



## ORIGINAL RESEARCH ARTICLE

# A call to action to inform patient-centred approaches to obesity management: Development of a disease-illness model

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## Funding information

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Patient-centred care is an essential component of high-quality health care, shown to improve clinical outcomes and patient satisfaction, and reduce costs. While there are several authoritative models of obesity pathophysiology and treatment algorithms, a truly patient-centred model is lacking. We describe the development of a patient-centric obesity model. A disease-illness framework was selected because it emphasizes each patient's unique experience while capturing biomedical aspects of the disease. Model input was obtained from an accumulation of research including contributions from experts in obesity and patient-reported outcomes, qualitative research with adults living in the United States, and two targeted literature searches. The model places the patient with obesity at its core and links pathologic imbalances of energy intake and expenditure to environmental, sociodemographic, psychological, behavioural, physiological and medical health determinants. It highlights relationships between obesity signs and symptoms, comorbid conditions, impacts on health-related quality of life, and some barriers to obesity management that must be considered to attain better outcomes. Providers need to evaluate patients holistically, understand what changes each patient is motivated to make, and recognize what challenges might impede weight reduction, improvements in comorbid conditions, signs and symptoms, and health-related quality of life before pursuing individualized treatment goals. Patients living with obesity who do lose weight perceive benefits beyond weight loss. Ideally, this model will increase awareness of the complex, heterogeneous impacts of obesity on patients' well-being and recognition of obesity as a chronic disease, and prompt a call to action among stakeholders to improve quality of care.

## KEYWORDS

modelling, obesity, quality of care

## 1 | INTRODUCTION

Over the last several decades, a healthcare transformation related to the practice of patient-centred care has been taking place across medical specialties. The goal of this movement is to improve the quality of patient care by empowering individuals to take an active

role in health-related decision-making. Specifically, the Institute of Medicine defines patient-centred care as "providing care that is respectful of and responsive to individual patient preferences, needs and values; and ensuring that patient values guide all clinical decisions."<sup>1</sup> Key dimensions of patient-centred care are outlined in Box 1.<sup>2,3</sup>

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**BOX 1 Dimensions of patient-centred care**

- Respect for patient preferences, values and expressed needs
- Coordination and integration of care and services
- Information, education and communication
- Access to care and services
- Physical comfort
- Emotional support
- Involvement of family and friends
- Continuity and transition of care

The concept of patient-centred care is now included as a key feature of comprehensive disease models and treatment algorithms in a broad range of diseases, including diabetes, dyslipidaemia, kidney disease and atrial fibrillation.<sup>4-7</sup> With the implementation of patient-centred care strategies, improvements have been observed in clinical outcomes and patient satisfaction, and some healthcare costs and resource utilization have been reduced.<sup>8-10</sup>

Despite growing recognition of the value of patient-centred care, evaluation of the published literature indicates that relatively little guidance is available on the use of patient-centred care strategies for the management of obesity.<sup>11</sup> Additionally, within the sparse data on patient-centred care for obesity, most literature focuses on prevention of obesity, often in childhood and adolescence,<sup>12-14</sup> with minimal emphasis on patient-centred approaches to obesity management in adults. However, patient-centred care is valuable as patient engagement throughout the decision-making process may lead to increased uptake and more favourable outcomes. The relative absence of patient-centred care literature in obesity is not surprising, given the profound stigma and unawareness surrounding obesity and the fact that obesity was only recently recognized as a complex, chronic disease that has substantial negative effects on population health.<sup>15,16</sup> While several organizations recognize obesity as a chronic disease,<sup>17-21</sup> this concept has not yet been recognized by most governing bodies and health authorities, hampering obesity-related policy changes.

The need for better guidance on the delivery of patient-centred care has prompted a call to action to develop a model of obesity that captures individual patient perspectives at its core and encourages all stakeholders, including healthcare providers, caregivers, payers, policymakers, employers, mental health professionals, scientists developing obesity treatments and researchers studying the pathophysiology of obesity, to reflect on how the quality of obesity care can be improved. This article describes the development of a patient-centric model of obesity, including decisions related to the basic structure of the model (disease-illness) and how the model differs from more traditional pathology-centric models of obesity. This disease-illness model of obesity is provided to readers with the understanding that it should be used as a starting point in the dynamic process of patient-centred obesity management. The model is evidence-based and includes many facets of patient experiences with obesity. Its aim is to increase

**WHAT IS ALREADY KNOWN ABOUT THIS SUBJECT**

- Patient-centred care is an essential component of high-quality health care that can improve clinical outcomes and patient satisfaction, and reduce healthcare costs.
- Despite growing recognition of the value of patient-centric care, strategies are lacking for provision of patient-centred care for people living with obesity.

**WHAT THIS STUDY ADDS**

- This manuscript describes the development of a disease-illness model of obesity that places the patient at its core and links pathologic imbalances of energy intake and expenditure to environmental, sociodemographic, psychological, behavioural, physiological and medical health determinants.
- The model highlights relationships between obesity signs and symptoms, comorbid diseases, impacts on health-related quality of life and barriers to obesity management that must be considered for the attainment of better patient outcomes when developing individualized obesity treatment strategies.
- This model can be used as a tool to promote patient-centred care for people living with obesity and as a call to action to stakeholders to consider ways in which they can improve the quality and success of obesity care.

awareness of the multifactorial determinants of obesity, as well as the far-reaching and complex impacts obesity can have on a patient's well-being. Further, we hope to stimulate a call to action for stakeholders to focus on patient-centricity in obesity management as a means of providing effective, affordable, high-quality care.

**1.1 | Current models of obesity**

Relatively recently, obesity has been classified as a disease in which adipose tissue is considered to be an endocrine organ that is not functioning normally.<sup>16</sup> This classification has prompted research efforts to improve understanding of the epidemiology, genetics, environmental and social factors, and other mechanisms that may affect development and maintenance of obesity. In addition, much more is now known about the relationship between obesity and associated comorbidities, including diabetes, cardiovascular disease, cancer, sleep apnoea, gallstone disease, osteoarthritis and neurodegenerative diseases. As a result, several informative models of obesity and staging tools have emerged from leading medical societies.

The American Association of Clinical Endocrinologists (AACE) and the American College of Endocrinology (ACE) have published a guidance on the use of the diagnostic term “adiposity-based chronic disease,” in which they present a model of how development of abnormal adipose mass can progress to clinically relevant disease and associated complications.<sup>17</sup> The AACE/ACE model focuses on “complications-centric” disease management.<sup>17</sup> The World Obesity Federation classifies obesity as a “chronic relapsing progressive disease process,” and has published both an epidemiological model of obesity illustrating how various environmental factors promote obesity in a “host,” and a model of the central relationship between obesity and numerous pathophysiologic processes and associated diseases.<sup>18</sup> The Obesity Medicine Association publishes a comprehensive obesity algorithm each year to guide healthcare professionals in developing individualized treatment strategies; models within this algorithm focus on obesity as a multifactorial disease affected by genetic/epigenetic, environmental, immune, endocrine, medical and neurobehavioural factors.<sup>22</sup> Obesity treatment algorithms are also available from other major research organizations, including AACE/ACE<sup>23</sup>; the Endocrine Society<sup>20</sup>; and the American Heart Association (AHA), American College of Cardiology (ACC) and The Obesity Society (TOS).<sup>21</sup>

Although many treatment strategies and guidelines are available, there is a strong focus on weight loss and body mass index, which are easy to measure, but are not good indicators of body fat or health.<sup>24</sup> Additionally, anthropometric measurements do not accurately reflect an individual's obesity-related health risks, comorbidities or health-related quality of life. The Edmonton Obesity Staging System, a classification system for obesity, is aimed at incorporating patient-relevant measures in clinical decision-making.<sup>25</sup> However, other approaches for incorporating patient-relevant measures are needed.

## 2 | MATERIALS AND METHODS

While all of the currently available obesity models provide high-quality, authoritative information on various aspects of obesity, patient-centred care is not the core tenet in any of these models. Upon identification of this gap, we sought to develop a new model that incorporates important guidance from major obesity research organizations within a truly patient-centric framework.

### 2.1 | Data sources for model framework and input

To develop this model, we gathered input from experts in the field of obesity and patient-reported outcome measures. An advisory board was convened with 15 subject matter experts to review the disease area, key symptoms, and impacts of overweight and obesity during which a strawman conceptual disease illness model was first introduced.

We also performed qualitative research with adult patients living in the United States who had excess weight and obesity with and without type 2 diabetes mellitus to obtain direct input to understand the holistic patient experience of living with obesity, and to better

understand the concepts of hunger, appetite, cravings and satiety. Three separate qualitative research studies were conducted by experienced researchers using one-on-one interviewing techniques that followed semi-structured interview guides (Study 1: 20 participants; Study 2: 60 participants and Study 3: 35 participants). Analyses were performed individually for each study using anonymized interview transcripts and the interviewers' field notes. Interview transcripts were coded in accordance with each study's coding frame which was based initially on the interview guide and iteratively revised based on the interview data.

Lastly, we performed two non-systematic targeted literature searches to identify and review published research on the natural history of obesity and key concepts associated with obesity and weight loss. We also searched for literature reporting the perspectives of patients living with obesity on weight, reasons for wanting to lose weight, expectations, and willingness to pay for weight loss interventions. Targeted literature reviews were conducted in October and November 2017 from which 35 articles were selected for detailed review. Some key search terms included in our targeted literature evaluations were as follows: obesity, obese, overweight, appetite, hunger, satiety, craving, weight loss, qualitative, focus group, experience of weight loss, activities of daily living, physical capability, health-related quality of life, patient-reported outcomes and patient-reported outcome instruments.

### 2.2 | Selection of model framework: A disease-illness model

Healthcare models are hypothetical descriptions of complex processes that can be used as constructs to help stakeholders better understand real-world determinants of clinical outcomes. Several different types of models have been used to inform patient care strategies, ranging from more authoritative (provider-centred) to more facilitative (patient-centred). These models differ in their emphases on variables such as comprehensive understanding of the patient's condition, effective patient education, and developing and maintaining effective patient-provider relationships. Models also differ in their emphasis on behaviours that can facilitate a strong shared understanding between the patient and provider about the patient's health needs, including the patient's level of education and motivation for change. Importantly, these models are not meant to be static; they should be adjusted and refined based on real-world patient, stakeholder, disease and treatment factors.<sup>26</sup>

A disease-illness model was identified as a tool that can be used by healthcare providers to weave between disease and illness frameworks to understand both the biomedical history of disease and patient experiences with illness. In a disease-illness model, the term “disease” is used to define the pathophysiologic processes adversely affecting the structure and function of organs and systems.<sup>27,28</sup> The term “illness” defines the complete patient in terms of physical, psychological, social and cultural factors that reflect each individual's unique subjective experiences associated with being unwell. This type of model was developed more than 30 years ago by McWhinney and

colleagues, with the aim of transforming patient care from a traditional provider-centred method, in which the patient's condition is interpreted solely based on disease pathology, to a more patient-centred method that includes practical consideration of patient-specific experiences.<sup>26,29,30</sup>

Disease-illness models have been used in patient care studies for conditions including chronic pain, respiratory diseases, cancer and psoriasis to better understand concepts such as the value of multi-disciplinary care, factors affecting adherence to therapy, and the effect of personal and cultural experiences on self-reported symptom distress.<sup>31-34</sup> However, we believe disease-illness models have not been used to describe obesity or inform its treatment.

Based on our evaluation of healthcare models, we hypothesized that a disease-illness model of obesity could be used to help capture the full patient experience of living with obesity. Because obesity management is driven in large part by individual patient experiences, the disease-illness model is extremely well-suited to promote incorporation of patient-centred care as an integral part of obesity treatment.

### 3 | RESULTS

#### 3.1 | Development of the obesity disease-illness model

##### 3.1.1 | Patient-centricity

The most important feature of the obesity disease-illness model is that it is patient-centric. Thus, placing the patient with obesity at the core of the disease-illness model was the first step in highlighting how all aspects of disease are uniquely driven by the characteristics of each individual (Figure 1). This means considering each individual patient within the context of his/her particular health determinants and disease impacts.

##### 3.1.2 | Health determinants

To categorize the health determinants that contribute to obesity, we evaluated several national and international health organizations' definitions of key determinants of health.<sup>35-37</sup> The Centers for Disease Control and Prevention recognizes five health determinants that contribute to a patient's current state of physical, mental and social well-being. These determinants are (a) biology and genetics, (b) individual behaviour, (c) social environment, (d) physical environment and (e) health services. Other groups include the conceptual framework for determinants of health psychological factors; knowledge, attitudes and beliefs; socioeconomic; and access to health services.<sup>36,37</sup> Using guidance from these organizations<sup>35-37</sup> and input from obesity experts, we classified the health determinants of the obesity disease-illness model as environmental, sociodemographic, psychological, behavioural, physiological/biological and medical (Figure 1).

Notably, it is important to differentiate between the psychological and behavioural determinants of obesity, and to recognize that the factors that contribute to obesity are, in many cases, also

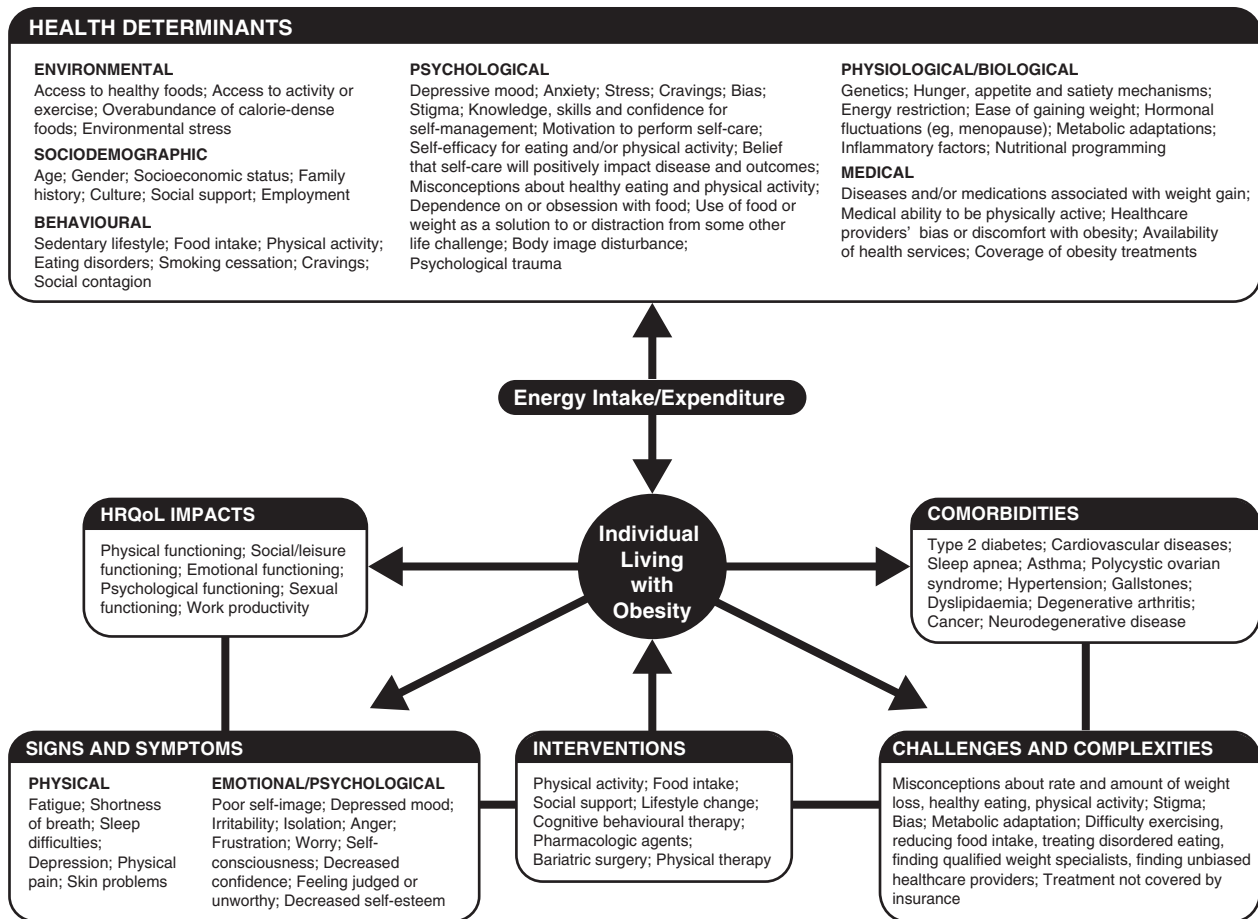
consequences of obesity. Thus, many of these relationships are bidirectional. In addition to understanding the effects of how each individual's behaviours impact obesity outcomes, it is also important for stakeholders to recognize that the distinct psychological impact of obesity can be profound. For example, stigma related to obesity is associated with risk for depressed mood, low self-esteem and body image dissatisfaction.<sup>38</sup> Patients have different coping mechanisms for dealing with stigma; patients who use positive strategies (eg, self-acceptance and strong social support) often have better psychological well-being than those with more negative coping responses.<sup>38</sup>

Due to the complex relationship between food environments, social influences, biological triggers and biological responses, individuals have less control over eating behaviours than may be commonly believed, which is a major contributing factor to weight bias. Understanding the psychological factors associated with eating behaviours (eg, eating as a distraction from difficult emotions, eating as a source of pleasure, eating as a coping strategy), with family/cultural/community biases and expectations related to food, and with negative patient and societal perceptions (eg, that people with obesity lack willpower, are overindulgent or are lazy) can help providers better appreciate the multitude of factors that patients may not be able to control and the true need for more intensive interventions (eg, pharmacologic therapy or bariatric surgery) to help patients to improve their health and health-related quality of life.

##### 3.1.3 | Management of illness factors in obesity

Rather than continuing to focus primarily on change in weight over time for patients living with obesity, the bottom portion of the obesity disease-illness model was designed to highlight the complex relationships that must be considered when developing individualized strategies for the treatment of obesity (Figure 1). To effectively set individualized treatment strategies, which may or may not include weight loss, diet or exercise, healthcare practitioners need to understand which outcomes are most important for each particular patient. Issues such as poor sleep, negative body image, low self-esteem or arthritis pain should be addressed prior to suggesting other lifestyle changes. For example, individuals living with obesity who experience poor sleep may benefit from referral to a sleep clinic to understand and ameliorate contributing factors, such as sleep apnoea or poor sleep hygiene. Similarly, referral to physical therapy may be needed to address arthritis pain; although pain may be exacerbated by obesity and weight loss may improve painful joints, it should not be assumed that the patient must lose weight. Cognitive behavioural therapy may be useful for body image issues, and various psychotherapeutic approaches may teach skills to enhance self-esteem.<sup>39,40</sup> Above all, the practitioner needs to ask the person living with obesity if weight loss is desired, or if the patient prefers instead to focus on improving comorbid conditions, signs and symptoms, and health-related quality of life.

Before pursuing weight loss, the AHA/ACC/TOS guidelines recommend that healthcare practitioners identify each patient's life situations and priorities.<sup>21</sup> These guidelines state, "The decision to



**FIGURE 1** The obesity disease-illness model. HRQoL, health-related quality of life

undertake weight loss efforts must be made in the context of competing priorities (eg, smoking cessation may supersede a weight loss effort and life events may make the effort at weight reduction futile until a future time). If the patient is not prepared to undertake these changes, attempts to counsel them regarding how to make lifestyle changes are likely to be counterproductive.<sup>21</sup>

With the obesity disease-illness model as a foundation, healthcare practitioners can use established tools to interact with their patients and better understand their needs. For example, they can use motivational interviewing to non-judgmentally explore a person's ambivalence or resistance to behavioural changes, support self-efficacy, and stimulate motivation to perform targeted behaviours. Motivational interviewing techniques are based on an integrative, biophysical model to conceptualize the process of intentional behaviour change.<sup>41,42</sup> When used as an adjunct to pharmacologic or surgical treatment, motivational interviewing can improve clinical outcomes related to weight and overall cardiovascular health.<sup>43,44</sup>

Thus, it is important for healthcare providers to evaluate patients holistically, understand what changes each patient is motivated to make, and recognize what challenges might impede weight reduction, as well as improvements in comorbid conditions, signs and symptoms, and health-related quality of life. However, even patients who are vigilant in making significant and sustained changes in their self-care

behaviours may struggle to achieve and maintain their health goals. This is because when the body is subjected to caloric restrictions and vigorous exercise, it responds with metabolic adaptations (eg, decreased metabolic rate and an increased drive to eat) in efforts to correct perceived energy imbalances and return to a previous set-point weight.<sup>45,46</sup>

Although most obesity treatment focuses on weight reduction, it is important to note that weight-neutral obesity management strategies that emphasize overall patient health can have substantial benefits. For example, programmes that focus on improving patient fitness and intuitive eating can have greater positive impact on markers of cardiovascular risk (eg, low-density lipoprotein and total cholesterol levels) than programmes that focus predominantly on weight loss.<sup>47</sup>

Our qualitative research conducted with patients has shown that patients living with obesity who do lose weight perceive benefits beyond weight loss, including changes in appetite, increased energy and physical activity, and increased confidence and social functioning, particularly among younger patients.<sup>48</sup> For patients who are interested in weight reduction, healthcare practitioners should identify individual patients' barriers to success before pursuing individualized treatment goals.<sup>21</sup> Addressing issues that could keep patients from making healthy lifestyle changes may increase the likelihood of success. When patients are able to achieve some degree of weight loss,

they may start to feel better physically and emotionally, and could experience improvements in comorbid conditions, signs and symptoms, and/or health-related quality of life.

Adopting healthy behaviours, such as increasing fruit and vegetable intake and becoming more physically active, can have significant positive effects on physical functioning, vitality, self-esteem and cardiometabolic fitness.<sup>47,49</sup> Additionally, increased physical activity may improve issues like poor sleep, low self-esteem and arthritis pain.<sup>50–53</sup> As shown in recent studies of obesity and type 2 diabetes, participating in a supportive obesity treatment programme and starting to achieve treatment goals (eg, weight loss, blood glucose control) can increase patients' motivation to perform healthy self-care behaviours (eg, eating healthier foods, becoming more physically active, quitting smoking), improving the odds of long-term achievement and maintenance of a healthier weight and better cardiometabolic parameters.<sup>54–58</sup>

For many patients living with obesity, behavioural changes may not be sufficient to maintain long-term cardiometabolic benefits. These patients may require more aggressive pharmacologic or surgical interventions as the body fights to maintain a prior heavier weight. Despite the potential for significant weight loss with bariatric surgery, only 35% of eligible patients consider bariatric surgery, 12% have had a doctor tell them that they are a candidate for surgery, and ~3% have had surgery.<sup>59</sup> Concerns about cost, the level of risk, side effects and fear are common reasons given for not having a procedure.<sup>59</sup>

Review of the clinical literature has shown that combining pharmacotherapy with lifestyle interventions helps people to lose more weight and sustain weight loss over time compared with lifestyle changes alone.<sup>60</sup> Furthermore, aggressive medical approaches to obesity management that include pharmacologic and intensive lifestyle interventions may significantly improve clinical and metabolic parameters and, in some patients, prevent the need for bariatric surgery.<sup>61</sup> Consistent with these observations, Endocrine Society, AHA/ACC/TOS and AACE/ACE guidelines recommend pharmacotherapy as an adjunct to lifestyle modifications for individuals with obesity who have a body mass index  $\geq 30$  kg/m<sup>2</sup> or  $\geq 27$  kg/m<sup>2</sup> and an obesity-related comorbidity.<sup>21,23</sup>

The recommendation for pharmacotherapy in addition to adherence to healthy lifestyle changes, ideally with the help of a patient-centred healthcare team that may include professionals such as nutritionists, exercise physiologists and behavioural health specialists, is largely underappreciated within the healthcare community. Many people are unaware that newer, long-term prescription treatments are available for chronic weight management, and, among patients who do receive pharmacotherapy, many have unrealistic expectations about the treatment effects, anticipating that they will experience more than the average observed body weight reduction of 5% to 10%.<sup>62</sup> Furthermore, underutilization of anti-obesity medications is recognized as an important contributor to the failure of obesity management in clinical practice.<sup>61</sup> In the United States, it is estimated that only 2% of adults who have obesity are prescribed pharmacotherapy as recommended by Endocrine Society, AHA/ACC/TOS and AACE/ACE guidelines.<sup>63</sup> This is an obvious missed opportunity to improve

quality of care for patients living with obesity, especially given that as little as 3% body weight loss can significantly improve metabolic control, and each 1 kg of weight gained is associated with a 9% relative increase in diabetes prevalence.<sup>64</sup>

## 4 | DISCUSSION

Over the past several decades, obesity has become widely recognized as a chronic disease that increases morbidity and mortality risks and can have negative effects on health-related quality of life. However, recent evidence indicates that most people with obesity face significant barriers to receiving high-quality, patient-centric, affordable, effective care. For example, in surveys of people living with obesity, healthcare providers and employers, the National Awareness, Care, and Treatment In Obesity maNagement (ACTION) study found that 44% of patients who have obesity believe that they are solely responsible for managing their own weight, but only 37% of patients indicated that they know what they need to do to manage their weight.<sup>65</sup> Additionally, many healthcare providers do not prioritize management of obesity, and more than half of employers (52%) have concerns about the cost of offering insurance coverage for obesity management. More broadly, factors such as socioeconomic inequities and the built environment, which are significant barriers for patients living with obesity, need to be addressed.<sup>66,67</sup> The Strategies to Overcome & Prevent (STOP) Obesity Alliance, a group working to identify and address systematic and cultural barriers that are failing to support success of individuals living with obesity, has published a chronic care model that integrates clinical and community systems to address obesity and related chronic diseases.<sup>19</sup>

There is a clear unmet need to provide stakeholders with strategies to overcome these barriers to quality obesity care.<sup>65</sup> One way that stakeholders have significantly improved quality of care for people with diseases related to obesity (eg, diabetes, dyslipidaemia, hypertension, cardiovascular disease) is by shifting treatment paradigms to be more patient-centred, focusing on each patient's preferences, values and needs.<sup>2,3,9,68–71</sup>

While there are several accurate and informative models of obesity that have been developed by leading experts and medical societies,<sup>17,18,22,72–74</sup> truly patient-centric models are lacking. Thus, the current initiative was undertaken to develop a patient-centred obesity disease-illness model and to issue a call to action to obesity stakeholders to utilize this model to promote activities outlined in Box 2, with the goal of improving quality of care. This disease-illness model of obesity aligns well within the context of current obesity research initiatives that recognize the high level of variability in individuals' responses to treatment. For example, the Accumulating Data to Optimally Predict Obesity Treatment (ADOPT) Core Measures Working Group is developing models that integrate behavioural, psychosocial, environmental, and biological predictors and moderators of treatment responses ([www.isbnpa.org](http://www.isbnpa.org)).

As new treatments are studied for obesity management, a disease-illness model for obesity, such as the one presented here, can

**BOX 2 Calls to action to improve patient-centred care for people living with obesity<sup>62,65,75</sup>****Healthcare providers**

- Treat obesity as a complex, chronic disease
- Educate patients about the complexities of obesity to remove the burden of guilt and shame
- Consider the individual's personal context and specific health determinants when communicating with them
- Educate patients on the social, environmental and metabolic barriers that can make weight loss more challenging than expected
- Educate patients about unexpected consequences of weight loss (eg, changes in social and partner relations)
- Offer patients a range of treatment options; encourage use of pharmacotherapy or bariatric surgery, if indicated
- Help patients set goals in addition to weight loss (eg, improve aspects of health-related quality of life, comorbid conditions, self-esteem)
- Help patients develop realistic expectations about weight loss, weight maintenance and long-term adherence to healthy behaviours
- Provide long-term support and follow-up by multiple disciplines
- Develop treatment strategies using shared decision-making and feedback obtained from patient-reported measures
- Use person-first language and respectful communication

**Family/caregivers**

- Understand the challenges patients face when managing their obesity, many of which are biological, inherited and difficult to control
- Ask the patient what they want or need in terms of support
- Be sensitive to stigma and weight biases the patient with obesity experiences, and avoid contributing to these biases
- Use person-first language and respectful communication

**Payers**

- Recognize the complexity of obesity and the implications this disease has on physical and emotional health, comorbidities and health-related quality of life
- Implement medical and pharmacy coverage and reimbursement models that increase patient access to a range of treatment options
- Improve the understanding of the cost-effectiveness of obesity treatment options
- Use person-first language and respectful communication

**Policymakers**

- Promote the involvement of government-sponsored multidisciplinary care for obesity
- Increase incentives for improved care and preventive health measures, including the prevention and treatment of obesity
- Promote the analysis of data captured in government health databases to improve population health in the patient with obesity
- Promote alignment of public health efforts with obesity treatment guidelines
- Implement performance metrics of obesity outcomes to guide patient care
- Use person-first language and respectful communication

**Employers**

- Understand that obesity is a complex, chronic disease
- Provide incentives for employees to maintain healthy lifestyles
- Provide employees with healthy food options and nutrition coaching
- Provide employees with programmes and information on health and wellness
- Appreciate the value of offering employees insurance coverage for obesity management
- In the appropriate patient, provide health benefits that include comprehensive reimbursement for obesity and related comorbidities, including bariatric surgery, pharmacotherapy and weight management counselling
- Use person-first language and respectful communication

**Scientists developing obesity treatments**

- Incorporate patient preferences and priorities when evaluating the effect of obesity treatments on outcomes
- Use person-first language and respectful communication

**Researchers studying obesity**

- Develop research agendas that emphasize the study of patient-centred care tools and techniques
- Prioritize the study of patient barriers to achieve weight loss and to evaluate tools that can be used to overcome these barriers
- Evaluate cultural and environmental factors that can affect a person's ability to lose weight
- Establish quality metrics for the patient with obesity that are evidence-based and improve patient outcomes
- Use person-first language and respectful communication

be used to inform the development of novel patient-reported outcome measures that evaluate personal experiences, including ease or difficulty of losing weight; hunger and appetite control; satisfaction with treatment; and improvements in daily activities and mental health. Using a disease-illness model for this purpose can help researchers to organize and visualize key features of the many aspects of obesity care and pathology. This type of information can guide evaluation of existing patient-reported outcome instruments and concept elicitation for new instruments, and can be used to inform clinical trial design/endpoint selection.<sup>34</sup> Lastly, well-designed patient-reported outcome instruments can provide substantial value to healthcare practitioners as beneficial tools to deliver medical care and to measure the benefits of care from the patient perspective.<sup>76</sup>

The obesity disease-illness model has been developed as a tool to promote patient-centred care for people living with obesity and as a call to action to stakeholders (eg, healthcare providers, caregivers, payers, policymakers, employers, mental health professionals, scientists developing obesity treatments, and researchers studying the pathophysiology of obesity) to consider ways in which they can improve the quality and success of obesity care. While this model has not been validated, we believe it is well-substantiated based on an accumulation of research collected through evaluations of the literature, qualitative studies with patients and direct input from subject matter experts. It illustrates the complexity and diversity of patient experiences with obesity, emphasizing the various health determinants of obesity, impacts of disease on health-related quality of life, as well as challenges faced by patients in achieving and maintaining long-term weight loss, healthy self-care behaviours and improved health. This model is intended to be used as part of the dynamic process of obesity management and can evolve over time as evidence emerges on new approaches to treatment, as patient attitudes shift, and as public and private policies change. Future research should evaluate these patient-centred care strategies for obesity management and assess potential improvements in clinical outcomes, patient satisfaction and healthcare costs in the context of our disease illness model framework.

## ACKNOWLEDGEMENTS

Medical writing support was provided by Cherie Koch, PhD, of MedErgy, and funded by Janssen Research & Development, LLC.

## CONFLICT OF INTEREST

J.F., M.A., W.C. and S.T. are full-time employees of Janssen Research & Development, LLC. R.L.K. has served as a consultant to Novo Nordisk, Eisai and Janssen; has served on an advisory board and steering committee for Novo Nordisk; and receives royalties from Duke University for the IWQOL-Lite. K.F. has provided consulting services to Orexigen, Novo Nordisk, Eisai, Zafgen, Janssen Global Services, Gel-esis, Ambra, KVK-Tech, Boehringer Ingelheim and Shire.

## AUTHOR CONTRIBUTIONS

J.F. and S.T. contributed to the conception of the model and performed literature searches to inform model design. All authors provided input on the design and interpretation of the model, were involved in the writing of the paper and approved the final version for submission.

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**How to cite this article:** Fastenau J, Kolotkin RL, Fujioka K, Alba M, Canovatchel W, Traina S. A call to action to inform patient-centred approaches to obesity management: Development of a disease-illness model. *Clin Obes.* 2019;9:e12309. <https://doi.org/10.1111/cob.12309>