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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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van de Faculteit der Bètawetenschappen
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door

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geboren te Asti, Italië

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CHAPTER 8. “And it snowballed from there”: The Development of Orthorexia Nervosa from the Perspective of People who Self-Diagnose.

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This study aimed to investigate the perspectives of those who share content on Orthorexia Nervosa (ON) on Instagram and self-diagnose with ON (SD-ON) to trace their development of ON, gain insights into risk factors, symptoms and recovery, and explore differences with those who do not SD-ON. This research used mixed methods, with a sequential explanatory design. The quantitative component (n = 185) aimed to measure prevalence and severity of drivers, symptoms, challenges and help seeking of people who SD-ON. The qualitative component (n = 10) aimed to probe how and why individuals who SD-ON feel that certain experiences shaped their development of ON. Respondents defined ON an obsession with healthy eating and clean or pure foods, with unhealthy effects on physical, mental or social wellbeing. A minority of participants did not view ON as problematic, but instead as a “salvation” from chronic diseases. Three phases characterizing the development of ON were identified: onset, progression and help seeking. Regarding the onset, two routes were identified, both characterized by a snowball effect of interacting factors. Regarding the progression of ON, several symptoms were identified, with obsession with healthy eating being the most frequent one. The majority of participants were trying to lose weight during ON, but their rationale was health rather than appearance. Regarding the help-seeking phase, reasons for problem realization were identified. ON was not noticed by loved ones until major health problems occurred, this being a barrier for recovery. While most believed that recovery is possible, respondents agreed that ON is a condition that will always linger in the back of the mind. This study contributes to addressing the shortage of qualitative studies investigating ON from insiders’ perspective.

Keywords: orthorexia nervosa; biopsychosocial model; development; patients’ involvement; mixed methods

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8.1 Introduction

Worldwide, people are experiencing increased societal and moral pressure to conform to a Western, healthy ideal. This ideal is characterized by an individual responsibility for one's health, where healthy eating and exercise are encouraged and unhealthy eating and lifestyle tend to be viewed as immoral, lazy or impure [1]. Within this context, the promotion of healthy eating is central and happens through the spread of health messages. Apart from being often characterized by negative and moralist undertones, many of these messages also contradict one another, with some endorsing particular foods as healthy and others disparaging the same foods as unhealthy [2], [3]. Consequently, individuals report feeling anxious and unsure of which nutritional recommendations to follow, and in combination with a perceived pressure to be healthy, may lead to the development of pathologically obsessive and restrictive eating tendencies [1], [4], [5].

The term "orthorexia nervosa" (ON) was coined in recent years to describe those who develop an obsession with healthy eating that leads to problems with health and functioning [6]. While health is the ultimate goal of people with ON, their restrictive and rigid eating practice may lead to malnourishment and social isolation if they spend excessive time thinking about and preparing food perceived to be healthy [7]. As ON is a relatively new and under-researched concept, there are debates about its status as a valid disorder with characteristics that can be reliably distinguished from existing eating disorders (EDs) like anorexia nervosa (AN) or bulimia nervosa (BN) [7]. With the ultimate goal of being able to measure ON and to distinguish this from other EDs, measurement tools have been developed; however, many of these are widely criticized for their lack of sensitivity [8].

Without a valid diagnostic tool, there is uncertainty about what actually constitutes ON, since it is not clear what its drivers are or whether it disproportionately affects certain groups [9]. While new diagnostic criteria have been proposed that emphasize impairment of bio-psycho-social functioning in order to reduce overdiagnosis and thus improve sensitivity, they have not been validated, are based largely on case studies, and take little input from those who suffer from proposed symptoms of ON [7]. In order to inform efforts to measure and validate ON, research is needed to understand how ON develops and manifests, and how to distinguish ON from benign restriction and healthy eating.

The inability to distinguish healthy eating from ON may lead to prematurely applying the label 'disordered eating' to a non-pathological eating practice. To prevent this, Bratman introduced a two-phase approach to the development of ON, where the first phase would be the benign choice of an individual to eat healthy, and the second phase would be the intensification of healthy eating until it becomes an obsession [10]. Building upon that, a recent bi-dimensional construct of ON was proposed. This construct conceptualizes ON as a duality of *healthy orthorexia*, characterized by a healthy interest in diet with no concurrent psychopathology, and *orthorexia nervosa*, characterized by negative bio-psycho-social impairments [11]. These theories are a step

towards preventing healthy eating from falling under the construct of ON, yet setting cut-off points to separate normal from pathological is difficult, particularly in situations such as conscious dieting [12]. Listening to personal stories of people with ON can help retrace their development of ON and thus establish how and at what point healthy eating would turn into ON. Comparing experiences of those with ON and those without may also indicate whether there is a ‘threshold’ between benign healthy eating and excessive restriction, and what factors lead to crossing this threshold.

Consulting people with ON may also shed light on risk factors for ON. Research shows that, among the psychological risk factors for ON are: perfectionism, dieting behavior, drive for thinness, anxiety, fear of losing control, perceived vulnerability to a disease [13], and difficulties in regulating emotions [14]. Broader socio-cultural factors affecting ON are healthism [3], [15], a goal-oriented society that sees the body as a ‘project’ [16], the Internet and social media [17], availability of organic food and overall wealth of Western countries [4], [13], and alimentary fears and anxieties [3], [18]. An investigation into personal stories and perspectives of people with ON could provide insights into how and to what extent these risk factors influence the development of ON, validating these findings and depicting a more complete picture of ON.

While people cannot currently be diagnosed with ON, research involving the experiences of those who self-diagnose with ON (SD-ON) may indicate which symptoms are problematic and deserving clinical attention, adding valuable insider’s perspective to the literature and providing direction for future research. Research on ON can benefit from the involvement of people who SD-ON for two main reasons: first, involving end-users of health research enhances legitimacy; second, it incorporates experiential knowledge from people who have experienced symptoms and severity of the disorder, knowledge that is argued to be so crucial that it qualifies sufferers as “non-certified experts” [19]. Despite the evidence supporting the benefits of involving patients in health research, only a few studies so far performed qualitative investigations involving people with ON [16], [20], [21]. Cinquegrani and Brown (2018) [16] and Greville-Harris et al. (2019) [21] performed internet ethnographic research and analysis of online blogs respectively. Both studies were aimed at investigating people’s experiences with ON. Fixsen et al. (2020) [41] conducted interviews with three cohorts, including individuals who SD-ON, in order to explore ON from a social constructivist perspective. An in-depth exploration of how people who SD-ON developed their diagnosis has never been performed. This is an important gap that this study aims to bridge.

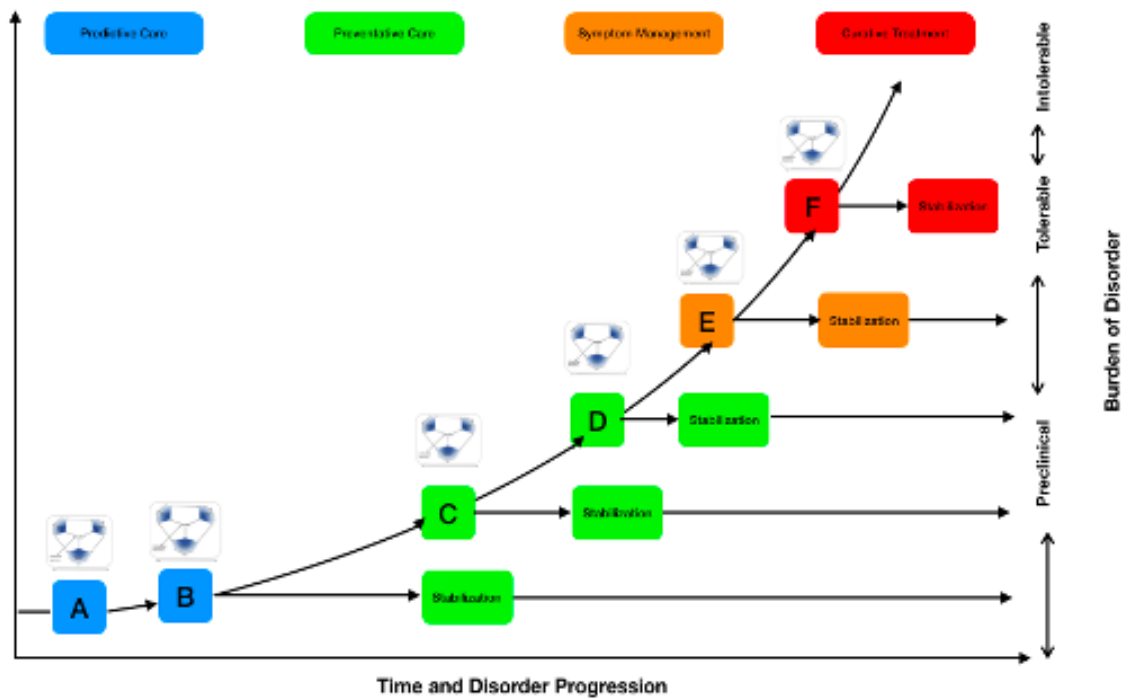
This study aims to include the perspectives of those who post about ON on Instagram and SD-ON in order to trace their development and gain insights into risk factors, symptoms and recovery from ON. Specifically, the questions this study aims to answer are: (a) *How is ON conceptualized by people who self-diagnose?* (b) *What biological, psychological, and social (i.e. interpersonal and contextual) factors contribute to people’s progression along the developmental pathway of ON? (e.g. perfectionism, pressure to eat healthy)* (c) *How do people develop, experience and recover from ON?* (d) *What differences can be identified between people who*

SD-ON and those who do not SD-ON - but post about ON on Instagram - regarding possible risk factors and life histories?

8.2 Methods

8.2.1 Theoretical Framework

In order to observe the developmental pathway of ON by considering the influence exerted by biological, psychological and social factors, we based our study on a theoretical framework (Figure 8.1), which is the result of the integration of two existing models: The Adaptation of Snyderman's Curve of Growing into Deficit and Developing Common Complex Diseases [22] and The Dynamic Biopsychosocial Model of Health [23]. The adapted Snyderman's curve is useful to capture the developmental pathway of a disorder because it traces its development over time, beginning with genetic vulnerabilities and progressing through preclinical, tolerable and intolerable stages of symptoms and disorder manifestation [22]. The dynamic biopsychosocial model of health theorizes health as a product of biological, psychological and social dynamics that influence individuals' health over time. This model further divides social dynamics into proximal interpersonal dynamics (e.g. social relationships) from more distant contextual dynamics (e.g. culture) [23], a distinction that has been considered important and therefore maintained in the integrated framework. Consequently, the theoretical framework used in this study places bio-psycho-interpersonal and contextual dynamics at each transition point of the adapted Snyderman's curve, in order to account for the various factors that may act as drivers of an individual's progression from one stage of disorder development to the other.



A) Parental genetic profile at conception. B) Baseline genetic risk with minimal history of environmental effects at birth. C) Environmental effects may or may not act as initiating events in the process of disorder formation. The precise time point may vary. D) Further cumulative exposure to environmental effects may or may not lead to further preclinical progression of the development of the disorder. E) Gene-environment interaction may or may not lead to disorder initiation. Few symptoms can be seen. They do not cluster to a diagnosis, but cause suffering. F) The symptoms may or may not intensify until they structure to a diagnosis. At this stage, suffering is close to intolerable, and treatment may be costly.

Figure 8.1. Model integrating The Adaptation of Snyderman’s Curve of Growing into Deficit and Developing Common Complex Diseases [43] and The Dynamic Biopsychosocial Model of Health [23].

8.2.2 Research Design

This research used mixed-methods, with a sequential explanatory design. In accordance with the theoretical framework, the quantitative component consisted of a questionnaire designed to identify biological, psychological, interpersonal, and contextual factors that may play a role in each phase of ON development. This was done through a mix of self-reported experiences, opinions of those who SD-ON regarding which factors were key, and group comparisons between those who do and do not SD-ON. Those who SD-ON were directed to additional questions about their symptoms, personally significant struggles and treatment seeking. The qualitative component consisted of interviews with some of the questionnaire respondents and was designed primarily to probe how and why individuals who SD-ON may feel that the factors identified in the questionnaire could have shaped their development of disordered eating, lived experiences during ON, and recovery journeys.

8.2.3 Sampling

Since ON is not an official diagnosis, it is difficult to identify individuals who struggle with the condition due to a lack of patients and participant databases. As there are over 150,000 Instagram posts using the hashtag #orthorexia, this provided a starting place to find potential sufferers of ON. Previous research indicates a stronger link between Instagram use and increased symptoms of ON compared to the use of other social media platforms, which were found to have little to no association with ON symptoms [17]. While this study was primarily interested in people who SD-ON, those who do not self-diagnose but still post about ON were also included in the analysis to allow for group comparisons. While this study was not an experiment with a true matched sample to control for extraneous variables, this comparison group was chosen because of their engagement on social media and interest in ON and healthy eating. We take that this group may therefore be more closely ‘matched’ than a simple random control sample, allowing for sharper comparisons to be made between healthy behaviors and interests vs. the unhealthy obsession that typically characterizes ON.

8.2.3.1 Quantitative sampling

Instagram posts using the hashtags #orthorexia, #orthorexianervosa and #orthorexiarecovery were identified. The account owners of those posts were contacted through a direct message on Instagram sent from the research team’s project-related account. The direct message contained a brief explanation of the study purpose and an invitation to fill out the questionnaire. Only responses of participants aged 16 or older, who had given informed consent, were included in the analysis.

8.2.3.2 Qualitative sampling

The sample for the qualitative component included participants who SD-ON and who indicated at the end of the questionnaire their willingness to participate in an interview. In order to ensure that their contact details could not be linked to their survey responses, interested participants were directed to a separate survey link where they could fill in their contact information. In order to be interviewed, participants who previously SD-ON also had to have proficient command of English, had to be 16 years of age or older, and had to give informed consent.

8.2.4 Data collection and analysis

8.2.4.1 Questionnaire

The questionnaire was made up of five sections: (i) basic demographic information, (ii) opinion about ON, (iii) personal history, (iv) experiences with ON (if applicable), and (v) social media use (outcomes reported in different paper). For this study, sections i-iv are considered. These sections alternated yes-or-no questions (e.g. “In your environment do you see or hear messages about healthy eating?”), multiple-choice questions (e.g. “During the time you believe you have/had orthorexia, did you experience any of the following? More than one answer is possible”), ranking questions (e.g. “On a scale of 1-10, how much social pressure do you feel to eat healthy in general?”), and open questions (e.g. “Could you describe what orthorexia is to you, in a sentence or two?”).

All responses were recorded using *Qualtrics XM* online survey software and, upon completion of data collection, they were exported into *SPSS* statistical software for analyses. Prevalence and mean/median scores for the presence and intensity of different drivers and symptoms were calculated to provide descriptive information. Chi-square, t-tests and analysis of variance tests (ANOVAs) were conducted to compare sub-groups within the sample.

8.2.4.2 Interviews

The qualitative component included semi-structured interviews (45-60 minutes) designed to expand upon information gathered in the questionnaire, by tracing interviewee’s experiences and development of ON. Questions on the interview guide were organized primarily according to the theoretical framework and aimed to divide participants’ journey into “onset,” “progression” and “help seeking.” Participants were also asked to provide a definition of ON.

Interviews were carried out online via Skype and other videoconferencing tools. After obtaining verbal informed consent, interviews were recorded, transcribed and analyzed using *Atlas.ti* software. In order to analyze the interviews, open coding was used and then codes were grouped into themes which aligned with different aspects of the theoretical framework (e.g. contextual drivers of ON, psychological symptoms of ON, social drivers of recovery). Then, these themes were analyzed and related to one another to create an overall picture of the development of ON over time.

8.2.5 Ethical Considerations

Ethical approval was obtained from the Ethical Committee of Athena Institute within the Vrije University Amsterdam. All participants were required to give informed consent on both the questionnaire and interview prior to data collection and were made aware that they may discontinue participation at any time, without naming any reason. During the interviews, special attention was paid to avoiding any psychological harm to the participants by monitoring signs of distress. For the interviews, to maintain anonymity of participants, all names published in the results section of this paper are pseudonyms. The data collected was anonymized, saved on secure server of the VU university and access to the data was restricted to the co-authors of this paper only.

8.3 Results

The section begins with a description of sample characteristics. Then, participants' definitions of ON are analyzed. Subsequently, the development of ON is explored by following the theoretical framework. Three subsections will follow: onset of ON, progression of ON and help seeking. At each sub-section, quantitative results identify key factors influencing the progression of ON, while qualitative results explain how and why these factors influence this progression, painting a more detailed picture of people's experiences with ON. Quantitative and qualitative data were used to mutually strengthen each other.

8.3.1 Sample characteristics

8.3.1.1 Quantitative sample

In total, 246 Instagram account owners were contacted. The sample for the quantitative component included 143 participants who self-diagnose with ON. Forty-two participants who have posted about ON on Instagram, but have never personally experienced ON, were also included. Therefore, in total, 185 respondents (range 16-55 years, median = 24) were included in the study (75.2% response rate). A more detailed overview of the quantitative sample characteristics is provided in Table 8.1.

Table 8.1. *Quantitative sample characteristics*

Sample Characteristics	N(%)
Female	177 (95.7%)
Nationality	
North America	73 (39.6%)
United Kingdom	39 (21.0%)
Europe	51 (27.5%)
Oceania	10 (5.5%)
Other	12 (6.4%)
SD-ON	143 (77.3%)
Expatriate	20 (10.8%)
Students	76 (41.1%)
Employed part- or full-time (includes employed students)	108 (58.4%)
College or other professional degree	110 (59.5%)

8.3.1.2 Qualitative sample

Fifty-two questionnaire respondents who SD-ON indicated interest in a subsequent interview. All interviewees were individuals who SD-ON, and gave an email address to be contacted. From these, 24 were contacted via email in chronological order based on response date, which allowed for time-efficient recruitment, and were given the option to choose an interview with this study or with a sister study on orthorexia and social media use (results published elsewhere). Of these, 10 chose to interview for the present study, 7 were interviewed for the sister study, 1 was interviewed for both studies, 4 did not respond, and 2 changed their minds. Sample characteristics of the qualitative component were similar to those of the quantitative one. Of the 10 participants, 8 were women. One young woman was 16, the remaining 7 women were in their early- to mid-20s, and both men were in their 40s. Seven participants lived in North America, 2 lived in the UK, and 1 lived in Ukraine.

8.3.2 Defining orthorexia nervosa

One hundred and eighty questionnaire respondents were given an open-ended prompt to define ON. They typically described the condition as an *obsession* (68.3%, n = 123) with *eating healthy, clean or pure foods* (80.5%, n = 145), which has *unhealthy effects on physical, mental or social wellbeing* (52.7%, n = 95). Some participants mentioned some important components of ON, namely *avoidance of unhealthy foods* (17.8%, n = 32), *exercise* (14.4%, n = 26) and *anxiety* (8.9%, n = 16). It is noteworthy that one participant (0.1%) described ON as a *salvation*, while another participant (0.1%) defined ON as a divisive term used to discourage healthy

eating, indicating that a minority of participants did not view ON as problematic or worthy of a diagnostic label. Definitions given by most interviewees aligned with the questionnaire respondents, as they primarily described ON as an “obsession with healthy eating.” In agreement with the quantitative findings, not every interviewee agreed that ON is a problem. Though one believed his eating habits could be defined as orthorexic, he emphasized that ON was his “salvation” from a lifetime of chronic disease, helped him become a good father, and helped him reach peak physical fitness. In this regard, he raised attention to the potential danger of pathologizing healthy nutrition:

“I’m very sensitive to this issue because I see how [ON] can be used as a weapon to defend ignorance on nutrition and beat back the people who are having success ... I think this may be kind of a made-up condition.” (Kenneth, early 40s, USA)

8.3.3 Onset of orthorexia nervosa

Respondents depicted primarily two routes as responsible for triggering the onset of ON: one influenced by distal contextual factors, the other influenced by biological, psychological and interpersonal factors closer to the individual sphere. While they are hereby presented separately, it is also possible that there is an interaction between the two routes.

8.3.3.1 First route: influence of contextual factors

Questionnaire respondents were asked about being exposed to contradictory information about healthy eating (e.g. “Do you see contradictory or conflicting information about healthy eating? (e.g. someone says one thing, someone else says the opposite)). In total, 97.3% (n = 180) respondents reported seeing conflicting messages about healthy eating, and 97.8% (n = 176) reported having seen such conflicting messages on social media. Notably, 77.4% (n = 106) of those who SD-ON felt these conflicting messages made it confusing to decide on which foods to eat, while only 33.3% (n = 13) of those who did not SD-ON reported such confusion, a difference that is statistically significant (chi-square = 26.89, p<.01).

Interviewees contributed to a better understanding of how and why being surrounded by such confusing messages would trigger the development of ON. According to them, contextual factors interacted with one another to create a snowball effect, working together as drivers of the condition (Figure 2). During the interviews it emerged that individuals felt exposed to Western sociocultural health and beauty ideals early in life, where happiness and success were equated with health and thinness. Social media appeared to amplify

participants' exposure to these ideals and, at the same time, promote confusing and conflicting messages about health and nutrition:

“Nobody really knows what diet is best, there are so many fads and diets out there, so really social media plays a big part, like me who was confused really about diet, so I feel that plays upon the mental aspect: one day you know something, the next day you read something and you think ‘oh I should cut this out because that’s bad.’” (Julia, early 20s, USA)

Seeking to make sense of these messages, people began increasingly looking up more and more information, slowly fueling and intensifying their development of symptoms such as obsession. As they continued to gather evidence, fewer foods became safe, thus fueling dietary restriction:

“I really immersed myself on Instagram and learned all I could about nutrition, and the more I learned, the more confusing it got ... I tried pretty much any kind of diet and then that progressed and then I kept learning more and more about nutrition and I got a lot more restrictive.” (Camille, mid 20s, USA)

8.3.3.2 Second route: influence of bio-psycho-interpersonal factors

When moving from broader societal triggers to closer bio-psycho-interpersonal drivers, questionnaire respondents identified perfectionism and perceived pressure to eat healthy as underlying mechanisms influencing onset and development of ON. When asked to score themselves regarding how perfectionistic they are on a scale of 1 (not perfectionistic) to 10 (totally perfectionistic), those who SD-ON averaged a score of 8.36 (SD = 1.34), which was significantly higher than those who did not SD-ON ($t = 4.94, p < .01$), who rated themselves on average as 7.10 (SD = 1.73). Participants who SD-ON also perceived greater social pressure to eat healthy on a scale of 1 (no pressure) to 10 (extreme pressure), as they averaged a score of 7.52 (SD = 2.23), while those who did not SD-ON averaged 5.46 (SD = 2.30), and this difference was statistically significant (Mann-Whitney $U = 1336.00, Z = -4.81, p < .01$). Respondents indicated also whether certain experiences had an impact on their eating habits (Table 2). Those who SD-ON were significantly more likely than those who did not SD-ON to report that major life event, onset of psychological problems and onset of physiological illness impacted their eating habits (Table 8.2). Table 8.3 reports an overview of the perceived impact of various health conditions on the onset of ON, indicating that those who SD-ON were significantly more likely to have both personal histories of other eating problems, psychological problems, food allergies or intolerances, and family history of eating problems and psychological problems. Personal and family history of gastrointestinal illness did not significantly differ between groups.

Table 8.2. *Participants Indicate whether they believe life experiences impacted their eating habits*

Personal/Family History	Self-identifiers (%)	Non-self-identifiers (%)	Chi-square
Major life event	92 (64.3%)	19 (45.2%)	4.93*
New onset of psychological problem(s)	73 (51.0%)	14 (33.3%)	4.09*
New onset of a physiological illness	43 (30.1%)	7 (16.7%)	2.96*
Other major change or experience	41 (28.7%)	11 (26.2%)	0.10

Note. * $p < 0.05$

Table 8.3. *Lifetime history of various health conditions*

Health History	Self-identifiers (%)	Non-self-identifiers (%)	Chi-square
Personal history of eating problems	115 (80.4%)	13 (31.0%)	37.27*
Personal history of other psychological problems	111 (77.6%)	20 (47.6%)	14.14*
Personal history of gastrointestinal illness	40 (28.0%)	8 (19.0%)	1.35
Personal history of food allergies or intolerances	50 (35.0%)	7 (16.7%)	5.10*
Family history of eating problems	52 (36.4%)	8 (19.0%)	4.44*
Family history of other psychological problems	73 (51.0%)	11 (26.2%)	8.09*
Family history of gastrointestinal illness	36 (25.2%)	6 (14.3%)	2.19

Note. * $p < 0.05$

In agreement with questionnaire findings, when explaining how bio-psycho-interpersonal factors influenced their development of ON, interviewees primarily mentioned perfectionism and anxiety, describing another snowball effect (Figure 3). Perfectionism and anxiety were described as lifelong traits that manifested in adolescence, prior to the onset of difficulties regarding food or body image. Perfectionism often centered on a desire for control over all of the happenings in life, whereas anxiety would occur in response to a loss of this

control. Thus, when major life events, weight fluctuations or onset of physical issues occurred, this created instability and lack of control in participants’ lives and triggered a heightened anxious response. Diet became something that participants could control in order to relieve their anxiety, improve their lives and/or treat their health using “food as medicine”:

“I moved away to college and really struggled with the transition ...[it was] this big life change of moving and not meeting all new friends and not being with my family or my old friends or my safety nets... So, because my life felt so out of control, I decided to try to control food and eat healthier. And it snowballed from there.” (Jade, mid-20s, United States)

8.3.4 Progression of orthorexia nervosa

8.3.4.1 Symptoms and experience of distress

Participants who SD-ON were asked to report how frequently they experienced certain symptoms during the time they had ON (Table 8.4). Obsession with healthy eating was the most frequently occurring symptom, while moderately-to severely-low bodyweight was the least frequent. It is noteworthy, however, that 79.5% (n = 134) of the women reported that their menstrual periods were irregular or stopped altogether during ON, and that a majority (81.7%, N = 107) of participants were frequently trying to lose weight during their SD-ON. Respondents who SD-ON were also asked to report how different domains of life and functioning were affected overall by ON. For most, psychological and social health were the most impacted by ON, followed by physical health; occupational health was least-impacted.

Table 8.4. *Frequency of symptoms experienced by those who SD-ON*

Symptom or difficulty	No, never	Rarely	Sometimes	Yes, often
Obsessed/preoccupied with healthy eating	0 (0.0%)	1 (0.7%)	10 (7.1%)	130 (92.2%)
Cut out more and more foods from diet	3 (2.1%)	2 (1.4%)	17 (12.1%)	119 (84.4%)
Healthy eating distracted from other areas of life	1 (0.8%)	3 (2.3%)	18 (13.7%)	109 (83.2%)
Strong negative reactions to eating unhealthy foods	2 (1.5%)	4 (3.1%)	14 (10.7%)	111 (84.7%)
Trying to lose weight	3 (2.3%)	8 (6.1%)	13 (9.9%)	107 (81.7%)
Moderately- to severely-low bodyweight	33 (23.4%)	16 (11.3%)	21 (14.9%)	71 (50.4%)

Strengthening and complementing quantitative findings, interviewees described that their “full” ON had begun once their eating interfered with biological, psychological and/or social functioning. Impairments in social functioning, unhealthy relationships, and the resulting isolation contributed to the psychological harm of interviewees and were often described as the most distressing aspects of living with ON:

“People go through [ON] thinking they are alone and there is nobody to help them, because it makes you feel that way, it persuades you that you don’t have anything, anyone and you even don’t have yourself anymore.” (Karolina, early 20s, Ukraine)

While psychological and social harm were described as mutually influencing each other, interviewees tended to describe physical harm as a more separate component that did not have a clear impact on their social or mental functioning. Nonetheless, physical problems such as severe weight loss and malnourishment could be quite serious and lead to other physical problems such as amenorrhea and bloating. Similar to questionnaire respondents, interviewees shed light on their desire for weight loss. During ON, they held the belief that weight is associated with health because overweight could lead to cardiovascular problems or chronic diseases, and therefore this desire for weight loss was primarily motivated by health reasons:

“I definitely think [my dietary restriction] was based in fat-phobia. But it was the perception of not being healthy, that aspect of it... So, I kind of latched onto the idea of getting healthy, that was the main goal, [and] there were underlying body image issues.” (Jade, mid 20s, USA)

8.3.5 Help seeking

8.3.5.1 Problem realization

Among questionnaire respondents who SD-ON, 79.0% (n = 113) believed that their healthy eating was negatively impacting their lives. An overview of the reasons that prompted this belief is reported in Table 8.5. Among these respondents, 77.0% (n = 87) had considered treatment at some point.

Table 8.5. *Reasons that prompted realization of the negative impacts of ON on health*

Reasons for problem realization	N(%)
Noticing a negative impact on relationships	78 (45.6%)
Loved one who expressed concerns	73 (42.7%)
Bodily discomfort or illness	67 (39.2%)
Time/money spent on diet became too costly	60 (35.1%)
Noticing a negative impact on study/work performance	48 (28.1%)

Interviewees confirmed all of the reasons for problem realization already identified by questionnaire respondents. For those who realized for themselves that they had a problem, this was usually sparked by difficulties that were not easily observed by others, such as anxiety, pain or discomfort due to malnutrition, and feelings of isolation when relationships suffered. When loved ones expressed concern about participants, this was only described in relation to severe weight loss by interviewees, indicating that others did not understand they had a problem with eating unless their problems were visible:

“I got help because I fit the mold of what someone with an eating disorder is supposed to look like. Which is shitty that that’s the case.” (Jade, mid 20s, United States)

8.3.5.2 Recovery journey

As not all people who SD-ON noticed or experienced physical health problems in addition to their psychological and social struggles, this may constitute a sociocultural barrier to recovery for people with ON. Another barrier to recovery was identified during the interviews: an ineffective healthcare system where health professionals were believed to possess a lack of knowledge about ON and disordered eating. In the case of the Ukrainian participant, a lack of empathetic and affordable care for individuals suffering from mental illness was identified:

“In Ukraine, they don’t believe in mental illnesses ... There are some therapists and they are willing to help you, if you pay tons of money ... but they don’t really care about you becoming mentally healthy.”

(Karolina, early 20s, Ukraine)

Despite the description of social media as a driver of ON onset, it was also described by some interviewees as a stimulus to recover. Participants described how they found solace by engaging with accounts on social media that emphasized a counter-culture to mainstream sociocultural ideals of health and beauty, by promoting body positivity and intuitive eating. This gave interviewees new ideas and insight into forming a healthier relationship with food and their bodies, as well as a sense of community and support that many craved after periods of isolation:

“Facebook I use a lot for the groups. So one of them, or a couple of them I guess, are nutrition groups for health at every size dietitians. So dietitians that are pushing against the normal weight-centric model and are pro-intuitive eating and just no restriction in any way. And I think the good thing about that is that it fills me with a lot of positive resources and positive places to turn to if I have questions or anything” (Nicole, mid-20s, USA)

For those interviewees who felt they were far along in their recovery journeys, recovery was characterized by a restoration of bio-psycho-social health, as well as willingness to face problems such as anxiety directly, rather than using ON as a coping mechanism to gain control in life. Participants also talked about the importance of self-forgiveness and not judging themselves if they were to experience a relapse in symptoms of ON because recovery was viewed as a continual learning process rather than a finite point in time. And, while most believed that recovery from ON is possible, it was a condition that was often lingering in the back of their minds long after the start of their recovery journeys:

“There’s always an echo, a shadow of [ON] somewhere. You can lock it away while you’re in your day to day life ... but you kind of learn to live with it.” (James, late 40s, UK)

8.4 Discussion

This study aimed to include the perspectives of those who post about ON on Instagram and self-diagnose, in order to trace their development of ON, gain insights into risk factors, symptoms and recovery from ON, and explore differences with those who do not self-diagnose. To achieve this aim, the study sought to uncover: (a) how ON is conceptualized by people who self-diagnose, (b) what bio-psycho-interpersonal and contextual factors contribute to people's progression along the developmental pathway of ON, (c) how ON and subsequent recovery are experienced by people who SD-ON, and (d) what the differences are between people who SD-ON and those who do not SD-ON regarding possible risk factors and life histories.

ON was defined as an obsession with healthy eating, clean or pure foods, which has unhealthy effects on physical, mental or social wellbeing. A minority of participants did not view ON as problematic, but instead as a "salvation" from chronic diseases. Three phases characterizing the development of ON were identified: onset, progression and help seeking. With regard to the onset of ON, two routes were identified, both characterized by a snowball effect of factors interacting within each other: the first route influenced by broader contextual factors, the second route influenced by bio-psycho-interpersonal factors closer to the individual sphere. With regard to the progression of ON, several symptoms were identified, with obsession with healthy eating being the most frequently reported one. The majority of participants were trying to lose weight during their ON period, but this was driven by health rather than appearance purposes. Considering the help-seeking phase, several reasons for problem realization were identified. Interestingly, ON was not noticed by loved ones until major health problems occurred. This was recognized as a barrier for recovery. Lastly, despite the largely prevalent belief that recovery from ON is possible, respondents agreed that it is a condition that will always linger in the back of their minds. Despite having a highly international sample, findings reported quite an agreement on how ON develops over time.

Differences between individuals who SD-ON and those who do not have been identified, which can inform the search for a 'threshold' between benign healthy eating and ON. For example, individuals who SD-ON were more likely to feel confused on what to eat following exposure to conflicting messages. This validates the findings of Rangel et al. (2012) [3] regarding the onset of feelings of confusion and anxiety following the attempt to navigate today's nutrition recommendations. Individuals who SD-ON were also more likely to have perfectionistic traits and to perceive greater pressure to eat healthy. These findings are in agreement with the review of McComb and Mills (2019) [13]. Feeling greater pressure to eat healthy also strengthens the idea that healthism would influence ON; i.e. healthism contributes attributing moral value to the pursuit of health, thus individuals would perceive societal and moral pressure to take care of their bodies [5], [15], [16]c. Confirming the findings of McComb and Mills (2019) [13], our findings indicate that individuals who SD-ON are more likely to have a history of other eating disorders and psychological problems.

During SD-ON, participants developed obsession and restriction, which always resulted in some form of bio-psycho-social dysfunction, with social isolation and deterioration of relationships been considered the most distressing aspects. An explanation can be found considering the relationship between disordered eating and fear of cognitive dyscontrol (the inability to control internal experiences such as anxiety), as disordered eating and avoidance of uncomfortable situations (e.g. social eating) may be maladaptive strategies to regulate anxiety [24]. Our findings align with this argument, suggesting that ON could be a coping mechanism for anxiety reduction. A study recently published by Vuillier, Robertson & Greville-Harris (2020) [14] provides evidence that similar to other eating disorders, individuals with ON would struggle with emotion regulation: “individuals with high ON tendencies have difficulties identifying and accepting their feelings, resisting impulses, engaging in goal-directed behaviours, and finding right strategies when upset” [14]. Future studies on the relationship between emotion regulation and anxiety reduction in individuals with ON may provide interesting new insights to the field.

It is noteworthy that a few participants saw ON in a less problematic light. They drew attention to how a diagnostic label of ON could pathologize individuals who may not need clinical intervention if the label or diagnostic criteria were constructed carelessly. It is therefore important to not lose sight of what defines a psychological disorder (e.g. distress) [25] when seeking to create and apply diagnostic labels, especially as this is something that past diagnostic criteria and tools of measurement (e.g. the ORTO-15) are criticized for not taking into account [7], [8].

Considering ON a positive phenomenon can also derive from how different individuals could be in different phases of the development of ON. According to Bratman (2017) [10], there are two phases in ON: a positive phase that consists in the choice to eat healthy, and a consequent negative phase that derives from taking the first phase to the extreme. Based on this theory, we can hypothesize that the first phase of ON would be still relatively healthy, working as a coping strategy for those individuals who have anxiety traits or other psychological problems. As such, in this phase, ON would lead to a decrease in anxiety and at the same time to an increase in self-esteem and optimization of health [26], [27]. Individuals in this phase would therefore consider ON as positive. While attempting to achieve the “perfect” health, however, individuals may run into confusion deriving from contradicting information regarding food and health because of the overabundance of messages coming from many different sources. Individuals with stronger perfectionistic traits may try to fight these uncertainties by increasing control over diet, with the risk of this control becoming an obsession, thus running into the negative phase of ON. A possible explanation for how, in the present study, some individuals did not consider ON as negative could therefore lie in their still being in the former, positive, stage of ON. Further information on how individuals with ON dealt with anxiety in earlier phases of their lives would be of value for testing this hypothesis.

Congruent with past findings, the current study found that participants who self-diagnose with ON typically live in a Western context in which they are exposed to sociocultural ideals which value thin, healthy bodies [1], [4]. The association between ON and Western culture opens up new hypotheses regarding the potential role of culture in the development of ON and whether ON could be interpreted as a ‘cultural manifestation of distress’ rather than a universal, distinct disorder. While ON seems to predominantly belong to Western societies, it can be said that despite its advancement, the literature assessing ON in non-Western contexts is still limited (e.g. Poland [28], Hungary [9], Lebanon [29], China [151]). Some comparative studies between Western and non-Western countries [30] identified differences that revealed the potential influence of culture; however, advancements in this direction could be made once culturally sensitive diagnostic procedures for ON are available [12].

The effect of Western sociocultural health and beauty ideals on ON appears to be magnified by social media. This finding is confirmed and strengthened by a recent content analysis of “fitspiration” websites in which researchers found that such sources would over-value the importance of physical appearance and promote unhealthy behaviors like excessive dietary restraint [31]. Furthermore, as past studies would predict [3], the advice that people came across on social media and other platforms was often confusing and contradictory, which reinforced their symptoms of restriction and looking up information about healthy eating, inciting a snowball effect. Notably, in the present study, social media has been identified as helpful to enhance recovery too. This positive impact of social media can be traced back to its ability to connect people in need of support through the creation of online communities, which would facilitate the sharing of positive and supportive content [32]–[34]. This double role of social media is thought-provoking and leads to hypothesize that, if certain content (e.g. fitspiration content) is deleterious for ON, online communities around #orthorexia would be, instead, mainly supportive and aiding recovery. The sister study carried out concurrently with this one collected data specifically on the use of Instagram by people with an interest in or self-identify with ON (to be reorted in another paper). Data of both studies shed light in this double role of Instagram.

Participants who SD-ON affirmed to have anxious and perfectionistic tendencies that preceded their development of ON, both of which are traits that have been consistently linked to disordered eating in general [35] and to ON in particular [13]. As a consequence of this, when major life changes occurred, this triggered an anxious response and food and diet seem to become a way to relieve the anxiety and regain a sense of control over one’s life. The onset of chronic conditions, for example, was considered an event able to trigger ON symptoms by some interviewees, who felt they could use food as medicine to treat their condition. As young people with diet-related chronic health conditions have been shown to have an increased risk of developing restrictive and disordered eating [36], this finding may also be true for people who SD-ON. Future studies regarding how and why individuals with ON believe they can treat chronic conditions with inclusion or avoidance of particular foods are needed to better understand the development of ON in this subset of individuals.

Unexpectedly, the majority of participants tried to lose weight during SD-ON. Interviewees provided an explanation for this, describing how they equated bodyweight with health status, and were more motivated by health than aesthetic reasons. Therefore, they felt that conditions such as AN did not describe them as accurately as ON did. Nonetheless, they felt afraid of gaining weight, indicating shared underlying anxieties with other EDs. A possible supposition could be that affirming to be following a diet for health purposes is more socially acceptable than affirming to be following a diet for appearance-related purposes; nevertheless, this suggests that it may be difficult to disentangle disordered eating motivated by health vs. thinness, and therefore ON from other EDs. In their review on psychosocial risk factors, McComb and Mills (2019) [13] argued that, despite the need of more investigations, preliminary research would suggest an association between drive for thinness and ON. Along the same line, we encourage future research to take this into account before seeking to distinguish ON from other EDs. Furthermore, we recommend future research should assess the extent to which weight could be seen as a parameter for healthiness.

When considering recovery, it was noteworthy that although many interviewees believed that it was possible to fully recover from ON, they also felt their own recovery was incomplete due to a lingering “shadow” of ON. This aligns with the experiences of people suffering from other EDs [37]. Further research is needed to explore how this shadow can affect psychosocial functioning even after the symptoms of ON have faded. In light of the aforementioned two-phase construct of ON, recovery could be interpreted as a phase in which the individuals learn how to face their anxieties without the use of ON as a coping mechanism. Within this perspective, the lingering “shadow” would be the temptation to still rely on coping strategies that could appease anxieties deriving from the uncertainties that permeate today’s world. According to this hypothesis, recovery would serve the purpose of teaching individuals how to live with uncertainties and difficulties of life by facing them, instead of using coping mechanisms which provide an initial satisfactory feeling, but which subsequently turn into dangerous traps.

In conclusion to this paper, it is worth reporting that among the people who filled out the online questionnaire, a number of responses came from people under the age of 16. These responses were not included in the analysis for ethical reasons, but this alarming finding warns us that such a disordered eating behavior may have spread among very young people.

Some limitations of the present study are reported as follows. As there are no official diagnostic criteria for ON, it was impossible to determine whether participants truly had ON. Thus, this study relied on self-report data. Additionally, we did not control our participants for possible other non-ON co-morbidities. As ON is not an official diagnosis, there were no patient databases or other official records from which a representative sample could be drawn. For this reason, participants were recruited through social media. Therefore, these findings may not be representative of all people with ON. Moreover, the sample size for the qualitative arm of the study was limited. Similarly, in the statistical analysis, respondents who did not SD-ON were used as a

comparison group to people who SD-ON. Respondents who did not SD-ON were composed largely of social media users and people who had an interest in ON and are clearly not representative of the general population without ON. The current study also relied upon retrospective data, as participants were asked to reflect on past experiences. As memories can change or fade over time, this may have introduced recall bias. As such, prospective, longitudinal studies on the development of ON over time may add additional depth and validation of these findings. Lastly, we reached out to people who posted about ON in English, therefore non-English speaking social media users were automatically excluded from the study.

Nonetheless, this study represents a step forward towards more qualitative studies examining the perspectives of those who SD-ON. While the sample was not representative of all people with ON, these findings provide new directions for research aimed at understanding, defining and treating ON. Its mixed-methods, sequential explanatory design allowed the team to identify important points of discussion in the quantitative results that were used to guide qualitative interviews, resulting in a more complete picture of individuals' journeys. Ultimately, this study meets the calls and the need for more qualitative research on the topic [8], [9], [38], [39].

8.4.1 Conclusion

Our study involving individuals who share content about ON on Instagram found that most participants defined ON as an unhealthy obsession with healthy eating, which results in bio-psycho-social impairments. Participants who SD-ON reported that ON develops gradually and is driven by interacting and mutually reinforcing contextual and bio-psycho-interpersonal factors. Most people who SD-ON affirmed that they wanted to lose weight for health purposes, indicating that ON may not be easily distinguished from other EDs. Once ON symptoms lead to intolerable bio-psycho-social harm, participants who SD-ON or their loved ones realized they had a problem, and most considered seeking treatment. However, not all received it, calling attention to sociocultural, financial and/or institutional barriers. Future research is needed to better distinguish ON from other forms of disordered eating before seeking to create new diagnostic labels, explore contextual and bio-psycho-social drivers of ON in greater detail, and identify ways to facilitate access to effective treatment for those suffering from disordered eating.

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