“Healthy” When the pursuit of health turns into a mental disorder: the case of orthorexia nervosa.

Valente, M.

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

ACADEMISCH PROEFSCHRIFT

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door

Martina Valente

geboren te Asti, Italië

promotor:	prof.dr. J.G.F. Bunders-Aelen
copromotoren:	dr. E.V. Syurina
	dr. T. Cesuroglu

CHAPTER 11. Discussion

The main research question of this research project was: "*How can we understand the development of orthorexia nervosa and its socio-cultural contributing factors?*" Two sub-questions were derived from this research question, and addressed by the studies that make up this research project: (1) *How does ON develop?* (2) *What are socio-cultural factors influencing ON?* The sections that follow answer these two sub-questions and attempt to interpret the most significant findings in light of the literature. This is followed by a digression on interpreting ON as a cultural manifestation of distress. The methodological approach and validity of findings are then discussed. Finally, we make recommendations for future research and reflections on the social relevance of findings.

11.1 How Does Orthorexia Nervosa develop?

By investigating the perspectives of health professionals and people with ON, this project has contributed to the understanding of how ON develops and progresses over time. Specifically, predisposing factors, triggers, symptoms, characteristics of the 'tipping point' between healthy eating and ON, treatments, and the influence of the external environment have been identified and are summarized in Table 11.1. By consulting the perspectives of health practitioners and people with ON, and subsequently analyzing data in light of the theoretical framework, it was possible to identify two routes exemplifying how some of the factors shown in Table 11.1 interact in developing ON. Below, these two routes are presented separately; though, they can interact with each other. After presenting these two routes, the *illusion of safety* construct is introduced to interpret some interesting results; subsequently, a reflection on the tipping point between healthy eating and ON is presented.

First Route.

According to the first route, Western socio-cultural health ideals influence individuals by promoting the idea of personal responsibility for health and by equating health with being thin and muscular. In the attempt to fulfil their role of being "responsible, healthy citizens", individuals would start to eat healthily and exercise. Those with perfectionist traits would navigate the food-information landscape searching for the "perfect" diet. However, the contradictory and overwhelming volume of information about healthy eating would cause confusion and stress. This stress would fuel the search for ever more information, leading to obsession. ON would start once the obsession and compulsion become self-sustaining, meaning that they persist even without external triggers (Chapters 7 and 8).

Second Route.

According to the second route, individuals with pre-existing traits of perfectionism and anxiety would be perturbed by major life events/changes, such as a divorce or moving to another country. The inevitable confusion that derives from these life events might lead individuals to feel that they are not in control of their

life. This fuels anxiety and, as a coping strategy, individuals would try to exert control over an area of their life they can control: diet. The increasing control over diet would lead to obsession. Once again, when the obsession persists in the absence of external stressors, the obsession would become ON (Chapters 4 and 8).

Table 11.1 Overview of factors involved in the developmental pathway of ON

Categories	Findings	Practitioner perspective Ch. 4; 5; 6	Insider perspective Ch. 7; 8	Lay People perspective Ch. 9; 10
Baseline risks	young age	x		
	mid-to-high education	x		
	perfectionism	x	x	
	active lifestyle	x		
	anxiety traits		x	
Triggers	life events (e.g. break up)	x	x	
	family problems	X		
	comorbidity with other mental disorders	x	x	
	changes during puberty	X		
	interest in specific diets	X		
	prescription of a diet for medical reasons	X		
	excessive concern for chronic conditions		x	
Symptoms (*bio*)	low food intake	x	x	
	weight loss/nutritional deficiencies	x	x	
	stopped menstruation		x	
Symptoms (*psycho*)	preoccupation with healthy food/obsession	x	x	x
	depression	x		
	anxiety/catastrophic thinking	x		
Symptoms (*social*)	time spent on eating-related activities	x	x	
	social isolation and social dysfunction	x	x	
'Tipping point'	bio-psycho-social interference	x	x	x
	obsessive approach to diet for 6 months	x		
	food exclusion with phobic attitude	x		
	strict food regimen with physiological consequences	x		
	influence on self-confidence/identity	x		
Treatment & Recovery	restoring weight	x		
	education about nutrition	x		
	learning how to manage anxiety		x	
	CBT	x		
	exposure/group/social therapy	x		
	family therapy	x		
	home guidance	x		
	psychiatric treatment	x		
	admission ED clinic	x		
Barriers for treatment	non-supportive parents	x		
	not experiencing physical problems		x	
	unaffordable/ineffective health system		x	
Facilitators for treatment	preoccupation expressed by loved ones	x		
	experiencing bodily discomfort	x	x	
	desire to recover for the sake of family	x	x	
	supportive parents	x		
	behavior that become too costly		x	
	social media communities and supportive accounts		x	x
	negative impact on study/work		x	
Influence of the environment	social media	x	x	x
	pseudo-scientific nutritional experts	x		
	exposure to contradicting health messages		x	
	Western health & beauty ideals/diet culture	x	x	
	societal pressure to eat healthy		x	
	lack of religious faith			x

11.1.1 The Illusion of Safety: Counteracting Anxiety with Over-Control

The *illusion of safety* is an interesting point of view on the etiology of ON, which is introduced here to explain and further expand upon the findings described above. According to this construct, ON would develop as a search for *physical safety*, meaning a perceived sense of safety from illnesses and death, and *psychological safety*, meaning a perceived sense of control and self-esteem associated with following a ritualized, healthy eating pattern [1]. *Psychological safety* results in positive feelings of self-control and self-management, which appease anxiety in individuals with anxiety traits or other psychological issues. Furthermore, the sense of control that derives from following a strict healthy eating regime is particularly beneficial for those who experience a lack of control in most areas of their life [1]. This "illusion of safety" is linked to "mental healthism," meaning the growing focus on personal responsibility for mental health – e.g. individuals are increasingly deemed responsible for optimizing their mental health, or healing from mental illness, through healthy eating and exercise [2]. As such, mental healthism could contribute to engaging in ON-like behaviors in order to achieve the illusion of safety.

Illusion of safety and mental healthism may also be masked manifestations or side effects of health anxiety (HA). HA is characterized by a preoccupation with the inaccurate belief that one has, or is in danger of developing, a serious illness [3]. From a dimensional perspective, HA represents a continuum ranging from an absence of health concerns to pathological HA [4]. The development of clinical hypochondriasis and other forms of HA are largely driven by mistaken beliefs about illnesses and maintained by maladaptive coping strategies (i.e. safety behaviors) [3]. ON can be considered one of such safety behaviors, as a coping mechanism for HA. In fact, research shows that HA is positively associated with an increased fixation on food and nutrition [5].

From this perspective, ON could initially start as an attempt to cope with uncertainties of life, health anxiety or pre-existing psychological problems. In this initial phase, ON would be a coping mechanism ('*healthy orthorexia*' [6]), from which positive feelings of self-control and self-esteem derive (i.e. illusion of safety). This behavior would subsequently enter its distressing phase ('*orthorexia nervosa*' [6]), once pressure to eat healthily and desire for control crash with the uncertainties of society and the incongruencies of the modern food-information system [7]. At this point, anxieties would take over and the individual would attempt to appease these by imposing stricter control, thus fueling the obsession.

11.1.2 The Tipping Point between Healthy Eating and Orthorexia Nervosa

As conceptualized by Natenshon (2020), eating practices reside along a *continuum*, where healthy eating patterns, at one end may progress into disordered eating behaviors at the opposite end. When progressing along this continuum, individuals increasingly lose capacity for self-regulation and enter into a pathological, distressing state. The 'tipping point' indicates at what point of this continuum the eating practice crosses the line between normal and disordered eating. Despite being very difficult to identify, this "tipping point" is very

useful for therapists who work with clients presenting with an obsessive-compulsive approach to healthy eating.

Distinguishing benign healthy eating from ON is tricky because the idea of what is a healthy diet has changed, as diets become increasingly extreme. If once eating a bit of everything with moderation and avoiding junk food was considered healthy, today eating healthily has come to mean adhering to extreme diets that encourage exclusion of different food groups, or that are extremely strict in their food preparation rules. This has led to an increasing normalization of disordered eating practices, which challenges disentangling healthy eating from a disordered eating behavior [8]. Furthermore, people following certain specific diets adopt "health" as their cover-up story for something that is instead more psychologically driven [9]. Being unable to disentangle healthy eating from ON is risky, in that it causes pathologizing something that is neither impairing nor distressing. This is confirmed by our study on Twitter (Chapter 10), which shows that people use the accusation of over-medicalization as a counter-argument to resist the medicalization of ON.

In this project, consulting experts and health practitioners on diagnostic criteria for ON was useful in that it provided interesting insights into the "tipping point" between healthy eating and ON (Chapter 5). Notably, it was found that, in order to be considered ON, the obsessive-compulsive approach to diet has to last for six months. Moreover, food exclusion with possible phobic behavior and/or propensity to choose only food that is considered healthy, impairments in biological functioning, and negative interference with daily life, are features characterizing the tipping point between healthy eating and ON, and serve to distinguish the two. In agreement with a recent qualitative investigation into the experiences of recovered orthorexics [10], what seem to be crucial traits of ON are the persistent obsession and its anxious and paranoid traits. This highlights the psychological burden of ON, which make it unbearable and lead to the realization of a problem.

11.2 What are Socio-Cultural Factors Influencing Orthorexia Nervosa?

While there is a large body of literature supporting the idea that EDs are culturally bound, these disorders tend to be studied and written about as highly individualized and marginal conditions. This risks pathologizing EDs without accounting for potentially harmful environmental factors [7]. ON is no exception. Research on ON tends to be purely individualist and based on psychological aspects of ON, failing to grasp the complex social and cultural contexts in which ON arises, survives and thrives [7]. Our research project aimed to contribute to filling in this gap. It found that the increased health accountability has a dual and important role in the development of ON: it both influences the development of ON in individuals through *healthism*, and also the development of ON as a medical entity through *medicalization* (Chapters 5, 7, 10). Social media plays a crucial role in mediating the influence of healthism and medicalization on ON. In the following sections, the influence of healthism and medicalization on ON is presented and discussed. Subsequently, the role of social media in ON development is explained and put in context of the literature.

11.2.1 Increased Health Accountability: Healthism and 'Nutritionism'

Health is an increasingly ubiquitous aspect of people's lives and discourses. *Healthism* has meant that individuals feel increasingly responsible for their health [11]. Lifestyle is medicalized and people embark on lifestyle changes in order to optimize their health and to reduce the risk of chronic conditions [12]–[16]. Diet is generally the first aspect that is manipulated and kept under control. Furthermore, an increasing attention to nutrients, i.e. *nutritionism*, has led to a reductionist approach to nutrition. Food choices are usually based on what nutrients are 'good', 'bad' or 'functional', meaning those that improve particular bodily functions and processes [17]. As a consequence, the choice of proper foods, which contain the proper nutrients, is considered crucial for pursuing a healthy life, and thus for fulfilling the role of 'responsible, healthy citizen'.

Salter and Dickson (2020) refer to a "datafication of food", meaning "the management and mastering of the body through the conversion of the food intake into data. Such techniques include the keeping of a food diary, portion monitoring" [18]. Keeping track of foods and nutrients is promoted in name of *awareness*, as this is the means through which individuals are empowered to manage their own health. Within this logic of care [19], the individual collects all possible information to make appropriate consumer choices. Those who fail to take sufficient responsibility for their life are consequently considered immoral [18]. The sense of superiority that arises from moralizing food choices is rooted in the belief that individuals can and should be in total control of their lives, diets and health. The illusion of total control over life is utopian, as individuals find themselves facing a more complex and unpredictable reality, where self-discipline is not sufficient to guide lifestyle choices. Those who are not able to loosen their need for control and embrace the complexity of reality end up in a spiral of restriction, frustration and anxiety, which ultimately triggers ON.

11.2.2 Increased Health Accountability: Medicalization and the Creation of a Diagnosis

Medicalization indicates a sociocultural process by which non-medical conditions become defined as medical - typically, 'deviant' behaviors are defined in terms of disorders, and normality in terms of health. Medicalization takes place when a medical frame is applied to understand a problem, leading this problem to enter into the medical domain [20], [21]. The driving forces of medicalization are: (1) increasing secularization, meaning that medicine has replaced religion as an institution for 'social control'; (2) increasing faith in science, rationality and progress; (3) increasing power of the medical profession; (4) widespread individualism; and (5) humanitarian approach of Western society [20], [22]. When Conrad first introduced the concept of medicalization, his aim was to discourage the expansion of medical power over wider spheres of life. Today, however, medicalization occurs without the involvement of the medical profession, as individuals themselves furnish medical explanations for their problems and experiences [23]. This happens because today's health system is increasingly 'buyer-driven', as it encourages direct-to-consumer advertising as the primary form of medical education and leads patients to be actively involved in managing their own health and diagnoses. For this reason, talking about 'self-medicalization' would be more appropriate [24].

The process of medicalization appears to be happening to ON and social media seem to have an increasingly prominent role in this. What we found by analyzing social media conversations and content, is that ON is going through a discursive process of medicalization, where it is increasingly described as a medical condition and where people advocate for its inclusion into the DSM (Chapter 10). Therefore, just as healthism is the result of an increased health accountability, so too is medicalization, in that it promotes finding medical explanations to social/behavioral phenomena. Yet, while it is possible that healthism and medicalization are both moved by an increased health accountability and ubiquity of medicine, it is also possible that they are driven by two opposing trends, namely the tendency to individualize social problems whose root causes lie within society (healthism) and the tendency to socialize, or even politicize, individual health problems (medicalization).

11.2.3 Social Media

Social media mediate the influence of Western culture on ON [25]. Healthism and medicalization being aspects of Western culture, their effect on ON is also mediated by social media. Social media contribute to amplifying the influence of healthism on ON, primarily by allowing the sharing of unfiltered health claims from pseudo-scientific nutritional experts, by continuously exposing individuals to different opinions and precepts that instil irrational health-related fears, and by making individuals susceptible to advertisements from the wellness industry, which encourages health self-management in unorthodox ways [13]. Social media also contribute to the process of medicalization that ON is undergoing. This happens because medicalization is a discursive process, meaning that it takes place through communication among different actors (e.g. lay people, health professionals, advocates, patients). Thus, social media allow generating discourses around ON, which socially construct ON as a medical condition [26]–[28].

In the present project, it has been found that social media also have a more direct impact on ON. They have a potentially harmful impact, in that they convey content that is dangerous for ON, such as ‘clean eating’ content (Chapters 8, 9, 10). They also have a positive impact, in that they enhance the formation of supportive communities around #orthorexia (Chapter 9). This dual role of Instagram, also identified by McGovern, Gaffney and Trimble (2020) [10], is thought-provoking and opens up for new opportunities to investigate social media and mental health. A suggestion for future investigations concerns the role of body image in the relationship between Instagram and ON, as Holland and Tiggemann (2016), and Saunders and Eaton (2018) report that social media’s effect on disordered eating habits is mediated by body image concerns [29], [30]. It may be therefore relevant to further investigate whether body image and appearance-related concerns mediate the influence of Instagram on ON.

11.3 Orthorexia Nervosa as a Cultural Manifestation of Distress?

This section attempts to reflect on the relationship between ON and modern Western culture, hypothesizing that ON could be interpreted as a cultural manifestation of distress.

This project shed light on the fact that ON is highly embedded in our time, culture, and approach to health. The socio-cultural driving forces of ON are healthism and the increased accountability for one's health that permeates our culture, as well as the abundance of information that can be found on social media, which empowers citizens in taking care of their health, but at the same time sow confusion and stress. The complexity that characterizes our era creates a certain degree of fear of 'loss of control,' which triggers a snowball effect of interacting factors and symptoms that result in ON. Disentangling ON from Western contemporary culture is therefore impossible. This may lead to considering ON as a cultural manifestation of distress. Discourses on the extent to which ON is confined to Western culture can be found in literature. For example, Hanganu-Bresch (2019) points to the influence of modern Western cyber-culture on the rise of ON [16], and Strahler and Stark (2020) warn against ethnocentricity and suggest developing culturally sensitive diagnostic procedures to understand and interpreted ON in non-Western contexts [31]. All of this seems to suggest that ON could be a cultural concept of distress, either a *cultural syndrome*, a *cultural idiom of distress*, or a *cultural explanation* [32].

Although the road to understanding whether ON is a cultural manifestation of distress, or a universal condition, is still long ahead, our research suggests that Western socio-cultural trends and ideals contribute to the development of ON. This is particularly relevant because it has implications for preventive and therapeutic practice, as well as for future research. First, it suggests that disordered eating is not fixed, but rather adapts and changes according to different times and cultural trends. This is important because it allows for considering that people may manifest distress through means of food in different ways, depending of the era and culture in which they are embedded. Second, it is important because it opens up opportunities to investigate ON in other cultures and therefore to assess if ON manifests differently according to different countries' historical backgrounds, or different cultural interpretations of food and health. Last, it is important because it consolidates the idea that Western culture is a risk factor for EDs, and this should be taken into account when developing and implementing preventive interventions for disordered eating practices.

11.4 Methodological Approach and Validity

This research project collected various data, from various different sources (e.g. self-administered questionnaires, interviews, focus group discussion, social media content analysis). Furthermore, diverse perspectives were taken into account (i.e. practitioner, insider and lay people). Although it must be acknowledged that the samples had all been quite limited in number, the collection of data from multiple sources and perspectives is a strength of this project, since it allowed for triangulation, and contributed ensuring

validity of results. Data collected in this research allow grasping a complete and comprehensive picture of the development of ON and its contributing socio-cultural factors.

Two considerations are worth making regarding two critical aspects of our methodological approach: the consideration and consultation of multiple perspectives; the involvement of people who self-diagnose with ON.

The broad spectrum of perspectives involved in the present project was beneficial for several reasons: it allowed understanding what ON is for different stakeholders, it was a way to validate results, it provided a more holistic understanding of ON, and it allowed displaying different perspectives and opinions regarding ON. Nevertheless, it is worth saying that our research never opened a dialogue for all stakeholders to interact together. This is one of the reasons why we believe it may be appropriate to refer to a *transdisciplinary approach*, rather than to transdisciplinary research. We acknowledge that the interaction among different stakeholders would have brought benefits to the research and would have allowed to better display power relationship among them. Therefore, we strongly encourage future studies to explore new opportunities for participatory research about ON, by involving different, interacting, actors – e.g. health practitioners and people who self-diagnose.

Regarding the involvement of people who self-diagnose with ON, we did not assess whether those people truly had, or have had, ON. It must be said, therefore, that it is possible that some people wrongly identified themselves with ON, or reported self-identifying with ON, even when this was not true. One can argue that the best thing to do would have been to assess ON through one of the existing diagnostic tools. We decided not to do this for two main reasons. First, because our literature review (Chapter 6) and recent studies [33], [34] confirmed that existing diagnostic tools have debatable psychometric properties, therefore it is possible they are not measuring what they are expected to measure. Second, because we were not interested in diagnosing ON as it has so far been described in the literature, but rather in contributing to achieve a new, inclusive, contemporary understanding of ON.

11.5 Future Research

This section addresses interesting topics that emerged from this project, which could be further delved into by future research, i.e. ON and conflicting nutritional information, ON and weight loss, ON and identity, and ON as a future diagnostic category.

11.5.1 Orthorexia Nervosa & Conflicting Nutritional Information

An interesting result that emerged from this research is that the confusion deriving from being ‘bombarded’ by conflicting information about health and nutrition contributes to the development of ON in predisposed

individuals (Chapter 8). This confusion seems to have a central role in determining when healthy eating turns into ON. This aspect is poorly taken into account when developing diagnostic tools, or in preventive and/or curative practice. We would invite future research to investigate this aspect of confusion and stress exacerbated by the way in which food information is promulgated and disseminated in society. In this regard, it may be interesting to investigate not only the way in which information is disseminated by the media, but also the way in which this information is received and internalized by individuals.

11.5.2 Orthorexia Nervosa & Weight Loss

Future research should continue investigating the association between weight loss and ON, in order to understand the role of appearance-related motives in the development of ON. A hypothesis that could be explored in more detail is that strive for thinness and strive for healthiness have now become so inextricably linked that the distinction between 'being thin' and 'being healthy' has blurred. The way in which thinness and healthiness are spoken about on social media has already proven to be misleading in distinguishing thinness from healthiness. For example, fitspiration content (i.e. online content promoting fitness and healthy lifestyles) and thinspiration content (i.e. online content promoting thinness) both focus on appearance, showing that heath is increasingly intertwined with body shape [35]. Moreover, although thinspiration content has greater focus on bones and thinness, thinspiration and fitspiration content do not differ in their emphasis on objectification, dieting, and guilt about body weight [36].Therefore, if this hypothesis proves to be true, paying more attention to the way in which exercise and healthy lifestyle are promoted and spoken about online could be a step towards preventing ON.

11.5.3 Orthorexia Nervosa & Identity

As other EDs, ON can be described as a "disorder of the core Self of self-regulation, self-perception, self-esteem and self-care, affecting life spheres far exceeding eating-lifestyle and weight management" (Natenshon, 2020). Identity plays a great role in development, maintenance of, and recovery from ON. The relationship between the self and mental health problems is complex. If, on the one hand, individuals may perceive their illness as something external that threatens their self, on the other hand, it may be that individuals do not consider themselves as being 'mentally ill', because the mental health problem defines how their self is defined and perceived [37]. This implicit overlapping between the sense of one's self and the mental health problem may be strengthened by the internalization of negative self-definitions, which can change individual's perception of self, leading the individual to associate identity with the mental health problem [38]. The intricate relation that exists between identity and mental illness has implications for recovery. Of particular interest is the study conducted by Williams et al. (2016), which distinguishes five theoretical phases characterizing the relationship between anorexia nervosa (AN) and identity: (a) AN taking over the self, i.e. being changed by AN; (b) AN protecting the self, i.e. using AN as a means to be detached from others; (c) sharing the self with AN, i.e. having a double self; (d) being no one without AN, i.e. fear for recovery (who am I without AN?); (e)

discovery the real me, i.e. separating the self from AN [37]. These phases can have a relevance also for ON and could be further investigated in this regard.

11.5.4 Orthorexia Nervosa as a Future Diagnostic Category

This thesis discussed medicalization as a neutral process through which ON is socially constructed as a medical entity. Assessing whether the medicalization of ON is positive or negative falls outside the scope of this research. From my personal perspective, I am convinced that there are both positive and negative sides to medicalizing ON, which should be equally taken into account in future research. I think that it is important to acknowledge that people may manifest their distress through means of food choices and eating practices, which may vary from one person to another, from one context to another, from one time period to another. By limiting ourselves to the strict DSM criteria, we will inevitably end up not considering that distress is manifesting in a 'modern' way, and will end up not helping people who are suffering. A broader view of what can be considered an eating disorder could be useful in practice. I also think, however, that there are negative sides to medicalizing ON. For example, I am particularly concerned about impeding a broader societal change. The individualization of suffering that happens by attributing the cause of suffering to a diagnosable disorder could mask the social determinants of this disorder – such as, for example, the increasing health propaganda that tends to associate healthiness with thinness, or the popularity of the insufficiently regulated wellness industry. The creation of a diagnosis may postpone the implementation of interventions aimed at a broader societal change. Future research is therefore needed to investigate if ON should be entitled to a diagnostic label. I believe it is important to explore whether the benefits outweigh the possible negative consequences of medicalizing ON.

11.6 Social Relevance

It is important for the results of this research to be able to inform therapeutic interventions in order to help people who are suffering from ON in practice. Some interesting topics emerged in this project (i.e. ON as a coping strategy, ON and identity, peer-to-peer support on social media), which suggest the possible efficacy of certain therapies in treating ON. Beyond being prescriptive, this section is intended to stimulate reflections on how the results of this research could be translated in practice.

11.6.1 Acceptance and Commitment Therapy for Orthorexia Nervosa

Going back to our argument about ON being a coping strategy for (health) anxieties or other psychological problems (section 11.1.1), it follows that it might be beneficial to first address the underlying anxieties and conditions in order to reduce ON. Since ON is characterized, among others, by cognitive inflexibility, rigid thinking and perfectionism [39], [40], the Acceptance and Commitment Therapy (ACT) [7] could be a useful option for increasing psychological flexibility and therefore reducing the chances of ON being used as a maladaptive coping strategy. ACT applies mindfulness and acceptance processes to promote psychological

flexibility and, in turn, discourage psychological inflexibility [41]. Broadly speaking, psychological inflexibility means the inability to face emotions and life events that make one feel uncomfortable, with the consequent tendency to deploy coping strategies to reduce anxiety. Being psychologically flexible, in contrast, means being able to manage behaviors even in the presence of uncomfortable thoughts or events [42]. Recovering from ON through ACT, therefore, would imply learning to be more flexible when facing uncomfortable situations and life challenges, without necessarily engage in potentially dangerous eating-related coping strategies. Since psychological inflexibility already characterizes anorexia nervosa and obsessive-compulsive disorder [43], which are both likened to ON, ACT may be a useful therapeutic approach to ON.

11.6.2 Identity Intervention Program for Orthorexia Nervosa

This project formulated the hypothesis of a potential relationship between ON and identity (section 11.5.3). Specifically, it has been hypothesized that individuals would identify with ON, becoming 'one with ON' (Chapter 4 and 9). Yet, in the attempt to recover, they would shift from a 'orthorexia identity' to a 'communitarian identity,' which instead drives the formation of online communities around ON (Chapter 9). This suggests possible underlying identity issues. Therefore, a potentially useful therapeutic intervention for ON could be the Identity Intervention Program (IIP). IIP acts on self-schemas, being highly elaborated representations of the self that function to modulate one's behavior [44]. With the primary goals of increasing individual's involvement in more diverse behavioral domains and therefore diverting individual's attention from weight/nutrition management or compensation strategies, IIP attempts to modify the self-schemas that comprise the self-concept, by stimulating the creation of new, positive self-schemas [44]. Identity can be targeted by EDs prevention programs too. Because identity formation is strictly related to self-esteem, and poor self-esteem is a risk factor for EDs, acting upon healthy identity development can be an effective preventive strategy for disordered eating behaviors like ON [45]. An example of a strategy that has shown to have positive health effects for identity strengthening is bolstering a valued aspect of the individual's identity [45].

11.6.3 Peer-To-Peer Support on Social Media

Lastly, this project shed light on the formation of cohesive online communities around #orthorexia supporting recovery (Chapters 8 and 9). A promising option for facilitating recovery from ON would therefore be self-forming peer-to-peer support groups on social media. Supportive online communities allow individuals to share their understanding of living with a certain condition. Identifying with an online community that shares certain values and beliefs increases self-esteem and self-efficacy, and thus reinforces identity. Social media offer a valuable option to those individuals who are skeptical about opening up in person with other people, because of fear of disapproval, rejection or stigma. In fact, on social media, individuals can regulate their own level of engagement and be in control of what type of content and information they share [46]. As such, peer-

to-peer support groups on social media can be an effective ally that can make recovery more sustainable in the long run.

11.7 General Conclusion

This research project started with the ambitious objective of contributing to a more coherent, unified and inclusive understanding of ON: How does ON develop in individuals and, as a concept, in society? And what are its complex socio-cultural contributing factors? The studies conducted in the course of this project provided an answer to these questions. In sum, ON progresses over time, starting from an initial positive stage characterized by healthy eating, and subsequently snowballing into a distressing state. Bio-psycho-interpersonal and social factors interact with each other and are responsible for the transition from healthy eating to ON. Various people engage in conversations about ON on social media. By doing so, they socially construct ON as a medical problem, thus contributing to the process of medicalization that ON in undergoing. The main socio-cultural factors influencing ON are healthism, and the overall health accountability of modern Western society, contradictory health and nutritional information propagated online, and Western beauty and health ideals.

Appendix

Appendix 1. Data Management Plan

PhD project: Orthorexia Nervosa

Creators: Martina Valente, Elena V. Syurina, Tomris Cesuroglu

Affiliation: Athena Institute, Faculty of Science, Vrije Universiteit Amsterdam

Project abstract: The aim of this project was to unravel the complexity of Orthorexia Nervosa, a new disordered eating behavior. Multiple perspectives were included in this project: professional perspective, client perspective, and societal perspective. The phenomenon of Orthorexia Nervosa was explored from different angles, starting from its developmental pathway, to its development as a concept within society. The project employed a transdisciplinary perspective and predominantly used mixed methods; quantitative techniques were online surveys or analysis of data extracted from social media, qualitative techniques were interviews and qualitative analysis of social media content.

Data Collection

What data will you collect or create?

Multiple types of data are collected:

- Interview data (transcripts of face-to-face or online interviews)
- Responses to questionnaires (databases containing responses to online questionnaires, these include open ended questions, multiple choice questions and Likert-scale type questions)
- Social media data (content, in the form of pictures and text, are extracted from Instagram and Twitter)

Volume of data collected:

- Interview data: considering all the studies, a total of approximately 40 interviews are conducted
- Questionnaire data: considering all the studies, a total of approximately 300 responses are collected
- Social media data: 17,000 posts are downloaded from Instagram, of which approximately 3,000 are used for analysis, and 500 tweets are downloaded from Twitter and analyzed

Data that can be reused in future may be the Instagram pictures that are downloaded in this project. The other data, such as interview transcripts, are strictly confidential and highly related to the research questions of this PhD project.

How will the data be collected or created?

Main data collection techniques are: semi-structured interviews, online questionnaires (created through the software Qualtrics), and extraction of data from social media platforms.

Data are organized in folders. Folders and files are named in accordance to the titles of the studies. New sections are created within existing folders to handle versioning.

Documentation and Metadata

What documentation and metadata will accompany the data?

Databases containing data and transcripts of interviews are stored in the respective folders of the studies they refer to. These folders also contain summaries of findings and information regarding data collection and analysis. In the case of data extracted from social media, documentation concerning ethical handling of data is also reported.

Overall, every study has a detailed report describing how data are collected. These reports also include, in their appendices, all tools used for data collection (for example, interview guides or questionnaires). These reports would help to understand all the steps taken for data collection.

Ethics and Legal Compliance

How will you manage any ethical issues?

Self-check tests are performed for every study. For some of the studies[1] ethical approval is necessary and is obtained from the ethical working committee of the Athena Institute and the Faculty of Science, within the Vrije Universiteit (VU) Amsterdam.

Anonymity is ensured in every study. All interview transcripts are anonymized, meaning that names are replaced by fake nicknames. Information provided during the interviews is only shared within the research team and only used for the purpose of the study. Questionnaire responses are also anonymous, and it is impossible to identify respondents given their answers to the questionnaire. Data collected from social media are anonymized as well, meaning that names and nicknames are cancelled from the database, and it is not possible to identify users from data reported in the articles.

Prior to any data collection, written and/or verbal consent is obtained from every participant, except from data extracted from social media, which are already of public domain. Data collected from social media are handled with extreme caution: preservation of users' anonymity is considered our main priority; data are shared only in an anonymous format and only within the research team. In the case of Twitter data, the text of Tweets is re-phrased and not reported verbatim in the article, in order to make sure it is not possible to identify users from data reported in the article.

How will you manage copyright and Intellectual Property Rights (IP/IPR) issues?

This project does not involve IPR. Issues regarding copyright are not applicable.

Storage and Backup

How will the data be stored and backed up during the research?

On a daily basis, data (analysis, manuscripts, etc.) are saved on a USB pen of the property of the main author and on the university drive. At home, data are daily backed up on an external hard disk with no autonomous Wi-Fi connection. To preserve security of data, and to limit movements of the hard disk to a minimum, the hard disk is kept at home. Storing of data on a hard disk will allow recovery of data in case of damage or incidents.

'Raw' data collected in the studies (transcripts, questionnaire data, social media content), which require long-term storage and extreme security, are stored on a password-secured USB pen of the property of the main author. Similar to the hard disk, this USB pen is kept at home to limit movements to a minimum. These data

1 - "And it snowballed from there": The Development of Orthorexia Nervosa from the Perspective of People who Self-Diagnose & The #Orthorexia Community on Instagram

are also saved on the Surf Drive of the Vrije University Amsterdam, which is very secure and satisfies all EU criteria for long-term storage of research data.

How will you manage access and security?

Data are not accessible to external parties, and they are solely accessible to members of the research team. Data stored in the hard disk and USB pen of the main author can be accessed only upon request to the main author. Data in the Surf Drive are password-secured and only the main author and the PhD supervisor know the password.

Selection and Preservation

Which data are of long-term value and should be retained, shared, and/or preserved?

The only data that could be re-used in future are pictures downloaded from Instagram*. In fact, all the other data (interview transcripts or questionnaire responses) are not re-usable.

Pictures downloaded from Instagram are stored in a password secured online platform, Google drive, which only the research team has access to. These data, which are anonymized, could be accessed in future only after receiving consent from the research team. These data are not strictly confidential, since these pictures were shared online by users in the first place.

* The number of photos shared on Instagram increases a lot every day, so even the use of these photos for future analysis is discouraged as they would be quite 'old'

What is the long-term preservation plan for the dataset?

'Raw' data collected in the studies (transcripts, questionnaire data, social media content) will be stored for 5 years after completion of the PhD. These will be stored on a password-secured USB pen of the property of the main author. This USB pen will be kept at home to limit movements to a minimum. These data will be also stored for 5 years on the Surf Drive of the Vrije University Amsterdam, which is very secure and satisfies all EU criteria for long-term storage of research data.

Data Sharing

How will you share the data?

Data will be solely available to external parties upon request to the corresponding authors of the studies. Data will be shared with external parties after consultation with the research team, who will consider whether this will protect anonymity and confidentiality of those who participated in research.

Are any restrictions on data sharing required?

Data can be made available only in an anonymous format, after request to the corresponding author, and only within 5 years from the obtainment of the PhD.

Responsibilities and Resources

Who will be responsible for data management?

The main author is responsible for data storage and management. All sharing, managing and handling of data should be done after consulting the whole research team.

A Data Management Plan created using DMPTool

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About the Author

Martina Valente (1995) was born in Asti (Italy). After attending a high school in applied sciences, she enrolled in a bachelor's in Biological Sciences in Alessandria (Italy), cultivating a passion for microbiology. She conducted an internship in the microbiology laboratory of her hometown hospital, investigating sepsis caused by vascular catheterization in the clinical setting. She graduated *cum laude* and honors. Willing to approach health in its most holistic sense, and motivated to have a study experience abroad, at the age of twenty-two she moved to the Netherlands to study Global Health. The years of the master have been very significant for her professional and personal growth. During the master, she conducted two research internships on the topic of orthorexia nervosa, one within the Athena Institute and one at La Sapienza University, in Rome. At the end of the master, from which she graduated *cum laude*, she was offered a job at the Athena Institute as a junior lecturer & researcher. In this role, she was also given the opportunity to carry out research on orthorexia nervosa as part of a PhD. By combining her involvement in education in the Global Health master and the research activity, in just one year Martina managed to obtain seven scientific articles on orthorexia nervosa, which have been collected in the thesis you currently hold in your hands.