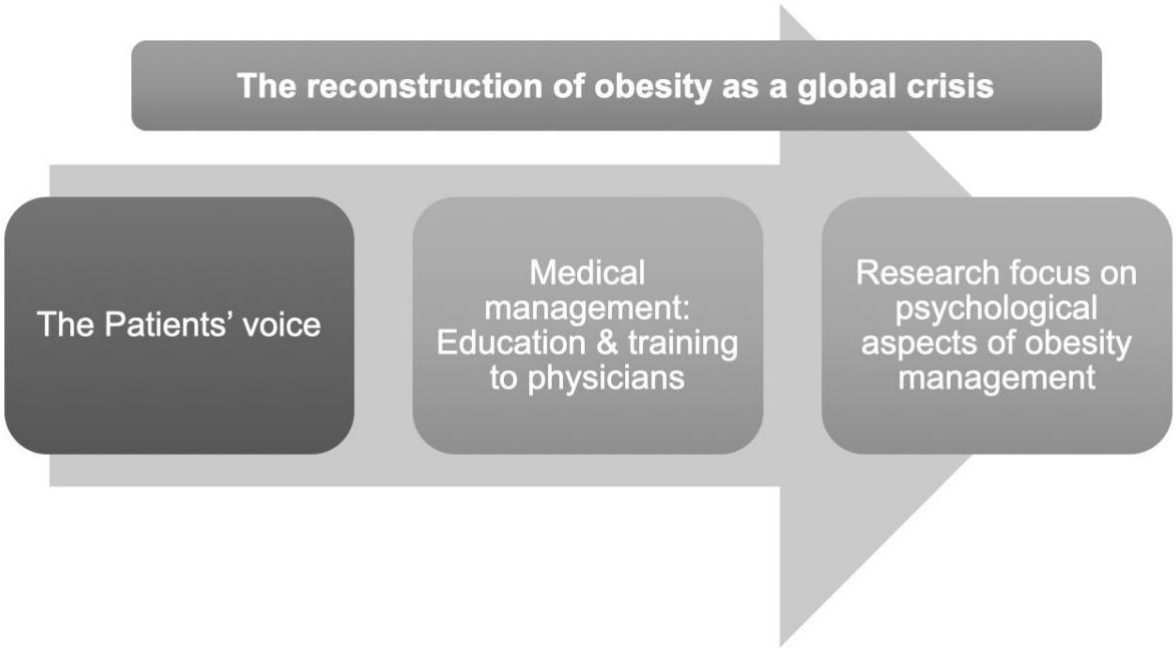

Figure 3: Self-Model the Reconstruction of Obesity as a Global Crisis: An Approach to Tackle Obesity Through Advocacy Efforts.

Lastly, such categorising might collaborate to enhance society's ability to use legal ways to protect people with obesity from discrimination especially in doctors' offices, the media and work environments. Patients will then be able to step on legal platforms to stand onto the demand for respect and justice.

Integration of stakeholders: How to find common ground?

The collected empirical data exposed in the Analysis Section crystallised the need for combining forces among all different actors - including the people affected by obesity - to address the burden of weight bias and stigma and create better and more effective solutions to the worldwide obesity crisis. Based on the analysed data, ideally, obesity treatments should focus not only in weight loss but also the quality of weight loss, genetics, psychosocial problems, physical disabilities, among others as mentioned before. Hence, people with obesity need a multidimensional evaluation aimed to design an individualised treatment plan using different approaches, all at the

same time, such as diet, physical activity, educational therapy, behaviour therapy, drug treatment and, if applicable, surgery. Such treatment and evaluation require effective and committed multi-professional teams that integrate different medicine areas and competencies. These skilled teams then demand the integration of not only medical professionals but also non-profit organisations; health providers, private sector (pharmaceutical industries); researchers and academia; patient organisations and people with obesity that recognised the current environmental and individual biological challenges to tackle obesity. Such interaction and integration of forces could not only support medical treatment but also that, for example, governments cover surgery and counselling with dietitians and psychologists; medication, etc. In other words, success in tangible treatment results that tackle obesity requires dynamic and collaborative multi-stakeholder strategies where scientific research is indeed crucial to educate not only patients but also medical professionals, key actors involved and the general public. However, this cannot be done in isolation. Effective solutions must be created in collaboration among these actors in order to answer the needs and priorities of all the stakeholders while addressing social (self-)stigma.

A unified definition of obesity

Furthermore, such integration could potentially facilitate a very lay, unified and definable way of describing obesity and why should be categorised as a chronic disease. The above due to the different definition approaches provided by the research participants during the analysed data collection. Thus, while the consensus of the group was that obesity is indeed a disease, their reason why should be categorised as such differed. Some mentioned the strong correlations with metabolic processes, while others emphasised the psychological side of such condition. For instance, Clare,

Chairman of WLSinfo, UK, and member of the committee of the Association for the Study of Obesity (ASO), was the only participant who provided a wider explanation that involved non-modifiable and modifiable risk factors from an individual and personalised treatment level. His approach was that there are different types of obesit**ies** including not only the four schools of thoughts - mentioned in the Literature Review Section - but also other factors such as eating behaviours, physical activity, social and structural determinants associated mostly with urbanisation, psycho-sociological implications, among others. These factors play crucial roles when treating obesity as they determinate what could be potentially the root cause(s) of obesity in each individual as sometimes it does not depend only on the traditional narrative *eating less and move more*. Thus, this approach could shed lights into a potential multi-professional definition that integrates all thematic clusters involved when discussing obesity. In other words, defining what is and is not a chronic disease and why is not only necessary to create awareness about this global and alarming trend but also to have a clear and unified message when advocating for obesity in different scenarios, especially towards regulators, payers, and politicians. By having a clear, objective, scientific-based and widely, unified and accepted definition of obesity, the understanding of this new obesity paradigm - and the need for urgent actions - could be improved and addressed taking away the rather high stigma around obesity been perceived as a consequence of individual choices.

Based on the advocate dynamics between the participants, *Figure 4* shows the advocacy priorities among the stakeholders involved in the research study. These three points seems to be the current main objectives in the obesity advocacy agenda having as priority, as already mentioned, the categorisation of obesity as a chronic disease, followed by obesity awareness, education and support as a strategy to

eradicate weight bias and stigma inside the obesity debate and stakeholders, schools, the media and the general public; and, finally, the active participation of people with obesity throughout the collaborative approach against the obesity epidemic.

Figure 4: Self-Made Model Obesity Advocacy Priorities based on the collected empirical data exposed in the Analysis Section.

Nonetheless, there are some aspects noteworthy to highlight in regard to the field of advocacy in obesity - and its challenges - as the approaches discussed above cannot guarantee the effectiveness nor any attempt to measure such effectiveness, if any. Based on the collected data, advocates are missing ways to evaluate success that could provide valuable insights not only to people with obesity and patient organisations but also to their funders and supporters. One could see that even though great steps in obesity advocacy have been taken - AMA designated obesity a disease in June 2013; the Canadian Medical Association, in 2015; IMA in 2018; RCP in 2019; followed, as mentioned before, by the international organisations WHO and WOF, and countries such as Portugal and Israel - advocacy actions need to change depending on the fast changes in political and social contexts. It seems that in terms of obesity advocacy there is a long path to drive still even though states, scientific and research

organisations, and strong obesity movements have been working for more than a decade. In sum, a clear and unified definition of obesity - and why should be categorised as a chronic disease - is needed to reinforce advocacy work, especially in high governmental environments. However, this does not secure success nor bring any indicators on how to assess and measure such advocacy programmes as these depend on political and socially dynamic contexts.

Diversity among advocates that represent people with obesity

The data-collection process and its followed analysis showed the challenges when seeking for patient advocates without medical intervention or access to drug treatment. Seven of the nine participants in the research study live with and suffer from obesity; six of them have had bariatric surgery from countries such as Brazil, Canada, UK and the US. They argued that even though the surgery did have a significant impact on their lives, the challenge afterwards concentrates mostly on maintaining and not gaining weight loss, as some of them have been gaining weight despite not having changes in their behavioural routines within the first decade after having an intervention. For the study at hand, diversity was one of the main factors to analyse substantial and fruitful voices of representation not only from different countries but also gender, race, economic background and healthcare system, both access and treatment. Thus, the majority of the advocates representing patients in these discussions seem to have had bariatric surgery, being rather challenging to find voices of people who try to manage obesity without treatment and/or access to medicine. The importance of acknowledging the current lack of diversity among people with obesity inside the global debate is crucial as there is a clear misrepresentation for those who are a significant majority - and dramatically increasing. For example, as mentioned by

the American Society for Metabolic and Bariatric Surgery in the US, bariatric surgery, the most popular weight-loss procedure among obesity interventions, remains limited as only one percent of all patients who qualify for surgery undergo surgery despite being the most successful long-lasting treatment for obesity. In addition, besides the challenge of finding advocates without medical intervention, it was noticed that representation based on race and ethnicity was also a difficult task. Throughout the collected empirical data, only one person of colour could be found: Kesha Calicutt. When asking her about this matter, she expressed frustration in relation to the lack of representation of black communities in the advocate world, especially inside the obesity debate, where most of the patient advocates come from Western countries with healthcare covered mostly by the publicly funded system (with the exception of Brazil whose healthcare system is covered by insurance companies, and Canada and the US whose health system coverage depends on each state). Calicutt argued that such misrepresentation is especially reflected when discussing techniques in advocacy matters during meetings and events with patient organisations. The above is rather important if advocates in obesity want to contribute to the (re)construction of obesity as a global crisis through the patients' voice and their experiences with obesity management. By missing the majority of those trying to manage their condition without any health support, the advocacy agenda might be missing key objectives such as access to proper and timely treatment for all, prevention inside vulnerable communities prone to suffer more from obesity, economic and social limitations when managing obesity, among many others. Lack of representations among those who cannot get access to treatments, medicine or surgery should be the main concern when trying to include people with obesity in the global debate.

In summary, this section touches upon three main discussions about the (re)constructed narratives by the nine participants interviewed and how these actors are advocating in order to find solutions to the exponential growth of the obesity public health crisis through patient-centric narratives. The first approach reflects on the need for more scientific research that ratifies and endorses obesity as a chronic disease in order to I) contribute to eradicating weight bias and stigma among actors involved in the obesity debate, especially physicians and patients; II) provide better tools to treat obesity to healthcare providers; and lastly, III) discover more effective and less invasive treatment options to people with obesity. The second approach aims to discuss the urgency for finding common ground among stakeholder, explaining that obesity should be defined and treated by multi-professional teams able to define 'chronic disease' as this concept is perceived differently among the nine participants. The above can facilitates a unified definition of obesity and even ways to evaluate advocacy work in obesity matters. Lastly, the voices of those who have tried to manage their obesity without access to medical intervention and/or drug treatment are missing. Six of seven people with obesity in this project had bariatric surgery as it was challenging to find people without intervention. In addition, it seems that there is not much representation from black community perspectives living with obesity inside the obesity global debate. In sum, it is rather worthy to mention that in order to involved patient's voice to the discussion, the vast majority of them - those who have not gotten the opportunity to receive treatment or representing specific ethnic groups - it is key to create an objective and well-founded new paradigm narrative regarding the categorisation of obesity as a chronic disease.

Conclusion

When you are repeatedly beaten down for your physical appearance, it beats you down so hard that you consider suicide, you do! You consider taking your life! You don't want it. Who wants to live this way? No one wants to look this way.

(Enokson, Person with Obesity, 40:45)

Throughout the research study, I attempted to explain how the patient perspective voice has been used by key actors inside the obesity global debate, and what narratives have they constructed around the obesity worldwide crisis especially during the last seven years. By answering these questions, it was expected to contribute to the literature on obesity, based on the alarming exponential growth of such condition, and its advocacy work from a social and psycho-sociological perspective. Hence, in order to address these matters, a literature review was completed to (1) highlight the increasing prevalence of the global obesity debate since the mid-twentieth century; (2) point out the prominent patient advocate movements that contribute to such debate from a global scope; and finally, (3) crystallise the growth of patient engagement narratives used by different stakeholders involved. Additionally, interviews were conducted to explore and reflect upon the narratives constructed by nine different actors from community groups and non-profit organisations; health providers; private sector (pharmaceutical industry); researchers; patient organisations and people with obesity from countries such as Brazil, Canada, United Kingdom, United States and Denmark. After analysing and discussing the findings, the following conclusions have been identified.

Firstly, all experts and parties from different fields who participated in the research study agreed that obesity is a chronic disease. However, the narrative that

obesity is a lifestyle condition and a personal choice based on behaviour only still remains among many health professionals - including family doctor and general practitioners - key stakeholders involved in the global debate, the general public and people with obesity themselves. The above is rather challenging as social discrimination and self-stigma towards people with obesity lead to negative consequences for their physical and mental health, excluding them from suitable and early drug treatment or intervention. It is through different forms of advocacy influence that a narrative changing process inside the international environments can be well-implemented in order to bend the significant personal and public health issue that has spread especially during the last decade. Fighting against obesity cannot mean fighting against people with obesity, as this only perpetuates the predominant and stigmatised traditional narrative without effective solutions to the global pandemic.

Secondly, in order to have an effective and impactful advocacy movement inside the global debate, a unified definition that integrates all thematic clusters involved when discussing obesity is highly required. Defining what is and is not a chronic disease and why obesity should be categorised as such, used by all advocates inside the movement, could 1) reduce the stigma, 2) improve the understanding of the condition and 3) address the need of creating effective, meaningful, ethical, innovative, and sustainable impacts on bending the curve of obesity among communities. Based on the analysis, obesity seems to be the result of diverse and complex interaction among different non-modifiable and modifiable risk factors (i.e. genes, environment, psychological states, etc.) where not only weight loss but also quality of weight loss, medical and psychiatric comorbidity, psychosocial problems, and physical disability, among many others are involved. Such multidimensional and unified definition of obesity - or obesit**ies** - associated with medical, psychological and social functional

causes still missing. Thus, two basic questions, ‘what is obesity’ and ‘when is a person having obesity” remain unanswered. Nevertheless, what the research study has shown is that considering obesity as a homogeneous condition based on ‘eating too much and exercising too little’ seems insufficient, vague and rather superficial after analysing and discussing the profound psychological, social, economic and health implications that obesity brings to individuals, their families and their communities in general.

Thirdly, obesity research is at a very early stage still leading back to a need for resources that alleviate the categorisation of obesity as a chronic disease through scientific evidence. The majority of the research focuses on obesity has been mostly developed during the last seven years causing hesitation among stakeholders whose traditional narrative about obesity being a lifestyle condition remains. Therefore, all participants agreed that in order to elevate the global debate, obesity research needs to be more profoundly focus on 1) psychological factors, including behaviour and culture; 2) genetics and biological causes of obesity, and 3) elements of society with other external causes such as the environment, economic factors and urban areas. For some interviewees, obesity presents considerable levels of psychological comorbidities as such condition predominates in people diagnosed as having a mental illness. Some studies have found that anxiety and depression often coexist with obesity in children as in adults, in addition to a potential bidirectional relation between obesity and depression. Here legitimation will be crucial in order to set the boundaries of political, economic and cultural obesity debates in the global discussion, owing to the fact that alternative narratives sometimes success and sometimes don’t. Hence, what it will be interesting is to see these coming years is if this new narrative of ‘obesity seeing as a chronic disease’ will be the one succeeding or, on the contrary, the one

keep hiding from the dominant narrative of obesity seeing as a lifestyle condition or risk factor.

Fourthly, there is a strong advocacy space in the global obesity arena where disease awareness and patient-centricity are the core frames - or ways of framing - the (re)constructed new paradigm narrative of categorising obesity as a chronic disease. Such cores are being portrayed mostly through education and support with the objective of having access to treatment and including medicines in early stages inside healthcare systems that should focus on prevention rather than treating complications. The majority of the Interviewees expressed the importance of better education especially towards patients and physicians, first main actors to get on board. For many of the participants to educate people living with obesity - while providing emotional and psychological support - must be one of the main and immediate advocacy activities as this can help to initiate conversations inside doctors' offices where people with obesity demand access to proper and early treatment throughout the knowledge of how they can manage obesity from both personal and social levels. The above due to statistics that show how obesity tends to happen especially in low-income environments where restrict access to education takes place. In addition, this could facilitate the understanding of what it means to live and suffer from obesity as well as how stakeholders can help them to manage their condition.

Fifthly, working simultaneously with narratives, framing and advocacy theories helped to understand the current social movements strategies when referring to the global obesity debate from a patient-centric perspective. The narrative theory has been used from a social level of collective identity to bridge the gap between the individual - in this case people with obesity - and the rest of the group, building a shared movement community that aims to create a new paradigm through the

construction and reproduction of common frames, beliefs, values and commitments among diverse stakeholders and parties who 1) advocate for patient-centric implementation and/or 2) define obesity as a disease. Such continuous discussion about obesity and its global epidemic will help to maintain an active public debate to inform people about the issue and turn off the alarms especially within the governments. Thus, advocacy in obesity is creating a more participatory and active health democracy scenario where patients can participate without being seen as the weakest or 'unhealthy' actors in the global debate. In other words, advocacy in obesity must have a strong emphasis on the need for enriching democracy to have more people with obesity involved and together obtain structured, effective, meaningful, ethical, innovative, and sustainable medical treatments.

Lastly, regardless of whether or not obesity could be potentially categorised as a chronic disease in the coming future, the current care for people with obesity demands improvement. Nowadays, effectiveness in obesity treatments is limited and rather invasive, not mentioning that it's quite limited for the majority of those who need or qualify for surgery. Research has shown that people have a tendency to gain back more than they lost after diets and even surgery. Thus, the limited success of current treatment, including medicine and prevention awareness, need to be flagged and undertaken from not only obesity advocates but also international, regional and national actors within the public arena. Obesity is a clear example of the short shrift given to prevention in contrast to complication treatment. Hence, the challenge here is even bigger as this worldwide epidemic requires an enormous shift in public priorities taken by multiple sectors of society as the consequences of not acting can be far worse and even more expensive. Advocates need to start seeing beyond the categorisation of obesity as defining obesity as a chronic disease will not minimise the

urgent need for bending the curve of obesity. Prevention and early intervention remain crucial aspects of this urgent pandemic where acknowledging and recognizing the infinite complexity of each person's relationship to food, exercise and body image is at the centre of each treatment. Hence, the next years will be critical for applying the advocacy knowledge developed by the obesity advocacy movement especially in trying to limit the spread of obesity that affects more people around the world especially children and young populations.

Recommendations for further research

The research study at hand explored the narratives (re)constructed by different key advocate actors involved in the current global debate about obesity from a social and psycho-sociological perspective. Based on the insights received from the nine participants, it seems that the currently new paradigm of categorising obesity as a chronic disease could overwhelm tax-paid healthcare systems and insurance companies worldwide. In case obesity is widely viewed as a disease, a great number of people will be categorised as 'sick' which means that healthcare systems would be obliged to include obesity in their health plans. More so, it is rather difficult to see the negative implications that this might bring to the healthcare system's economy and general structure. For further research, it would be extremely valuable to explore this potential phenomenon and bring back clear repercussions, especially from a health insurance reimbursement perspective. Furthermore, the above would help stakeholders inside the debate to clearly understand the economic and healthcare system structural implications when supporting and/or adopting this new narrative of categorising obesity as a chronic disease. Thus, a 'health economic study' that look into the current free market structure (analysing the cost of obesity today letting people with obesity decide for themselves) versus regulations and incorporation of obesity as

a disease within the health plans (breaking the curve by providing strict regulation to food companies and early treatment to those that qualify for medicine or surgery) would be very beneficial. An objective and clear overview of real cost and investment from the healthcare system compare to the current one, would provide a better idea of implication and potential convenient ways of involving the governments (payers and regulators) into the new narrative in case costs of prevention result substantially more suitable that treating the condition and all the risks that its bring to individuals with obesity (develop cardiovascular diseases, diabetes, cancer, joint pain, among many other complications).

In addition, this study research aimed to underline the advocacy actions that people with obesity have been doing worldwide inside the obesity debate to find (more) access to effective and sustainable treatments and bend the curve of the obesity epidemic. While prevention efforts have been focused on individual behaviour change only, advocates concerns lean more towards an approach on vulnerable populations, especially low-income communities. However, an applicable technique of measuring such success or ways of evaluating advocacy activities in the obesity discussion are still needed to facilitate current status and potential repercussions of this new paradigm. As mentioned in the Discussion Section, the advocacy efforts do not have a metric system of evaluation that allows ardent financial supporters and non-profit organisation to see the positive/negative process of the advocacy activities. thus, advocates are missing ways to evaluate success that could potentially provide valuable insights and learning from their activities and results that could help to find more funders or resources.

Finally, based on the analysis and further discussion, it seems that obesity arises from different causes including, as mentioned before, altered environments,

accessible food items, personal situations, psycho-social factors, medications, other diseases, trauma and even genetic variations. There are plenty of studies yet no many representing the voice, opinions, insights, desires and/or experiences of people living with obesity, especially those who have not gotten medicine treatment or any intervention. Several facts show that despite the high prevalence of obesity, individuals with this condition are frequently the targets of discriminatory comments and other poor treatment in a variety of settings. In order to involve and create patient engagement activities and actions, all actors need a true understanding of the patient's' medical and lifestyle conditions (including the burden of the condition they experience and the way this affects them, their families, social interactions and economic circumstances). The patient's challenges, goals, desires, symptoms and side effect treatments are insights that can collaborate to develop better and more efficient medical, social and economic solutions for the patients, the final consumers. Once the needs are clearly understood, all stakeholders - including academia, healthcare professionals, policymakers, influencers, pharmaceuticals, agencies, etc., can work together to develop practical and implementable solutions and achieve more meaningful outcomes for the obesity global debate, and this must include those vulnerable population who has no access to treatment and is dealing with obesity on their own. In an era where global civil society, transnational social movements and corporate globalisation are focusing the attention on activism and active advocacy more intensively than ever, the voice of the people with obesity need to be louder.

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Appendix

Interview Guide - Community Group

Board Member of the European Association for the Study of Obesity (EASO)

Paul Chesworth

Conducted: Scottish Event Campus, Glasgow, Scotland

1. Please introduce yourself.
2. Could you share your story and your experience with obesity? (When your interest in obesity first began? For how long have you be living with obesity?)
3. What does it mean obesity for you?
4. Do you think your definition is shared by other actors involved in obesity matters (HCPs, pharma, legislators, researchers, patient organisations, people with obesity)?

I would now like to move on to a different topic:

5. From your own perspective, what do you think is the current discussion about obesity? Has anything changed during the last years?
6. Could you describe how the obesity debate has been changing in the last decade?
7. Have you been able to be involved in any of the milestones mentioned? If yes, which ones?
8. Do you think people with obesity is involved in the obesity debate? How are they involved? Have you seen any changes regarding this involvement in the last decade?
9. Why involving people with obesity in the discussion is so important?

Let's talk about advocacy:

10. What does it mean for you to advocate for obesity?
11. Do people who advocate for obesity need to live with the condition?
12. Why advocating for obesity?
13. Are there any obstacles when advocating for obesity? Which are the most difficult obstacles? Why?
14. Do stakeholders involved share the same understanding of obesity than people with obesity?
15. What are your expectations regarding obesity within the next 5 years?

Transcript of Interview with:
Paul Chesworth, European Association for the Study of Obesity (EASO)

- Conducted face-to-face on Sunday 28 April 2019 at 26th European Congress on Obesity (ECO), Scottish Event Campus (SEC), Glasgow, Scotland

Researcher: Recording now. I would like to start by having an introduction from your side. So if you're very kind to introduce yourself.

Interviewee: Yeah, I'm Paul Chesworth from the UK. I've suffered with obesity. I've lived with obesity from being probably about six or seven years of age which over the years has developed and developed through the life and affected a lot of things within my life to a point that I reached mid-forties realising I needed to do something that was going to have a real big effect to make my life healthier and happier that was my kind of goal with it.

At that point, I started researching what alternative was there than just as I'd always been advised by societies that “you need to eat less and move more”. I've never been particularly lazy. I've always done physical active jobs. I used to play rugby when I was younger. So training nice play for the local teams. So never been particularly lazy, but whatever seem to do I'd go on a diet, and I stick to the diet, and I'd lose weight and gain weight. It's a game of the regime of the diet again, weight and gain more, and the fact that it came to the point where a friend of mine advise me the medical technology to advance so far with the thought of having surgery was something I started to research after chatting with this friend for the first time.

Researcher: How old were you?

Interviewee: I was in the probably about 48 coming up to 50, were in my mid 40s I developed Diabetes Type 2. I'm from the side on the research, the bit that really

drove me that this was definitely the route to go down. For me personally was the fact that it would put the iron wire bypassed normally puts diabetes into full remission. So I've still got that diabetes, I'm still technically diabetic. However, my blood sugar is normal as anybody else who is cluster as ‘normal’.

Researcher: So, that means you are not in insulin?

Interviewee: No. No, I got to the point that the day before the operation was the last time I took any medication. I was on oral medication, which was the maximum, I could have orally the next step if I couldn't control it was to go on and chilling. So, that was another driver that didn't want to go down. Because, it's hereditary: My dad had diabetes, my mum had diabetes. Just wait control, but me dad did end up on insulin and with all the comorbidities. He had through his probable 20 years of these in his later life and probably 60 to 80 when he did pass away date wasn't a good quality of life. And that was another driver for me was to get a good quality of life for the rest of my life and to put diabetes in remission.

From having the operation one day to not taking medication since for me personally is great for the NHS in England is very good because there is no cost implication with it now so it probably to maybe around two years for me to kind of hear back what the operation costs was just in medication because that's kind of the equivalent about to two years of medication would be equivalent to the price of the operation. So after two years, I'm still in remission. I've been probably started dieting around about 16, 17 years of age. So I've done most diets that are out there at different stages lost weight and then put more weight. Try another day, lost weight, but never been able to sustain the actual weight.

Researcher: Since your operation. Have you been able to maintain the weight or not gain the same amount?

Interviewee: Yes, definitely! With the bariatric surgery, there are studies all the terms been used - because it's still kind of an infancy operation - but the studies show that you get what they look at if you're looking to graph you get over those. The weight will just severely drop down lose weight in the first 12 months. Then, probably two to three years, it's time to come back up your weight and then it will flatter! The biggest thing that bariatric surgery gives people - and this is the bit with even for education with people who go for bariatric surgery - It's an opportunity to change the habits of a lifetime. It's you: “I need to eat things. I need to eat small portions. I need to eat the right food. I need to win stuff that are not mass-produced”. So it means “every day change”. It is “the one decision”.

I always tell people at the support group that I'm involved with it is “the one change”, “the one decision” you make to have the operation people think that's massive. That's one decision every single day you make hundreds of decisions: Do I eat? do I have chocolate biscuits over there? I do eat playing biscuit. Do I have the biscuits at all? Do I eat the meat to eat something with lots of carbohydrates? So you've lots of decisions every day, whatever it is you do. So, every day, I kind of get up and think “right! I'm not going to, I don't want to go back to being... because I'm happier now than I've ever been! I'm healthier than I've ever been!” I'm thinking “I'm living life. I'm healthy. I'm happy of being able to advocate what I've done now, what I've learned ensure with people” because, I think, the biggest thing with the advocacy out of things is that more people in this room as patient at some point they haven't got good self-control the to easily led the eat the wrong things.

All these things! So you punished yourself where actually it gives you the feeling of being alone, and you're not alone because when everybody in the room shares the story, you won't relate to each person because everybody's journey is different, but

what you do, Is that you put yourself out there and open up and tell people your story which sometimes is very emotional is very hard. It's very difficult. However, the people in the audience going, “it's me. I thought I was only me”, and advocacy focusing in doing that connection: Lets people know that they're not on their own. And this is one of the biggest things: Is people not knowing - because more people who are in society tells people all through the life, all through my 55 years nearly, is “that's your issue”, “It's you who don't do enough exercise” and they are punishing themselves.

Researcher: So let's go a little bit back into how and why did you jump into advocating for obesity? What was your motivation?

Interviewee: The motivation came from going through a process which I did with the NHS system. It took me probably about two and a half years to go through what people classes jumping through hoops to get the surgery. You've got to go to so many classes, all the medical people tell you “this is what you need to do to get through this point to lose weight” and they get the really good and the fastest difference being is that one of the sessions I went to through with the dietitians recommended, you know, “you may be interested in to some support groups”. So they put me into attractive newest info which is wearing my support the UK, which is a patient group. Its people who had the operation who can talk the talk and they came out and day the little things that the professionals don't tell you then you get from the group situation. So. I probably got at least the same amount of information from people in the support group and they are patients, they were real people, then, I probably got more from them than I did from the clinical profession because in the medical world, it seems that information come across in very black and white and the way of explain things is on a very professional level and I give you an example of it and it and the people. The medical side of things is that they did not explain i lay language. My doctor talks and

he uses these big words and he, they don't explain the self. An example of it was I do some work with a guy called John Moss. He's head of endocrinology and the first time he told me that it's a meat that was in a big meeting about we go around the table and explain who they are and introduced. And I'm thinking all right, obviously, he's head of something Endocrinology. I'm not fake. I didn't know what Endocrinology is, you know, it's a medical term. In a little subgroup that we had I gave it back to him as an example. As I said “one of the things you wanted. I've got a clue where an endocrinologist and some not thick so I don't work in the medical world. I'm a patient and the layperson”. “I'm sorry. Paulie” said he said, “I'm, I study hormones, is the study of arms” and I went “All right, I understand what hormones are the effective. I don't understand it what does but I recognize that's the medical field. They work in all the intricacies of the hormones in the body”. Great and even I'm really sorry about your job. If you didn't know then that's so his way of explaining it. We went back into the big group meeting. Somebody was late. A lot of the people professionals work with John and Luke up to him is he's gone. So in the profession, he's the top of the tree and when he introduced himself the second time round because some guy was late. He introduced himself. “Hi. I'm John Watson. Yeah, I study hormones”. People in the room were going for you. Do you want some? Because that's basic. I'm not that link between me and him I've done stuff with him now. He asked me to do a talk at without the RCP last year in London session needed about obesity and stigma and me telling my story because we had that connection but it was a simple connections that. I see him as a person and he needs to see me as a person not he's the boss he's that knowledge man. The patient needs telling me that in that cross over it was worth explaining and I've used a lot talking to people and talking in groups. When I've gained work for companies where I've been asked to speak to you in we went out to our meal in Singapore and Sport 220 delegates

from all over the place your old top of the tree what they do and that's how I explain things is simply that's how they and the feedback we get from that interaction works really well. Because it's just being honest and open people to say “I'm a person I'm not a patient”, but I'm not I'm not people in England now refer to patients a service users, “not I'm Paul. I'm a person” this is how I expect to be spoken to to get an understanding. So the advocacy side of things was what I saw initially with WLSInfo was for people who live this life before me have to share that learning for me was great and then being able to be in a position with some companies with the pharmaceutical companies with it cause it is now with all we end which is obesity or pelmet network, which John is part of chemical over WLS in for are all people who you can share your experience with to benefit others, and it was like, I thought we that group was never started as volunteers then it's kind of giving something back. Because I've masses of support from those people. So it's going to give any back and looking at the bigger picture that the more people we can get to talk about it and discuss and that events like this one where you are talking to professionals who you know where relationships is to just take Kyle. He's done the presentation this morning. We've never met him but on Twitter and the interaction on social. The things is that they're see that of people that kind of proactive pushing stuff and oven and just asking a question and that's why I we can do is myself when Angela is that we don't just retweet something we didn't think that's what are your thoughts on this. How do you how do you see this working? What a new any kind of get engaged you get the feet and then other people come on and then the next thing such a bodies following you and because they're interested in what you've got to say. We know way we feel we're added benefit from a layman's term from a from a low level if you like because within the medical world some of the words room pronounceable to me. I'm not hungry knowing it's like when I look at a word on some

of these presentations making how the hell do you say that never mind just and what he does and for me is that that the medical fraternity the surgeon to consultant sill have that loop as we say, so there are up here and we are more down here and we need to come closer together to understand each other's world a little bit not in depth, but an appreciation what they've got to do, you know, all the old things went from novel point of view, all the ethical side of things that they've got to do to make sure it's right and that's the reason why it takes so long to get anything moving because all the stuff in the background, which has to be done to ensure that whatever anybody's doing is correct, and that in the end of the day it will benefit people, not harm people, and that's one of the one of the drivers for the advocacy.

The other one, as much as of being what I have learned with this journey is that you've got to be selfish. The more people live the life for other people, you know, people do little things that it's like, you know, nice things that they want to do for him. But if it's an inconvenience for me, most of the time I am go with the floow, you know, it's old friend design. I don't know we're not going to go here. We're going to go there and I really wanted to go over I'll go with a bigger group. I'll go with the floow, as they say, that's one of the things is that a lot of the people involved in advocacy are nice people, they care about the people more than they care about yourselves. So, if they can if they can help other people that makes give you a feel good factor: “You wanted, your helpful, you really good”, but then sometimes it's in your experience and for me the selfish bit about the advocacy is that it gives me the driver again on a daily basis is that I've lost the weight - Yes. I have put some way back on a probably put on about 10 kilos in the last probably 18 months - so slowly but, for the last probably four five six months it's exactly as it it splattered, hopefully and it doesn't go more so the focus but the focus is I don't want to be coming to events like this and saying standing up

and made one of probably the biggest kind of compliments I get out was that I am not that fat. I had a talk with some people last June, and after the meeting I got the chance to talk to some of the people. This guy came in the room and his first thought was “what could he tell me about obesity because… I'm not… in his eyes, I wasn't obese” and like what can you tell me that was his first and that's how we started the conversation. Because one of the things you do something - that's hard not to - but you still see yourself your own, can you still see something the size of pants or sheer size and it's great when you can go pictures of the job, but actually for some nice to say takes a lot to accept it.

Researcher: Did you said that to him?

Interviewee: Yeah, because this is this isn't it was a really good and when I talk to other people, I'm not going to look like talking but I do use that as an example is the as Marty did this morning? He he's he has a good way of putting it over is that “nobody knows, nobody sees that he's got diabetes. He's got blood pressures, but as soon as walks in the room the only word is obesity and everybody decides”. So, in that room for that day that guy said “What's he going to tell me? He's not obese”, So that side of it gives you the momentum to keep doing what we're doing. So it's in the selfish way, I feel good being involved with the advocacy is absolutely what we need to be doing and it keeps me motivated and if I can do the stuff that I do, I think it's again with the scale of being involved with with the Pharmaceutical side, me and Angela look it at the we go on this 50 people in the room, but we can touch 10 of them to take our story or to get them to think. Well, if they even could tell 10, 10 and 10 before, you know, which touch millions and that's the power of it. I said to someone before. He's a friend. I'm not seeing him for years. He emigrated to Australia we followers on Facebook. You know, I was worried because he's we've got stuff on Facebook. And

one of you this morning breaking news on the BBC is about childhood obesity being on the its effects and is causing depression children, and it should be that children should be obese that we should be classified children as being obese. So there's a little bit of the stigma, but he said that to me. He knows we're here. So he's thinking about it. So that connection and the power of reaching other people is part of the advocacy. Unfortunately, the people within the advocacy, if you like, a different groups, we see on a regular basis people have an agenda, their own agenda and this is the selfish bit if I can make benefit for me, then I'm going to take advantage of it. We've said this is volunteering.

The benefit of our advocacy work hopefully will change the world eventually and if people didn't do it, then they've been all changed and it's, all for me, It's about that change and in advocacy, I'm being involved with people that we connected we get to know a little bit more we get to know the actually this isn't our fault. There is a gene, there's a fat gene. There's a thin gene, the psychology, all the things that had made a good point: If you want a diet anything, I'm just going to recruit something in your body. I'm not getting the right thing. So, it pushes something else to replace what you're not doing. It's all these into link things that push against each other and you get a better understanding.

Researcher: And talking about that a little bit and I thought your experiences not only by having obesity but also by being able to join these kind of advocacy movements, how would you define obesity today?

Interviewee: I'd always believed that it was my fault, that I was eating too much and I was eating the wrong things and you get to learn it is actually that complex is that many things, it is out of your actual control and the disease is a disease. I'd actually got out of the Oxford English Dictionary the definition of the disease and then the

definition of what that means. So we have the two things which of course people's perception: Is that diseases is you've got my disease now something you can catch, it is contagious, it's a nasty thing and it's no different than anything else. It's something in your body that is not working correctly. So for me the understanding and the education I have git with these guys and learning more appreciated the big picture not just what you told by the media. That is so powerful what people at all sorts of my friends. I can have discussions with our friend. I've known for 30 on years and it's really difficult for my point of view and Angela's point of view and that is tell them the same things every month. We see them once a month, similar things will come up. And it's that understanding, because you people are brainwashed. "You just need to go to the gym", "You just need to go and do more exercise". They don't get is because they've never had to live with them. For me the biggest thing with obesity is to what it's controlled by. When I'm talking to people about bariatric surgeries, they think it is the easy option when you have bariatric surgery, you'll never look back it fixes everything in your life. It gets rid of all your debts. All your relationship issues. You live happily ever after and to sail off into the sunset all because the surgeons made his stomach this big. No, it doesn't.

Researcher: It is also very invasive.

Interviewee: It's a major operation and it's the easy bit of the whole process. That's the easier the bit. The bit I've learned with the advocacy and education side of it is the thing that changes people's way of life and life is what's in the mind every day is the challenge of the mind if you have a really good day if you have a really good day today, you'll go for a meal late night. We'll go grab something to eat. Nice to eat. I'm gonna have a drink I'm gonna go out with friends. We love a good time. Great if you have a really bad day, what do you do? Exactly the same, but probably a little bit more

“I'm gonna have something I really like, I'm gonna go. I'm going to get a kebab. I'm going to be this on and you just like a bit because it's kind of a comfort thing”. So, the thing that controls that is all personal everything that this process is: How you feel, how good they feel, I get emotional talking about. You never used to unlock I wasn't emotional, you know, but it's that realization that it's the mind that controls your life, it doesn't matter if anything light of all the elements, the biggest thing that should be on the agenda for all of this is the psychological part because some of the stuff is mentioned from this morning in the stigma session is that it started in an early age as a child use your sponge to soak up all them things and it's the mental pattern is that the demonstrated to all the studies that people who have trauma in their life as a child whether they've been abused, whatever, is down to that affects our idea. The one thing that I know is that a lot of people who suffer with obesity, is disease, is the one thing they can control and we'll a certain point make them happy, give them some comfort with their food, because you can't live without it. How did she get to 400 pound in weight? What either I did it a pound a month for 12 months for 20 years. So if you put a pound of weight on your back and get rid of that I'll just got do a bit more. I'll cut down food and you get rid of that bar. But when it's constant and the comfort needs to be there and people emotionally connect that with food. To become like more and more from listening to other people is that one of the biggest lack of understanding if you like using that's across the world these psychological big is the most difficult bit to plug something into to get psychological help to understand and put strategies in place because that's all psychologists because accurate it's always going to be there seems I'm always gonna have diabetes if I put weight back on it's going to come back and I'm gonna have to go on medication. But psychologically, I don't I don't feel I have psychological issues - are probably off somewhere - I always will yeah, I always I

always I always you know, I've said it on BBC TV when I was interviewed the them I always read my sister. She left me when I was like six or seven and emigrated to America and I always say to her “I got this big because of you, because you abandoned me”. And… Is that what you told me to eat more food? Because she wasn't there, I was six. So it just didn't know nothing.

If things do happen, that children traumatized or abused or whatever. For lots of them, that's normal. You don't know any different. It's only when they get it's like you'll be all these people's stories that have been AG's the thing in England not too long ago was all these young football players who were been abused by a certain coach. They didn't know, they were kids. They didn't know it's only when they get to adults and thing and then they meet and talk to people and it's like “that happen to you? How did that it was the same guy?” because obviously people now talk more openly about things it then has become what's wrong. It's all the kinda things in society used to go on probably have some places still go on, but that effect.

Researcher: So, do you think that during the last, I don't know, maybe seven years, we've been seeing kind of a shift in the conversation, in the discussion of obesity and not only for example in the UK but also globally?

Interviewee: Yes!

Researcher: Because it has become a global issue. Would you say that psychology is part of that shift like together with new research or studies the says that socio-economical parts are also involved.

Interviewee: Yeah, I'd say all the research. I think that's been done needs to be acted on and that's that's the bit that's lacking from all this is that that little bit for everybody to it's kind of you know, the dots when you draw a picture. It's having all the dots to join up and this is the bit that you're doing the thesis is that the bit is to. Cool

people in a room for two or three days to say “we need to map out. Our we're going to do it.” All of the same belief is that they can out there can help they can help and you join the dots up as well. But the psychological thing for me. The more I see is got is the biggest element that drives People starts the Obesity of yes, it's in your genes. Yes, you can predispose. To say most people can eat you can probably sit and eat more more food than meat and you don't put weight on me. Even when I was big where I can sit and look at your plate and I can put weight on because my physiology differently and that obviously is a key part, but I do think psychological side is the biggest element that need more focus throughout the doubt.

Researcher: Why do you think is important to include patients in the discussions of obesity?

Interviewee: Because the patient is the person who's experiencing a daily, every day of their life, they've experienced whether it's whether he's talking to it or consultant like I'm saying about it needs to be simplistic. So people could needs to be the other Society in England which isn't reviews. And it's got to be in plain English and I always say to people when you being explain something it needs to be played simple English. So you can understand what the say and then the fact that from the way that support with everything else that's got to be on a level that we can help each other and from the fact that. Come to say always loved set it up so that when I've been at Novo is that they are kind of a stigmatizing company. If you leave around novel. There's not very many people in the room are suffering with obesity. They're all very slender people not all thing. They're all Slender people and that might be just the society they come up with in Denmark that I see but it's that everybody being treated and seen same would help to that understanding that working as a patient with people who are then go and ensuring results to the patient's because one of the biggest things I get

from people, I've dealt with the medical fraternity, is a lot of the decisions, they don't follow ABCD and if you tick ABCD, this is what it should be. It's not it's in my opinion their opinion should. It should be based on medical fact, which the disease obesity is a medical fact that it's this this this this this this this there's lots of things that impact on it, but it's medically proven that's what it is. It's a disease it shouldn't be treatment shouldn't be a doctor or consultants opinion while “my opinion is” that's your opinion. It's free. “This is my life” I'm not the best but I think that the patient can be seen quite freely just because if that surgeon and I see quite a few people at walking around this conference that suffering with obesity that work in that professional work, but we're again when you loop around the National Health Service in England has got an issue with people who work for them ever will be obese. So they've got the experience. But again, if people don't talk about ensure their experience mix that sure in to give understanding to get people to think in a different way and somebody else is very clever. You got to the level of got might the penny drop for them and they might find something actually is going around lots of people because the mind is different to our my works at a different level to understand it basics. I always thinking in life the more. Simple things that are the most effective things and that makes me it's because we turned out and people can identify with their understanding. Yeah. That's that is the the key for me

Researcher: Last question. What are you hopes? How do you see this conversation going within the next five years?

Interviewee: I think, I think the moment in the in the time I've been involved not just because I've been. But in the recent years, I see the momentum, picking up and, I think more by the fact that this becoming more integration has been more acceptance whether it's from the Physicians from the clinical people that actually. No, it is I do

understand what they're saying. Now. I don't because in a normal or has a normally people don't you get 10 minutes with a consultant and he's got to move on to somebody else. So they don't get the understand they can't we've had a conversation for 30 minutes and you get an understanding and if you have that time with somebody and that was happening on a regular basis. I'm sure that the question if you change the first and they probably get it down to they can get that information out simply by asking the right question in 15. So give it an extra, you know, so there's that development of everything with it. I think in the next five years. I think the I think what I'd like to see is that within the next five years that more government acknowledged that there is that it is a disease that we know it's a disease, but it's the acknowledgement of the government which will then have a step change because the bias we say about you so I could go out if I went out in that hallway now started Shelton of somebody was in Asia and being abusive to Jewish and anti-semitic comments on this and be prosecuted because it's legal under the law needs to represent them if the government recognized that the Obesity is a disease. Yeah, we'll put more funding after but more funding and more research more support more this more that great but there's going to be a benefit because people will be less and less and less inclined to be obese even so the healthier spend as much money. So there's there's there's a Tipping Point with that investment. But I do them think that the change will be that it isn't accepting you can't shout. You can't I mean one of the things that one of all friends and WLS employees have surgery. He was probably not older than you and he was as round as he was told if anybody wanted to give him any abuse, if you had an argument with some day I felt it was somebody at work or a bit of road rage the first thing they said to me that's because he's worried. The other surgery in but 12-18 months after surgery. You have some Rod rigged with a woman or a guy and come to

a stop at a set of traffic lights Jim. He's bald. Yeah, it's been bald for years and years when he was big and this lady was all these when he said you and he sat there and he's going I'm not fat anymore. Yes. And that's the step change is because she didn't see that and I think that's where we need to be with the changes.

Is that the government see the achieve and the change and again the pressure to change that will come from in the states. Obviously. We see obviously a very big organization and do have a very good way of putting it and I hope that obviously with the course that we've got now with the European Coalition for People Living with Obesity as a separate group that is recognized as a business if you like, will gain momentum to be a voice for others, to get the change, to go to the European Parliament to lobby government to challenge television programs to all the things that need to just like push back. It's not Paul having around it's the European Coalition for People Living with Obesity is saying “that language isn't representative”, “that language isn't acceptable. No! it's wrong” and if we can get to that in five years. Who knows where we can go, you know, it's one of these things. We're all here to change the world because it is a massive thing and if we can start the ball, which we are, gets momentum to snowball. And that is where I think we’re out. The verge of a bigger change, but it's that power of one voice and one of the key words, if you like, the drivers that “nothing about us without us” that's come from the States, from OAC, and that's where it's big and it's true it is that people make decisions.

You're looking a business people have working groups in the business. So you've got different levels within the business to say, you know from the CEO to the leaner, and the cleaners got a very valid point. It's that working together integration through all the levels that we can affect.

Researcher: Regarding to that. I don't know if I've heard there are actually two - and I didn't find it anywhere - but there's apparently two movements in obesity, those who think that if your numbers are ok, as you know, it doesn't really matter if you have obesity or not.

Interviewee: That is exactly right. There are people who are living with obesity, who are happy. They have no other health issues, were just that's how their bodies disposed to did. They not get anything else wrong with it. I don't know if I want to lose weight. From my perspective, there are more who says “I want to change, I wanted to fit in, I want to be whatever normal means, I want to be normal” and that's because of the pressures of society were of the some people out there. I'm not gonna be better and you see and for you know, you'll have heard people say is that people who have got your big, overweight. You're always happy, you are always joy. They're always laughing.

Many people say “I don't want to be big”. When you listen to what society says different is that everybody should be the same size, everybody should want to be and the reason that you are like you are is because you're lazy, don't want to do stuff, you're eating the wrong foods, you're not going to exercise, etc. Only if you look around in the world, the majority of people who are obese are in full-time employment for a starts. It doesn't make them lazy because you get up every day and go to work but.

Interview Guide - Health provider

PhD, Health psychologist Founding-Member and President of the Canadian Obesity Network and Associate Professor in Family Medicine at Dalhousie University, Canada.

Michael Vallis

Conducted: Skype Business Call

1. Please introduce yourself.
2. Could you share your story and your experience with obesity? (When your interest in obesity first began? What areas in obesity you find more relevant or interesting within your field?)
3. Could you explain what is the meaning of 'Health Behaviour Change'?
4. What does it mean obesity for you? What is the psychological impact of obesity?
5. Do you think your definition is shared by other actors involved in obesity matters (people with obesity, HCPs, pharma, legislators, researchers, etc.)?

I would now like to move on to a different topic:

6. From your own perspective, what do you think is the current discussion about obesity? Has anything changed during the last years?
7. Could you describe how the obesity debate has been changing in the last decade inside the psychological field?
8. Have you been able to be involved in any of the milestones mentioned? If yes, which ones?
9. Do you think people with obesity is involved in the obesity debate? How are they involved? Have you seen any changes regarding this involvement in the last decade?
10. Why involving people with obesity in the obesity discussion is so important?

Let's talk about advocacy:

11. What does it mean for you to advocate for obesity?
12. Do people who advocate for obesity need to live with the condition?
13. Why advocating for obesity?
14. Are there any obstacles when advocating for obesity? Which are the most difficult obstacles? Why?
15. Do stakeholders involved share the same understanding of obesity than people with obesity?
16. What are your expectations regarding obesity within the next 5 years?

Transcript of Interview with:
Michael Vallis, Health Psychologist, Canada

- Conducted through Skype Business on Monday 29 April 2019

Researcher: The research is very focused on how to find a common ground among the different stakeholders. So, because we have those that says that obesity is not a disease and we have another group that says that it is a disease indeed. However, at the end of the day, the discussions there are, you know, between them so far - what I've been finding is that - we can find some common ground and to kind of find a solution to bend the curve of obesity within the research. I'm also studying the impact of psychological factors in obesity. Here is where I actually found you work, I think you've been doing very interesting stuff regarding obesity and the physiological impact.

Interviewee: I think it's a it's a really important topic to address. I've taken to survey taking the following comment that diabetes introduced medicine to chronic disease, but we really didn't fully embrace how to, how to address chronic disease and diabetes. We still “teach & tell”, we still operate from the perspective of where the experts and we're there to instruct the patients with diabetes and you see this reflected in the experience that people have where they feel very much judged. So diabetes introduced medicine to chronic disease, but obesity is going to hold their feet to the fire because there's no way that you could address obesity without taking the whole person into consideration, and I think that's really kind of where up, you know, these kinds of projects become really important because, you know, without a common ground it's actually going to be really difficult, you know.

In psychological work, a lot of times what happens is that the psychologist and the and the, and the individual will will have a session. And in a session there's a certain ground covered and maybe it's insight, maybe it's coping skills, maybe it's emotional expression, maybe it's kind of retelling The Narrative of your early life experiences, whatever that experience would be, and then the patient kind of goes away and it kind of percolates and then they come back for another session. So, this is the sort of standard kind of approach. In obesity, It's much, much more difficult! Because whatever Insight, whatever coping skills, whatever perspective of patient gains inside the session as soon as they leave the encounter, they run into messages that UNDO whatever Insight coping skills has happened.

So the lack of common ground is really the reason in a way that though the work that obesity management can accomplish is actually, you know being undone by virtually every other aspect of society. And yeah the key example is, you know, I work with a patient. The patient starts to develop a concept of best weight. In other words, they start to detach themselves from the number on the scale. They try to focus in on their health behaviors. They try to you know, improve body image acceptance and then they go out and some bozo, excuse my language, physician says “you got to lose 75 pounds before the end of the year, or if you think you're going to get pregnant in the next year or two, you've got to lose that hundred pounds” and then all of a sudden all that work is just disappeared. Yes, message kind of dominates, that we're too hard sell to to present in a world where people are made, you know, insane promises that aren't cap. So anyway, I think it took the idea of the Common Ground is actually really, really important.

Researcher: Thank you so much Michael. I would like to start by asking you to please introduce yourself.

Interviewee: Sure. Yep. So, my name is Michael Valles. I'm a health psychologist in Canada. And in Canada psychologists are PhDs, so we sort of blend both clinical and academic work. So, most clinical psychologist will also have work in in academics to certain extent. And then there are some psychologists who really very strongly blend. So I'm one of those psychologists who really spend as much time in clinical work as I do in academic research teaching. And my area of expertise has always been around Behavior Change through the lens of this sort of psychological experience. So, obesity, diabetes, cardiovascular risk are the sort of me.

Researcher: And what has being you experience with obesity? Why are you focus on and why have you been interested in obesity?

Interviewee: Yeah, so that's a good question. So I kind of began... so, in my training in Ontario, I went to the University of Western Ontario and actually as a graduate student, I worked in in a program where we were doing psychological screening for patients who were seeking for weight loss. So, because of the sort of Health psychology train, that was my first sort of involvement and then, and then, my area of expertise is always been Behavior Change and so that very quickly got connected to diabetes. So, is of course, you know, a vast majority of people have type 2 diabetes and the vast majority of people with type 2 diabetes have obesity. And so it's always been a sort of peripheral involvement when I came to Halifax 30 years ago. I continued my association with surgeons and that's where people were doing gastric stapling for vertical banded stapling for obesity. So, in the sort of around the in the 90s, I did a lot of work on supporting patients getting ready for surgery post-surgery and we develop some scale so called the Obesity adjustment scale to sort of understand that what became clear to us was that the the issue was always, you know, if someone is psychologically distressed should they not have surgery now? Of course, this is not a

issue any longer because you know, we've discovered that in fact, the Psychopathology doesn't really shouldn't really be a barrier to you know, helping people access surgery with support but back then we were trying to understand that and so the my our understanding of the literature was that if, if you're just stress was based because of your obesity, that is obesity based distress, you actually did better with surgery because the surgery kind of address the concerns, whereas if you had Psychopathology based distress, then it was a barrier. So, so, we develop the scale and then I've just continued to, to be involved through diabetes and then I with an endocrinologist, we co-directed and obesity management program called 'Partners for Healthier Weight'.

Researcher: Okay, and with that experience that you have already and with all the work that you've been doing with obesity, what it means obesity for you?

Interviewee: Well obesity is fascinating to me because obesity is sort of the consequence of the human brain no longer being adapted to the environment which it lives. and so if you, you know understand the way in which we really operate, right, we just make immediate decisions based on pleasure, we sort of avoid the more, the most in more inconvenient options. We sort of focus in on the moment. So, so it's kind of knowing the way that that you know humans tend to operate the limbic system really having a huge amount of of a role to play in many psychological problems, you know, talk about fear, talk about depression, talk about relationship problems, so much of all of these have been rooted in that sort of conflict between "what I feel and what I know" and so that, that's always been sort of a dominant theme.

And we've sort of discovered now the neurobiology underlying the Obesity which was kind of there if you look at some of the research you'll see that Albert's Dunker to psychologist, you know, 25 30 years ago. I collected some data looking at

genetics, you know, you know sort of fraternal and identical twins and what happens in experiments where you either under feet or overfeed, but we never really put it together until very recently. So, you know, for me, I think it's the sort of consequence of being in the, in the sort of dysfunctional world's that we've achieved we've been and so obesity has become I think for me, I've really benefited from the neurobiological research because it really helps us to frame up, you know, what are appropriate expectations and how do we understand it. I love the there's a group in the US the American hypertension and cardiovascular Association. Suggested the term adipose based chronic disease ABCD as and for me, I really you know that for me describes obesity, you know.

So what are the what are the limitations? Right? And this is where the I was one of the founding members of the was the Canadian Obesity work, network now Obesity Canada and its really the focus behind the Edmonton obesity staging system, you know, getting away from weight to look at function and quality of life. So, you know, I think, I think it's almost like a obesity is an occupational risk of being a person in the world. So it's you know, so for me, I see the normal, I see obesity is kind of like it's almost the norm, well, the evidence would support it, if you can get through the world and you do not develop obesity, you're either, you're either genetically and not doing anything that's protecting you or you are working incredibly hard, but that for the people who are vulnerable to developing obesity. The normal response is to develop obesity. So, for me, I've always sort of, I've always looked at it from the perspective of “let's understand, you know, What the patient's, you know, drivers are, what are the pathway that a person has experience that gets them to the weight that they are and then from that figure out with the individuals. What is an effective Pathway for improvement which could be, you know, anything from not gaining weight, You know, to completely

ignoring the way to focusing on in a reasonable expectations around weight management.

Researcher: Yeah, you know, I think that's so interesting what you just said, because I've been talking with a lot of HCPs, and a lot of them do a lot of things within the obesity field, but not a lot of them actually work together with patients to actually find the needs of the patients so, do you think that's kind of like the changing that has been happening, let's see during the last decade inside the psychological field, like to actually add patients into the discussion of obesity?

Interviewee: I think it's been very hard. I think it's hard for two primary reasons. And the first is that in this is going to sound a little harsh. But I do believe that it's true when you actually look at the people who are in obesity management, most of the people who are in obesity management, and I'm talking primarily around physicians in the medical management approach, most of the people currently who are in this field have a personal story. So, if you ask me, you know, I can tell you if I if we had a conversation about who are the primary obesity doctors in Canada. They almost all have a story and they almost all have an idea in their mind of what the best Pathway to success is.

And so that and that is that is the first comment I would make is that in a way the current approach to obesity management really reflects Immaturity, and I use the word immature not in a judgmental way but in a descriptive way.

Researcher: When, sorry Michael, when you say they have a story, what you mean is they've been suffering with obesity or any other complication?

Interviewee: Exactly! They've all gotten something. So, some of them have had had weight struggles themselves and they've been successful and they want to pass the word on. Others have discovered that, you know, their athleticism has been

advanced by the ketogenic approach and they've been able to achieve their marathoning or their triathlon and these doctors are actually really, you know, either with a very ambitious people so they often, you know, have a strong success stories themselves and they want to pass on the word. So, and that's fine. I'm not it's not a criticism. It's just an observation of maturity and the sign of maturity is differentiation. And so if this is actually called The Law of instrument or Maslow's hammer, And what this expression means is that if you give a child a hammer everything they encounter is a nail and so and it's a it's sort of like the beginning and so one of the challenges that we face right now is that we have to look at obesity as a chronic condition that has innumerable number of reasons, why write the differentiation of the causes and the treatment approaches are as varied as there are human. So you can't take a One-size-fits-all approach. But that's the typical way that people will do it.

And for instance your part of Novo. So you'll be familiar with the diabetes attitudes wishes and needs studies that Novo is sponsored where we were able to really take the concept of depression. And really kind of differentiate that into diabetes distress and then of course, what we've discovered is that the real issue for the individuals living with diabetes is actually diabetes too stressed not clinical depression. And so that's an example of maturity and I think right now we're not quite at that differentiation point in obesity. So the first problem is that a lot of times you'll meet with the doctors and they actually have a plan for you before you walk in the door and there are other sizes medicine, there, there the medical management, they believe that the patient each do it all on their own. They're a ketogenic approach or they're a low-fat approach whatever it would be and that's okay, but we need to get beyond that. We need to start to realize that “no, no, no, we're not there to convince patients that our pathway is the right pathway, as in any chronic disease, we’re there to understand the

patient and find from all of the various effective treatment. So one of the things that I do actually is I actually trained people in a structured interview to engage patients in a conversation about the various Pathways to success. So we literally educate the patient that there are behavioral things and understand how ready are they to do that. We educate patients that there are medical management approaches medications and then we understand try to understand where the is what their attitudes what their Brilliance is and if it's appropriate we introduce surgery and so in other words, it's very much of a shared decision making and that's got a locking pin.

The second major barrier is that doctor still, and the profession, still wants to hold onto the reductionist model which is called the it's a simple system perspective and this reflects What's called the Newtonian Clockwork. Isaac Newton's view of science the body medicine was that the if there was something wrong, it'd be like a clock you could take a clock apart like a broken piece replace it because the clock back together and everything works perfectly fine. And this is the essence of the quote-unquote scientific method, but the scientific method has really been in the implicit approach that we've trained all Healthcare Professionals in and so the scientific method based on this model is has two characteristic reductionism. What is the diagnosis. What is the problem. That's where you see the medical approach to ruling in and ruling out and differential diagnosis and if this. That and then also determinism what is the mechanism of action? And so all of this is looking for like the singularity and of course obesity behavior does not fit into a simple system. It’s either a complex or chaotic system. And so one of the things that I find myself challenged with is, and I did this actually last week at obesity Canada meetings in Ottawa, as I did a workshop and one of the big parts of the workshop was to actually help the healthcare providers

make that shift from a simple to a complex or a chaotic system. And so what what I'm saying here is we have to change.

We Health Care Providers have to realize I'm gone this, you know, and I have a slide at and I stole this from The Wizard of Oz but the title is you're not in Kansas anymore Dorothy to to reflect the idea that you know, what we can't approach obesity with a simple system. “Let me tell you what the problem is here. Let me tell you what you have to do about it. Okay. Now you you bow do it and then I'll see how. You do when I see you in follow-up” do that with with in obesity or chronic disease in general, but specifically obesity the patient's going to feel judged, the patient's going to fill criticised. The patient is not going to feel supported. So we have to, we have to sort of change and a lot of my work has in Behavior Changes both a parallel process. I call it in other words training Healthcare Providers to develop the competencies to help patients change, but in the very same moment. Challenge the provider to shift and change as well.

Researcher: But Michael based on your experience, can you see some kind of statistics or metrics that actually prove that by doing this Health Behavior Change you can see how patients are actually feeling a little bit more involved in the process of losing weight? Like, it's not just doctors telling them what to do, but rather they are actually feeling a little bit more autonomous and a little bit more like “I am in control”.

Interviewee: To comments there. If you look at at behavioral attempts, so patient leaves a clinician's office and what do they do? And There's a nice recent systematic review and meta-analysis that shows that the odd ratio of the patient actually making significant attempts at change based on the doctor making sensitive recommendation is like seven, so there's like a seven times increased effort by the patient.

So second point is we know that these communication skills in finding common ground the patients and Method asking and listening and summarizing before inviting the patient to consider your recommendations, that this improves the patient's sense of collaboration and shared involvement. So, there is significant evidence that really shows it another the problem of course is here. We have to understand that because it's very very complex, Changing Behavior, improving patient provider communication doesn't necessarily translate into pounds lost. Because there's, we know there's so much more complexity there which is why I find this field fascinating for the following reason: the power of the surgical intervention cannot be disputed. The potential for medical management is incredibly exciting

So on the one hand, we've got all these great treatments, but guess what? The behavior is critical if you don't take the medication, “I'm going to help you. Yeah, if you don't actually prepare properly for surgery or you don't support the post-surgical behavior piece”. So, it's a perfect kind of collaborative field for me where my medical and surgical management is really being promoted. And that we need to really understand the behavior.

So one of the things that I just make a comment to is that we all sort of are familiar with the **Obesity treatment pyramid**, which is their lifestyle is the base then when that doesn't work, you would consider medication, when that doesn't work, you better search for surgery. And **I'm looking forward to the explosion of the pyramid that is the pyramid in my mind is completely wrong.** You should never, you should never wait till the program fails. I mean, what does that do to a patient? Right? If a patient feels like, you know, and sometimes you'll even see in these algorithms, **don't consider medication until they failed behavior therapy.** That's terrible!

And so I think you're going to start to see obesity management having really three pillars of interventions or I consider them Pathways: 1) behavior, 2) medication and 3) surgery. And it's really, you know finding the best Pathway for the individual patient and not having that kind of pyramid approach. So, so I think there's a lot of real optimism around the sort of integration and the and behavior will do what it does, which is it will, it will get a person engaged in health promoting behaviors. And then we need to look at what are the biomedical outcomes that, that behavioral change produce and then try to imitate sort of impact using multiple Pathways the, you know, greatest sort of healthy weight outcomes that we can do

Researcher: Michael all these things that you're sharing with me sounds very much like you are advocating for obesity. Am I right?

Interviewee: Oh, absolutely!

Researcher: Okay, and then for you, what is what are the kind of, the major obstacles when advocating for obesity? Would you say there is like these kind of changing perspectives about ‘eat less, move more’?

Interviewee: I think that's a great, great question. I would say that, you know, In the in chronic disease in general, I think we recognize that one of the biggest barriers is that is that we tend to simplify it and we're not putting enough resources into the, into the whole person perspective. But in obesity, I think it's even worse and the two things that make it worse from an advocacy perspective is the 1) bias against obesity that is so implicitly implicit and intrinsic in policymakers, healthcare providers, the public in general. And so I think the stigma the bias issues have got to be addressed and I've got to be exposed and and and I think that's a huge huge barrier to the advocacy.

The second is because of the bias issues, because and, and this is something that is really, really unfortunate because if you look at bias, if we were to, you know, look at will just look at at women's rights issues, look at that the kind of you know, Black cultural revolution, right? These are people that have felt hard done by and have been have a lot of resentment towards their controllers and then there's been an emancipation where, that you know, and it's that expression, you know, sort of like “I've had enough”, right? It's like okay “no more, I am done. This is it, I'm done!”, and the **problem is the bias against obesity is actually reflected by the individuals who live with obesity themselves**. **So, obesity is this cutting a unique condition in which there's Self Bias and as a result the individual feels that it is their fault. And so I think that the two barriers to advocacy are the bias in the system and then, importantly, the fact that individuals living with obesity have to be appreciated as an as a vulnerable population**.

They have to be seen in the same way that we would look and we would say “no, we have to protect the children, but the children cannot protect themselves”. And so so every society has to impose affirmative action, you know recognize the vulnerable. “We have to protect our elderly, our elderly are taken advantage of look at”, what's happening right now on when with technology and how many people you know, elderly people get scammed, right? Because they're vulnerable they don't same kind of exposure and for the reality and it's exactly the same thing with individuals living obesity. So we truly have to engage in some kind of affirmative action and that's why I think you know, I would just offer up Obesity Canada as a as a really example of doing something correctly and and what I mean by that is the **the patient facing engagement part.**

So one of the most important accomplishments of Obesity Canada is this patient engagement committee where you know and it's you know really tries to advocate for that expression: “Nothing about me without me”. And so, for instance last week every single plenary session, so every single scientific presentation, began with a patient's story. So, an individual from the patient engagement committee would stand up in front of the room and tell their personal story of their obesity challenges and then the session begin.

So, I think that the bias issues and the and the vulnerable population issues need to be acknowledged because I think that's essential for advocacy efforts.

Researcher: Okay, Michael one last question and then I'll leave you alone. What are your expectations regarding obesity within the next five years?

Interviewee: So, that's really good. So, so I think that, and this again sounds a little harsh, but being involved in this field for a very long time, I think that - and also experiencing I think the almost the hijacking of resources by the surgeons - That is because of the bariatric surgery being so effective, there's been a tendency for people to invest just in surgical programs because that's all that is really the table. So my expectations are that with the legitimacy of the medical management of obesity, the doctors now have a role to play. Right? because the surgery option will not have much relevance to a primary care doctor, a family doctor. Because no family doctor is going to do surgery and I can show you thousands of family doctors in Canada who say I've actually only ever referred one patient for surgery.

So surgery is not mainstream. It's not scalable. And so, doctors have typically taken. This is quite appropriate. If you can't do anything about it, why would you assess it? And doctors have always seen themselves as not really having a role in obesity, as a matter of fact a lot of the doctors look at these medications and even orlistat has a

bad reputation, and they look at these medications and they say “that's a disaster these medications have been. Harmful”, and so doctors want nothing to do. This is the past with obesity.

And I would say that one of the most optimistic things in my opinion is the met the illegitimate medical management of obesity. And so you're starting to see things like, okay, we've had Victoza for a while people know about that. That's a diabetes medication. Okay leader came along and said, hang on there's cardiovascular safety here. Wow, and now Victoza is just dressed up in another, in another. You know cloak increased in its dosage to become saxenda, all of a sudden this becomes very appropriate. There's another medication in Canada. We only have three medications in Canada, andhe contrary medication is a comma to medications that have been on the market for over 30 years. So, so doctors are now saying “okay, so I know this drug, I know that you know, I've used that. I know people pre-owned I've used that is the form of Wellbutrin, which is an antidepressant medication. So family doctors kind of our okay, so it's just been kind of tweaked. Okay, I can get that”. The regular tide comes along we think some egg Latinas going to be even better. So I what I suspect here is that doctors are going to say okay. I have a role to play in Obesity. And so that gives me the opportunity to assess it and to support the patient. So I will tremendous optimism. Also, I think that that that the complexity issue makes people really really receptive.

So, so I think a lot of the combination will come together: the patient voice, the psychological aspects of obesity management, and the medical management. And I think those three things will kind of weaved together and so my hope is five years from now and I can only talk about Canada because this is where I live. Yeah, but I've been working. Actually with some Novo people here in Canada, and what we're trying to do

is get obesity management a fee code for the doctors. So this is how doctors get paid. They do a medical service and there's a code that they submit to the government and the government pays them and so we're really trying to get obesity and as that happens then I think you'll see the formation of clinics. We're already seeing this where you get, you know, the doctor is paid by the medical system. And then there's the team that works around the individual, so I can see the development of medical management clinics. And so that those three things coming together I think will be the the real sort of that will potentiate.

I think the the treatment approach know we'll have better informed patients with patients who have a voice, will have realistic strategies, and then we'll have very important medical management rules for doctors. And I think that's these then it and then it will look like hypertension. Yeah that it will look like type 2 diabetes and it'll be just another one of those complex diseases that the doctor. Need to get their head around so that's that's my source of optimism for the next little bit.

Researcher: That's that's great. And that's actually very positive. So I'm just happy that someone that's been so involved in the process of obesity actually can see these kind of changes within such a short period of time, you know, because, to be honest ,since the last seven years, the debate of obesity globally has been changing dramatically. You can find a more discussion. You can see patients finally talking about. So, thank you so much Michael for all your time. It's been such a fruitful conversation. Thank you so much.

Interview Guide - Private Sector

Public Affairs and External Relations Manager, Obesity Patient Access and Public Affairs at Novo Nordisk S/A

Amy Peters

Conducted: Skype Business Call

1. Please introduce yourself (How long have you been working at NN? How long in your team?)
2. Could you tell me when your interest in obesity first began?
3. How did you come to be the person who is taking the lead for the obesity matters and projects within Obesity Patient Access and Public Affairs-NN?
4. How does NN define obesity? How do most people internally think about obesity, is it the same perception?
5. What about you, is it the same opinion you have regarding obesity?

I would now like to move on to a different topic:

6. What is the current discussion about obesity? Has anything changed during the last years?
7. Have you been able to be involved in any of the milestones mentioned? If yes, which ones?
8. Are people with obesity involved in the obesity debate? How are they involved? Have you seen any changes regarding this involvement in the last decade?
9. Why involving people with obesity in the discussion?

Let's talk about advocacy:

10. What does it mean for you to advocate for obesity?
11. Do you think it is relevant to advocate for obesity?
12. Do you advocate for people with obesity? How? Why advocating for people with obesity?
13. Are there any obstacles when advocating for people with obesity? Which are the most difficult obstacles? Why?
14. What are your expectations regarding obesity within the next 5 years?

Transcript of Interview with:
Amy Peters, Novo Nordisk UK

- Conducted through Skype on Friday 05 April 2019

Interviewee: Growing up as a child, I carried a lot of extra weight. So, I would say at one point, I'm sure that I had childhood obesity myself, and then my father and my mother and my sister all have obesity and I would say not extreme but probably, you know, BMI of between 35 and 40.

Researcher: Okay.

Interviewee: Although my sister, to be fair, It's probably more in the class 3 obesity now and she's very, very large. And so as a child, I grew up seeing a lot of their problems. So my dad always had high blood pressure. His father died of a heart attack would use 52, and then my dad developed diabetes properly and his, I would say it ,as mid-forties. Interestingly shortly, afterwards, my sister develop type 2 diabetes and she was in her early 20s and high blood pressure and a whole other problems, you know, which is continually sort of happened throughout the years.

And now at the same time, I all of a sudden decided, you know, thatI do not want to be like that and I lost a ton of weight. I very purposely went through a stage - and this was right sort of in my early teen years - So I grew like six inches and I lost a ton of weight. So all of a sudden, I was a very thin

Researcher: Yeah, and can I ask you how did you lose all that weight? It was to exercise or through determination or eating habits.

Interviewee: It was determination and not eating. So I ate, you know, I really, really cut down my calories, and if I'm just completely honest with you, I exercise obsessively, obsessively to the point where I would probably do two hours of exercise

every day, every single day. You know, and as a problem must have been 14 or 15 year olds. That's quite quite a lot!

Researcher: Yes, that's quite a lot. But at any stage or at any age, I will say, 2 hours of exercise everyday is quite a lot for someone who is not a sport professional.

Interviewee: Yes. So, we ended up losing a lot of weight and, you know, in my head I still felt like a fat kid. And, so, I had a lot of sort of really, you know, very much that the mental side of a struggle throughout most of the rest of my life and I will say that I have maintained and kept the weight off for a very long time. I've my kids and gained a lot of weight, but I've subsequently lost it that drive.

I'm still at a healthy BMI now but it's very much until this day a struggle, every day I think about what I put into my mouth. So, when I got a job at Novo Nordisk - I am a molecular biologist by training - and then I got into pharmaceutical because what it was really missing from me is the connection with the person: So the patient that I was helping.

So a lot of what I did was R&D, very much, at you know, in a scientific level under a microscope, you know, so really far away from the actual patients.

Researcher: Okay, so for how long have you been working there for?

Interviewee: Oh God! let's see… I did that line of work for probably 12 maybe 15 years, no! 12 years I would say, and then I got into sort of the biotechnology group and I was there for about seven years and I've been working with Novo Nordisk for five years now. My first and only pharmaceutical experience.

Researcher: I can see you working in the Obesity Patient and Access and Public Affairs team. Is that the official name of the team?

Interviewee: So, we are the Patient Access and Public Affairs team, as a whole, and that I'm the only person in the public affairs team that's dedicated to

obesity. So that is my whole roll is sorted a public affairs external relations advocacy. Through these last years of experience at Novo Nordisk, I really started to become very aware of the disease awareness space and of that sort of, you know, advocacy space and then I figured out actually this was really what I wanted to do, and the reason for that, and why it became very important to me, is because I want to make a real difference, and for me, that real different that's part of what gets me out of bed in the morning, is thinking actually “in some small way I've helped someone”.

So, for me to be able to advocate at a very high level - we're talking governmental, you know, ministerial, Member of Parliament level - that had a huge appeal to me because ultimately they are the final say decision makers and everything that will trickle down from that including the national health service.

Researcher: So, what is the national health service set up in the UK?

Interviewee: So, the way that it's set up is that we are taxed and we have a sort of a social tax, which this then goes into the government and then the government pays for the National Health Service so that the National Health Service is free of charge at the point of care, but we do pay taxes to the government for that privilege. So, really the government is where all of those decisions are taking place and that includes a National Health Service level. So for me, if I can make those fundamental changes there, then that is a massive change to a gigantic system, which some describe as like trying to check our a shoal of fish, you know, trying to get everybody to move in the same direction, and it is quite difficult. So, you know, we can make changes at that big, big, top level then, you know, you've got some really good leverage there. You know, that's really kind of how it all started and I think the more that I sort of dug into it, the more opportunities I find, the more people I find who are

really super interested in it, the more groups I find, you know, it's just it kind of a snowball.

Researcher: So, let me just get this clear, as someone who actually had obesity and, that as you say, keeps struggling with, you know, with different symptoms and different ways of how to eat and how to take care of yourself. How do you define obesity?

Interviewee: I mean for me there is just no question in my mind that obesity is a disease for sure. I think being a scientist by background and reading all of the papers and all of the genetic associations, you know, up to seventy percent of your weight is made up by your genes. I mean, that's, that to me fundamentally makes sense. And I also, know people to you know, I grew up with some people, who struggled with it all of their lives and yet they ate less or the same as me and they're probably twice my size. So, how do you explain those people? You know, and I also fundamentally believe that if it was as simple as ‘eat less and move more’ none of us would have a problem, because nobody ultimately wants to have obesity, nobody. It's not something that people aspire to, at least in the western world and in this culture, you know.

Researcher: And you think that definition of obesity is also aligned with the definition of obesity inside Novo Nordisk? You think that's where the company is moving forward?

Interviewee: As a disease, yes! I think the people who are working with obesity in Novo Nordisk, I think they do believe. I mean, it is, and I would be honest, It's a really hard concept to wrap your head around. But I think that is because there's two rationalities in my head that I kind of go through and I do struggle with it sometimes, you know, about really thinking of obesity as a disease, but I also think it's because for my entire life people have been saying it's a lifestyle choice. And when something is

so ingrained within society that is a lifestyle choice. You can't help but believe that it's like if everyone said, you know, the sun is yellow and then actually we found out it was red. We would all still go “no, no, it is yellow”. Hmm But no, okay. That's red. You know what I mean? So, it's really it's a strange concept.

Now. What I would say is outside of the Obesity area [in Novo Nordisk], I think there is more of a struggle, and in fact. I did a survey inside the office about ‘What is obesity’. After the survey, I had a healthcare professional come in and talk about why obesity is a disease. Then, I had patients come in to say why they think obesity is a disease, and then I had a psychologist come in and say that actually there's a massive reason and a massive link with sort of mental health - That's why obesity should be recognized as a disease - and then I did a second survey afterwards to say: “Okay. Now, what do you think?” And you can actually see the shift that more people started believing that it was a disease that before. So, there is an element about - And certainly we find this in our advocacy on a day-to-day basis - There is an element of education that needs to happen in order for people to really understand it.

Researcher: Definitely! I would like to move to a different topic now, but carry on the Obesity subject field. There's a current discussion about obesity today. You think, and after all these years you've been working, let's say, in this environment, and after your seven years working with obesity in the company, have you seen any changes from then to now regarding obesity and its matters?

Interviewee: I will talk about the UK. So, what seems to be happening now is that - and the way that we sort of thought about this from the beginning is - that in order for any sort of change around obesity starts happening, first thing, or the first people that we need to get on board are the healthcare professionals. Okay. Once

they were sort of on board and starting to believe it and understand it and think about it and then we can start looking at public awareness and public perception.

So what is currently happening in the UK? And over the last sort of two years, I've definitely seen the change.

Researcher: Why do you think we should involve first the healthcare professional first rather than public awareness?

Interviewee: Because ultimately the healthcare professional, in my sort of opinion, if they don't buy into a, you know, a disease, then they're not going to talk about it. And, if they don't talk about it, then the patient isn't going to come in and actually ask about it, specially in obesity! because quite frankly the stigma that's associated with it means that most people with obesity don't proactively bring it up in conversation because they're embarrassed or they feel ashamed or whatever else. So if we get the healthcare professionals on board to understand obesity, to open up proactive conversations about it in an empathetic way then all of a sudden it empowers people to go: “Actually, you know what? I do have a problem and I do want to talk to you about this, and I do want you to give me options”.

Over the last years, there has have been published, in one most recently by a professor, Ricky, and, you know, her work has actually showed that there are genes that protect you from getting big, from gaining weight. So, you know, there is such a thing as a thin gene, you know, and conversely there will be one that means you gain more weight. So it's absolutely genetic without a shadow of a doubt. So, so, you know, so there's more and more evidence building. We continue to see it in the press. We continue to have a healthcare professional Community who is building and bringing this to the table. And in fact, it's you know for me is sort of culminated in the Royal College of Physicians, recognising obesity as a disease, and stating that, you know,

“we hope that this will start to address stigma so that we can actually learn how to do stuff”.

Researcher: So, you can say that in the UK there is a lot of new coming research, new laws and statements, for instance, the Royal College of Physicians who just, very recently, in January, consider obesity a disease. Have you been able to be involved in any of these milestones in the UK?

Interviewee: Absolutely. About again about two years ago, I met a professor called John Walsh and he decided that this was his fight and he was going to take the leadership and I was like: “I'm here to help you”. He assembled a team and in the team there were 9 people representative of a couple of different things. So, there were 2 patient organisation representatives, there was the World Obesity Federation (WOF), there were 2 GPs and there were also endocrinologist and specialists in this group. Throughout the course of that first year, the group wrote a position statement, which basically said that obesity should be recognised as a disease. And then, the idea was that they would go around to all of the different Royal colleges and all of the different societies and all of the different professional organisations and ask them to endorse this statement and say: “yes, we believe in this”. So, in June of last year (2018) we held a meeting which was called ‘The Obesity Recognition Summit’ and the heads of the royal colleges and all of these professional organisations got together in a room and debated it and they talked about it: “And this is what needs to happen, this is how it go”. They gave feedback on the position statement that John had written. He then went back and suitors and made any necessary changes that they have requested, sent it back around and then started the process of endorsement and to date he's had 13 different organisations endorse a position statement and the Royal College of Physicians was the one who landed in January.

Researcher: That sounds amazing!

Interviewee: Hahaha! It was a really exciting!

Researcher: What an experience! So you've been able to be completely involved with it and even engaging patients and people with obesity in all the process. That's actually just incredible! But, why do you think it is important to involve people with obesity in these discussions?

Interviewee: Well, I guess this is where all my own personal connection comes into it. Fundamentally, I get it. I understand the challenges that people face and I think, you know, what's really missing and what the government and what the Department of Health and Social care really needs to be very, very aware of is that patient voice. It has to be out there because, as I said before, you know, it's been ingrained in our bodies and our souls and our mind since birth that it's all your own problem that it's all 'eat less and move more' and that, you know, it's a control issue. It's all that sort of stuff, but people who have obesity know that it's bigger than that. They understand that "actually I have tried every possible thing in the world and I still can't do it. So what do I have to do now?" And so, you know, without that sort of knowledge and without that sort of real understanding of the everyday struggles that people face, there isn't going to be changed, you know, because everybody would just say: "You're just lazy", you know, whatever! so I think until their voices are really heard, you know, those changes can happened.

And, if I'm honest with you, the voice in the UK, although it is absolutely growing stronger. It is still very weak.

Researcher: That's something that we can see, for example, in a lot of places when advocating for obesity is quite strong, but still a long way to go because of stigma and very strong traditional conceptions.

Interviewee: Oh, yeah, absolutely and I think part of that is still about, you know, the stigma and the even social inequalities piece of it. It just means that people are not willing to put their head above the crowd and say: “You know what? I am, you know, I do have obesity and I am struggling with it and I need more help than just telling me to eat less”.

That's where our real challenges is: People brave enough, Helping them to become brave enough to actually do it.

Researcher: So, now let's talk a little bit about advocacy. So, for you, what does it mean to advocate for obesity?

Interviewee: that is a very good question. I suppose for me, my sort of, you know, where we're at. Probably been like a real-world situation or whatever. It would be like, you know a protester or someone who's like, you know, really very vocal who is essentially doing advocacy, right? But for me what it really means is: Getting down to a level that people can easily understand exactly what it is that you're talking about. So, for example, and my advocacy, I feel like I build through the relationships that I have with people, so I go in and I visit members of the parliament, and I talked to them and go through the story of obesity and why we're doing what we're doing, and then I tell them about the science behind obesity. I can give them fully, you know, peer-reviewed references and then I can say, you know, “this is why we have a problem in your area, this is what it looks like. So, what are we going to do together to change that?”and it's sort of that real relationship where? You were speaking a language that they understand, that they fundamentally understand, and then, they have that sort of mind shift to go. “Actually, you know what? I really do need to do something”. So it's kind of just, if I'm honest with you. It's a little bit like a sales job. Although you're not selling a product you're selling a concept. Yes, and it's just about it's just about getting

people to understand it. And then, going out and telling others the same thing that you've told them.

Researcher: I can see there's a lot of obstacles when advocating for people with obesity. But what do you think are the biggest obstacles when advocating for obesity?

Interviewee: Yeah, well. Number 1 is that I am on a pharmaceutical company, so I've got to get over that. Number 2, the next sort of biggest obstacle that I face is yeah, they're “just fat and lazy” and it's at the perceptions the social perceptions of actually what obesity is. Then the 3rd one is support: So much bandwidth and so much of the ministers and the members of parliament's time hadn't been around Brexit that they almost have no other time in the world for anything else and even when they do they're very distracted.

So what I started doing lately, and I think I'm going to really explore this, is that each MP has a Parliamentary Assistant so they've got like the right-hand man, which is essentially sort of like fair. These PA they're kind of like a secretary, you know, they made you all to meet you though some and your schedule appointments whatever but they also have their MPs ears very much. So they also have more time and they have less in terms of Brexit decision making things that they have to go to so I actually started meeting with a lot of the PA. And actually, when you actually go in and you chat to them and you talk to them and understand their goals and their aspirations and how they might fit in with some of the things that you're doing. It's really quite fascinating to see how many of them are really interested because I think health is a topic where people understand that that will be. Around forever whatever that health topic maybe but health in general is a topic that will be around forever.

And most of these part of Entry AIDS are Parliamentary AIDS because they want to at some point to become an MP. Do you know what I mean? Just kind of having in their, their nature and in their blood to be the next step up and try to get into Parliament themselves. I'd say it's sort of advocacy from it from a different wavelength. But, I think they are really interested. I think that you know, there's definitely some scope to see what you can do there.

Researcher: That sounds a very good strategy! Just to finish this very, very interesting and very fruitful interview. What are your expectations regarding obesity within the next five years?

Interviewee: Where do I begin? So the one thing that was brought up to me by a very, very high level Minister is that he said “politically this is an extremely sort of, you know, hot potato”, and he said “the reason is because there is no clear definition, even though there is, but there's no clear definition of when obesity becomes a disease”, and he said “so then if you use BMI or waist circumference or a combination of them all”, he said. “what you essentially are doing is say, okay, you have a disease and therefore you deserve treatment but someone who is exactly the same same BMI same everything else don't have a disease and therefore you don't need treatment”, and he said “politically that is going to be your biggest challenge”.

So I suppose for me. I'm ultimately working towards the goal of sort of having some sort of very definable, non-political way of describing obesity when it becomes a disease and so in five years time, I suppose my real hope is that the Health Care Professionals, and the patients, and the professional organisations all sort of band together and come up with this definition then government guys: “I get it!”, you know, even if it was as simple as something like, you know, is there a type of test that you could and essentially you could do a genetic test in theory! I mean, realistically,

because if they've already identified the genes you could then do that test and say “Oh! Well! you've got the genes, therefore we, you know, we will treat you”. So, I think ultimately my ultimate goal is sort of widespread recognition that obesity is not that simple and that the government is actually trying to do more to sort of overcome it.

Researcher: Okay, that sounds very ambitious.

Interviewee: Oh! I know honey.

Interview Guide - Private Sector

Director at Global Patient Relations in Novo Nordisk S/A

Douglas Ordonez

Conducted: Headquarters Novo Nordisk, Copenhagen, Denmark

1. Please introduce yourself (How long have you been working at NN? How long in GPR team?)
2. Could you tell me when your interest in obesity first began?
3. How did you come to be the person who is taking the lead for the obesity matters and projects within GPR-NN?
4. How does NN define obesity? How do most people internally think about obesity, is it the same perception?
5. What about you, is it the same opinion you have regarding obesity?

I would now like to move on to a different topic:

6. What is the current discussion about obesity from a global perspective? Has anything changed during the last years?
7. Have you been able to be involved in any of the milestones mentioned? If yes, which ones?
8. Are people with obesity involved in the global obesity debate? How are they involved? Have you seen any changes regarding this involvement in the last decade?
9. Why involving people with obesity in the discussion?

Let's talk about advocacy:

10. What does it mean for you to advocate for obesity?
11. Do you think it is relevant to advocate for obesity?
12. Do you advocate for people with obesity? How? Why advocating for people with obesity?
13. Are there any obstacles when advocating for people with obesity? Which are the most difficult obstacles? Why?
14. What are your expectations regarding obesity within the next 5 years?

Transcript of Interview with:
Douglas Ordonez, Novo Nordisk Denmark

- Conducted face-to-face on Friday 05 April 2019 in Headquarters Novo Nordisk, Copenhagen, Denmark

Researcher: So I'm going to start recording and of course, the first question will be to please introduce yourself. So, this introduction is going to be used on the paper. I just want to be clear by saying that everything you say is going to be added in the research and the study will be public. Hence, avoid to mention any confidential information.

Interviewee: Alright! my name is Douglas Ordonez. I'm the Associate Director for Global Patient Relations and then I've been working in the pharmaceutical field for about 15 years starting in Medical Education and then working in advertising agency specialising in pharmaceutical in the US before joining Novo Nordisk in 2008.

Researcher: And, what is your background?

Interviewee: My background is actually very far from pharmacy. I went to the New York University. I have a BFA Bachelor of Fine Arts Major in dance and performance.

Researcher: Okay! And how did you end up into the pharmaceutical industry?

Interviewee: So, it's really interesting because I started in the Medical Education side and I started actually as just a part-time and job because this one agency that I worked with hired a lot of like, this was in New York City, and so they hired a lot of like actors and dancers and people with flexible schedules because they needed us to run these 'Phone Banks'. And so, I sort of just got really interested in what they were doing and especially the medical side, because my father is a doctor. So, right, so, yeah, so I've kind of had that medical stuff around me growing up. Which

at the time I was like a kid, you're just like “oh whatever so what my dad does”, but then, when I started working with doctors and looking and working with them on developing medical programs, education programs, and some others, I started really getting interested in and, you know, since I have been involved.

Researcher: So, when did this interest for obesity begin?

Interviewee: So, quite honestly the interest in obesity began specifically working here at Novo Nordisk with obesity, but prior to that, I've always been very interested in patient advocacy because when I was in New York, you know, 1985, and lived there for 15 years, and so at that time, and 1986 of course, was the height of the AIDS crisis and so I was involved with that. Well, it wasn't the first, but it was a major patient advocacy group, and definitely one of the first that showed how patient advocacy can affect policy change. And so the Act-up organisation was the one responsible was one of the many groups responsible, for forcing the FDA to change the way that they reviewed and approved drugs, especially in life-threatening situations, because they used to treat all drugs, you know, this really long approval and review. And Patient Advocates in HIV and cancer said “this is ridiculous!”. You know, “while we are waiting for you to review, this people are dying by the thousands” and so they are the ones who really kind of forced FDA to say “alright, that's you know, we've got to change the way that we review certain drugs”.

Researcher: Okay. So from there you started getting more and more interested in health care and from there connecting the dots with obesity.

Interviewee: Yeah! So, because I think by being a gay man, being a latino man, and growing up in a very small town in Tennessee, I've always felt as an outsider, as an others. And especially, you know, especially the way, it's always angered me the way people is a from, what are called marginal the marginally displaced group, are re

not treated as you know humans, as equal humans to everybody else, and so it's not just patient advocacy. I've always been very involved and, you know, just pushing and pushing for dignity and equality for most all groups.

And so, when we started working in Global Patient Relations and Novo started focusing on Obesity, I got, you know, I was very excited about this because it is I'm, you know, obesity is still one of these socially acceptable forms of stigmatizing that it's still very socially acceptable in most places to, you know, make fat jokes. There are no laws really protecting people with obesity against discrimination in regards to losing their jobs or hiring practices or anything like that. And I think that's another key factor getting obesity recognised as a disease, because then it would be a medical condition which, you know, there are laws against those who discriminate people and to prevent discrimination against people with pre-existing medical conditions. So that would do a huge thing! And regards their legal and rights. It's just ridiculous to think that, you know, people living with obesity still okay to treat them like, you know. That's one of the realities of activities in advocating for obesity.

Researcher: So, how do you come to be the person who's taking the lead of all the obesity projects within Global Patient Relations at Novo Nordisk?

Interviewee: That's a good question. So because of my marketing background, I was the person responsible for all the commercial stuff. And so, that time that included diabetes and obesity and everything else. And so, then, when Charlene came up and took over as director, she decided to make it more aligned with the way that our company actually works: Let's have people responsible aligned with in that therapies. So, I then became obesity focus only but now do commercial and a little bit of R&D and across the other stuff.

Researcher: And do you think Novo Nordisk defines obesity up until now?

Interviewee: So that's a very good question. That's something that also is in a lot of discussion in the clinical world as well and then regards to how obesity has been defined. And so, the basic definition of obesity is based upon BMI (body mass index) and the standard cut off level of obesity between people who have excess weight to become then technically obese is about a BMI of 30 to 32, 34 depending in some countries, Asian countries have some little bit lower.

We used to talk about obesity in terms of just like “okay there was people who had obesity and then people with who were morbidly obese”. And so, that's another thing that we're trying to do is, you know, change the that language and talk about obesity in classes. And so you have class 1 Class 2 and class 3 and those. And again based upon class 1 would be 30 to 35 BMI, Class 2 would be 35 to 40, and then class 3 would be anything that would be the BMI above 40.

Researcher: It is the same perception that you have about a obesity?

Interviewee: No! my perception has changed a lot since working here I think. That's good. And I think it's a, you know, for a lot of things because, this is just this is what's really fascinating about working and pharmaceuticals and working in the medicine is watching the development of science and watching us as, you know, world as we learn more about the way the body works. We learn more about the way diseases work, you know. I mean, so my example, that I use to compare this to is - you're too young to know this - so prior to 1984 stomach ulcers were considered a lifestyle issue. And so, they were treated primarily through diet and people, to reduce the stress in their lives, and they were given and acids to, you know, to help with the acid in the stomach has on and it wasn't until 1984 that they realized that they discovered that the majority of people with stomach ulcers, recurring stomach ulcers, it was actually caused by a bacterial infection. And so, I mean you think about it 1984.

I mean for me wasn't that long ago, you know. Even HIV! think about how HIV! the virus wasn't discovered and, you know, until 1980. 84 85 86. I think the virus was finally isolated and you know and in the HPV virus, you know, and the 90s and them being able to identify the link between that and cervical cancer. And so, we are continually constantly learning more and more about the way the bodies works.

And so, you know to find out okay, no! obesity is not a just a diet lifestyle thing, I mean, they're very specific biological things happening in your body or happening in the bodies of people living with obesity that prevent them from losing weight. I mean, it actually this is the best thing I ever heard was this one doctor, anthropologist talking about the fact that our bodies evolved not to lose weight, our bodies evolved to gain and store wait because in the past that helped us whenever there was a famine that came through or whenever we were injured and we couldn't go out and hunt and gather our own food, that way kept us alive until we were better again until the path. There is nothing in our evolution in our genetics to make our body lose weight when it has excess weight it will always want to keep it and hold it on and so it's just it's been fascinating to really get into the science and learn more and more about, you know, what are the biological causes of obesity in conjunction with the other things that are going on like genetics and the environment and all that other stuff such as the economical factors and urban areas.

Unfortunately, we are living right now in a perfect storm for the obesity epidemic because food has become so cheap and available, but it's not nutritious for food, but it's still easy to fill up on its high fat, it's high salt. It's not, you know, it's all these other things that we're not supposed to be eating but it's just so convenient and easy for people to have access to this. Yeah, and then and on top of that we've moved away from either rural or industrial lifestyle. And so, those areas continuing to shrink

especially industry in factories. I mean, more and more things are becoming automated and have robots and so on and so you see more and more jobs and more and more people moving into a more sedentary lifestyle where we spend most of our day sitting at a desk and you know watching looking at computers.

Researcher: So, for you, your definition of obesity will be not only a stage of how our bodies are reacting towards the outside world where we live in let's say the urban areas the economical factors, right?

Interviewee: Yeah. So those I wouldn't say that as a definition of obesity. I would say that as contributing factors to obesity. Okay, and then so and what is contributing to a person developing obesity?

Researcher: So then, for you obesity will be a disease?

Interviewee: Oh, absolutely!

Researcher: Why?

Interviewee: Like I said, if you think almost like an autoimmune disease where your body's normal function sort of starts going a little crazy. And so, and they, you know, the things that they normal process then actually becomes a bad thing. And so with obesity back to the whole evolution and that our body is developed to store all this fat and so on that normal process then becomes a bad thing is because we try to lose weight and you know and you get down to a certain level and then your body kicks in, and starts releasing hormones to say, “okay, you you're hungry. You need to eat” when you don't really. It slows down the way your body actually processes food and burns calories. And so, all of a sudden, the natural process, of evolution process, you know, doesn't starts becoming - it's still working the way it should but it's become a challenge in a barrier than to people's health because my evolution says I need to keep your weight on but then the rest of your body your heart is going no. There's all this weight

is causing problems on this. So that's why I consider a disease because it is a biological issue that then affects a person's overall health.

Researcher: Okay. So let me just move on to a different topic. It seems there is a current discussion about obesity from a global perspective, has anything changed since the moment you started listening and being a little bit more involved in this obesity debate towards now? Have you seen any change in terms of how people understand obesity, new research coming into the perspective?

Interviewee: Well, absolutely! I've seen a change in regards to their there's a movement within the healthcare profession than more physicians and more healthcare professionals are really pushing the Obesity as a disease and a perfect sample is in the UK just this past January the Royal College of Physicians release their statement saying “we view obesity as a disease”. That change is coming.

I do see people getting more educated in regards to the factors contributing to obesity. However, it's a change that is very, very slow.

Researcher: Oh, yeah, you can see it and I see it is very slow in. In Europe and also in the United States. Who do you think it’s going a little bit more ahead, Europe or the USA?

Interviewee: Well, go back, the World Health Organization (WHO) recognized as a obesity as a disease as early as 2005 so they made the statement as such, but there really hasn't been getting anything done to address it then as a disease, and say like “okay if this is a disease, where is that task force? Why isn't this being talked about like as part of the NCD Alliance?” you know, “why aren't they working?” You know, “why aren't we working to address this as a disease?” There's a lot of task force out there talking about prevention, which is great and what it needs to be done. But, that's like saying: “okay we need to prevent cancer. We need to prevent smoking. We need

to prevent all this stuff and then ignoring the people who are actually dying from cancer". So their needs, their needs to be that treatment task force as much as their needs to be the prevention trust force.

Researcher: So, do you think people with obesity is not involved in this global obesity debate?

Interviewee: No, they're getting more and more involved. There are a lot of stuff that are happening to this point. I think the US has actually taken the lead in regards to advocacy on the advocacy aside. And so, you have the Obesity Action Coalition (OAC), who is a very strong patient advocacy group and doing a lot. France, actually, has a really strong advocacy group as well. And so, they're getting you know, there are a lot more countries that are slowly coming on board and more patients are really starting to get into obesity advocacy. The interesting thing is that you have 2 different advocacy movements happening in obesity. And so you have the people, the patients living with obesity going: "Okay, obesity is a disease, we need to treat this, we need to talk about the all". And then you have the 'body positive movement' that goes "there is nothing wrong with being obese. I am what I am supposed to be". They are focusing on respect and focusing on dignity and all that stuff, but they refused to talk about the health consequences of it. And there's, you know, there's a lot of people who say "look I have obesity, you know, or we have a large body, but my health is fine" and it's like, "well, yes, but it is it's fine now! But you cannot say that it will always be fine. Can you not see that? This may actually increase your chances for developing something that down the road..." so it's a very interesting to see 2 advocacy movements growing at the same time who are just so different and their messages and what they're saying and what they're promoting.

Researcher: And why do you think it is important to involve people with obesity in the discussion?

Interviewee: This gets back to my HIV and ‘Act up’ and all that stuff. It's just: We are the people who are living with the disease, I mean, we are the people, we, of course, should be talking about ourselves. Of course, of course, we should be advocating for our rights and for how we're being treated and what kind of drugs were being given.

So one of the first drugs that became available for HIV was this drug called ACT which, you know, and again it was a learning curve. We look back now and doctors were doing what they could with what information they had. But, you know, giving people high doses of ACT made them really, really sick. So it was comparable to like previous chemotherapy drugs. It wasn't, you know, the treatment was almost as bad as the disease. And quite honestly, there are many people in the healthcare profession who have that attitude: “Look you should be grateful you're getting any treatment at all”. And it's just like, “Well... I am, but there's got to be something better there”. You know? why should we settle for treatments that are worse than the disease? and the same with patients living with obesity is like, “Okay. Yes. It's important for them to have a good diet”. Yes! it's important for them to exercise, yes! But that's true for everybody! You know, and so it's just like for them to say “This is your only treatment: is to diet and exercise” when we know it doesn't work. It's like that's when it's time for patients to go: “Like wait a minute doctor. You're wrong. This doesn't work. We need to come up with something better”.

Researcher: So, you were talking a little bit before about these two different movements in advocacy in obesity. Have you encountered any experiences with any

of them? Like for example people, from both advocacy groups, having different discussion together?

Interviewee: So far I haven't personally. But, we did have an issue just recently with Marta, and she was working on this event at our R&D, one of our R&D locations in Seattle, and she was identifying, you know, some major online influencers to attend this event obesity focus and there was this one who is a 'body positive', was part of the body positive movement that has a huge following, and so Martha reached out to her and said, you know asker about, you know, attending this, and Marta said something about our D program and the woman was like well, "what's that?" and Marta, without thinking said, "you know. just to show it stands for disease experienced expert panel". and the woman immediately "what? you've got the wrong person because I don't have a disease. I am not sick, you know, please don't talk to me again".

Researcher: Auch! So, usually what our team is working on is in this part of the obesity group who does belief obesity is a disease.

Interviewee: Yes.

Researcher: Okay!

Interviewee: Yes!

Researcher: Do you think there is any obstacle when advocating for people with obesity?

Interviewee: Oh, absolutely! Absolutely! I think the majority of the people still refuse to believe that obesity is a disease or still refuse to believe that it's anything other than just a matter of lifestyle.

Researcher: So the obstacles are actually knowledge and stigmatisation?

Interviewee: Yes.

Researcher: Let me ask you to 3 more questions. What are your expectations regarding this obesity debate or this obesity advocacy movement within the next 5 years?

Interviewee: So, I hopefully will see, we will see, more healthcare professionals come around to understanding that obesity is a biological issue, that it does, often times, require some sort of medical intervention, It can't always be solved by lifestyle changes of diet and exercise. And so, there will be more focus on that and more treatments and better and more available for patients who struggle because right now, you know, the number one treatment medical intervention of course is bariatric surgery. And, I mean, that within itself should prove to most people that we're talking about some sort of biological biological issue here when, you know, 85% - 80% of people gain weight again after surgery.

Researcher: And when they gain that weight again? Is it within the next year or within the next year?

Interviewee: It always depends on people, it normally takes longer. It's probably more like two to three years out after surgery.

Researcher: This is not that long.

Interviewee: It's not. Yeah! it's not that long and some people, you know, it's a very small percentage of people who actually lose the weight and keep it off, and you're just like, “oh, well these people, you know with their surgery and obviously they're not following their diet or they're not doing there”. So, that is just like, I know many people with surgery! They have to follow their diet! their stomachs physically cannot do handle massive amounts of food or the massive amounts of fat in fatty food and stuff like that, there's all these things that happen. There's just being called dumping where it's just if they eat too much fat or are they, you know, it goes through

the button the stomach can't process it, and so it pushes it out through the body as quickly as possible. Yeah, which can be a very unpleasant experience for people.

And so, there's you know, hopefully to get back to your question and time, better, better treatments and even less invasive treatments will become available and help people understand people with obesity. Also, I mean so many people look at it as just like, “oh if once I lose this weight, everything's going to be good”. And it's just like “hmm, no! because it's, you know, you're going to have to fight continually with your body for the rest of your life to keep that weight off! It's never going to be easy! It's never going to be anything! You can't just forget about it and go! “Oh problem solved. I can just get back to doing what I used to do”. So, it's also, you know, we need to do a lot to help. Better educate people living with obesity and from an emotional and psychological support to understand what it means for their lives and how to help manage them. So there are my expectations.

Researcher: So, from the pharmaceutical perspective, or let’s call it from a Novo Nordisk perspective, what do you think will be important for the company to advocate for democracy in the advocate for obesity as a disease debate?

Interviewee: As a disease? So, first and foremost: Get a recognition of obesity as a disease, because from a legal perspective, once it is recognised as a disease by, you know, established medical organisations and governments, then both doctors and patients can have a legal platform to stand on to demand access to treatment and coverage of treatment and just say : “Okay! Look there's, you know, you can't deny us treatment anymore, this is this is a disease. You've got to treat it as such”.

Researcher: Okay, so you think that will be kind of the focus of Novo Nordisk.

Interviewee: Yeah. I think that's a HUGE step. It's like first getting it recognised and then, of course, they'll always be the continued advocacy in regards to, you know,

once it's recognised locally, how can we get treatment? How can we get coverage? How can we do all this other stuff? So, you see like the first step is getting that recognition and then further on start the treatments.

And also stigma itself in the way that people with obesity are treated because, I mean, you know, you don't treat a person with the disease as like going “it's all your fault”, and you don't remove their jobs just because they're sick. You shouldn't be allowed to! And other things, I think that's why that's another reason of why it's so important to get a recognised as a disease and educate people about the biologically aspects of It, so you can start having this conversation. Then you've got to stop treating people this way! This is not their fault. You've got to stop blaming them and shaming them because of this, you wouldn't do that for any other disease.

Researcher: Well, some people do unfortunately. That's another story.

Interviewee: Yeah.

Researcher: That's all. thank you very much Douglas! That was great!

Interview Guide - Researcher in Clinical Trials

Senior International Obesity Trial Manager in Global Development at Novo Nordisk

Flavia Christina Ladwig Robles

Conducted: Headquarters Novo Nordisk, Copenhagen, Denmark

1. Please introduce yourself.
2. Could you tell me when your interest in obesity first began? For how long have you be living with obesity?
3. What does it mean obesity for you? Do you think your definition is shared by other actors involved in obesity matters (HCPs, pharma, legislators, researchers, patient organisations, people with obesity)?

I would now like to move on to a different topic:

4. From your own perspective, what do you think is the current discussion about obesity? Has anything changed during the last years?
5. Could you describe how the obesity debate has been changed in the last decade?
6. Have you been able to be involved in any of the milestones mentioned? If yes, which ones?
7. Do you think people with obesity involved in the obesity debate? How are they involved? Have you seen any changes regarding this involvement in the last decade?
8. Why involving people with obesity in the discussion?

Let's talk about advocacy:

9. What does it mean for you to advocate for obesity?
10. Do you think it is relevant or necessary to advocate for obesity? Do people who advocate for obesity need to live with the condition?
11. Do you advocate for obesity? How? Why advocating for obesity?
12. Are there any obstacles when advocating for obesity? Which are the most difficult obstacles? Why?
13. Do stakeholders involved share the same understanding of obesity than people with obesity who advocate inside the global debate?
14. What are your expectations regarding obesity within the next 5 years?

Transcript of Interview with: Flavia C. Ladwig Robles, Novo Nordisk Denmark

- Conducted face-to-face on Tuesday 11 May 2019 in Headquarters Novo Nordisk, Copenhagen, Denmark

Interviewee: My name is Flavia. I was born in Brazil. I am 42 years old just recently become 42 last Friday.

Researcher: Congratulations! Happy birthday.

Interviewee: Thank you. Thank you. And I am a pharmacist by training. I have worked for the past 20 years in the clinical development field and I have worked in different companies and small companies in Brazil, but also multinational companies. Then the last 14 years, I have been in Novo Nordisk, I was in the Brazilian affiliate. So I work as a CRA a monitor and what was called back in time 'Local trial manager' or 'project manager' on our local perspective; and the past 10 years, I have been here in Denmark working as a 'Global project manager' and I have done basically phase two, three and four trials and yeah. And then working in different therapeutic areas. I have worked with different medicines and products. And now I'm in the busy to the last year. Okay, so I have been working with obesity just for the last year.

Researcher: Why are you interested in working with obesity?

Interviewee: I have a personal interest with obesity. I'm a person living with obesity. It is started the year that I become pregnant and I was 16 years old back in time. I gained 18 kilos in Total and by the board I just lose 9 kilos. So those other extra nine over a period of 15 year more or less become 40 kilos extra, and then despite my efforts in controlling the diet and and also exercising and also taking medication, that was available in the market back 15 years ago, I didn't succeed in losing the weight

that I needed and I was becoming I was becoming resistant to insulin and then because of my weight and they're accounted for a BMI 37, I was really afraid to turn as a Patient type 2 diabetes, so I decided to go for gastric bypass surgery, and that was 11 years ago, and then I succeeded and losing those 40 extra kilos. And I have pretty much kept that weight a stable weight until the last years.

So the last 12 months I can see that is being a slightly increased in my body weight despite the fact that I have not changed my diet, I have not changed my physical activity compared to the last decade that could explain why. I think that as much as I have discussed this with doctors and people that knows about obesity, It seems to be a natural that the body wants to be bigger and I have made a surgical procedure,I have been counterpunch faithing what the body wants, but it's not know now the body come up with a new strategy to actually gain more weight because that is how it feels comfortable.

I think that it's much of what is unknown about obesity to us, that nobody really understands why this is happening and why after a decade my body seems to putting weight on? But it's again, It's my struggle. Although my BMI today It's twenty four point something almost, 25, so we could say it's a normal BMI, but I am a person living with obesity because I still have to t be continuously watching what I'm eating, watching how much I'm exercising in order to keep try, to kind of prevent the weight gain or minimize the weight gain if it will come anyway.

Researcher: And how did you end up being in trials in obesity?

Interviewee: I think in obesity was just the company had this franchise and for a while, I wanted to be part of the Obesity franchise because it is a way to work for something that is personal to me and use all my technical knowledge or my Professional Knowledge, but it wasn't possible before, I was heavily involved with the

projects in diabetes that I had before that and I was... They obesity area was still growing so was not many positions opened yet so I mean it wasn't just in the last year that I succeeded in moving from installing in devices to finally obesity.

Researcher: How does a Flavia's day at work look like?

Interviewee: I am heavily involved with lots of things for patient engagement. And then, for example, I am part of the DEEP which I'm very happy for, but and that this membership has actually triggered me in to a lot of other patients and engagement activities, so I'm very much now connected to people that is hearing from patient's experiences while they are in clinical trials. Novo Nordisk is not a good company, It's not a good example yet in engaging with patients during the clinical trial. Engaging in the fact of asking the patient's for their experience during and after the trial. I don't think we don't have a system a systematic way of collecting data and that's going to be necessary for the next coming years. The Regulators are going to ask us this so Novo Nordisk needs to start implementing it.

Researcher: Why knowing the experience of patients after the trial will be that important?

Interviewee: Because then we can design we can know the pitfalls of the tribes and we can design better future trials with a less burden of the patient with the core of the things. Traditionally, we ask way too much to the patients, we collect way too much data that we never used. So it's I mean historically we have an issue between Needed versus Nice. We ask too much because it is just nice to have that information. It's nice to have another thing, but then we ended up having the trials are a big burden to our patients.

One classic example is what we've seen in one of the programs right now. The first visits for the patients, the screening visit, it can take up to eight hours! You were

asking a person having obesity or of being overweight to come spend the whole day doing all sorts of Assessments: having blood samples, taking and doing an ECG, and doing another exam, and seeing a doctor, having a physical examination, and then waiting for something else, and talking to it dietitian, and talking to talk to each patient, has this screening visit. that's the first visit. What should they expect for the rest of the trial? Right? So I think this whole thing about the patient engagement what we leave today, we live in an environment where Regulators, Pharma companies, doctors, scientists decide what is good for a patient. We do not ask the patient, “What do you expect with a new drug?” “Yeah. I have diabetes” in one case, “I have obesity”, “Yes, I expect to lose weight”. Yeah, but also I suspect that perhaps I don't lose that much weight, but I improve other parameters, you know, my cholesterol will be nice, nicer, or lower not necessarily normal. We don't ask patients. What is the endpoints for the patients?

I have been a in a seminar about patient engagement recently and it was about you know, those healing the woods that never heal in the skin. So when people design a dressing, when you want you to have a dressing point will be painful when you take it off. The dress aims to have less pain as possible, but that's what doctors think, that's what caregivers think, families and so on. If you ask a patient, what is the most important thing? They will not say ‘pain’ because they have painkillers to deal with the pain. They would actually expect that our dressing can controls the smell of the woods. Because that has a direct impact with the social interaction, they cannot see other people, they cannot go out. And just to give an example that when don't ask the patient's what you would like to have your the treatment. You're not addressing completely the endpoints and that makes no sense because in any other market research if you want a new smartphone, you asked users: What do you want to do

with this? But we're not asking the patient's how they are actually using the drugs and this goes across their particular areas across companies, you know, even the Regulators are just now starting introducing guidelines on how to deal with patients. Ask the patients in the beginning of the trial for the trial design, ask for their input to the endpoints, ask for their input about the questionnaires. You want to choose submit them. And then during the trial as to the patient's how they are doing, I mean, what is their experience with the trial what they were feeling about it and also, When the trial ends because it's also something that we have to keep in mind. If you ask a patient about something about the trying during the trial the patient may think “Mmm. I think I have to answer what they wanted to hear in order to continue in the trial”. While if you ask at only the end of the trial will be a completely honest because now the trial is over so that it's nothing to do with it would be most honest and transparent feedback.

Researcher: And what is happening in the trials with obesity? Have you seen for example, I don't know, the patients join the trials because they get a lot of benefits rather than actually the research that can get out from the trial? Because, I can imagine for obesity is not as complicated to find, you know, participants.

Interviewee: Yes, you're right. It is being, it's a bit easier to find patients for obesity trials. So we don't have problems in terms of Recruitment and to my knowledge none of the trials have problem in recruitment. I have a specific problem in my trial but it's a different thing, the patient's our: first, kids. So it is the kids and their families that have to agree to the trial. The kids are between 6 to 12 years old and right now that I'm recruiting those patients. They actually, they have an underlying disease, and then those obesity is the main problem so they get obesity because they have this underlying disease. It is a genetic disease, which does just , It gives them more crave cravings for food that they are looking for food all the time since the very early age and

they don't understand. So it's the picture of a typical family will be having the kitchen the cabinet's locket, the fridge locket ,the garbage you have to take away because the kids will go to the garbage. So all the food you put you have to put the food away because they were eat and chew, they can't say simply cannot stop in the head. And again, they are kids they do not have a comprehension yet. So they just eat eat in it. And as something is wrong in their system because they never reach the sensation fullness the full and sensation doesn't exist for them. And then if their kids are left unattended during childhood They can actually die earlier. There isn't a direct impact in their life expectancy because they are become so big big big and then shows all the copper beeches shoe obesity type 2 diabetes that are other hypertension and they metabolic syndrome basically and this is lovely you don't destroy. This trial is global, seven countries are in, but but this is a different thing because the patient has obesity because this other genetic disorder and this genetic disorder also tricks a lot of other issues. Meaning those families have a complicated kid home that is going to doctors all the time, all different especially, and on top of that you are asking a patient to come to our trial and the first week of the trial at the first month of the trial they are coming every week. So just to explain a little little bit of a burden that a clinical trial is for patient and then you can say this is could be one benefit because if you don't get usually if you don't get a good medical care for your condition being in a trial it's like heaven. You have the best specialists in the field. You get it you get a check it up all the way, you know inside out. That's great. And if you go for countries in development that do not have access to care. That is a blessing. That's what we see a come from Latin America. But if you go to South Africa and if you go, you know that kind of injury would say and that that's what it was for talking about European patients or even. Best some of the US Patients they already have the access to care and they will be just a board

and for them because you asking we ask much more and that is much more is that historically the pharma company and then perhaps going specific to this one have not been Keen in those. Let's just ask for needed know just how is put a little bit more and put a little bit more and this is done. Usually by the scientists. They are you know, you know, they are brainstorming but they are not in at the clinics. They not deal with patients on a daily basis. They cannot they have difficulty in seeing. What is the meaning if you ask one blood test more and that kind of stuff.

Researcher: Okay. So after your experience with trials in obesity and your experience to your own personal life, how would describe obesity today?

Interviewee: For me obesity is a disease, but I think a lot of problems that we see comes from the fact that it's not everyone, is not a consensus yet. It's becoming an awareness but you see is a long way to go. For me is a disease and has to be addressed as such for example, I cannot accept why we cannot get a drug. If you are above 25, I cannot accept that because if diabetes of someone having diabetes is with the glucose 1 milligram per deciliter above it's getting something. It's getting something. Perhaps not getting insulin yet, but it's getting something, now, We're not getting anything. So, from BMI 25 to 27, the only thing that is recommended is diet and exercise. This is something that we hear since always, so it's not really changing anything.

And because it's not recognized as a disease when the patient has no control, the blain and shame is there, the lack of trust - the healthcare professionals do not trust their patients. When I say to my doctor, “but I have tried! I have controlled my diet, and I always have been, I always keep track of my exercising”. There is no trust, we have to prove, I mean, being a person living with obesity is that I have to prove that I have worth of help, that's the reality. Today for any person living with obesity, doesn't

matter the BMI, once you start telling your story to the hcp, you have to go on probation for a period of time.

You also have to go on probation here in Denmark if you want to have a gastric bypass, you have to go on probation before the surgery. You have to lose some weight to prove the doctors that you have willpower, efficient willpower, to keep up after the surgery. You see, it is incredible! You have a patient that is suffering from something, but that's the problem because nobody has recognized that it is something external to willpower.

Researcher: And during that process the patients get any help from nutritionist, dietarians?

Interviewee: Yes in the trial, before the clinical trial, before the bariatric surgery, or even before. Yes, I can tell I don't know. I don't know how it is here in Denmark, but I can tell my case. My BMI was 37 and the protocol for surgery back 11 years ago was: Patients that are BMI above 40 or both can go to surgery regardless any comorbidity, or patients above 35 if there is at least one comorbidity. I had three I have fat in my liver. I had problems in the joints simply because the joints could couldn't carry all the way. And I had already some slight my lung function was it slightly compromised. What's not much, I was not having apnea and but something was wrong when we did the screening tests, lung function tests. Then I qualified because I wasn't BMI 37 and then as a preparation for that surgery. First of all, I was in a multidisciplinary team. It has of course the surgeon. Yeah, but also the psychologist, the dietarian, the clinicians, the nurses. Yeah, so it was a number of professionals involved taking a good care of their expertise areas to help the patient.

Researcher: Do you have a good experience?

Interviewee: Yes. When I was there, they had good 10 years or maybe 15 that they were performing the surgery

Researcher: Was it free?

Interviewee: No, was payed by the insurance company.

Researcher: Okay

Interviewee: And also the public health could also provide but then it's longer quiews. That is long quiews. I never try ahead. I was paying the for insurance. That's very common for our worker in Brazil. We just rely on the insurance company we and. So as a preparation for the surgery was explaining very, very good explanation about the risks involved. I actually join lectures where patients from that clinic the head already is I'm talking about the huge Auditorium like full of patients that were being presented with the surgery. So they were hearing the benefits and the risks, both from the surgeons but also the patients so and then they actually made very specific that we were presented with the cases were failures occurred. So patients that had regained weight after the surgery or despite the surgery and never lost The amount of weight they wanted, and then explaining why so, you know a lot of short term complications that are I mean, do we true the basically do introduce surgical procedure itself, but also in the long term because there is a lot of long-term.

Can we imagine someone that is huge for so many years and uses that I mean, the body image is something actually you get us some sort of protection and suddenly when you just reduce the weight, you'll no longer yourself. So, then you have all the psycho things happening in you're looking at the mirror because that happens in few months in few months, You are completely different person, and then do you feel different? also do you behave differently? are you different? So all It is Well documented, marriages that have been dissolved after the surgery because suddenly

the partner doesn't feel confident because while now, You know, why my wife or my husband how it's so great and then it's going to cheat on me or others are going then. It's a lot of Cybex true that you have to be aware and prepared for it. I think that was really really great. Because it's shown with the reality what happened, So be prepared! and also in my case and it was case for all the patients. They were also seen by a psychologist prior to the to the surgery where those consultations the psychologist would also assess how illegible the patient was should take the surgery because the surgery should be seen as a trigger to help for the weight loss process not what will make you... so what you reduce your body weight will be basically everything in the new behavior. You going to adopt after the surgery in place. The surgery is a mechanical thing right, is reducing the stomach. It's just making physically impossible you have so much food, right. And then if you combine that mechanically prevention with a Changing Behavior, having better choice of food, because now you reducing weight now you finally can move more because your joints are not so overloaded, then you actually then Walking more and I started looking for other physical activity become that now with the I could actually do without hurting, right?

So all these things that the change in behavior that I had during the two years after the surgery was actually combine, and of course good with the surgical procedure itself, was what helping me in succeeding reducing 40 kilos and the patient has to understand that because. Especially for countries that has this, you know, too paternal approach towards medicine: the patient's put their lives in the doctors hands. So, you going to his limit no, no, no, it's you as a patient that is going to do that, you go through a process and learn understand and it's not somebody else doing it for you, is not a surgical procedure doing for you. It's huge! You have to it's also about ownership.

Taking ownership for your own process, because then it can last for longer. Okay and successful for life time. Hopefully.

So coming back to, just thinking about the question you asked: what is obesity? It is a condition that is this too... just because it's not seen as a disease completely yet. We are in baby steps for treating obesity. It's incredible to have our magical doctors are treating us without having any speciality in obesity. I mean, they have no idea. Everything they are doing and basically on the poor research that has been done so far. The magical schools are not prepared. We basically do not have specialist taken care of for us. We do not have people understanding the the impact of this on the society. I couldn't care less if I'm a trustfull for not taking medication or not. I just know that one part of this planet should be its overweight. And if you don't not do anything now, including giving drugs to them including putting them on surgery doing whatever has to be done, That number tomorrow will be half of the plan and then how long you take to the everybody in the same page? Everybody has some slightly gaing of wait, everybody is not fitting in the airplanes anymore. How long is going to take? And I'm more worried about all the people getting there in the hospital. Should they having a myocardial infarction, whatever, name it, and it is because of obesity but that doesn't show up in the medical journals, right? The suggestion is not sure what that all that's what “because of its was a cardiovascular disease”, was a whatever, whatever, whatever but they don't try to, they're not tracking why so everybody's treating like it's. Treating as we didn't exist. And that's that's a problem. We are suffering a our health systems cannot afford this.

Researcher: How do you apply in all these thoughts into your work into the clinical trials that you are managing? Have you been able to see any changes during the last 6 months?

Interviewee: Now we are trying to improve the trials when designing new trials, we are trying to implement the learnings, the good learnings that we have. This is a dynamic process that we always have done. But of course, again, when we as we are talking about a new area that is new to everyone, and everyone is learning together. The scientist, the doctors, even the patients, everybody's learning together how to deal with this, how to tackle the problem. So, we are try, but I think it is true a long run, It is a show a long run. I attended Nashville last year, the Congress. And it is impressive to know the basic discussions among the scientists or the doctors, you know University people and so on about obesity when I compared to other Congress that I have attended like for cardiovascular disease, for diabetes.

We are, the stage that we are today is like diabetes 20 years ago.

Researcher: And what is that stage?

Interviewee: It is very basic. It is basically people who still wondering if it is a disease or not. This is true people wondering! And the reason segments saying to not labels that obesity is a disease is because then suddenly the insurance companies will not cover because it is something that it was pre-existent. And I do recognize that is very problematic, especially for the US Patients relying today in insurance companies, everyone relying on insurance company might compromised when suddenly the patient comes and say “I have a disease”, and the company goes, “Yeah, but you didn't told us back them”, patient: “Yeah, but it wasn't recognized as a disease before”. But nevertheless is pre-existence, so it's not covered, right? But I can't I simply as much as I some people will suffer because of this but I think on a long run for the next generations, the only way is that we will strive to have this recognized as a disease and then you take away the burden from the patient because right now at someone having obesity you are blamed for your own condition. We don't have other patients

that are blamed for their condition, right? Like other patient that was together with me on the stage. Nobody says to you if you have depression “go home and do some serotonin, now go home and produce some insulin”, or, “Come on! pull yourself together and put in produce some insulin”. Right? I mean you've ever tried to stop having inflammation in your joints feel yourself together, That is what we are asking the patients: “stop eating a lot and do something, come on! because your condition is poorly how you behaved, that is all” No, it's not. No, it's not! There's a lot of things that we don't know. What about the genetics. My doctor the one I have had throughout the 10 years living here in Denmark. She is as skinny as the first day I met her. And then she thinks that is so clear if it works for her why why when she tells me stop or reduce the amount of food and do more exercise? because it works for her, but doesn't work for me, but she doesn't understand that she's wasting her words turning these about me.

What about patients that have zero obesity knowledge and just had the courage to start the conversation about their weight with their doctors and then receive something like this? Do you think a patient will ever come back to that clinic?

Another approach is, and that is very much the magical doctors, unfortunately this have this, they have this how do you say in English? They think they know everything: “Oh, you know, I see if you eat less food and do more exercise, that will be fine”. You don't know everything, stop and listen to me. Let me tell you if not… First of all, she doesn't have the time because the health system doesn't allow her to have the time that I described the 15 years that takes to go over 40 kilos, my ideal body weight, and then what I have done afterwards, and now the situation I'm for the last 12 months where I see my weight increasing again. She doesn't have the time nor even to listen to me.

And then the next question. Well, okay, but. “Who is going to help me with the diet? Because if I need a plan, you know, I'm a pharmacist. I'm not a dietician. So we don't have access to one. “Oh I have to make up then the plan by myself?”. Oh, yeah, of course. They do not have also physical therapist or whatever whatever person because then I asked okay, how much exercise should I do? And she said: “there is never too much exercise you can do”. And then I start wondering “what happen in case of injuries”. You know, I'm but no it's just no sense. It's just to tell you that it has no sense. You, you clearly see the person has to listen to any word you say and not education on how to treat patients. They're actually coming and saying “I'm worried about my weight. What should I do?” they have no idea! They cannot help because they do not have to treat patients and get rid of their own bias. they have not been trained.

You know, the problem is even deeper because it is there in the medical school. Look there is something that is a disease called obesity and then that are about and then you should treat an array should treat her spectrally your patients who should trust. I've tried but this whole mindset is not there yet and don't ask me how how long it would take to be there. I just hope that I don't know. That someday we'll be there for the sake of the next Generations because I don't think that that this obesity probably will stop, today is 650 million. And this number is just increasing sadly. Sadly.

Researcher: I have one last question is. I mean clearly you are advocating for obesity. Have you been able to share these experiences not only within the company but also outdoors?

Interviewee: I have have started this process but I must say that I have not succeeded yet in being fully external. That's my goal in kind of challenge this kind of go beyond Novo. It's just happened that I'm working for a company that is working at

that has the Obesity portfolio, but I wanted to go beyond that and that's where I'm very thankful too deep because woke me up for something that I haven't thought I could use keep could be more vocal about this problem.

So I'm trying now I made connections with the Danish Obesity Patient Association and I'm trying to work with them what I can do for them, what I can help because luckily I am a patient that doesn't need help. Of course. I still have my struggles, but there is a lot of other people. but I'm well-educated, I'm open-minded to the problem, I'm not afraid of telling my name and say I do have the problem. It is a problem. I leave with obesity today.

Researcher: And what about locally within your work with your colleagues?

Interviewee: I do that all the time. I do that all the time. I am asked by people, ask questions, ask for my feedback for my input on something and I want to hear from a patient perspective: “What do you would say about this? Is this so we small things I have been approached by some of my colleagues and that is being very, very nice to be able to help and that's what I really I want to do with my whole experience, It's help, help others.

Researcher: And what are your expectations regarding obesity within the next five years? What do you think needs to change dramatically within that period of time?

Interviewee: I think, I hope that in five years is more consolidate the concept of obesity as a disease and that we have a disease that needs to be tackled, and then we will change up our judgment on how we treat patients, how we do with patients, how, how we see patients. Because again, although it's not the terminology, I was I think I was a patient. I don't have any problems in being called the ‘patient’, but maybe because I'm hcp myself.

The moment that we realized we have a disease and then we take the burden from the patient, we then we are really assessing what is the root cause of the thing because right now everybody is wasting way too much energy and time blaming the person. It has a psychological issue behind. Yes, in the end you could see as an addiction, but with a problem because, alcohol, you can abstain alcohol smoke wheat drugs whatever sex you can try to not do this. Right? but you cannot live without food. So you are dealing with something that is addicting you every time and this the relationship that someone establish with the food and if it is a bad relationship, if it is a comforting relationship because it's comforting me because I feel ugly, it's because I was sexual abuse or bulled. There was a trauma that it's behind whatever is the reason so you have there is a psychological component. That is very strong.

My husband is also a psychologist and he specialized in Eating Disorders, so he has been working with people having anorexia, bulimia and obesity. He is also Brazilian and when we were in the country, He was working with patients for bariatric surgery as a psychological counsellor. It's very important before the surgery, but also after the surgery to deal with the problems of a new image a new person, a new me, who I am?

Yes, you have to the patient has to have willpower in some extent, willpower should be recognized and should not be in denial because first thing is the first phase is denial: I'm not fat. No, I'm not big on. Oh, it's fine. Everything is fine. Maybe I am my weight is in the roof, so.

Interview Guide - Patient Organisation

Chair of WLSINFO

Ken Clare

Conducted: Scottish Event Campus, Glasgow, Scotland

1. Please introduce yourself.
2. Could you share your story and your experience with obesity? (When your interest in obesity first began? For how long have you be living with obesity?)
3. What does it mean obesity for you?
4. Do you think your definition is shared by other actors involved in obesity matters (HCPs, pharma, legislators, researchers, patient organisations, people with obesity)?

I would now like to move on to a different topic:

5. From your own perspective, what do you think is the current discussion about obesity? Has anything changed during the last years?
6. Could you describe how the obesity debate has been changing in the last decade?
7. Have you been able to be involved in any of the milestones mentioned? If yes, which ones?
8. Do you think people with obesity is involved in the obesity debate? How are they involved? Have you seen any changes regarding this involvement in the last decade?
9. Why involving people with obesity in the discussion is so important?

Let's talk about advocacy:

10. What does it mean for you to advocate for obesity?
11. Do people who advocate for obesity need to live with the condition?
12. Why advocating for obesity?
13. Are there any obstacles when advocating for obesity? Which are the most difficult obstacles? Why?
14. Do stakeholders involved share the same understanding of obesity than people with obesity?
15. What are your expectations regarding obesity within the next 5 years?

Transcript of Interview with:
Ken Clare, WLSINFO Patient Organisation

- Conducted face-to-face on Monday 29 April 2019 at 26th European Congress on Obesity (ECO), Scottish Event Campus (SEC), Glasgow, Scotland

Researcher: I'm just gonna start recording now. I would like to start by asking you to please introduce yourself.

Interviewee: Okay, my name is Ken Claire. I'm from Liverpool in the United Kingdom. I've retired. I started as a nurse when I was 16 years old. I worked initially in mental health and then as a general nurse, and I work 40 years and the Health Service and then retired worked at very last jobs as in the Health Service were computers in local doctors surgery. I had Bariatric surgery living with obesity all my adult life.

Researcher: How old were you when you have the surgery?

Interviewee: It was 2002 so I was 41. However, I started taking my obesity seriously in 1999. And the reason for that was when I grow up, I used to talk about the year 2000 and we didn't know we'd have mobile phones, but nobody believed that we thought the world was going to be a very different place and when I was born in the 60s, I didn't want to be old. I want to live to be 21 or me life. Yeah. When you get to 40, you start thinking “this is serious”. I'm getting old. I had a child and 1988 with my wife. I'm still with now. We've been married for 31 years tomorrow. And this is a treat. She's come to Glasgow. She works as an occupational therapist and she saw my weight goes up and down and she and my GP. I was working with Tommy. There was a weight management clinic. I was able to get refer to that and that's where it decided I wanted some help, and that was where I was offered biotic surgery.

Something happen after the surgery. I was very sick. Every day or vomited I thought that was how you lost the weight. Nobody had told me I didn't know anybody

else. I know it so I need help. I need friends. So I set up a website and I got a librarian friend of mine and we set up a website and we got some money off the surgeon who did my operation and we got a group of people from the local newspaper and we met in my house: “Let's talk. Let's get together. Let's come together and have regular meetings”. We started meeting once a month.

Researcher: And this is right after for your surgery?

Interviewee: Yes. And the first thing we did was - there was to was no Facebook. Nobody has smartphones. So this is 2002. So, I learned how to write a programming language. Seems crazy! I stayed up all night. I run up a survey in my bedroom. I was crazy. I was I didn't know it at the time, but I was high.

So I set up this website and, I said, you know by Christmas, this is September, by Christmas will get 10 people. On Christmas we had a hundred and ten people registered and then Google pick those up and we really work for the Google algorithm because they were not for profit. We were patient leads and it's went through the roof of our members. We got a thousand members of movements. And it was tremendous. And then we have an official launch on the 27th of January 2003.

Researcher: What did you lounged?

Interviewee: The name of the charity is WLSINFO and I got set up a committee and I did it for me. I wanted some help.

Researcher: When you say that you did it because you needed some help, is it because sharing that things with others make you feel like you were not alone?

Interviewee: I didn't know if my experience was the proper lives experience and it wasn't. You shouldn't be sick every day, every meal whatever. I also did a blog and blogs are still going but not so popular. So 2002, I said, I wrote a Blog every day for four years. I wrote everything down on the internet and I said “one day somebody

may find this interesting". My surgeon read me blog and called me at home. He said "come in. I want to see you. It's not right the way you vomit".

And after he fixed me the weight started dropping off. And my life changed completely before the operation I couldn't so I was 216 kilo, top ways, almost needing a wheelchair some situations, still working, still driving. All of a sudden I had energy like never had before. People don't talk about it, but when you are that big you got lots of problems in your skin. You can't wash yourself properly. But my wife is an occupational therapist, is a job in the Health Service like a physiotherapy, but they help you with activities of daily living. And she git to perform some basic tasks, but she helped me to get independence and very soon I realized I didn't want to work where I was working.

Researcher: Why?

Interviewee: Why? I wanted to help people with obesity and I'm a nurse. I went to the psychiatrist. I don't know what happened. I had been in antidepressants for years. And he said what's happening is all the antidepressants have stored up in your body fat and now you've lost the body fat, your body is releasing the antidepressants. I didn't believe, I was high as a kite. and then being depressed in the past. My mental health wasn't going very well.

And I got diagnosed with a high again. It was like, you know, like when I did the software for the project. Yeah, I was high. Looking back up inside you couldn't do that now on the normal unless you're on drugs or something crazy. No, I'm not super intelligence. I was better than them. But I just did it and I look back, how do you manage that? and at work they were worried about me? My mental was a problem. I'd also developed a problem with alcohol. And that happens a lot. I don't know you pick that up in your jocks and people with bariatric surgery, but something happens. I think it's

on two levels one is about the reduce capacity in your stomach. 3 levels. Another one is about much the enzymes that metabolize of change and the third that's more important is people who live with obesity sometimes try to fill a hole in the soul. You know what I meant? So it's an emotional component of my knees if that's removed or then what do you do and some people turn to alcohol, some people turn to shopping, or relationships, sex or eBay. It change your behavior. So we're in the UK where our service and I have very good pension. So they gave me money to live. I was very upset, and then I thought “this offers me a really good opportunity”. So I gave up carried on with a child. I got a little job working in the hospital and my job was to help with the photocopy. And I saw patients who had bariatric surgery. So I used to go and see them.

Researcher: And do you manage to talk to them about the surgery and stuff?

Interviewee: Yeah, the education and a roast and education package. And then I mean I still know people remember me from when they saw me and asked what they thought was going to be terrible. I come and told them what it'd be like because the best thing that happened to me when I was in hospital. There's a guy called Jeff. He is like a normal BMI guys. I decided to trained and got skills of being a specialist Nash. Great about writing and your life is going well, charity grown from strength, to strength nationally now. It has probably Ten thousand members in the UK also, and some in America, but not many and some in strange places, you know, like the Emirates. Some members and people who have moved from the UK to Australia. I mean, yes, the internet is global, but where it works best is people locally.

Researcher: How could you define Obesity today?

Interviewee: Things have moved on. It's a lot more sophisticated that it was. There's a lot more out for people in the UK still a National Health Service problem.

There's not enough treatments available. Our charity has improved that. There is 1.5 million people in the UK need or qualified for bariatric surgery out of 52 million.

Researcher: Do you think there has been a change within the debate of obesity?

Interviewee: Yeah. Well the charity, we've got a national reputation. I've probably got a national reputation. Sometimes good sometimes bad. Sometimes, I see my role sometimes to ask the difficult question, beyond popular. I just been in a meeting and I said doctor said “what we need is, we need to bring all the top all the patients on there are our organization”, but the patient's don't want them. What's enough for us? I've been invited to places that I never go to, go into Parliament, with a chief medical officer who's a top doctor in the UK. I never thought I'd meet him. He asked me opinions of lots of things.

Researcher: Have you been able to drive, for example in the parliament, some of the discussions?

Interviewee: I've been involved in them. Yeah. Although I had pneumonia last year. I have not the best to help. I develop alcoholism. And I have not drink for 13 years. What I'd like to think, that is someone's discussion of obesity in the UK and surgery people, say give and all the top dietitian and UK work either job with it when call the Obesity empowerment Network. Which is run by a doctor called Rachel, work for every six months, but to be honest, it didn't deliver what I thought it would because it was impatient centric enough. I'm strong about a patients, this is about patient lives. It's not about what a doctor wants or surgeons think is good, you know. I've got lots of friends that are surgeons, but they're not God, but the problem is their job makes them feel like God.

t took me a long time to understand what a family doctor is. Number onem the small businessman, number two a doctor, and once you start realizing that your eyes open and a family doctor in the UK, in 95% of the cases, won't do anything that doesn't has any money. Why should him?

Another problem is severe obesity. I work, I go to a practice and my doctor is fantastic. He's the best doctor in the world and he really is, Frank. In that practice is 850.000 patients, as far as I'm aware today, there's only five of them have had bariatric surgery. So if the average GP got 250.000 patients, how much are they going to know about bariatric surgery? Nothing. So why do we drawdown education to them?

We were talking about this group most of the members have had bariatric surgery and that's a misrepresentation. Most of these people in Europe will never get bariatric surgery? So what are we doing wrong? I bet you the DEEP, most of the DEEP in obesity, how many percent of people who wasn't have bariatric surgery? So I think we've got to have some alignment there because I don't think we're telling the right stories. Do you agree?

Researcher: Yes. Maybe. I actually never thought about that, but I think you have a very good point there because if you put patients in a group, it needs to be some sort of diversity, you know, and then have some sort of agreements from two or more different perspectives. So, I think you have a very valid point right there. What is ECPO doing regarding that for example? Are you guys looking for someone who has not getting bariatric surgery?

Interviewee: We are not in that level of the discussion. And I think we should have a normal distribution site. So I think we should be looking at people [without bariatric surgery] and tell their story or letting them tell their own story.

The other thing I think we should be doing is helping patients to tell their own story. I don't think we do enough. I think the patients need to be strengthened to tell the story that can be very difficult. And I think we need a variety of people across the board.

Researcher: I actually have a question. What has being the biggest obstacle when advocating for obesity?

Interviewee: There's a couple. Ignorance. People will bring it on themselves, bias. I'm not prevalent in healthcare professionals Although it's got better and I think we've got to accept things have improved and have changed. And accept that you can't keep on fighting when people, majority of people who were here in this building with you and me today are interested. However, how many people is out there without knowing or getting support? And those are the people we've got to target, so you've got to go beyond.

I can think of and I'm willing to be challenged. It's something like when your kidneys do not work and it will interfere with your life on lots of level. And I don't see any other disease that is exactly like obesity, for me it does. And I think that's part of the problem.

I think there's lots of different types of obesity, the systems map about the causes of obesity and I believe, you know, we'll find an increase a single gene causes obesity. I think there are separate bunch over there. That's a single cost genetic problem and nothing else is ever going to change. We see people with environmental problems, the same people with things about the way you were brought up by their family also, things about the food needs and, and then trauma. And I think what we what, I want to do, and I don't know if I don't see it. When I talk to people with obesity sometimes, a guy or that girl “is very like me. She's got a lot of what I've got” and I see

that and I think that. When you look at our four side diagram, you can cost the people you can start to understand them. And I think that's something that needs to be worked on and have enough signs. There is a downside to that. There is a lot of people, patient that I work with, who want to say “it's a disease and it's so there's nothing I can do”. Yeah, I bring in this chronic model that works for me, people live every day with the chronic disease, but you have to make changes.

Researcher: Ken, one last question. How do you think the discussion about obesity is going to be within the next 5 years?

Interviewee: Well, I tomorrow we are launching Obesity UK which is bringing together 2 bigger organisations. 40,000 members across the UK. We have been talking over the last two years. So that's started. And yes, at 24 hours away from launching, I've got more questions and answers, but that's okay. We're coming together and we're going to be a formidable force. It is still another organisation in the UK, Obesity Empowerment Network, I'm a friend with them, but they have a different set of values though that by physicians while our aim is to be a patient lead group. You know, we're going to have a new way of working. We're not going to have the old website, we are going to have a new website. We're going to have a new set of values. We got a new and lot of patient materials and I suspect the next six months is going to be like a bit like a new relationship. I know. Maybe I'm going to compromise and get along and it won't always be easy. But at the end of the day the important thing is we're doing it. Well, I think that we're going to become the organisation to go in the UK. Obesity UK is going to become the goal organization for user and patient involvement and obesity in the UK.

Interview Guide - Patient Organisation

Board Member of Obesity Action Coalition (OAC)

Pamela Davis

Conducted: Skype Business Call

1. Please introduce yourself.
2. Could you share your story and your experience with obesity? (When your interest in obesity first began? For how long have you be living with obesity?)
3. What does it mean obesity for you?
4. Do you think your definition is shared by other actors involved in obesity matters (HCPs, pharma, legislators, researchers, patient organisations, people with obesity)?

I would now like to move on to a different topic:

5. From your own perspective, what do you think is the current discussion about obesity? Has anything changed during the last years?
6. Could you describe how the obesity debate has been changing in the last decade?
7. Have you been able to be involved in any of the milestones mentioned? If yes, which ones?
8. Do you think people with obesity is involved in the obesity debate? How are they involved? Have you seen any changes regarding this involvement in the last decade?
9. Why involving people with obesity in the discussion is so important?

Let's talk about advocacy:

10. What does it mean for you to advocate for obesity?
11. Do people who advocate for obesity need to live with the condition?
12. Why advocating for obesity?
13. Are there any obstacles when advocating for obesity? Which are the most difficult obstacles? Why?
14. Do stakeholders involved share the same understanding of obesity than people with obesity?
15. What are your expectations regarding obesity within the next 5 years?

Transcript of Interview with:
Pamela Davis, OAC Patient Organisation

- Conducted through Skype Business on Monday 06 May 2019

Interviewee: I have been a nurse for 26 years service message degree in 1993. And then I got my bachelor's degree in nursing in 2009. Yep 2009, and I knew that I wanted to continue my education that should be able to focus more on the like the business side of obesity and Bariatric Treatment. I felt like the providers were all. Yeah, like They wanted to help more patients but they didn't really know how to get more patients in, as far as I know, people knowing that they were appropriate for treatment that you know how to face all of the insurance Optical that kind of thing. So, I got my MBA in 2014. With a concentration in leadership, so, from that. Well, that's kind of the education side.

So then I have always always struggled with my weight since day first grade. I think I was you know, it was the heaviest kids in the class and that, you know, make fun of picked on that first day and that lasted all through High school as well. So, when I had first started working as a nurse, we took care of patients that had bariatric surgery. This is course back in 1993. And at the time those patients all had an open incision. Yes, they've long incision and remove Intensive Care Unit overnight on the then later overnight and just you know, they were sick and I had never really thought of myself being sick enough to need to have surgery to treat my weight, but then over the course of the summer I started having symptoms. I thought I was having cardiac symptoms, but we actually figured out that it was my gallbladder, which I have my appointment of my gallbladder and I heard an ad on the radio for bariatric surgery and I decided to learn more about that. I had my bariatric surgery in 2001 and I really need

like that. That really solidified that I wanted to work with people affected by obesity, that I wanted everyone to have the opportunity that I have had to have treatment.

Researcher: It was easy for you to get access to biometric surgery? How is the how is the Health Care system in your state?

Interviewee: So at that time it was really easy because that was 2001 and my husband worked for General Motors and it was you know, that was a union, it was a unionized workers and it was like really easy for me to get approved. It was like less than a week from when the doctor sent the information off till when I got approve.

Of course that has changed a lot in the US over the last several years. It's become, you know more difficult for people to get approved. They have to do certain types of weight loss the can. And depending on the insurance that can vary anywhere from the three-month attempt to an 18 months.

Researcher: That's crazy. And you think it's getting like that because of the number of people they say willing to take their surgery or is more into the government economical issues?

Interviewee: I think, I think it, I think it falls down more to it's not as much government as it is the individual private employers and whether I like to purchase a rider to cover and bariatric surgery on their insurance plan. So, I guess in a way it could be the government, if the government at you said that obesity needs to be covered on every basic insurance plan, like every other, you know, type of chronic disease. Yeah, but they have actually had tried that in a few State and what has happened is that it will be included on a state plan. But then they make that state plan really not very accessible to the individual by either making the criteria very difficult or not having any pain such a little reimbursement that then none of the providers, like

the surgeon through the hospital, will accept that insurance because the reimbursement is so low.

I also feel like it's very much a numbers game in that. I don't think it's because more people are wanting to access surgery because I think they that they're still a wide misperception that surgery is for. That are you know, five six hundred pounds that it's not for the five steps weren't female delays 234 pounds and has a BMI of 40. So, you know, I think there's there's that issue in 2017, 228 million people in the US had a BMI that put them, you know, where they would qualify for surgery if there were only two hundred and twenty four thousand surgery. So, I mean it's, it's really still that less than 1% of the people that are appropriate for treatment are actually accessing the appropriate treatment.

Researcher: Yeah, so the trouble is actually access to treatment rather than just, you know, having available surgery.

Interviewee: Yeah, so and and you know I learned over. Of course, you know I had surgery and I two years after I began working in a surgery program and that was our three years laters, 2004, and that is about the same time that the Obesity Action Coalition was being formed and I know, actually it's funny because one of the, one of the vendors that we work with at our Hospital. That you know, she worked with a company that provided support for bariatric surgery. She was the one that told me about the Obesity Action Coalition. So I reached out, I reached out to them and you know sent my application and I wanted to be on their Advisory Board and then I had a conversation with Joe on the phone and a little under a year after moving to the board of directors and so many things that kind of come together.

I think when you when you are an individual affected by the disease process that you also treat, that it all becomes kind of inner woven like there's no clear line

between. This is work. This is volunteer. This is advocacy. This is like every volunteer organization that I'm a part of also serves patients affected by obesity in some capacity. So, you know the OAC. I took also part of the Eating Disorders Coalition, Tennessee, they covered, you know, like the full spectrum of eating disorders. Several committees on the American Society for metabolic and bariatric surgery. So, you know, it's just like it's kind of always a blend and like you said like I know when I'm being Interviewed or writing articles or, you know, things like that. I know which had them, where you but that doesn't mean that my brain isn't also thinking about. This could be something really good that, you know, we could incorporate at support group or this is something that you know, obviously there's a need for this we need to create a course for that. You know that type of thing.

Researcher: So yeah, going back a little bit about what you when talking regarding advocating for obesity. What is the meaning of obesity for you?

Interviewee: I think you can really boil it down to giving a voice to those who aren't ready, willing or for whatever reason, able to share their. The people with obesity are often afraid, you know, if they speak up or speak out that they're going to be ridiculed, belittle, that type of things, and I can give you a real, I think it's a good example that explains a lot.

So, in one of our visits on the hill there were five of us in our group and it just so happened like it. We didn't plan it this way. It just so happens that all five of us in our group had surgery. Yeah, so, we actually, we went in to meet with with one of the legislators and they had a brand new healthcare legislative aide and at this point the OAC it already made multiple visits on the hill, but this, this person was near and she had not heard about. She acted to all kind of introduce ourselves and, you know, say why we were there, so as we introduce ourselves and that, you know, like we had had

surgery and the Commodities that we have had and the effects and she says “so you're a surgery organization” and I said, “no, no, we're not. We're not a surgery organization. We represent thousands of individuals affected by obesity” and she thought “but all of you here today have had surgery as well” - “Yes”, I said, “let me give you an example”, I said: “today since we have been here. We started a hotel. We walked from our hotel here to be Senate building. We've been over to the house building, back to the Senate building, and now we're back to the house building. With 130 pounds, I could not have made this trip because I could not have walked this far and, you know, back and forth with all these visits. So each of us that are sitting here with you have undergone successful treatment for our chronic disease of obesity. It just so happens that each of us, the treatment that was the most successful for us to the surgery and that has allowed us to be here. There are many, many other patients like that that have not yet undergone successful treatment in order to be here and that's who we represent”.

Researcher: What did you say about that?

Interviewee: She was like, “oh, oh, okay. Okay”. She's like “I so, I get that!”and I choose taking copious notes. I mean, she was really, she was really good and then in a weird Quirk of Fate the following week, so that was in DC, So then the following week I was in, in Nashville, at our state capitol with the Tennessee Eating Disorders Coalition and it just so happened that the representative like that she worked for but he was coming down the hallway in the in the state capitol building. So like I made sure I got right in line with him. He was shaking hands. So as he come down and he shook my hand at the “oh, it's so nice to meet you. I was in DC last week and I met Ruth in your office”. Hmm, and he stopped and he said “well, now what were you talking to Ruth about? And so, you know, like I hate to say this but you know in that

moment, I took off my Eating Disorders hat and I put my OAC hat back on and I gave them, you know, like just really breathe as you know, I was there with OAC and you know, we're very fortunate in Tennessee that our state cares and covers bariatric surgery. They don't cover all treatments, we don't have it for all of our state employees and in that put it was his and he said “will you keep Ruth informed, because she's the one that lets me know everything. I need to know” and then he was gone. It is like a brief light. 90 second encounter at most, but that it was kind of one of those things like it. It made it full circle for me to really see that “yes going and talking to you know, a healthcare legislative aide that looks like they're 12 years old and you're you know, you're not sure if they're really getting it or not. And then like seeing the actual legislator and then saying yes, “that's the person you need to talk to. I'll follow up with them” and then making that connection that you are someone that sought out sought them out both in DC and locally to make your point. I, it just reinforced to me that okay, you know, sometimes people do listen to our voice and like with our with the ways of the legislators are in our country.

You can't expect anybody to know everything about everything. So, you know some of our legislators there are a few that haven't Healthcare background, but you know, very, very few. They're the minority not the majority, you know, their lawyers and farmers and marketing, you know, they have multiple different backgrounds and what I find is that you know, Check by doctors. They want to look like they know everything about everything and if you're not the one willing to educate them on the topic that's important to you, someone else will do that. And you may not like how they educate that person. Yeah, it could be just as easy that somebody go in and have a meeting with them and talk about you know “that obesity Is not a disease” and that, you know, it reinforce the concept that is just all a “lack of willpower” and you know

blah blah blah if he's got to offset all the other voices that they're hearing a buzzing in their ears when you're doing.

Researcher: What are the obstacles when you advocate for obesity? You thing is like what you mentioned, this bias and stigmatization the still among many people?

Interviewee: Yeah, and and we actually, actually co-authored an article and very active times just this past month that looked at bias instead bias and stigma among healthcare workers specifically even among those that treat patients with obesity. So, we develop our our biases very early in our lives and it is really difficult to overcome those once they are ingrained and Ted Kyle explains this or goes over this in a study that he shared actually just went over this last week that: While you're seeing a decrease in explicit bias, you're seeing an increase in implicit bias. So it's kind of like I equate it to racism and that people understand, most people, understand that it has become Politically Incorrect to make fun of people of color people, that are ethnicity, gender related, you know, those types of issues. So instead of been making those comments publicly, they still have those thoughts, they just realized that they're supposed to keep their mouths shut and not share them publicly, but it doesn't mean that they really change their way of thinking and like we're not even to that level yet with obesity. When you look at one of the things that we've highlighted in the last couple weeks through the OAC was Jay Leno went on Jimmy Fallon and did his angry rant and it was all about obesity. I mean, it was just it was bad and it right, that right before that, there was a CVS episode of blue blood that you know, they, the whole story line was around and officer had had bariatric surgery and then use that information to blackmail him to get him to do with a one of them to do because, you know, you want people to know that he had had bariatric surgery to deal with his weight. So, you know, it's one of those things like it and both of those both of those

things aired with in like a couple of weeks of each other. And it's just kind of reinforces publicly and in the media that well, you know, “it's still okay to make fun of fat people because you know, they did this to themselves”. So and it's like no we had you know “research that would fill the Coliseum showing that you know, Personal accountability is a contributing factor, but it is not the sole source of someone's weight”.

Researcher: Have you seen any changes during the last year's when people is addressing obesity? Let's say, the last decades?

Interviewee: Yeah. Definitely! I think, I think that definitely things are getting better. And I think that the way that things are getting better is that we are in the, we are at that Tipping Point right now where before everyone would Black to Jay Leno and and they would have been like ha ha ha, you know, even if it was an uncomfortable last that no one would have called that out. Now people call it out. And then as a response you have people who are like, “well you're just being insensitive. That's ridiculous. Jay Leno makes fun of everybody”. But then you have, you know, you can open it up and actually have a meaningful conversation about it. So, I think that we have moved the needle in that now people are open to having a conversation about obesity as a chronic disease, about obesity treatment and the lack of access to care and Truthfully the lack of access to Providers. I don't think by any means that we are you know, we have it conquered but I think when you see celebrities. That you know, they've had surgery and they're willing to speak out and talk about it that, that is helped. I think when you see more plus size models and more designers doing that size clothing and you know, like Christy Mets and this is us, you know, you're seeing more and more things become more commonplace. Which opens up the opportunity for additional conversation about it

Researcher: The way I see it is that Indeed a change has started but it goes very slow.

Interviewee: It does. Yeah, it does and any one of the things that we try to use as a platform is that again, it kind of goes back to insurance and to coverage here in the US that so, all of our government is a government funded health plans Cover bariatric surgery and we have been lobbying them through the OAC to cover obesity medication. So that our Medicare covers surgery, our Medicaid for those that have you know that are below the poverty line cover surgery. Tricare, which is the insurance for our military and their and retirees cover surgery. For federal employees cover surgery, and I believe for the federal employees that now covers medication. So the part of what we've been trying we being the OAC and the actually OPM which is, It's like a whole network of organizations like The Diabetes Association, the sleep apnea Association, Nash, like all of these other groups have joined us. So when we do our lobby days we talk about not only. That not only has a supporter of obesity organizations that also the support as these morbidities that are directly related to obesity and you know part of what we're what were lobbying for is that you need. It's great that. Our government covers surgery, but they also need to have a counseling with a dietitian. They need to cover the Obesity medications that are out there. We need to have truly comprehensive coverage because, you know, not everybody's ready to go from zero to surgery and they should, they be many people can respond to treatment as you know, a lower level of treatment without having to go to surgery. Yeah, so I think that we're seeing move. There because like I mean Joe and Dad Kyle there on the hill like almost weekly, you know, they've been to FDA hearings. They that he liked to all different kinds of Organizations and group meeting to discuss this. So, I think we're definitely seeing movement there.

I think the information that, that never helps with words for the action study those here in the US and then the international results that we just saw last week shows that, you know, it kind of always been that disconnect of ‘primary care physician don't want to bring up the weight discussion because they're afraid of making their patients mad and they won't come back and patients don't want to bring it up because they want their doctor to bring it up’. Yeah, and so, you know, like you've got this huge gap, like everybody wants to talk about it, but nobody wants to start a conversation.

That's so you know, it's like so you know, my thing is I think we just like to really like wave a magic wand and make it better. We need to be able to educate everybody and meet them where they're at. So, you know, like at their level, like we need to be able to educate Healthcare Providers on appropriate treatment options and how to initiate the conversation with their patients. We need to educate the public that obesity is a chronic disease and then buying whatever thing they saw on TV at 2 a.m. with a double your money back guarantee is not going to work that yet also, like I will use it so much information about bullying kids not only by their peers but by their teachers in their family and I mean like you just got to be able to get people to understand that you wouldn't bully the your the child in your home that had cancer you wouldn't be a teacher wouldn't bully a kid in their classroom. That was you know, undergoing chemo. So why would they think that it's okay to bully and shame any other child? And I mean, it's just it's amazing to be some of the stories that you hear.

When we were doing treat adolescents and some of the stuff that they would tell us and you know the stuff in their chart. Like I just wanted to go to school with them. Then white beat people up for him.

Researcher: Okay, so just one last question for my part. After all these days you've been involved, and after all the things that you have being telling me, what is the meaning of obesity for you?

Interviewee: What is the meaning of it?

Researcher: Like if you have a definition of it, what would that be?

Interviewee: Okay, so I think that my definition of obesity has nothing whatsoever related to a number on the scale or a number on the BMI chart, it would be that is when an individual, when individual has the level of excess fat storage or issues with processing calories to the point that it affects their mental, physical, physiological or psychosocial health, then they have a diagnosis of obesity and they are worthy of seeking and receiving treatment.

Researcher: What are your expectations regarding obesity within the next five years?

Interviewee: Well, I think because there's so much research coming out and there's so many new treatment options in the pipeline and because it is becoming more, especially acceptable not the right grades, It's becoming I think we're increasing awareness among Healthcare Providers slowly, but surely, that obesity is a disease.

Over the next five years, I see more more individuals with obesity being comfortable having a conversation with their doctor asking for assistance with treatment saying, you know, I just can't do this alone. One and that's the thing is they shouldn't be doing it alone. They wouldn't treat their high blood pressure alone. They wouldn't treat their diabetes alone. Why do we expect them to treat their obesity with you know, over-the-counter hopes and dreams that get them nowhere.

Interview Guide - People with obesity

A person living with obesity

Kesha Calicutt

Conducted: Facebook Call

1. Please introduce yourself.
2. Could you tell me when your interest in obesity first began? For how long have you be living with obesity?
3. What does it mean obesity for you? Do you think your definition is shared by other actors involved in obesity matters (HCPs, pharma, legislators, researchers, patient organisations, people with obesity)?

I would now like to move on to a different topic:

4. From your own perspective, what do you think is the current discussion about obesity? Has anything changed during the last years?
5. Could you describe how the obesity debate has been changed in the last decade?
6. Have you been able to be involved in any of the milestones mentioned? If yes, which ones?
7. Do you think people with obesity involved in the obesity debate? How are they involved? Have you seen any changes regarding this involvement in the last decade?
8. Why involving people with obesity in the discussion?

Let's talk about advocacy:

9. What does it mean for you to advocate for obesity?
10. Do you think it is relevant or necessary to advocate for obesity? Do people who advocate for obesity need to live with the condition?
11. Do you advocate for obesity? How? Why advocating for obesity?
12. Are there any obstacles when advocating for obesity? Which are the most difficult obstacles? Why?
13. Do stakeholders involved share the same understanding of obesity than people with obesity who advocate inside the global debate?
14. What are your expectations regarding obesity within the next 5 years?

Transcript of Interview with:
Kesha Calicutt, Person with Obesity

- Conducted through Facebook Call on Sunday 05 May 2019

Interviewee: I am Keisha Calicutt. I am 39 years old. I'm a Mother and Elementary special education teacher. I'm also in school. I'm in graduate school at Southern Methodist University and recently started doing some real estate development with my partner.

Researcher: Nice. That sounds very interesting! And, could you tell me when your interest in obesity first began?

Interviewee: I was fairly normal weight most of my life. I was just bigger than the other kids. and, because I was bigger than the other kids, I thought I was fatter than the other kids, but when I look back at pictures of myself as if I was a fat girl, I was just, you know, more muscular more taller just physically bigger. I remember when I was in fifth grade, we had to weight for PE and I remember I weightes 147 pounds. I remember how traumatic that was to weight in front of everybody and has everybody make fun of me for weighing what I weighted, but, it for me it wasn't just that I was bigger than the other kids. I was also smarter, and I was also one of the only few black kids so there were several things that kind of singled me out to kind of be picked on and I was younger.

I was fairly normal weight actually, probably between 16 and 20, I could say that I was borderline anorexic. I didn't really struggle with obesity until I had my first pregnancy and well my only pregnancy, and I got started gaining weight as soon as I got pregnant, even before I knew I was pregnant and I couldn't figure out what was going on, and I was just desperate and I said, "I'm going to go to Weight Watchers".

And the day that I woke up to go to Weight Watchers, I rolled over and it just it felt like my breasts would just like explode that was like this isn't normal. And, so the day that I found out I was pregnant. I was actually planning to go to Weight Watchers because I'd already probably 10 pounds in two weeks. And from there I gained 75 pounds with my pregnancy and I didn't lose any, I breastfed and everything in my obesity for me was triggered by my pregnancy and my, my hormones changing. And I lose a little weight, but then I gained a whole bunch more and it just got to the point where my back was hurting, my joints were hurting. I just didn't want to go anywhere. But the time my son was probably about 2, I was sitting down and I went to go look for him and he wasn't there and I looked out of the window and he pushed the screen out of the window and he had run down the sidewalk. And I tried to run as fast as I could behind him to try to catch him, but I couldn't! My obesity it was trapped me in my body no matter how hard I ran. He kept getting farther and farther away and just you know by the grace of God and neighbor about three houses down happened to come out and he scooped him up and he caught him and brought him back home. And so for me that was the moment that I realized “I had to do something about my weight” because and wasn't able to be, I wasn't able... my body made it so there wasn't even able to protect my son!

Researcher: How old were you when that happened,?

Interviewee: Maybe about 30... yeah, yeah. In my early, early 30s.

Researcher: And, what did happen afterwards when you realize that you need to do, you know, something about it. Did you start joining, for example, the Obesity Action Coalition?

Interviewee: I hadn't heard of the Obesity Action Coalition at that point. But I had heard of Weight Watchers and Tops which is a volunteer organization that's very

similar to Weight Watchers taking off pounds sensibly, and I went there and I had to get on the scale for the first time. I hadn't gotten on the scale. So, one of the scale said I had 347 pounds. That was a shock to my system! I didn't know that I'd gotten that big. And I went there for a few months, maybe that's three months, and I didn't really lose weight. And I join forum like Obesity Help and other things just trying to find something. I was really desperate! At that point I didn't go anywhere, I didn't do anything. I was ashamed, embarrassed by the way that I looked. It was, it was painful to move, it was tiring to move and on the forums that's what I found about this new procedure called the 'gastric sleeve' and I kind of mentioned it to my husband at the time and my mom and I didn't have insurance or anything. So I didn't know how it was going to do it. And my mom actually offered to pay for half of the surgery. So it was January 19th, and I went. January 19 2010 that I went for my consultation and on February 19th 2010 is when I had the sleeve surgery.

Researcher: Could you tell me, what is this a sleeve surgery about?

Interviewee: It's the gastric sleeve where they remove the greater curvature of your stomach and they make it so that you can eat less food.

Researcher: Okay, so it's kind of the same of the bariatric surgery or is a little bit different?

Interviewee: It's a type of bariatric surgery.

Researcher: Okay. Okay, and then this was in 2010 and did you start seeing some losing or some results dramatically or it took longer than expected?

Interviewee: Within the first six months, I lost 100 pounds.

Researcher: Wow, that's very fast.

Interviewee: Yeah! And then the first six months I lost a hundred pounds and I started getting out and going out and being active. And I remember that one of the

things that most kind of scared me was my son's classmates making fun of him because he had a fat mom, like those were the things I worried about for him. It wasn't even just for me.

Researcher: How did you decide to join the Obesity Action Coalition?

Interviewee: Well, in 2012, they had an event it was their inaugural event was in Dallas and I'm and I live in Dallas. That's where I am. And so that's how I got involved with the community and I initially got involved with the community because some of my favorite personalities, Michelle, was there and that's before I knew I was Michelle, you know when she was just egg faced and she was just somebody I followed, somebody who gave me inspiration and it was in 2012 that I decided to join the Obesity Action Coalition.

Researcher: Okay, and why did you decide to join the organization?

Interviewee: Initially joined because I felt like there were so, it was, it was a community of people who understood me. It was a community of people who didn't judge me for having surgery. I felt like I took the easy way out. It was a community of people who understood the struggle of obesity and understood the struggle of trying to remediate obesity.

Researcher: And after all these years that you've been you know experience the surgery and being am on the community that actually understands what it means to have a obesity, what it means obesity for you today?

Interviewee: Well, I'm not quite as small as I'd like to be, but I'm also know when we are near. 350 pounds. So right now if you would have asked me three years ago, I probably would have thought that I had it all figured out, but you know Mother Nature she's she know your body does what your body wants to do and even though I'm doing all of the same things that I've done, I eat pretty much the same, I'm not quite

exercising as much, but I'm doing everything that I've done and it's not working anymore. So, I would probably, I would have said three years ago, “I have it all figured out” but now with, you know, a little bit more age and wisdom, I realized that I actually I don't have it all figured out and that obesity truly is a chronic disease and while I may not be as small as I want to be, I like to say that my obesity is in remission. And something that is in remission, It doesn't mean that it's cured, It means that it needs constant vigilance, constant monitoring for it to stay in the vision.

I hate it when people say “it's gone forever” or “it's cured”. No. No, it's just, it's in remission, now is in constant remission.

Researcher: Do you think that definition of obesity being a diseases as you just described is shared by other actors involved the Obesity debate? Like for example, let's say a HCP or researcher or pharmaceutical companies.

Interviewee: No, I believe that they think obesity is a state that you either are in or you're out of, and that there are discrete steps that you can take to exit the state of obesity. So, “if you do this, and do this, and do this, you won’t have obesity anymore”. Whereas I believe “you can do this, and do this, and do this’ and you may not have the outward signs of obesity. You may not have the excess weight, but the Obesity and the metabolic processes that are in place are still there. Yeah, and I think people look at obesity as “How fat you are”, not realizing that there are psychological, social, emotional and metabolic processes that go into obesity. It's not just how fat you are.

Researcher: No, not at all. Moving a little bit into a different topic. Have you seen any kind of changes during the last year's about obesity and its discussion? Have you seen any progress about for example obesity being a disease?

Interviewee: I don't know if it's because of the circles of people, you know, with whom I equate myself. I equate myself with people who are Advocates, with people like Marty who are on the front lines of this fight to have the disease recognized. So, on one hand, I do know that the voices are getting louder. I do know that the voices are getting louder and everything is more cohesive and even just how the OAC reaches out to television shows like the Blue Bloods episode how they handle obesity in a very negative light. Yeah, and you always see petition them and they're like, “hey, we'll actually reconsider”. So I think that even small steps like that are or going to be tremendous and the fight but, but the thing is even with these small steps obesity is, is huge. We have this huge case to, to some out so that people don't look at it as a personal failure. Obesity is seen as a person's failure and we has a lot more to do in that respect.

Researcher: Yeah, totally. So you think The Narrative of the society is “you do this to yourself” kind of?

Interviewee: Very much. Yeah.

Researcher: So, rather than being a little bit more people's first and, you know, people actually is struggling and they need some kind of guidance.

Interviewee: Even if we are doing this to ourselves, one of the things that I read before I had my last DEEP function where I was, I was at the semaglutide stage 3, and I spoke there. And a blurb in an article that says that fish, because there's so much plastic in the ocean, but they prefer to eat plastic and they prefer to eat algae or Krill or Crustaceans or things that they're supposed to eat. Yeah. So fish prefer to eat this fake food over this real food. So we have to ask ourselves are we mad at the fish? Do we blame the fish or do we blame the people that put this fake food into their environment?

Researcher: Yeah, because there are also a lot of environmental factors that are involved in this obesity debate as well. I can imagine Okay. How has the process after your surgery been? Have you seen any positive changes? And, are you advocating for people to find some sort of solution?

Interviewee: I do kind of go back and forth with obesity, and you know, curing obesity and because we want to accept people and their bodies way that they come but we also can't deny that there are very serious health effects and comorbidities that come along with obesity. So I'll tell people that “Whenever you, nobody can decide but yourself, so whenever you decide that you want to put your obesity in remission, there are definitely medical interventions, their behavioral interventions, there are surgical interventions, but you have to find the thing that is going to work for you”. Yeah, and I think that's one of the things that is happening that is really, really tremendous is that there isn't just one way to fight obesity anymore and even if you have surgery, surgery doesn't last forever. Even if you take semaglutide, it might not last forever, and we have to continue to find ways to treat it as a chronic disease. But, we at that's one of the most amazing things that's happening right now. Yeah, but I would always present surgery as an option, but you have to know the Good, the Bad and the Ugly, but ultimately the decision is up to the individual.

Researcher: Totaly. Let's talk a little bit about advocacy because you've been touching very interesting points about it. And I just wanted to talk to a little bit of common ground in terms of how would you define to be an advocate for obesity? What do you think that means?

Interviewee: So for me advocating doesn't necessarily mean that I have to be on stage at a conference. For me, so much of my advocacy, is day-to-day advocacy and standing up for the rights of people who are living with obesity.

Earlier this school year our PE coach and his best friend were making fun of a cheerleader at a pep rally because she was big and they're like all your “baby shark. Boom. Boom. Boom” - and just making all of these disparaging remarks about a kid about a high school kid. And I got extremely upset and I turned around to them and I said, “you know what? for you to be a coach and for you to be a teacher. These are the things that we get on our kids about, and for you to sit in this audience and make fun of this child with its obesity is like how fucking dare you?” yeah, and they both looked at me like they were just shocked. I was so upset like I had to walk out of the auditorium and they come back and they're like, “oh no no, we're sorry. We're sorry. We didn't know it affected you so much”. I was like, “this is not about me. You're missing the bigger picture. Yeah, you did not personally offended me you. You just don't get it”. “Oh, no, you don't because I have my own struggles with weight and I'm a little bit sad and you know, I used to be 20 pounds”. They care missing the picture here the picture is it, you know, “two adults making fun of a child child obesity and if adults will do it adults who are supposed to be teachers and coaches. It's who else is who else will do it?”

Yeah, and another thing. But I do is I'm not extremely the people that are close to me know about my surgery the people that asked me know about my surgery, but I'm not one of those that just wears it on my sleeve, my sleeve on my sleeve. Because I feel that everybody needs to make the decision that they need to make for themselves, but one of the best things about advocacy is getting a chance to actually with being involved with DEEP is getting a chance to talk to stakeholders, getting a chance to really talk to people who can make a difference.

That's, that's been one of the most eye-opening things is that people actually don't know, they actually don't know the struggle and we maybe naively assume that

people do and they don't care but a lot of times people just don't know. What is the struggle in there.

Researcher: Have you seen, have you noticed any obstacles when for example you are advocating for obesity within the community?

Interviewee: In my community everybody is so receptive. Everybody is, is just so willing to learn. But, I do on occasion run into people that absolutely believe it is personal choice, absolutely believe that it's “eat less move more”. Yeah, and I will talk to those people and talk about my own personal story. But if they continue to insist, I have a finite number of resources I just wish them the best and move on. Because I'm here to educate not to twist anyone's arm. Yeah, that takes too much energy.

Researcher: Yeah, totally. So, you think one of the big obstacles is actually these stigma and bias that people still have in relation to obesity.

Interviewee: Yeah! Even when I talk to stakeholders, I said “you look at me and here I am. Still 10 pounds up”, you know 10 years after surgery mostly maintaining my weight, making good food choices, going to the gym, but I also have a lot of privilege when it comes to managing my obesity. I have the money to be able to go to the grocery store and get what I need. I have a car I can go to the gym. I have a partner who supports me. So if I say don't buy a pizza or don't buy this he's not going to do it. So it's easy to look at me as a model patient. But what about those patients who are struggling with depression? What about those patients who have unsupportive families or families who actively sabotage? That was like those patients need support even more than I do.

Researcher: Yeah. And I think maybe that's when actually, you know, creating these groups and they support, and for example, what a Obesity Action Coalition is

doing, it's so necessary for these patients as well for these people. They have none support from their own families, support from their own family doctors.

Interviewee: And I think it's great that we're here, and we're educated or smart and beautiful like all of us, are beautiful people, the people that are up here advocating were amazing, with big personalities and it's easy to listen to us because we look the part. It's easy for people without obesity to align themselves with us because we kind of look like familiar way, the way they can see themselves and us. But what about the voices of the people who aren't being heard?

Researcher: Yeah. So why are your expectations regarding obesity within the next, let's say, five years? So you would you like to see more, you know voices out there shouting out advocating or maybe hearing these voices that we have not yet heard?

Interviewee: I don't know. I think it's going to take concerted Intentional efforts with health agencies. I think it's going to take Primetime commercials, you know, during the, the block when everybody's watching TV. I think there's going to we're going to have, to have a big National Movement for the acceptance of obesity as a disease. It's great that we as individuals are able to get into the ears of the stakeholders. Yeah, and these companies but it's going to take, we need them to be our voices. So what would the work that we're doing is absolutely crucial to get it heard by the right people within those people with the power, with the money, but the prestige I think it's absolutely going to take something big.

Researcher: Yeah. Yeah Okay. I actually can see your story also as a very inspirational story for those for example, the black communities out there, struggling with obesity especially for youngest, you know, women a little girls. Do you do you see

yourself like like that? Like maybe just being the voice of those, those communities as well?

Interviewee: I do! And that's one of the things like even even my story with obesity is different not having had obesity my whole life when I did lose weight. There was no Psychological recalibration that needed to happen I felt like myself because I was getting back into a body that I was familiar with. So for those who have never existed in this world in a normal sized body, It's a lot harder to adjust. I used to always wonder like why did they gain their weight back or why would it, it's so much nicer being smaller, but then one day I realized. But for those who have never lived in society in a normal sized body. It is probably as traumatic as me going to bed as a black woman and waking up as a white man.

Although, I would have more privileges people would listen to me people wanted so to not follow me on the streets, you know, I would still Want to go back to one I know because that's all I know regardless of the Privileges that come with it. So, I do think that there is a psychological component that even when people have lost weight. It drives him back to obesity because there's a familiarity and I would love, I don't know. I would love to do some graduate research on that.

I do and honestly. We need more black voices, we need more Black Faces, black people and black women who are disproportionately affected by obesity. But when I go to these conferences, when I go to OAC conferences, when I go too deep conferences, I'm one of the very, very few black people that are there. So, you think that it's important that, you know, as black women we share our stories and I don't think that there are several black women, but I don't even know that there's a black man that's involved with deep, you know.

Researcher: No, but you think it's because there's not a lot of black men representation out there? Do you know anyone that could be a like that representation that you feel is missing, and the definitely is missing, within the discussion?

Interviewee: I don't know why those voices are absent. Yeah, I think, It's necessary though. I don't know that I can get to the why. But it's but it's crucially important. Like I said and it's crucially important to hear the voices of people who have to try to manage their obesity without privilege with external sources so that we can understand the struggle.

Researcher: Yeah, but I think I think that's actually so important because we are indeed missing those who are not only advocating for the understanding of obesity as a disease, but also the struggles like, you know, having obesity and being, you know, part of the black community or part of latin communities in these discussions.

Because, for example, people in Latin America, they do not only talk about the struggle of having obesity, but also about having access to the treatment.

Interviewee: I have been in groups with all these European white women talking about “you need to be a pushy patient. You need to go over there and Advocate and if they don't want it you go somewhere else” and I'm like, “first of all that doesn't work in America”. You cannot bounce around it doesn't work like that and have to come up with another cope to go to the doctor. And second of all, as a black woman. I'm not necessarily able to be a pushy patient. People’s view of a pushy Black woman patient as somebody who needs to get put into place. As a pushy black woman, they could literally throw me out of a doctor's office in a way that would never happen to you, and it just it was so disheartening that that group of women did not listen to my concerns, what I was voicing, what I was bringing to the table, they just absolutely shut

it down and ignored it because it wasn't their experience. At the conference in Copenhagen.

Researcher: Yeah, but that's actually a very interesting perspective and of completely valid point because I have this sense that things are happening right now in let's say in the United States are not as equal as what is happening for example in Europe and definitely not in other parts of the world. I have one more one last question and is, how is that Health Care system in Dallas where you live? Is it half covered by the state? For example, just surgery and all these kind of a the Obesity treatment that you went through at you all need to pay completely by yourself. And of course the support of your family. How is the health care System back in Dallas regarding the Obesity treatments and access to treatment?

Interviewee: Oh, it's very difficult. And now a lot of insurance they have bariatric surgery exclusions. Yeah! and because of that a lot of people are going to Mexico to have bariatric surgery done. Like I said, luckily we had $5,000 in my mom was able to contribute $5,000 so that we had cash to pay for my sleeve surgery, but there are a lot of people for who financial and insurance is a huge hurdle.

Yeah, but before the sleep I didn't have blood sugar issues. I didn't have any high blood pressure. But you can't walk around the world as a 350-pound black woman and and think that you're going to be healthy. I knew that I needed to do something before any of that happened. And since then my complication is that I developed really bad acid reflux. I never had it before the surgery, but I have to take pills. I have to take those every single day or my acid reflux will be horrific. But I have to remind myself that at 350 pounds.

So although it's a minor annoyance. You know, it's a small price to pay to be healthy. I am completely 100% metabolically healthy. I just have all of my labs done.

My cholesterol is perfect. It's even better than perfect. My glucose is perfect everything about my body metabolically is perfect. Now I have joint and knee problems from existing Injuries that I had when I was a kid, hmm, and although they bother me now and would bother me a whole bunch more 350 pounds.

Researcher: Yeah totally, It is good to know that some of the people that have no idea what is going on in these kind of quite strong and invasive surgeries. They think is kind of the ‘easy exit’ when it’s actually, like in any other surgery, also comes with quite a lot of complications, you know, for example some experiences a leak and needed to stay at the hospital. And so for me is quiet of outrages that people is actually going to Mexico to get these kind of very serious, you know, serious surgeries.

But anyways Keisha, thank you so much for your time and thank you so much for your thoughts here. It's been so nice to hear your story.

Interview Guide - People with obesity

Patient Advocate, Past Chair Public engagement Committee Obesity Canada

Marty Robert Enokson

Conducted: Scottish Event Campus, Glasgow, Scotland

1. Please introduce yourself.
2. Could you share your story and your experience with obesity? (When your interest in obesity first began? For how long have you be living with obesity?)
3. What does it mean obesity for you?
4. Do you think your definition is shared by other actors involved in obesity matters (HCPs, pharma, legislators, researchers, patient organisations, people with obesity)?

I would now like to move on to a different topic:

5. From your own perspective, what do you think is the current discussion about obesity? Has anything changed during the last years?
6. Could you describe how the obesity debate has been changing in the last decade?
7. Have you been able to be involved in any of the milestones mentioned? If yes, which ones?
8. Do you think people with obesity is involved in the obesity debate? How are they involved? Have you seen any changes regarding this involvement in the last decade?
9. Why involving people with obesity in the discussion is so important?

Let's talk about advocacy:

10. What does it mean for you to advocate for obesity?
11. Do people who advocate for obesity need to live with the condition?
12. Why advocating for obesity?
13. Are there any obstacles when advocating for obesity? Which are the most difficult obstacles? Why?
14. Do stakeholders involved share the same understanding of obesity than people with obesity?
15. What are your expectations regarding obesity within the next 5 years?

Transcript of Interview with:
Marty Robert Enokson, Person with Obesity

- Conducted face-to-face on Monday 29 April 2019 at 26th European Congress on Obesity (ECO), Scottish Event Campus (SEC), Glasgow, Scotland

Researcher: I'm going to start recording. This is for the public university, Roskilde University, so everything you say is going to available for the public.

Interviewee: No, it has nothing to do with novel. Any private I'm getting nothing from this other than changing the world.

Researcher: Great! So please introduce yourself and tell me a little bit about your experience with obesity and why you think it is necessary to start addressing the complications of obesity.

Interviewee: Oh my God! currently... Okay… My name is Marty Enokson. I am a fifty two and a half year old male I've lived with obesity since the age of 12. So, for nearly 40 years now, I. Became. My journey with obesity began probably a little bit before the issues involving my brother but my relationship with food became out of control at the age of 12 when my brother started sexually assaulted. And from the time I was 12 until the time I was 17. I was repeatedly sexually assaulted and I turned to food to comfort myself and to protect myself and to bring me to a place where I could continue to live life. Although, you know, I don't know how much living life is when you gain such a significant amount of weight in such a short period of time so. Between the time I was in grade 7th and grade 12th. I was between the ages of 12 and 17. So in about 6 years time I gained about 200 pounds. So I was 150 when I was 12 and when I finished high school, I was 350 pounds. So in short less than six year period I gained 200 pounds of weight. As time went on I… the sexual assaults stopped but I didn't deal with the sexual assaults. And so I continue to use food to bring me comfort

to make me feel better to make me continue on living life. And as a result, I gained I continue to gain weight so over the course of the rest of my life up until. So, at the age of 42, 10 years ago, I had bariatric surgery, I was very sick. I was 300 and are not 505 pounds I had bariatric surgery it was successful, but I had some complications ended up in the hospital for three months with a leak. I had a leak where the where the esophagus was reattached to my stomach and they couldn't find the leak. And so I ended up in hospital NPO for. Nearly three months now 86 days.

Researcher: Okay, so when you say you were very sick just before having the surgery, what kind of complications were you experienced at that time?

Interviewee: I had probably 4 years before I got into the the weight loss program for bariatric surgery in my province in Alberta, where I live, I had suffered a mini-stroke when I was 38. So, when I finally went to the doctor and started to care about myself, I was at least 475 pounds. I was a type 2 diabetic my A1C when they did my A1C know when they did my first Blood prick, I think it was 17.2. I had just outrageous blood. It was out. I had high blood pressure I had. There was concern I'd had a heart attack. There was concern that I had, you know a stroke so heart disease there was I was as a sick, sick man. And as time went on I found it harder and harder to move around. So there was a point where I started taking Oxycontin I started off at five, five milligrams three times a day and it went up to 40 milligrams 4 times a day over a two-year period so that that helped me walk, that helped me live, but it also was slowly killing me as well. So it's a. there's just. Type 2 diabetes things are out of control had a wound on my foot. And the realization that I had, a I had a young daughter and I wanted to you know be alive to eventually walk her down the aisle or to be there just generally be there as she grew up and if I continue down this path, I wouldn't be there. I just knew that. I my, my realization my kick to the head was the mini stroke and then

the realization that “I'm going to be in a wheelchair by the time I'm 45”, and I'll probably be dead by the time I'm 50 if I don't do something about this, so and that's sort of what we focused on.

And we talked about the the possibilities of bariatric surgery we talked about. “Is this something that we should do? Is this something we shouldn't do” knowing full well that it was a long wait in my Province where I live to even get into a program. It was two years that I waited to get in and it was another two years in the program before I got surgery.

Researcher: Going back a little bit to the background of the Canadian Health Care system. Are those kind of surgeries completely covered by the state?

Interviewee: Surgery is covered. You have to prove that you need the surgery so bariatric surgery, but it depends on which province you live in, each province has its own Healthcare System. So in the province that I live in, Alberta, we actually cover bariatric surgeries, but if you went to the island of Prince Edward Island the province of Prince Edward Island, they don't have any surgeries that are covered. So if you want to Ontario where Toronto is, surgeries are covered. Wait times in Toronto are different than wait times in Edmonton or wait times in Edmonton. You can wait up to five years to get into a program in Toronto. People in Alberta, people would travel to Mexico to go have surgery because it was faster to get surgery and it still is it's faster to get surgery in Mexico than it is to get surgery in Alberta.

Researcher: That is completely inaceptable as if they have any complications…

Interviewee: They can die because you can't go back.

Researcher: This is very dangerous.

Interviewee: It's very dangerous. Very dangerous. Is they call it medical tourism? Yeah, so, you know, but they're people, people that live with obesity will do just about anything not to be obese. It's it's like, you know, I spoke yesterday here and it's like no one wants to be fast. No one wants to live this life. Nobody. Nobody chooses to be the obese person. Nobody wants to live their life this way. Nobody wants to join this club. We've were in this club and and it hurts it hurts because people, people generally think that you do this to yourself because you do this to yourself. You have no self-control. It's like, you know, you don't exercise enough, but you eat too much food and it's so much more we've learned over the course of the last many years that it's so much more than “eat less and move more” but you still have doctors that say that to today eat less and move more and you won't be fat.

Researcher: And what is the meaning of that…

Interviewee: Well! and that's exactly, what is the meaning of that? But that's the rhetoric that gets used. And so you beat down a patient. You keep telling them that and then they blame themselves and then they never get out of this. They know they they shut down. That's what they do. They don't go to the doctor anymore. They don't care. It's like so you end up where I was where I wasn't dealing with my type 2 diabetes. I was very sick obviously, but I didn't want to talk to my doctor about about my weight or what are the complications of being overweight, you know.

Researcher: And that step of considering doing into surgery was because you saw yourself being extremely sick or because you find a GP that was capable of taking the conversation with you?

Interviewee: It was a two-fold thing. You know, I had the mini stroke and when you're, it scared the hell out of me. I was 38 years old, like you, don't think you're going to die at 38 I'd who wants to die at 38? I have a I have a daughter at the time. I think

she was 10. No she was 8. So because, know she was six because two years later she would have been eight and I had surgery two years after that. So, I'd say, she was young and you know here at the dad you picture yourself walking your daughter down the aisle and she gets married and having that father-daughter dance and and it's like all I kept thinking of was and I'm not I'm not going to be here. I'm 38 years old and I'm not going to be here to see these moments. And so it's a kick to the head. It's okay. “I need to do something about this” and as you set your set your own ego aside, and you set your own pride aside, and you go and you have that conversation and it's a hard conversation, you know, you go to your family doctor and you finally sit down to have the talk about obesity the, the one word that, you know, you've grown to hate. You don't want to be called an obese person. You've always I've always hated the word. Hated the work. I would have preferred that you called me fat. I think that's changed. Now. I think that you know prefer to be called an obese individual because the that I've accepted the fact that that's the medical term, but it was a time when that word was used in an ugly way. And you know, we've got a medical profession that that that even created, you know, ugly words more ugly words. So you take obesity and then you say. Because you're a big really big you're “morbidly obese”. So you're not just to be you're morbidly. So. Yeah, it's just it's hard.

Researcher: What happened after the surgery?

Interviewee: After the surgery?

Researcher: Did you see your number getting better in terms of your diabetes?

Interviewee: I was getting better in terms of my diabetes, it cleared up within days, within days of the surgery my diabetes, my blood. Clear down. I went to normal blood sugar values, but I my blood sugar's have returned. So 10 years later my, but they told me my doctor said that “you may you may because you had such uncontrolled

diabetes for so long. You may have diabetes. It may come back" and it has and so I have diabetes again and the complications that I had from diabetes never run away. Never went away.

Researcher: So, are you in insulin at the moment?

Interviewee: I'm not on insulin. I'm on Metformin and DeLuca norm, and I take Victoza.

Researcher: Okay.

Interviewee: I was taking Victoza initially to help control weight to help make sure that I maintained weight, because I don't have coverage in my Province for Saxenda. So I can't get that because it's a weight-loss drug. But I can get Victoza, the sister drug, the same drug, the same molecule, the same everything just a little smaller dose, because it's a diabetic drug. So we treat people that have diabetes differently than we treat people that have obesity but we know that obesity causes type 2 diabetes, but we, we beat down the people that have obesity because they do this to themselves…

Researcher: And when did the interest for advocating start?

Interviewee: Why? why I do what I do? It came after surgery. I was very, interestingly, I'm a very private person with respect to my obesity. I was a very private person I was because I was shamed for so long and beatdown for so long. I always kept it inside. I tried to hide. You know, I'm the person that was always the back of the photographs. I was always the person that didn't want to be in the pictures. I didn't want to I don't want to be celebrated. I don't want to be recognized don't look at me don't see me. I'm just want to be invisible because it's better to be invisible and when I had the surgery you lose the weight obviously, there's weight loss and I had I had some tremendous weight loss.

I was asked by my surgeon if I would be interested in speaking to the government of Alberta, they were, they were they were going to be there was a presentation that was going to be happening with healthcare at the province of Alberta where the Health Minister was going to be present and they wanted to have a patient who had bariatric surgery and I seem to be somebody who was outspoken in the sense that I was a disc jockey and I did things I'd never spoken before I've never stood up for myself before it was it was a bit odd because that's not, that's not the nature of who I am.

This was 2009. This was after surgery. So after surgery. So I was out of the hospital. Finally. They, I my leak it finally healed and I got contacted by my surgeon asking if I would talk to the minister, and so they said we'd like you to tell your story so I wrote out my story for the first time and spoke to the minister and realised the power of the story, the power of a patient telling what they've lived through and the question that one of them the, the deputy minister of Health had asked me which was you know, “you were in the hospital for a very long time at cost a lot of money to keep you in the hospital cost of almost half a million dollars”. Then the deputy minister asked me instead: “Was it worth it?” And I remember him asking me that I just like of course it's worth it. I'm worth it. Am I not worth it. I'm a taxpaying citizen and say “I didn't ask for the complication. I got the complication, but am I worth it”. That's, that's an insensitive question. And I think that that was perhaps the Catalyst for me to step up and say “we need to find, we need to fight! There are, they're not doing enough surgeries. There are more people. There are more people that are afflicted with obesity in Alberta than they will ever be able to do surgery center at the rate that they currently do surgeries. That's and it's sad, it breaks my heart, that, that we have a world where we treat people

who live with obesity so differently than we treat any other disease out there. So we don't treat people with obesity with any dignity in any respect whatsoever.

Researcher: And there are no laws, neither non discriminatory laws…

Interviewee: You would never treat a person that suffers with cancer the way you treat a person that suffers with obesity. You would never question them. You would never look at them the way you do. Is it I've lived a life. I know the look. I know the words, it would it would never say to a person who's living with cancer: “You can't have treatment” but you will make a person who's suffering with obesity wait months and years and and provinces in Canada, some of the wait times, were up to seven years in the province of Nova Scotia, seven years to get their actual surgery.

Researcher: And depending of the complication, in seven years you might even die.

Interviewee: If you've not, you've not taken care of the, the actual weight gain or whatever caused the weight gain, it will just continue to gain it.

Researcher: So after almost 10 years of advocating for obesity and after your own experience with obesity. What is your definition of obesity today?

Interviewee: What is my definition of obesity today? Obesity is a person who suffers from excess weight. Hey! A person who suffers from excess weight and. I don't I don't think that the… I'm still obese. I'm not even obese, in medical terms I'm morbidly obese. My highest weight pre-surgery was 505 pounds. My lowest weight post-surgery that I'm currently at now is 380 pounds. I've lost a 125 pounds. Stressful year last year, Incredible stress where I was very sick last year nearly died.

Researcher: What kind of complications do you have?

Interviewee: I, I acquired a blood infection and had a blood infection in this foot my right foot and it crawled all the way up to my leg and cause some other

complications with my kidneys, misdiagnosed by the Healthcare System. They. They didn't recognize that this and infections. It said nothing was wrong and sent me home. Then, they called me two days later and said “you need to get him to the hospital immediately are days away from dying”. So I had a really scary 2018, very challenging year mentally, physically, and I'm a, I'm an emotional eater so when I get stressed, Life gets out of control. And so I gained weight again some, some pounds back and you work like the life of a person who lives with obesity is a very stressful life: This is like there is none of this. There's no. Oh no, it's not smooth sailing everything in my life is all based on stress. I work in a stressful job. So it's like I'm constantly fighting.

Researcher: And what do you do for living Marty?

Interviewee: I'm a paralegal in the crown Prosecutors office. I worked in the homicide unit. So, I deal with a prosecute really bad human beings who kill other people murder.

Researcher: Yes, and how such a sensitive person ended up doing such an emotional job?

Interviewee: I think that, I was recently having a conversation with a with a colleague about this, and I think it's my experiences in life. My all of the things that I've experienced. I firmly believe were meant to happen. Like I'm, I'm just a believer that the things happen because they're meant to happen. Say, so I've always said that I was I was the person that was supposed to go on this journey. I was the person that was supposed to, to have the experiences that I had with my brother because having those experiences now allowed me to stand up, to meet people to share my story, to change lives, to change other people's to let people know that not every single person's journey is the same, that there are many different reasons that childhood trauma plays a huge significant role. I've learned this over the years after telling my

story is as often as I've told my story and to so many different people. When people come back and they come and say “I thank you”, and I said “I never understand what they think me because I told him to them I am not doing anything special but you inspire people” and and I think that's the beauty of advocating and speaking up because not everybody is in that place, not everybody has built up enough of a skin to stand up and say “enough is enough, and I'm going to tell you my story” and, you know, my story is a pretty a pretty rough story. My story is a hard story to listen to. I can honestly say that I don't think that I've ever given the story and not had somebody crying in the audience. It's like that's that's just become the norm. You know, you tell the story. It's like you want to say don't cry because I've cried all the tears. I could possibly cry and but it's like I understand that people. I guess, I'm now beginning to understand that people and more empathetic than I ever thought they could be, because when you are beat down so often you're treated like shit, you don't, you don't think that anyone's really human and they you just you think that. It's the same they treat people the same way and I've learned that's not the case. There's wonderful individuals, there's people that keep those people, that there's so many that work at Novo, and and it's like this is not a plug for Novo. This is truly not, but I have met so many amazing people so many amazing caring loving people that I consider friends now that, I would not even know but for the journey that I've been on, you know that I get to make it to come around the world that I get to speak that I can to communicate that I get to share that I get to change. If you would have said to me five years ago “Marty, this is what you're going to do”, I would have said “you're not you're not just there's no way”, you would have said that I would go to Copenhagen and I would speak to people. No, one artist give you they said that I would be in Glasgow Scotland speaking to Professionals in the medical field of obesity and that I would be changing

lives. I would have said no, I certainly didn't see it in myself. But here we are mere four years later and I have done more in four years. Then I lived in the last 44 years.

Researcher: What are those activities, the most remarkable activities that you have done during these last four years?

Interviewee: Oh my gosh, you know every, every I like I don't take any of it for granted nothing, you know the very first time that I like having spoke for Obesity Canada. I did a presentation and met the Canadian, Canadian Novo Nordisk representative, Nora Madeon, and she reached out to me as session that we were at that I had spoke at and after I had spoken about weight bias in the medical system and she sat with me at lunch time, and she said “you moved me to tears and you speak so well. And I would like to know, there's no guarantee. Nothing. Nothing is for certain, but I would like to know if I could have your permission to put your name forward to go to Copenhagen to speak in Copenhagen and represent Canada”. So what? what? “There's no guarantee, but would you would you allow me to put your name forward so it wasn't?” You want me? When you've been beat down for so long, you couldn't possibly imagine that anyone that guys. Yes. I spoke in Obesity Canada because you know, I'm Anna with with Obesity Canada, you know, I got to work with her and she recognizes the story but you don't recognize it in yourself and then somebody's offering you the opportunity to travel to Europe to go speak to a bunch of people and represent Canada in Europe, really? think the really, okay. So, yeah, go ahead? No! You can have my name put It forward did I expect anything to come out of it ? and yet to you two months later, I get an email from Nora saying “that I forwarded your name on and we've accepted it. And so you're going to be going to Copenhagen”.That was that was September 2016. And after that I met Camila and she talked about the DEEP program and the next thing you know, there's there's six

of us. All of us except for one. Carlos was in Copenhagen in September 2016. He did not Step Up. But in January of the following year, all five of us the original five others than Carlos, and then Pam Davis. The six of us, we became the original six and we've forged forward in an area like we were all sort of awestruck and here we are we're speaking and we're sharing and we're sharing some of the deepest darkest stuff that you could possibly imagine as I haven't even told my story to I hadn't shared that story the beginning part where the sexual assaults all of that, that hadn't been shared ever, Camilla was the first to get that, it was long conversations with Camilla about, “you know, I don't know if I can talk about that”, the reality of her “You have to want to say there. There's the reason why you have gained the way we need to understand that, there's there's no point in not telling that part of the story because that will help us understand as we move forward”.

Researcher: And also to let all people that has been gone through the same sort of experiences to know that is nothing wrong about that.

Interviewee: There's nothing wrong with that, and that's what I learned. What I learned was that there are so many more people that have had the same story in the same journey that I've had and that, you know, I never thought that I would Inspire anybody. I never thought now. And I know, I know, I know now but I like a star no. No, he's right. Just some in the Novo Nordisk world. I'm a star. I don't, I don't do anything to be a star and I you know.

I spoke yesterday. It was every time I speak, you know, someone had posted “Marty got another Standing Ovation”. So, I don't I get embarrassed by it. I shouldn't and I've been told that but I find. I find it hard when you've been when you've been beat down for so long and you don't, you don't have a love for yourself. I've learned to love myself, but when you don't have a love for yourself and you're not used to being

praised and I'm used to hearing or not. You've never received a standing ovation in your life. I've received more standing ovations in the last four years that I've received in the first 40 years. And yet you're talking about something. That's so personal and you talking about something that's so incredibly painful and I never never thought that, that my experience with obesity would inspire anyone, would make anyone feel anything for me. So I don't want you to feel sorry for me. And I don't think people see feel sorry for me. I think that they feel empowered and there's this incredible feeling when I'm finished talking. That I'm now starting to feel, that I've accomplished something, that you know, I've started, I started the saying of late that I just want to leave the world a better place and I found it, so that I don't know how much time I have on this Earth. I honestly don't know but he could eat really does, but I know that while I'm here every breath I have, I will continue to do this. Yes, I will continue until I can't do it anymore. And when I can't do it anymore then that I know my time is done here and I will I just want to leave this place better than I found it if people could treat people who live with obesity better now, if we could find a cure, if we could find a solution I would have love that. That we could live in a world without obesity orr bias, bias for anyone bias for any disease is like we have diseases we shouldn't be suffering. We shouldn't be dying. We shouldn't be, shouldn't be treating people with such disrespect and it breaks my heart. I asked asked the question yesterday my presentation “how many that medical professionals how many of you have ever made fun of a fat person? How many of you have ever treated a person who suffers from obesity with disrespect?” and the hands that went up there just like, I, I was I was warned by the fact warmed in my heart by the fact that they were so honest but saddened in my heart at the same time that your medical professionals you should be better and soon open. You should know better.

Researcher: So let's talk about this obesity debate that you mentioned and all your kind of activities within the advocacy work. Have you seen any changes? Let's see, from the last seven years?

Interviewee: I think that there have been changes. I think that the conversation is changing, I think that it's not changing fast enough, but I'm seeing changes. I'm seeing, you see it when you do something like the ribbon campaign that we're doing right now. The “I'm people first”, “people first language” isn't new maybe perhaps here in Europe. It's new in Canada. It's not so new people first we've adapted. People’s First for me speaking “people first” was really hard to learn how to speak people first language because I've always talked about myself in such a negative way and it's not about talking about in a negative way. It's about remembering that somebody who is a person who lives with obesity is not defined by their disease. It's like I'm not defined by my cancer am not defined by my MS,. I'm not defined by any, I'm a person. And so it's been interesting. As this campaign has kicked off here. Europe has embraced for the most part but they're they're definitely doctors that have not embraced, that our medical professionals that have not embraced people first, and you know, so there's they're struggling to change but at the same time when you can get doctors to put their hands up when you ask have you ever treated a person who suffers from obesity with disrespect and they put their hands up. It's. “Oh, that's that's pretty deep”. That you have, you have influence maybe that you would ask such a question a that I would have the audacity to ask a doctor in a sec. I remember saying I said, “I just want you to set all leave your egos aside. Just put all of your egos aside doctors nurses. I don't care. I don't care. I'm not here to judge you. I just want to know” it's like “how many of you have ever made fun of a fat person” and as a to have the hands go up. It's like was was just a okay. “Well, I don't know if I was expecting that”. I liked I would I was

hoping, because ultimately you have to come to terms with your own internal bias, said if you can't come to terms with your own internal bias, then you're never gonna be able to treat people with dignity and respect. And if you have to understand that you have the bias yourself and if you can set that bias aside and treat people for the disease that they have and help them then you're making a difference in the world. So if I can cause you by listening to what I have to say “if I can cause you to change how you think then I won”.

Researcher: Have you ever seen any changes in Canada regarding the obesity narrative?

Interviewee: I think change is slow and Canada, but we certainly as a Canadian Medical Association, they've accepted obesity as a chronic disease. So that was a huge thing. I didn't particularly care for how they announced it, you know. Secretly in quietly announced it in a non really publicized way the Thanksgiving weekend in Canada four years ago Thanksgiving weekend. So in October of 2015, I think it was the Friday before Thanksgiving weekend, which is a holiday in Canada. They announced its at five o'clock in the afternoon. So nobody didn't make the papers. It didn't make the news. It didn't make the the six o'clock. Canadians did nothing, didn't it just it was like lost in a sea of Thanksgiving weekend revelry, and so it's like yeah, you, you sort of buried it because you didn't want anyone to know that we're recognizing obesity is a chronic disease.

Because there's still that ugly feeling, you know, “all these people did this to themselves, if they would just eat less and move more they wouldn't be this way”.

Researcher: And then they just go home not knowing what is the meaning of that.

Interviewee: Yeah, they have, they have no idea. They have no idea and I think that change is slow but change is coming and I think that more people stepping up and shouting out in more Marty's. We need we need more Marty's. We need more Vicki's and we need more Joe and we need more Ted Kyle's and we need more we just need more.

Researcher: What is the biggest obstacle when talking about obesity? Is it this bias assigning and stigmatization?

Interviewee: Bias in people I think. The prevalent attitude is still that “we did this to ourselves”. And so there's that bias and that stigma is still out there. It's like it's still okay to make fun of people with obesity. Why is it still Okay to make fun of fat people? Why is it? Okay for Jay Leno to get on The Tonight Show last week and go on his diatribe that he went on about obesity? Why? Why is why is that funny? Why does the public think that's funny? Why would you even think that the talking about that is fun? But yet, It's almost always happens, it we just treat people that live with obesity so poorly and I don't think that we honestly recognized the damage that you can do to somebody it's like when you are repeatedly beaten down for your physical appearance it takes a toll up here, and It beats you down, you consider suicide, you do! You consider taking your life! You don't want it, who wants to live this way? No one wants to look this way.

Researcher: That's why there's a lot of studies that relay the obesity with anxiety and depression, they're so tied together.

Interviewee: They are so tied together, mental health and obesity are so tied together. As if I have received help when I was 12. Would I be where I am now? I don't know. I don't think so. But had I not had the experiences that I had? would I be here now? Would I be doing what I do? say, I don't get paid for this shit. I believe

wholeheartedly, I'm making a difference as I like I have something to share. I think it's a value and I think that I can if I can stop somebody else from having to go through what I went through then it's worth it.

I can't change what happens. No, I can't stop what happened. I can't I can't make it go away, but I can take what happened to me and I can use that power and I can use that experience and I could say no more and I can take that away from my brother and I did and I said I stepped up and I said, "okay, I'm going to tell the story and I'm going to tell it".

So if I want to effect change and if I want to bring change and if I want people to think about what it's like to live life as a person who lives with obesity, I want you to understand what it is for some people. And that's what it's about.

Researcher: One last question. What are your expectations regarding the obesity debate within the next five years?

Interviewee: I often joke that I would love to see, you know, obesity eradicated in the next in my lifetime would be lovely, before I die. Let's the reality, the reality is is that we've moved a great distance, but it's going to take time. It's going to take time. What do I see as five years from now? I see a global patient alliance. Five years from now. I see, I see the ECPO, and I see Obesity Canada, and I see the patient Counseling in the US with the OAC and I see other patient councils that are not part of the European Commission. I see us all banding together, standing up and shouting out and effecting change. I see us fighting and I see eventually getting to obesity being seen as a chronic disease. I really truly believe that. I believe that you can't you can't ignore the science. You can't ignore, you can't continue to ignore, you cannot continue to ignore the millions upon millions of voices that will step up and I believe it will have I believe that we will, we will stand up and shout out and we will change the world. It

may take a little bit of time, one person at a time, 10 people at the time, that I'm a room full of the time, Congress at a time, but I really believe it. I believe that it will happen.

Movement will happen in five years. It'll be better in 10 years. Probably the better 20 years from now. But by that time the movers and shakers of today will be gone and they'll be a whole new group of people because we will have empowered them. We will have it. I've said that “you can have a voice”.

Researcher: Are you setting up the scene for those coming?

Interviewee: We are setting it up, absolutely. We, you know, I liken us to go back to the 1980s and the AIDS crisis and the US. You know the fact that they didn't have, they didn't have any coverage that didn't have any drugs didn't have anyone to care. They were treated the same way that we met.