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“Healthy”

When the pursuit of health turns into a mental disorder: the case of orthorexia nervosa

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor of Philosophy
aan de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. V. Subramaniam,
in het openbaar te verdedigen
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De Boelelaan 1105

door

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geboren te Asti, Italië

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CHAPTER 5. Diversifying and Integrating Views and Understandings of Health Professionals and Experts on Orthorexia Nervosa.

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Objective. With the objective to contribute to a socio-culturally embedded body of knowledge about orthorexia nervosa (ON), this study aimed to collect insights into definition, diagnostic criteria and risk factors of ON, by involving health practitioners and academics with expertise on ON. **Methods.** This study had an exploratory, participatory nature, where different stakeholders were consulted through means of qualitative participatory activities and involved in a focus group, email rounds, and interviews. **Results.** This study generated (i) a working definition of ON, which enriches current understandings and conceptualizations of ON (i.e. “Orthorexia Nervosa is characterized by *obsessive thoughts* towards a diet believed to be healthy, with *compulsive behaviors* towards consequent food choices [...]), (ii) five diagnostic criteria for ON (i.e. obsessive thoughts and/or compulsive behaviors towards healthy food choices; exclusion of foods with a possible phobic behavior; strict and self-imposed nutritional regimen based on personal beliefs, which can cause weight loss and/or malnutrition; negative interference with normal social functioning; and influence on self-confidence and identity), (iii) an outline of risk factors for ON, prioritized according to their deemed importance for the onset of ON, and (iv) a vignette exemplifying a hypothetical ON patient. **Discussion.** The joint agreement reached in this paper is a notable example of collaboration between health professionals and academics, and demonstrates a common willingness to move the research about ON forward. We encourage future research to expand upon the findings of this study and to involve other relevant stakeholders in co-creating knowledge about ON.

Key words: orthorexia nervosa; diagnostic criteria; diagnosis; risk factors; participatory activities

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5.1 Introduction

In 1997, a US physician practicing alternative medicine, Steven Bratman, created the neologism “orthorexia nervosa” (ON) [1]. This term, which clearly alludes to anorexia nervosa, was an attempt to draw attention to an altered eating behavior that Bratman noticed in several patients. This behavior consists of a fixation on eating proper food that becomes pathological because it implies the transference of all life’s values into the act of eating healthily, going beyond the mere desire to overcome chronic illness or to improve health [1]. As has been specified by Bratman in a recent publication, it is necessary to differentiate ON from the innocent choice to pursue a healthy diet [2]. People suffering from ON are excessively rigorous in following their restrictive self-imposed diet. Food becomes a pervasive thought; their meals and the consequences of what they eat occupy a great proportion of their day, and their unbalanced eating behavior acquires pseudo-spiritual connotations. Acts of penitence usually follow eating “transgressions,” and all forms of social eating are generally avoided [1]. “Diet purity” is the goal, as opposed to calorie restriction. However, food choices can become so restricted in name of health that weight loss and malnutrition can also occur [3].

Twenty years after the term ‘orthorexia’ was coined, it started attracting the attention of the scientific community. In the past years, the number of publications about ON has sharply increased [4]; several literature reviews on ON have been conducted, and, recently, studies have turned to those people with a direct experience of ON, e.g. people who self-diagnose with ON [5], [6]. Furthermore, a still relatively low yet significant number of studies have explored environmental and socio-cultural factors influencing ON [7]–[10], contributing to a growing body of literature on the root causes of ON.

While this increased body of literature has brought advancements in our understanding of ON, a consensus on contemporary conceptualizations of ON and its diagnostic attributes is as yet lacking [11]. Scholars continue to refer to Bratman’s definition of ON in their studies [12], which was formulated over twenty years ago. The lack of a consolidated conceptualization of ON influences the way ON is understood and diagnosed, and jeopardizes the scientific literature. For example, currently, there are five sets of diagnostic criteria for ON [13], [16]–[19], none of which has been validated or made official for diagnosis [3], [11], and seven diagnostic tools [16], [18]–[23], which are used inconsistently.

ON is embedded in our time and culture. Therefore, changes in the context and societal trends influence the meaning and interpretation of ON. Unlike twenty years ago, the interest in healthy eating has today pervaded popular culture for the widespread use of social media [2], leading to inevitable changes in the way “healthy” is conceptualized and perceived. For example, if once eating healthily meant eating a bit of everything with moderation, today it is more likely to be associated with very strict diets or ‘clean eating’, which often encourage food exclusion and promote very restrictive eating norms (Natenshon, 2020). The increasing normalization of possible disordered eating patterns challenges disentangling what is considered healthy eating from ON, and this is something that should be taken into account when attempting to measure ON. Without

this, it happens that features of certain non-traditional dietary theories are mistaken for characteristics of ON, while instead focus should be on the obsessive approach to diet, and its impairing nature [2].

It is therefore important to contribute to a unified understanding of ON, and to open a dialogue on what ON has come to mean today. In the absence of patients' databases for a condition that is not yet an official diagnosis, health professionals and academic experts constitute a valuable source of experiential knowledge [25]. The consultation of practitioners who encounter patients with eating disorders in their daily practice can provide meaningful insights into diagnostic features and manifesting symptoms of ON. Furthermore, the cooperation of diverse experts with an interest in and expertise on the topic of ON can pave the way for a process of knowledge co-creation and collaboration around the topic of ON.

5.1.1 Theoretical Framework

To investigate into the complex and still unexplored nature of ON, we collected and analyzed information by relying on a theoretical framework: the dynamic biopsychosocial model of health [26]. The holistic nature of this framework made it possible to explore ON in all its facets. The dynamic biopsychosocial model of health, proposed in 2017 by Lehman and colleagues, was used as a lens through which to conduct data collection, as well as to interpret results. This model conceptualizes human health as the product of the reciprocal influences of biological, psychological, interpersonal, and contextual dynamics that unfold over time (Fig 5.1) [26]. Biological dynamics include physical elements of the body that affect health; psychological dynamics include cognitive, emotional, and motivational systems affecting health; interpersonal dynamics include social relationships influencing health; and contextual dynamics include culture, norms and policies that affect health [26]. Bio-psycho-interpersonal and social dynamics are not static, but rather interact with each other influencing individual's health and any point in time [26]. In the context of this study, this model helped to consider bio-psycho-social factors influencing ON, as well as bio-psycho-social symptoms and attributes of ON. This model was presented to stakeholders during the Focus Group Discussion (FGD), prompting them to consider all the bio-psycho-social aspects of ON. The questions posed to stakeholders throughout the study phases were articulated in a way to allow them to reflect on the bio-psycho-social spheres characterizing ON. By visualizing ON through a biopsychosocial lens, it was possible for stakeholders to consider the phenomenon in a holistic way.

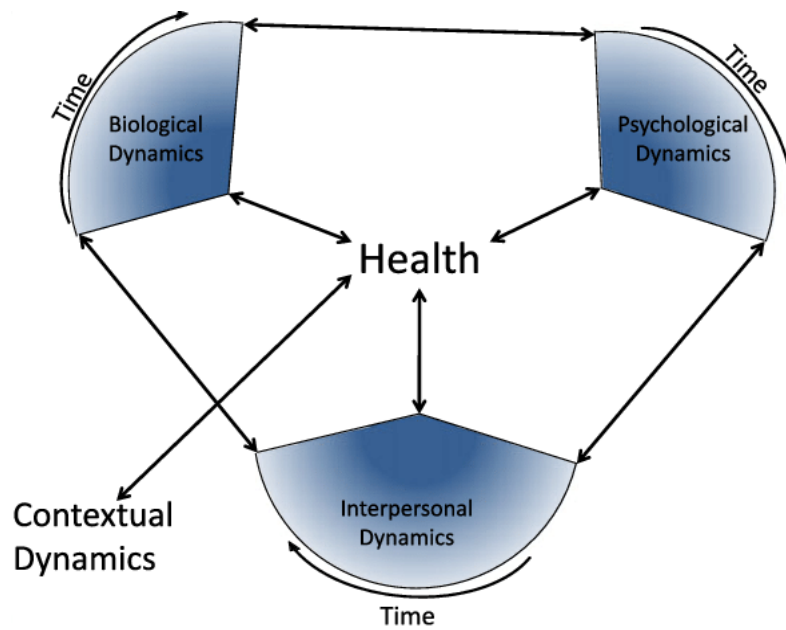


Figure 5.1. *Dynamic biopsychosocial model of health* [26]

5.1.2 Aim and Research Question

Definitions of ON are still scattered, and they do not yet successfully take into account that ON is a contemporary phenomenon, influenced by modern socio-cultural practices. We believe that, to truly understand the impact of ON on individuals, and to advance with therapeutic interventions, a redefinition is necessary. With the aim to contribute to a socio-culturally embedded body of knowledge towards defining ON and its impacts on our contemporary society, this study aimed to collect insights into definition, diagnostic criteria and risk factors of ON, by involving health practitioners and academics with expertise in the field, in Italy and internationally. The research question of this study, therefore, is: *How can combined insights of multiple stakeholders contribute to reaching a shared understanding and interpretation of ON?*

5.2 Methods

This study had an exploratory, participatory nature. The different stakeholders involved were given freedom to express their opinions, perspectives, and knowledge about ON.

5.2.1 Research Design

This study explored the perspectives of multiple and diverse stakeholders through means of qualitative participatory methodologies. The methods used in this study were a FGD, email rounds with participatory activities, and interviews. The shift from a linear cause-effect model to a participatory framework gave rise to an iterative research design, where phases of data collection and analysis followed each other in the timeframe of three months. Each phase of this research was developed according to the results of the previous one, resulting in an iterative and dynamic process. The final design was made up of five phases (Figure 5.2).

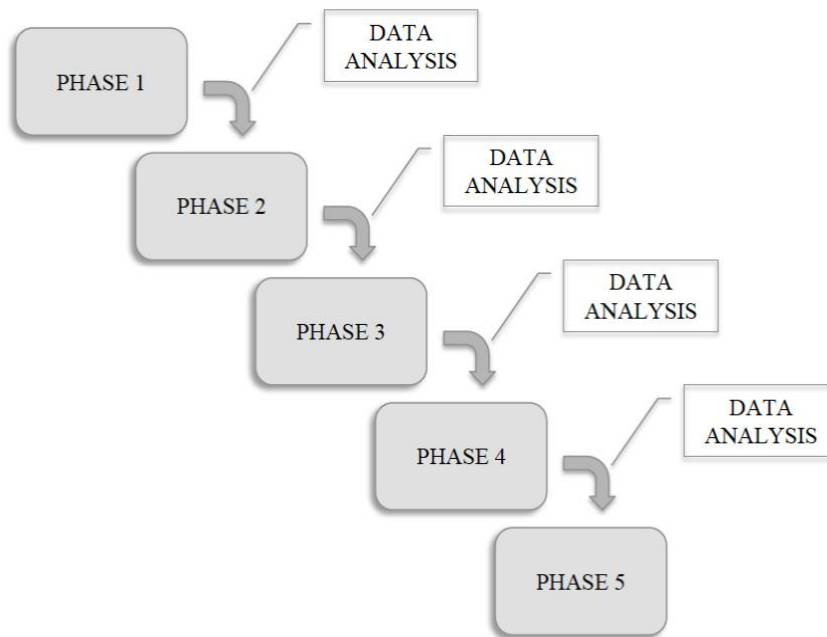


Figure 5.2. Diagram displaying the research design

Each phase of the research involved a specific action and was carried out for one or more purposes of the study. Actions consisted of different data collection techniques and analyses, and involved different stakeholders. Precisely, phases 1, 2, 3 and 5 were carried out with Italian stakeholders, phase 4 relied on international participants. The phases were organized in a “waterfall” design, where latter phases validated the findings of the earlier ones and also expanded on them (Fig 5.2). An overview of the research phases is reported in Table 5.1. Following is a description of the phases and the corresponding involved stakeholders.

Table 5.1

Graphic visualization of the research phases with corresponding purposes and actions

		Action									
Purpose		Phase 1 <i>FGD</i>	Data Analysis	Phase 2 <i>Lit Review</i>	Data Analysis	Phase 3 <i>Email Round</i> <i>n.1</i>	Data Analysis	Phase 4 <i>Email Round</i> <i>n.2</i>	Data Analysis	Phase 5 <i>Interviews</i>	
	Definition	Identification				Validation		Validation			
	Diagnostic Criteria	Identification				Validation		Validation		Validation	
	Risk Factors			Identification		Validation + Ranking		Validation			
	Vignette									Development	

5.2.1.1 Phase 1.

Data collection.

Phase 1 consisted of a FGD carried out in Modena (Italy) on the 4th of March 2019. The FGD lasted one hour and a half, and consisted of four participatory activities. The first activity required participants to write through the website mentimeter.com what concepts came to their mind when thinking at ON. Words written by respondents appeared on a slide, and this provided an input for discussion around the contemporary understanding of ON. The second activity required participants to identify possible bio-psycho-social diagnostic criteria for ON. A discussion around the criteria took place and was facilitated to reach a consensus. The third activity required respondents to compare the criteria they developed with the latest diagnostic criteria proposed in literature [17]. Finally, the last activity consisted in the identification of criteria necessary for diagnosis through a collective discussion.

Stakeholders.

The panel of experts who participated in the discussion was made up of 14 members of the SISDCA (Italian Society for the Study of Eating Disorders) (7 women & 7 men). Participants were selected according to their interest in and experience with ON, and were invited to attend the FGD by email. They were Italian health professionals coming from different fields and parts of Italy, all having years of experience in dealing with eating disorders – e.g. psychologists, psychiatrists, endocrinologists, dietitians. The language of the FGD was Italian.

Data analysis.

The FGD was recorded, and manually transcribed and coded. Open coding was used to analyze the transcript, and the main concepts associated to ON were identified. These concepts were used to develop a new definition of ON by using the definitions of existing feeding and eating disorders in the DSM-5 as a backbone [27]. Biological, psychological, interpersonal and contextual diagnostic criteria proposed during the discussion were merged together in order to obtain a list of criteria. Criteria that participants considered necessary for diagnosis were identified.

5.2.1.2 Phase 2.

Data collection & analysis.

The purpose of Phase 2 was to identify risk factors for the onset of ON. This was achieved by conducting a (non-systematic) review of the literature. A recent comprehensive literature review conducted by Cena and colleagues in 2018 was used as a base, and literature referred in this article was reviewed. The risk factors reported in literature as implicated in the onset of ON were extracted, until reaching saturation.

5.2.1.3 Phase 3.

Data collection.

Phase 3 consisted in development and delivery by email of a document containing participatory activities on ON for the reader (i.e. Email Round n.1). The document consisted in three sections, with three different activities. The first section required the reader to give feedback on the definition of ON derived from the FGD; the second required the reader to give feedback on the diagnostic criteria and to agree upon which criteria were necessary for diagnosis; the third requested the reader to grade from 0 to 5 the risk factors for ON obtained through the literature review, and to possibly add other missing ones.

Stakeholders.

Respondents were the same 14 people who participated to the FGD and the language of the document was Italian.

Data analysis.

The documents were analyzed in multiple sessions. The feedback respondents provided on the definition was implemented, and adjustments were made where the linguistic articulation was not clear. Changes were made when suggestions came from multiple respondents, and when they were deemed to be meaningful to the research team, or supported by additional material provided in attachment to the email. With regard to the diagnostic criteria, only the ones that received approval from the majority of respondents were considered for the final version. Finally, grades that each participant provided for risk factors were added up, obtaining a final score, which allowed ranking risk factors in order of their relevance for the onset of ON.

5.2.1.4 Phase 4.

Data collection.

Phase 4 consisted in the development and delivery by email of a second document containing participatory activities for the reader (i.e. Email Round n.2). The document consisted in three sections. The first reported the definition of ON developed during the previous phases. The second reported the diagnostic criteria selected in Phase 3. The last section reported the risk factors previously ranked. The reader had the opportunity to leave comments and give suggestions in all the sections.

Stakeholders.

Stakeholders to whom the email was sent were members of the ON-Task Force (n = 13). The ON-Task Force is an international community of researchers established in 2016 with the aim to reach a consensus around ON [11]. Members of the Task Force come from many fields and countries, and are the most prominent contributors in the field of ON, who have published multiple scientific articles on the topic and who are active in researching ON. Seven people out of 13 replied to the email (5 women & 2 men) providing their contribution to the study. The intrinsic diversity within the group and the deep knowledge on ON made the members of this community ideal participants in this study. The language of the document was English.

Data analysis.

The documents were analyzed and feedback was implemented by following the same process as in Phase 3. Additional risk factors proposed were added at the bottom of the list. In the end, a final version of definition, diagnostic criteria and risk factors was obtained.

5.2.1.5 Phase 5.

Data collection.

Phase 5 consisted of four unstructured interviews (5 women) aimed at constructing a vignette representing a hypothetical patient suffering from ON. Respondents were asked to read the diagnostic criteria developed in the previous phases and to base on them a description of a patient having such characteristics. The bio-psycho-social model of health worked as the underlying framework guiding inquiry. The ultimate goal of constructing the vignette was to create a representation of ON that could be used for a future validation of criteria and research into ON. At the same time, this phase allowed further validation of the criteria.

Stakeholders.

Participants were a nutritionist, a psychologist and two general practitioners working at the Policlinico Umberto I (Rome). The language of the interviews was Italian.

Data analysis.

Interviews were recorded and manually transcribed. Open and axial coding was performed using the software Atlas.ti version 8.2.4. The codes represented the characteristics of the hypothetical patient, and were used to merge together the four descriptions into a final one. The vignette was developed in Italian and subsequently translated into English for publication purposes.

5.3 Results

Results are presented as divided in four sections: (1) definition of orthorexia nervosa, (2) diagnostic criteria for orthorexia nervosa, (3) risk factors for orthorexia nervosa, (4) vignette of a patient suffering from orthorexia nervosa. Results are reported by outlining the process through which these have been co-developed by stakeholders.

5.3.1 Definition of Orthorexia Nervosa

During the FGD, several concepts emerged when participants were given the opportunity to mention the things that came to their mind when thinking about ON. The concepts that were mentioned by multiple respondents, which therefore appeared bigger on the slide, worked as a starting point for further discussion. Respondents agreed to consider *obsession* the main feature of ON. Interestingly, during the discussion, it emerged that it is not only an obsession that characterizes ON, but also the deriving *compulsion*:

“What makes the pathology is the form of the phenomenon, which is the obsessive nature. Obsessive-compulsive nature, which is able to cause damage” (Participant FGD)

Purity was also mentioned by multiple respondents as characterizing ON:

“I wrote purity because I see in this term [orthorexia nervosa] a religious component too, or a component of differentiation from a more secular community that pays less attention to values” (Participant FGD)

Another important concept associated to ON was *fear*. Not only fear for the negative consequences of food on the body, but a more extensive fear, which comes to mean fear of death:

“In some ways, fear is an excessive anxiety for body contamination from foods they do not consider correct”
(Participant FGD)

“It is the fear of death, the fear of illness, which leads to look for something certain in a world that lacks any parameters of certainty” (Participant FGD)

Another attribute of ON that was identified by participants was *rigidity*, and, interestingly, words like *veganism* and *organic* appeared on the slide too. While a few respondents considered that veganism could possibly lead to ON:

“I had the opportunity to see that [veganism] transcends the boundary of what is an ethical choice and results in a sort of rigidity, meaning that the conversation [with those who follow a vegan diet] often shifts

from a colloquial tone to an accusatory tone against those who do not adhere to the same idea” (Participant FGD)

Participants, in the end, agreed to consider ON independent from the type of diet followed, concluding that it is the approach to diet to be pathological, rather than the diet itself:

“[Orthorexia nervosa] starts from a concept that could be normal in itself. I mean, the individual who is obsessed and is afraid of contamination starts from a normal thought, for example that handles can be infected. But when does this become obsessive? When he/she sanitizes handles fifty times per day, or when he/she needs gloves to open doors. Here [in the case of orthorexia nervosa] we start from a behavior that can be approved, a lifestyle, but then there is someone that interprets this lifestyle obsessively” (Participant FGD)

These concepts were combined during data analysis in the form of a preliminary definition, which was structured by relying on the definitions of existing feeding and eating disorders in the DSM [27]. This preliminary definition was sent via email to the same panel of experts who participated to the FGD for further feedback and adjustments. Adjustments were made when more than one participant suggested a certain change, or raised the same concern. After the first email round, the definition was adapted according to the feedback: more emphasis was placed on differentiating the *obsessive thoughts* from the *compulsive behaviors*, the presence of *excessive preoccupations* was added, and the fact that *weight loss* can possibly result from this disordered eating practice was included.

A second preliminary version of the definition was therefore obtained, and this was sent via email to a second panel of international experts, i.e. members of the ON-Task Force, who provided further feedback. Again, adjustments were made when more than one participant suggested and motivated a certain change. Additional changes that enriched the definition of ON concerned linguistic clarifications about the differential diagnosis, and the addition of *overvalued ideas* about the healthiness of certain foods as another feature of ON:

“I assume that ON is not only about eliminating foods believed to be unhealthy, but that it is also about choosing foods that are believed to be healthy. [...] While e.g. AN is about eliminating foods, ON is about making the best food choice for your health. Of course, we still need more research to either support or reject this hypothesis, but I nonetheless think that this aspect is important to differentiate ON from AN”

(Respondent email round 2)

Once the feedback of the second panel of experts was integrated, a final version of a working definition for ON was obtained, which is presented in Table 5.2.

Table 5.2

Definition of Orthorexia developed by involving multiple stakeholders

Definition of Orthorexia Nervosa
<p>Orthorexia Nervosa is characterized by <i>obsessive thoughts</i> towards a diet believed to be healthy, with <i>compulsive behaviors</i> towards consequent food choices.</p> <p>Individuals suffering from Orthorexia Nervosa manifest <i>fear</i> and <i>excessive preoccupations</i> about the negative consequences that foods considered unhealthy or impure can have on the body. They can also have <i>overvalued ideas</i> about the benefits that the food they choose has on their health. This condition implies a strict adherence to a <i>rigid self-imposed</i> eating regimen, with the aim of preserving or improving the health status. The eating regimen is generally characterized by <i>food selectivity</i> based on personal beliefs, which in some cases can lead to malnutrition and/or <i>weight loss</i>. The food selection or exclusion from the diet may vary from one person to another, and is not attributable to a concurrent medical condition or not better explained by another mental disorder, nor economic conditions, cultural or religious beliefs and values.</p>

5.3.2 Diagnostic Criteria for Orthorexia Nervosa

During the FGD, participants were told to suggest possible diagnostic characteristics for ON and to categorize them as belonging to the biological, psychological or social sphere. These characteristics were subsequently discussed as possible diagnostic attributes of ON, and prioritized according to their being necessary for a potential diagnosis.

Among the biological characteristics initially mentioned were: rigid self-imposed nutritional regimen, food selectivity, malnutrition, and underweight. The fact of the diet being self-imposed has been remarked by respondents with the aim to disentangle ON from diets prescribed for medical reasons:

“When we talk about rigid dietary regimen, I would add self-imposed, because it may also be rigid but therapeutic (for a medical condition)” (Participant FGD)

At the intersection between biological and psychological spheres was phobic attitude towards certain foods:

“I wrote phobia of certain foods not for cultural reasons, I mean not because they belong to a culture, but a different phobia” (Participant FGD)

Psychological criteria were relatively easy to identify: excessive preoccupation for a diet considered healthy for at least six months, obsession and inflexibility related to diet, excessive fear of disease and sense of impurity, shame and guilt after an eating transgression, degree of egosyntonicity, rituality in food choices and preparation, and self-confidence dependent on respecting the diet:

“High self-confidence when the individual succeeds in respecting the self-imposed rules, and the opposite in case of transgression” (Participant FGD)

Lastly, social criteria were identified: harmful interference with normal social activities, isolation, imposition of food rules on others, and tendency to proselytism, sectarianism, and fanaticism.

During the FGD, the following criteria were commonly identified as necessary to potentially diagnose ON: rigid self-imposed nutritional regimen, food selectivity, excessive preoccupation for a diet considered healthy for at least six months, obsession and inflexibility related to diet, excessive fear of disease and sense of impurity, shame and guilt after an eating transgression, degree of egosyntonicity, and harmful interference with normal social activities. Malnutrition and psychosocial isolation were considered traits that could be possibly present and useful to identify ON, yet not indispensable.

The bio-psycho-social diagnostic attributes were combined to form six diagnostic criteria. These were included in the email sent to the first panel of experts. Participants were required to provide further feedback and select once again which criteria would be necessary to distinguish ON from healthy eating, and thus to diagnose ON. All criteria were considered necessary for diagnosing ON, except for the one concerning proselytism, sectarianism, and fanaticism. Phobic behavior was considered by the majority of respondents something that can be present, but it's not indispensable for diagnosis.

As for the definition, adjustments were made when suggested by more than one participant. The updated version of diagnostic criteria was subsequently sent for feedback and validation to the second panel of experts, i.e. ON-Task Force. Apart from minor linguistic changes, the presence of overvalued ideas about food healthiness has been added, together with the separation of obsessive thought from compulsions:

“I would break obsessing and compulsions into different categories to make it consistent with DSM-5 OCD diagnosis. That is, OCD can be diagnosed in the absence of obsessions, as long as compulsions are present, and vice versa” (Participant email round 2)

Once the feedback of the second panel of experts was integrated, a final version of working diagnostic criteria for ON was obtained, which is presented in Table 5.3.

Table 5.3

Diagnostic criteria for Orthorexia nervosa developed by involving multiple stakeholders

Diagnostic Criteria for Orthorexia Nervosa
1. Obsessive thoughts, for at least 6 months, for a diet believed to be healthy, and/or compulsive behaviors towards food choices, motivated by an excessive fear for illness, and/or aimed at preserving or improving health status.
2. The exclusion of some foods, food categories, nutrients, food additives, or food preparation and preservation methods considered unhealthy, with possible phobic behavior or fear of contamination; and/or the propensity to choose only foods considered healthy because of overvalued ideas about their benefits.
3. Strict and self-imposed nutritional regimen, based on personal beliefs, not related to economic, medical, cultural, religious purposes, which can lead to disability, nutritional deficiencies, weight loss, or hormonal disturbances. Appearance-related reasons should not be the main focus of the affected individual.
4. Negative interference with normal social functioning and with affective relationships, which can lead to social isolation and a decrease in quality of life.
5. The strict adherence to self-imposed eating rules may influence self-confidence and identity, with the consequent rise of a sense of self-control when adhering to diet, and feelings of shame, guilt, inadequacy and/or sense of impurity after an eating transgression.

5.3.3 Risk Factors for Orthorexia Nervosa

Twenty-four factors possibly implicated in the onset of ON were extrapolated from the literature and ranked in order of relevance for the onset of ON by the first panel of experts from Italy (Email Round n.1). Subsequently, the second panel of international experts (Email Round n.2) validated the ranking and added three more factors to the list, obtaining a total of 27 factors that may contribute to the onset of ON (Table 5.4).

The first factors on the list represent the most influential ones for ON, according to respondents. The pressure exerted by the ideology of Healthism on a personal responsibility for health received the highest score. Following are having a history of an eating disorder, self-oriented perfectionism, the intention to fight non-communicable diseases or to improve health through diet, and the exclusion of foods from the diet because of (alleged) intolerances or allergies.

Table 5.4

Risk factors for the onset of Orthorexia nervosa extrapolated from the literature and ranked in order of relevance by multiple stakeholders

Risk Factors for Orthorexia Nervosa	Source
Emphasis manifested by Healthism on a personal and individual responsibility for one's own health	[7], [10], [28], [29]
Having suffered from an eating disorder	[10], [30], [31]
Self-oriented perfectionism and tendency to impose excessively high standards for oneself	[30], [32], [33]
Adoption of a self-imposed dietary regimen, with the intention to fight diseases or improve the general health status	[1], [15], [34]–[39]
Exclusion of a conspicuous amount of foods from the diet because of (alleged) allergies/ intolerances	[1], [10], [37]
Being excessively influenced by media, with a tendency to internalize the information received (e.g. increased attention to chronic conditions, genetically modified organisms, nutrients, additives, alarmism towards certain foods, and eating trends)	[19], [31], [33], [35], [40], [41]
Desire to control any aspects of life	[3], [18], [28], [33]
Inflexible and dangerous dietary regimen imposed by others	[4], [42]
Need to define one's own identity through food choices	[3], [18]
High levels of exercise/ being an athlete, with excessive desire to improve body composition	[28], [43]–[45]
Following a vegetarian or vegan diet, mainly for health-related reasons and not for animals' welfare	[46]–[48]
Appearance orientation and social physique anxiety (for orthorexia nervosa, fear for being perceived as overweight, thus 'unhealthy')	[30], [33], [43]
Internalization of Western ideals of thinness or muscularity	[33], [43], [49]
Having experienced conspicuous weight variations (> 40 Kg) during life	[50]
Fearful and dismissing attachment style	[30]
Desire to be part of a certain community, which follows specific eating beliefs	[3]
Restriction of calories intake and/or adoption of a strict eating scheme, with the intention to lose weight (being on a weight loss diet)	[46]

Receiving education on nutrition and dietetics	[34], [41], [51]–[54]
Being excessively influenced by the content present on Instagram	[55]
Being overweight or obese	[44], [56]
Epidemiological transition, which refers to the transition from a high amount of infectious diseases to a high amount of non-communicable diseases	[33]
Search for spirituality in the kitchen	[3], [18]
State of welfare of 'Western culture', including economic prosperity and well-being of the population	[33]
Influence exerted by the yoga practice on eating behaviors	[57]
Imitation of significant 'others' who adopt an inflexible and dangerous diet	Participant email round n.1
(Psycho)somatic issues and hypochondriasis	Participant email round n.1
Concurrent anxiety disorder or OCD	Participant email round n.1

5.3.4 Vignette of a Patient Suffering from Orthorexia Nervosa

Unstructured interviews with health professionals were conducted to obtain a description of a hypothetical patient suffering from ON. The finalized version of the diagnostic criteria and the dynamic biopsychosocial model of health [26], were used as a basis for guiding enquiry.

When describing their idea of a patient suffering from ON, interviewees mentioned female gender and age going from 20 to 50 years. Interestingly, they agreed that ON may be more common in adults because of the ability to better process information about non-communicable diseases:

“I would see her more towards adult age, you know? Because maybe when one is adolescent, yes she can pay attention, but just until a certain point [...] while in adulthood there is that fear of going towards contracting some disease” (Interview – Psychologist)

With regard to the educational level, a higher level of education was mentioned:

“I imagine the patient very literate. Among my patients, poor education and few economic possibilities are more associated with obesity and to eating very simple foods [...]. Therefore, I would imagine a patient with a high education” (Interview – Nutritionist)

An interesting characteristic that emerged was the tendency of the hypothetical patient to steal as much nutritional information as possible from the doctor:

“Being in the environment, it often happens that (patients with orthorexic tendencies) seek even more information from me [...]. It often happens they ask ‘how much shall I eat of this?’ ‘How many eggs shall I consume per week?’ [...]. You see that they ask questions, like ‘Am I doing right?’ They may insist also on some aspects” (Interview – GP)

Rigidity with regard to eating was mentioned:

“A transgression, what in their mind is perceived as a transgression, is not experienced in a peaceful way”
(Interview – GP)

Furthermore, individuals suffering from ON were described as possibly anxious, not only with regard to diet, but also with regard to other areas in life. Finally, another feature that emerged was the tendency of the individual to convince significant others to eat healthily. The concepts that emerged during the interviews were combined in the form of a vignette representing an hypothetical patient (Table 5.5).

Table 5.5

Vignette describing a hypothetical patient suffering for Orthorexia nervosa

Vignette of a Patient Suffering from Orthorexia Nervosa
<p>Claudia is a 30-year-old female of middle-high social class, who attended university. Despite having lost a few kilos in the last period, she is normal weight. She is a well-groomed woman. She has an excellent school curriculum and stands out for her leadership skills. She went to the nutritionist to ascertain alleged lactose intolerance. She claims to have trouble digesting it and to have read about its possible association with cancer on the Internet. Claudia often visits the nutritionist and tends to ask as many questions as possible to gain nutritional information. Claudia follows a vegan and low-gluten diet; she completely avoids sugar, palm oil, industrial products and prefers whole grains to refined ones. She only buys organic products at a trusted store. She does not often "transgress" her diet, but when she does, she feels a strong sense of guilt and shame. Claudia has been having an obsessive approach to nutrition for 6 months. Food is a fixed thought on which she ruminates for several hours a day. The moments of the meal and the food shopping are experienced with anxiety. Although food is the main cause of anxiety, Claudia is a relatively anxious person even in other areas of life. For example, she trains in the gym, but when she misses a workout, she feels guilty. Claudia also seems to have hypochondriac traits, due to the constant fear of illness and the desire to reduce every risk factor through diet. Claudia has a history of eating disorder. Claudia has been avoiding eating out for 6 months, and her social life has been reduced a lot. When she is forced to eat out, she tends not to eat what she has in her plate, appearing tense and blocked. Claudia often tries to convince her family members to follow a healthier diet, exposing them to the various reasons why it would be better to consume some foods rather than others. Claudia spends several hours a day compulsively searching for nutritional information on the Internet, but Instagram also influences her. She periodically follows detox diets promoted by 'influencers'. Claudia does not realize that she has a problem, but her family members are worried about her visible obsessive approach to diet and the social implications that followed.</p>

5.4 Discussion

This participatory study adopted an exploratory approach and qualitative methodology to diversify, integrate and systematize opinions of multiple health professionals and experts on the topic of ON. By giving stakeholders the opportunity to openly express their perspective about ON, and by subsequently analyzing results with a funnel approach, this study generated a working definition for ON, which enriches current definitions, derived a proposed set of diagnostic criteria for ON, proposed an outline of risk factors prioritized according to their deemed importance for the onset of ON, and pictured a vignette exemplifying a hypothetical ON patient. The joint agreement reached in this paper is a notable example of collaboration between health professionals and academics, and demonstrates a common willingness to move research about ON forward.

The definition of ON co-developed in the present study provides new insights on the current understanding of ON. The review of the literature conducted by Cena et al. reports that the terms most commonly used in literature with regard to ON are “fixation,” “obsession” and “concern/preoccupation” [11]. The working definition of ON obtained in the context of this study confirms the obsessive nature of ON, but expands on that by distinguishing two aspects: “obsessive thoughts” and “compulsive behaviors.” The aforementioned review also reports that, according to many authors, the obsession is directed towards food that is “healthy/proper/correct,” “organic,” “pure” or “safe” [11]. The newly proposed definition states that the obsession is directed towards “a diet believed to be healthy” and an additional specification states “the food selection or exclusion from the diet may vary from one person to another.” This may provide a solution to the issue raised by Bratman about misinterpreting a particular diet for ON [2].

A further specification in the new definition allows identifying two routes through which ON manifests, the first triggered by “fear and excessive preoccupation” for the negative health consequences of food considered unhealthy, the second triggered by “overvalued ideas” around positive health consequences of food considered healthy. This helps to identify different motivational backgrounds triggering strive for health in ON. This working definition of ON is useful in that it paves the way for more unified research on ON and contributes obtaining a diagnostic construct that could be further expanded upon in future studies involving a diverse outlet of stakeholders.

Despite the fact that a majority of the studies have not set any criteria for ON, five studies attempted to do so [13], [16]–[19]. However, these criteria were never validated or used consistently. The last set of criteria that can be found in literature has been developed by Dunn and Bratman (2016). Although they have stated “it is our hope that other researchers will build upon these criteria and further refine them” [17], no one has done this yet, perpetuating the tendency to use different criteria to assess ON. When comparing the criteria co-developed in the present study with those of Dunn and Bratman (2016), some differences emerge. For example, the newly co-developed set includes a temporal benchmark of six months, mentions the possible presence of phobic attitudes and fear, and adds the propensity to choose healthy food due to overvalued ideas about food’s healthiness. Diagnostic criteria co-developed in this study are a useful starting point for future validation and are a step forward towards assessing ON. We invite future research to further expand on them and validate them.

A recent literature review on psychosocial risk factors for ON [58] can be compared to the risk factors prioritized by health professionals in the present study. All the psychological risk factors reported by McComb and Mills (2019) (i.e. perfectionism, dieting behavior, drive for thinness, neuroticism/anxiety, obsessive-compulsive traits, history of eating disorders, fear of losing control, and perceived vulnerability to a disease) were also found in the present study, and health professionals deemed more influential for ON having an

history of eating disorders, perfectionism and perceived vulnerability to diseases. McComb and Mills (2019) also identified social risk factors for ON (i.e. weight bias and obesity stigma, availability of organic/clean foods, higher income, access to food research and knowledge, positive reinforcement from others, and time for food planning and preparation). These were all confirmed by this study, except for positive reinforcement from others. The risk factors identified by the present study, with healthism on top of the list, highlight the influence exerted by Western culture on ON [33]. This ranked list of risk factors for ON enrich our understanding of the development of ON. Furthermore, it provides an interesting overview of health professionals' views and opinions on root causes of ON.

Last, the vignette that was derived by relying on experiential knowledge of health practitioners may work as a useful tool for future validation of diagnostic criteria, since it depicts an orthorexic patient.

Definition and diagnostic criteria have not been empirically validated. Future validation of these findings is recommended. Diverse stakeholders are encouraged to further contribute to and expand upon these findings, since we believe that joining forces is a key step to strengthen our understanding of ON. Overall, through a participatory qualitative approach, this paper provides a shared agreement for proceeding with researching ON and brings together the opinions of prominent actors in the field. This will hopefully reduce inconsistency of scientific literature and will serve as a valuable starting point for moving the research forward.

It is necessary to list some limitations of the present study. First, participants were limited in number and wider samples would have provided bigger spectra of perspectives. Although the involved stakeholders are among the major contributors in the field of ON, we are aware that several other people involved in research on ON were excluded from the study. Moreover, the study did not include patients, an inherently unstable category for this condition. This may imply that consensus reached by this study mostly serves the interests of health professionals and experts. The non-inclusion of patients in the study lies in the absence of reliable diagnostic tools for ON, which made it hard to identify people suffering from it. A suggestion for future research would be to focus on the perspectives of people who self-diagnose with ON in order to further validate the findings of this study. Second, participants of Phase 1, 3 and 5 were confined to an Italian sample. This challenges the generalization of results. However, it could be considered a strength to have taken a country as a base and to have expanded the validation phase (Phase 4) to an international scale. Still, further validation is needed in other cultures, for which the vignette may be a useful tool. Third, risk factors were established on a theoretical basis (literature search), and then evaluated by different stakeholders. For this reason, no causal relationship can be claimed, for which longitudinal studies are needed. However, having a list of factors considered by health professionals and experts as potentially contributing to ON is a useful starting point for future investigations. Finally, we are aware of the inherent subjective aspect of this participatory study, since each stakeholder had his or her opinion on the subject, dictated by his or her personal experience. Although this may be considered a limitation, we believe this is a strength of this study, because it reflects one of the founding

principles of transdisciplinarity: the involvement of different perspectives and different experiential knowledge leads to the co-creation of new knowledge that turns out to be more than the sum of its parts [59]. The last limitation of this study concerns its being conducted before the publication of the review from McComb and Mills (2019), which therefore could not be used as a basis for extracting risk factors.

5.4.1 Conclusion

Scientific literature about ON is growing, yet it tends to be fragmented due to a lack of a unified understanding and conceptualization of ON, diagnostic attributes and root causes. This study relied on the experiential knowledge of Italian health professionals and international academic experts working on ON to gain insights on a contemporary understanding of ON. We encourage future research to expand upon the findings of this study in order to move the research about ON forward in a unified manner.

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Compliance with Ethical Standards

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