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“Healthy”

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

Martina Valente

VRIJE UNIVERSITEIT

“Healthy”

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

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List of Abbreviations

AIC	Akaike Information Criterion
AN	Anorexia Nervosa
APA	American Psychiatric Association
API	Application Programming Interface
ARFID	Avoidant Restrictive Food Intake Disorder
BN	Bulimia Nervosa
BOS	Barcelona Orthorexia Scale
BOT	Bratman Self-Test
CBT	Cognitive Behavioral Therapy
CFS	Chronic Fatigue Syndrome
CI	Confidence Interval
DOS	Dusseldorf Orthorexia Scale
DSM	Diagnostic and Statistical Manual of Mental Disorders
ED(s)	Eating Disorder(s)
EDNOS	Eating Disorders Not Otherwise Specified
EHQ	Eating Habits Questionnaire
HA	Health Anxiety
ICD	International Classification of Diseases
ON	Orthorexia Nervosa
NCD(s)	Non-Communicable Disease(s)
SD	Standard Deviation
SD-ON	Self-Diagnose Orthorexia Nervosa
TDR	Transdisciplinary Research
TOS	Teruel Orthorexia Scale
WHO	World Health Organization

Account

Chapters 4 to 9 refer to articles that have been published in, accepted by, or submitted to international peer-reviewed journals.

Chapter 4. Douma, E.R., Valente, M., Syurina, E.V. (submitted). Developmental pathway of Orthorexia Nervosa: factors contributing to progression from healthy eating to preoccupation. Experiences of Dutch Health Professionals. *Appetite*.

Chapter 5. Valente, M., Cesuroglu, T., Donini, L.M., Galfano, V., Bunders-Aelen J.G.F. & Syurina, E.V. (submitted). Diversifying and Integrating Views and Understandings of Health Professionals and Experts on Orthorexia Nervosa. *Qualitative Research in Sport, Exercise and Health*.

Chapter 6. Valente, M., Syurina, E. V., & Donini, L. M. (2019). Shedding light upon various tools to assess orthorexia nervosa: a critical literature review with a systematic search. *Eating and Weight Disorders-Studies on Anorexia, Bulimia and Obesity*, 1–12.

Chapter 7. Valente, M., Syurina, E. V., Muftugil-Yalcin, S., & Cesuroglu, T. (2020). "Keep Yourself Alive": From Healthy Eating to Progression to Orthorexia Nervosa. A Mixed Methods Study among Young Women in the Netherlands. *Ecology of Food and Nutrition*, 1-20.

Chapter 8. Valente, M., Brenner, R., Cesuroglu, T., Bunders-Aelen, J., & Syurina, E. V. (2020). "And it snowballed from there": The development of orthorexia nervosa from the perspective of people who self-diagnose. *Appetite*, 104840.

Chapter 9. Valente, M., Renckens, S., Bunders-Aelen, J.F.G., Syurina, E.V. (submitted). The #Orthorexia Community on Instagram. *International Journal of Eating Disorders*.

Chapter 10. Valente, M., Cesuroglu, T., Labrie, N., Syurina, E.V. (submitted – third revision completed). "When are we going to hold orthorexia to the same standard as anorexia and bulimia?" Exploring the Conversation about Orthorexia Nervosa on Twitter. *Health Communication*.

Preface

I started being interested in orthorexia nervosa during the research master's program in Global Health. A recurrent topic being mentioned during the courses was the influence of culture on health and mental health. When we hear things like '*culturally-bound*,' '*idiom of distress'* or '*culturally sensitive*,' we tend to think at 'other' cultures. Instead, I've always been interested in our modern Western culture and its impact on health and wellbeing. This is probably because I am interested in phenomena that I can see every day, which I can identify with or that I can test on my own skin. I am a keen observer of the people and the world around me. My first-year internship during the master was about orthorexia nervosa, as this seemed the perfect opportunity to explore an emergent mental disorder, typical of Western society and embedded in the meaning we attribute to food and health. I suddenly became very interested in the topic and I felt a genuine desire to know more about it and to possibly contribute to increase the knowledge around this distressing phenomenon. Because I felt this closeness to the topic, I decided to conduct also the second-year internship on orthorexia nervosa. The second-year internship brought me to Rome and allowed for the establishment of an international collaboration on orthorexia. This PhD is the culmination of my 'journey' investigating this new, complex phenomenon. This journey advanced my knowledge on orthorexia nervosa and allowed me to hear the voices of those people experiencing mental suffering. It was also a path of personal growth and self-consciousness, which led me to dive into my lived experiences and feelings. My hope is that bits and pieces of this 'journey' can be glimpsed by reading this thesis.

CHAPTER 1. Introduction

1.1 The Emergence of a New Disordered Eating Behavior: Orthorexia Nervosa

Eating disorders (EDs), such as anorexia nervosa, bulimia nervosa and binge eating, are severe and disabling psychiatric disorders characterized by a disturbed eating behavior that leads to an altered consumption or absorption of food, which impairs physical, psychological and social functioning [1]–[3]. They typically arise between the ages of 15 and 25 years, with evidence suggesting that they are affecting individuals at an increasingly younger age [1], [4]. Not only EDs do affect primarily young people, but they are also relatively young disorders. Although historical descriptions of EDs date back to the Hellenistic and medieval eras, it is only 50 years since they have become widely recognized as, potentially fatal, mental disorders [5]. Recovery rates for EDs are still very low, since less than half of people suffering from anorexia nervosa and bulimia nervosa fully recover, and mortality rates for anorexia nervosa are nearly six times higher than among the general population [1]. EDs have also economic repercussions, since people suffering from these disorders experience high costs of health care and overall loss in earnings due to lower employment rates [6]. Lastly, these disorders are complex to investigate, because they are multifactorial, often accompanied by comorbid conditions, and influenced by genetic and environmental interactions [7], [8].

There is a blurred line between clinical ED and abnormal behavioral patterns, meaning that people may engage in disordered eating practices with impairment of everyday functioning, without meeting the behavioral frequency or other criteria of the primary ED diagnoses that are currently included in the Diagnostic and Statistical Manual of Mental Disorders (DSM) [3], [9]. For example, people may exhibit only some of the full range of symptoms of an ED, show mixed features of more than one ED category, or manifest a symptomatology for which there is insufficient information to provide a specific diagnosis [10]. While in previous DSM editions these behavioral patterns fell into the “catch-all” category Eating Disorders Not Otherwise Specified (EDNOS), with the fifth edition of the DSM (DSM-5), the category Other Specified Eating or Feeding Disorders (OSFED) has been introduced. This category encompasses people with distressing eating disturbances, whose characteristics, however, do not meet the full criteria for any of the existing ED diagnoses (i.e. atypical anorexia nervosa, low frequency bulimia nervosa or binge eating disorder, purging disorder, night eating syndrome). Alongside the OSFED category, the DSM-5 includes the Unspecified Feeding or Eating Disorders (UFED) category, which includes all those presentations for which there is insufficient information to assign a diagnosis [3], [9]. These changes to the DSM, together with the ‘relaxation’ of the criteria for anorexia nervosa and bulimia nervosa, have been very helpful in reducing the number of patients assigned the futile diagnosis of EDNOS. However, many disturbed eating practices, which impact everyday functioning, still fall outside the current classification system, thus excluding certain people from treatment. This has led scholars to question the utility of the DSM and, more broadly, of the current classification paradigm [11].

It can be said, therefore, that diagnosed EDs would be only the 'tip of the iceberg', encompassing various sub-threshold conditions that tend to be underestimated by the categorical approach of current diagnostic manuals [12]. This is particularly relevant because disordered eating patterns are not fixed, but rather change over time. Being strongly influenced by socio-cultural factors, history and societal trends play an important role in the development of new phenotypes [5], [12]. Only a few of these new phenotypes, however, succeed in entering the DSM. This is because, with the ultimate goal of ensuring the manual's usability and its alignment with the International Classification of Diseases (ICD) [13], new conditions need to undergo a rigorous validation process before entering the DSM. The strict criteria needed for a new condition to enter the DSM [14] discourage the establishment of new diagnostic categories and therefore diagnostic institutions favor the expansion of current ones [15].

A disordered eating behavior that has arisen in recent years is orthorexia nervosa (ON). ON can be described as an unhealthy obsession with a diet that is perceived to be healthy. Individuals with ON prioritize the purity of food above all aspects of life, spend a considerable amount of time thinking about, buying, planning and preparing healthy meals and feel superior to those who do not follow a healthy diet [16], [17]. This behavior becomes a clinically relevant problem only when the obsession with healthy eating intensifies and begins to impair physiological, psychological and social wellbeing [18]. Due to its recent emergency, research and work on ON is fragmented and at times inconsistent [19], which, among others, lead to the lack of unified diagnostic criteria. Nevertheless, three main criteria are shared by all sets of diagnostic criteria proposed in literature [16], [20]–[23], which can therefore be considered indicative of ON features: (a) pathological preoccupation/ obsession with healthy nutrition; (b) distress or anxiety as a consequence of non-adherence to the self-imposed diet; and (c) bio-psycho-social impairments [24]. Prevalence rates of ON in the general population are between 1% and 7% [25]. However, these estimates should be interpreted with caution, since they were calculated using various diagnostic tools that are highly debatable in their ability to detect and discriminate ON patients [26], [27].

An increasing amount of research is looking at the possible reasons for this behavior to arise. A recent review suggests the complex nature of ON and its links to, among others, psychosocial risk factors like perfectionism, dieting behavior, drive for thinness, anxious attitude, obsessive-compulsive tendencies, and having an history of an ED [28]. This review encourages considering these risk factors as being embedded in a broader sociocultural context – characterized, for example, by a bias to low weight and the stigma attached to obesity, availability of organic/ 'clean' food, high income and wealth [28].

As advanced by this review, ON is ingrained in our time and culture. In particular, one aspect of Western culture that has been linked to ON is *healthism*. In recent years - and because of the prominence of the neoliberal thinking – government institutions have paid greater attention to empowering citizens in managing their own health by avoiding 'hazardous' lifestyle behaviors, like smoking and overeating [29]. The shift

towards individual responsibility for health has been given the name of healthism [30]. Through the lens of healthism, health is considered a *supervalue* [31], and food consumption is medicalized, meaning it is framed in medical terms [32]. Consequently, the individual becomes a 'health entrepreneur', responsible for making the right health-related and lifestyle choices [32], [33]. ON is considered a product of healthism [34]–[36], because the promotion of the idea that health is controllable in all its forms causes anxiety and fear of loss of control, which are usually suppressed by exerting more control over lifestyle choices, and which can therefore snowball into an obsessive approach to healthy eating [33], [37], [38].

Healthism is not the only societal trend influencing ON, as the current Western food system also contributes to ON. In fact, the current food system incentivizes excessive production of industrialized foods, which are increasingly detached from their natural ingredients, and whose (un-)healthiness is therefore ever more difficult to decipher [38], [39]. This raises suspicion in consumers, who have consequently become more concerned about what enters their bodies and more proactive decision-makers [38], [40], [41]. To make informed decisions, individuals embark on an arduous information-seeking process aimed at unraveling health risks and benefits of the foods they buy and consume. However, the information they seek is not always accessible, reliable, and/or understandable, and the confusion that ensues may fuel orthorexic thoughts and behaviors [38].

The impact of modern food systems on ON cannot be detached from the influence exerted by traditional and social media. While traditional media still play an important role in disseminating discourses on health and lifestyle, social media are the most prominent source of lifestyle information individuals consult every day. Information circulating on social media is not filtered and allows for the spread of multiple, diverse, sometimes contradictory information about health and nutrition. Thus, in their attempt to navigate health-related information, individuals feel confused by the amount, type, and accuracy of information online [38]. Some features of social media can be considered particularly dangerous for ON. For example, through the *picture-superiority effect*, image-based platforms enhance the internalization of messages to a greater extent [42]. Or, social media encourage *selective exposure*, meaning they continuously expose individuals to a certain type of content, leading them to believe that some behaviors are more prevalent than others, and prompting them to conform to such behaviors [42].

Therefore, apart from an individual disorder, ON can also be considered a societal phenomenon, sometimes referred to as '*orthorexic society*' [38]. As such, ON acquires a broader meaning and relevance, but also more complexity. Untangling ON from the intricate intertwining of societal forces and trends characterizing today's society is not easy. Understanding to what extent healthy eating is still 'healthy' and beyond which it passes the tipping point to become pathological is also complex. Nevertheless, this stimulated our interest in contributing to unravel the complexity of ON, with the conviction that greater knowledge contributes developing preventive strategies and supporting those who are suffering.

1.2 Previous Research and Knowledge Gap

Despite a sharp increase in the scientific literature about ON in recent years (Figure 1.1), the scope of the studies published is limited [19]. For example, most of the literature has focused on assessing prevalence rates of ON in at-risk groups or student populations, or developing diagnostic questionnaires and adapting them to different languages. Broader investigations into the development of ON and its complex interaction with society have been rather neglected, and this has contributed to some knowledge gaps.

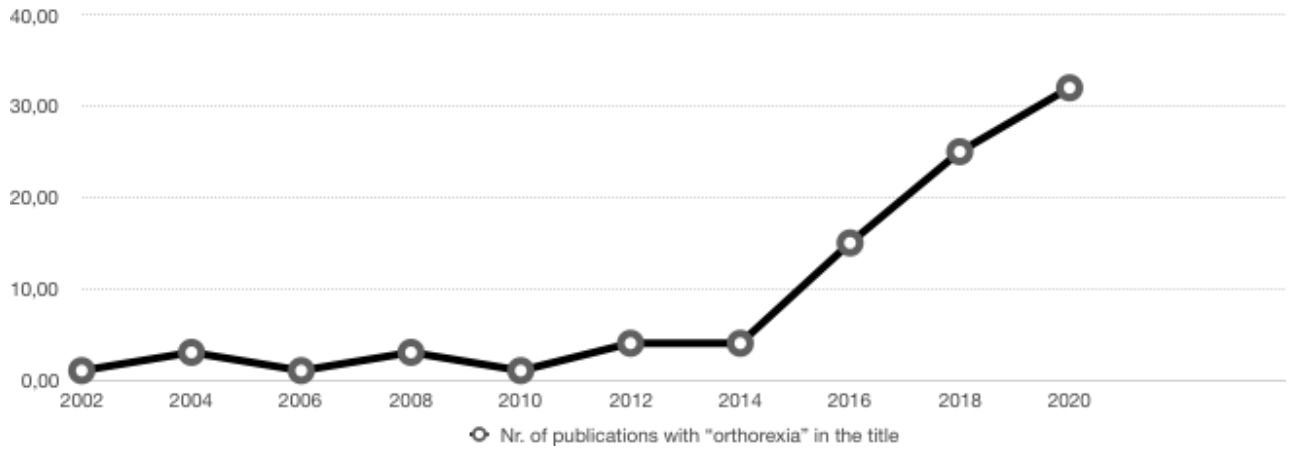

Figure 1.1. Chart depicting the increase in PubMed articles published per year with the word 'orthorexia' in the title (obtained in date 02/09/2020).

It is still unclear, for example, how ON develops over time, what its developmental pathway is and what its contributing factors are. This knowledge gap blurs the line between healthy eating and ON, and may lead to applying the label 'disordered eating behavior' also to non-pathological eating practices. To prevent this, a two-phase construct of ON has been proposed by Bratman (2017), according to which the first phase of ON would be positive, where the individual simply decides to eat healthily, while the second phase would consist of an intensification of such pursuit of health, until reaching an obsessive state. Although this two-phase construct advances our understanding of the development of ON, it remains still unclear why some individuals develop ON and others don't and therefore what factors are responsible for healthy eating to turn into an obsession. In addition, broader socio-cultural factors influencing the developmental pathway of ON have rather been neglected. Although some studies have hinted at the important link between ON and sociocultural forces of modern Western culture [43], [38], [42], [36], most of the studies about ON had a more narrow approach, leaving society's influence on ON largely unexplored.

A second knowledge gap concerns the involvement of multiple perspectives in understanding and conceptualizing ON. Previous research approached ON in a monodisciplinary way, meaning from the perspective of one single discipline (psychology, nutrition, etc.), and rarely consulted the perspectives of health practitioners, people with ON, or lay people with an interest in or opinion about ON. This can be particularly reductionist because ON is a complex phenomenon – i.e. it is new and therefore still under-researched, thus it is not possible to rely on prevalence estimates in population groups, or on diagnostic instruments that are shown to be internally valid; it is multifactorial and it has intertwined consequences, with one trigger causing multiple reactions. For these reasons, studying ON may require a broader spectrum of perspectives. If some studies attempted to explore the perspectives of health practitioners [44], [45], these were aimed at investigating opinions regarding ON, failing to engage in a process of knowledge co-creation more broadly, where practitioners' experiential knowledge is recalled to trace the developmental pathway of ON. Furthermore, the lack of an official diagnosis is possibly making it difficult to recruit and involve patients in research. Although this can be overcome by relying on the perspectives of people who self-identify as having ON, only a few studies have involved individuals with self-declared ON symptoms [46], [47][48].

1.3 Research Objective and Research Questions

These knowledge gaps show that the socio-cultural factors contributing to the development of ON remain largely unexplored, and multiple different perspectives have seldom been consulted to study ON. We believe that there is a need to approach ON in a holistic way, including the various aspects that make ON a complex phenomenon, while also considering different perspectives to understand its nature. The aim of this research project is therefore to unravel the complexity of orthorexia nervosa, by involving multiple perspectives (i.e. practitioners', insiders' and lay people's perspectives) in investigating the phenomenon, its development, and societal factors influencing it. Thus, the following research question paved the way for our investigation: *How can we understand the development of orthorexia nervosa and its socio-cultural contributing factors?* Understanding the phenomenon in a more comprehensive and inclusive way allows clinical practice to advance, as well as the development of preventive and therapeutic approaches.

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