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VRJE UNIVERSITEIT

“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  
ten overstaan van de promotiecommissie  
van de Faculteit der Bètawetenschappen  
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De Boelelaan 1105

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## CHAPTER 9. The #Orthorexia Community on Instagram.

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**Objective:** this study used mixed methods to delve into the relationship between ON and Instagram. **Method:** two quantitative data sources were triangulated: content analysis of pictures using #orthorexia (n = 3027) and an online questionnaire delivered to people sharing ON-related content on Instagram (n = 185). Following the questionnaire, interviews (n = 9) were conducted with people sharing ON-related content on Instagram and self-identifying as having (had) ON. **Results:** females, around their mid-20s, who favor Instagram over other social media platforms are those who share ON-related content on Instagram. The definition of ON they provide is in line with the literature, though those who self-identify as having (had) ON are more likely to remark on the negative impairments caused by ON. Instagram is considered to trigger ON, but is not its primary cause. Instead, respondents believe Instagram encourages problem realization. ON is encoded on Instagram in pictures of ‘food’, ‘people’, ‘text’ and ‘other.’ People started posting to recover, share information and help others. Furthermore, individuals felt inspired to post by other accounts. An overall sense of belonging to the #orthorexia community emerged, where people share values and ideals, and seek validation from others. **Discussion:** this study found that conversations around #orthorexia on Instagram generate supportive communities aiding recovery. Individuals use Instagram as a tool for helping others and themselves recovering from ON. Understanding how people help each other, manage their health, cope with symptoms of ON, and undertake recovery can inform implementation of therapeutic interventions.

*Key words:* orthorexia nervosa; Instagram; online communities; content analysis; social media

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## 9.1 Introduction

Eating disorders (EDs) are characterized by a disturbed eating behavior leading to an altered consumption of food, which results in impairments in bio-psycho-social functioning [1]. Main EDs in the Diagnostic and Statistical Manual of Mental Disorders are anorexia nervosa, bulimia nervosa, and binge eating disorder. People may engage in unhealthy eating behaviors without meeting the clinical criteria for specific EDs; scholars refer to these as ‘disordered eating behaviors’ [2], [3].

In addition to health implications of EDs such as osteoporosis, gastrointestinal issues, and cardiac arrhythmia [4], EDs also have elevated mortality rates. The weighted mortality rates for anorexia nervosa and bulimia nervosa are 5.1 and 1.7 respectively [5] and data show that EDs are rising in non-Western countries [6]. Given the substantial impact of these conditions on people’s lives, many preventive interventions have been developed over the years [7]. However, the road to understanding these complex and multifactorial conditions is still long, and researchers have yet to ascertain the contribution of certain factors in preventing and/or treating EDs; one of these factors being the Internet.

With the advent of the Internet, scholars have increasingly turned their attention to how information communication technologies influence disordered eating practices [2]. Some studies have assessed the potential benefits of Internet-based supportive interventions for people with EDs (e.g. [8]); others have reviewed the risks of visiting pro-ED websites (e.g. [9]). In general, past research has focused on the impact of platforms or devices which specifically target individuals with EDs; only recently attention has been turned to the impact of general-purpose online spaces, like social media [2].

Social media platforms have a dual role: they can aid recovery as well as stimulate pro-EDs thoughts. Positive effects of social media are, for example, facilitating the acquisition of information about recovery, allowing tracking of one’s own recovery, and reducing stigma. These positive effects are counterbalanced by negative effects, such as triggering EDs symptoms, or promoting comparison [2].

Communities are created on social media that influence disordered eating behaviors. These communities are groups of individuals who have a common interest, share and consume content related to that interest, and learn from and with each other [10]. Online communities are not static, since they are a product of participation rather than membership structures. For this reason, they are referred to as Communities of Practice (CoPs) [11]. Beliefs and narratives concerning disordered eating behaviors shared within CoPs may promote and reinforce disordered eating habits, or enhance recovery.

A disordered eating behavior that has recently gained scientific interest is orthorexia nervosa (ON). ON is an obsession with healthy eating, in which health concerns lead to a preoccupation with healthy food. The persistent and disturbing thoughts characterizing the obsession impact physiological, psychological, and social

wellbeing [12]. The emergence, development, and nature of ON seem inextricably connected to social media. After blogger and Instagrammer Jordan Younger confessed online to suffer from ON, the concept of ON began spreading among the general population, who suddenly realized they could talk about it on social media. Ultimately, this has led ON to be defined as a ‘cyberpathy,’ a digitally transmitted condition propagated online by a system of social influence and cultural contagion [13].

Being the platform of choice of the healthy eating community [14], Instagram is the social media most associated to ON. To date, two studies have been conducted on this association: Turner and Lefevre (2017) [14] conducted an online survey among social media users following healthy food accounts, concluding that higher Instagram use is linked to increased ON symptoms; Santarossa and colleagues (2019) [15] performed an exploratory analysis of Instagram posts shared using #orthorexia, and identified a relatively small but supportive community encouraging recovery. These studies are very useful, because they allow to grasp a connection between ON and Instagram. However, a broader overview of how and why people interact on Instagram regarding ON is lacking.

The aim of this study is to contribute to understanding the influence of social media on ON, by conducting a mixed methods investigation into the relationship between ON and Instagram. This will be done by considering three overarching aspects: (1) *Who* shares ON-related content on Instagram? (2) *What* type of content is shared on Instagram about ON? (3) *Why* do people share ON-related content on Instagram? This study contributes understanding the influence of social media on the development of disordered eating behaviors. More broadly, it serves the purpose of informing future research on social media and mental health.

## 9.2 Methods

### 9.2.1 Study Design

This study used mixed methods, with concurrent triangulation and a sequential explanatory design. Two quantitative data sources were triangulated: content analysis of #orthorexia pictures, which provided descriptive information about the type of pictures about ON on Instagram, and analyses of the online questionnaire delivered to people posting about ON on Instagram (both self-identifying as having ON or not). Qualitative data collection followed in the form of semi-structured interviews with people who posted about ON on Instagram and who self-identified as having (had) ON.

## 9.2.2 Quantitative Component

### 9.2.2.1 Instagram Content Analysis

#### 9.2.2.1.1 Data collection.

In total, 17,000 Instagram pictures using #orthorexia posted in March 2019 were downloaded using the command-line application Instagram-scraper (<https://github.com/rarcega/instagram-scraper>). From these, a sub-sample of 3,027 pictures was randomly selected for analysis.

#### 9.2.2.1.1 Data analysis.

After an initial look at the pictures and consultation of literature, a general codebook was developed. This was updated during the coding process, allowing the emergence of new codes as unexpected categories were encountered. The final codebook included 27 codes, which were used to categorize the pictures. One code was used for each picture, and pictures were coded based on the most prominent object they depicted, except for pictures containing some form of text, which were always coded as 'text.' Pictures categorized according to these codes were subsequently placed into four main categories ('food', 'people', 'text' and 'other'), to enable triangulation with the questionnaire results. Descriptive statistics were used to report results of the content analysis.

### 9.2.2.2 Online Questionnaire

#### 9.2.2.2.1 Data collection.

A link to the online questionnaire was sent through a direct message on Instagram to people who used ON-related hashtags, e.g. #orthorexia, #orthorexiarecovery, #orthorexianervosa. A post advertising the questionnaire was also shared on Instagram through the project-related account. The questionnaire was developed using Qualtrics Survey software, and consisted of six parts: (i) demographics, (ii) opinion and knowledge about ON, (iii) personal history, (iv) contextual dynamics, (v) experiences with ON, and (vi) social media and Instagram use related to ON. For this study, parts i, ii, and vi were used.

#### 9.2.2.2.1 Data analysis.

Questionnaire results were analyzed using IBM SPSS Statistics 23 and StataIC 15. Inclusion criteria were as follows: providing consent to participate, completing the questionnaire, and being 16 years old or older. Descriptive statistics were used to analyze demographics, opinion and knowledge about ON, and social media and Instagram use. Open and axial coding was performed in Excel to analyze open-ended questions. Fisher's exact test, Mann-Whitney U test and Pearson's chi-squared test were used to calculate associations between variables and self-identification with ON vs. non- self-identification with ON. When SPSS could not be used (e.g. >2x2 tables), StataIC was used. All tests were two-tailed and the significance level was set to an alpha of 0.05.

## 9.2.3 Qualitative Component

### 9.2.3.1 Interviews

#### 9.2.3.1.1 Data collection.

Questionnaire respondents who filled in their email address were sent an invitation to participate in an interview. Interviewees had to be at least 16 years old, post about ON, and self-identify as having (had) ON. Interviews were conducted in English through several platforms (Zoom, Skype, FaceTime and WhatsApp). Written consent was obtained via email, and, with permission, interviews were audio-recorded. The interview was aimed at gaining insight into what content the participant had shared about ON on Instagram, why this content was shared, what had been the process of posting, what was the intended audience, and lastly, if applicable, how Instagram influenced the onset and development of ON.

#### 9.2.3.1.2 Data analysis.

Interviews were manually transcribed and coded using Atlas.ti 8. Open and axial coding was used to analyze the interviews. To identify and classify intentions to post ON-related content on Instagram, the analysis relied on the model describing the intention to engage in online social networking from Cheung and Lee (2010) [16] (Figure 9.1). This model includes three modes of social influence: social identity, group norm, and subjective norm. Social identity refers to the self-awareness of one's membership in a group and consists in three second-order factors: cognitive, affective, and evaluative social identity. Group mode is about the resemblance of one's values, beliefs, attitudes, and goals to those of other group members. The last mode consists in subjective norm and refers to the need for approval from significant others [16].



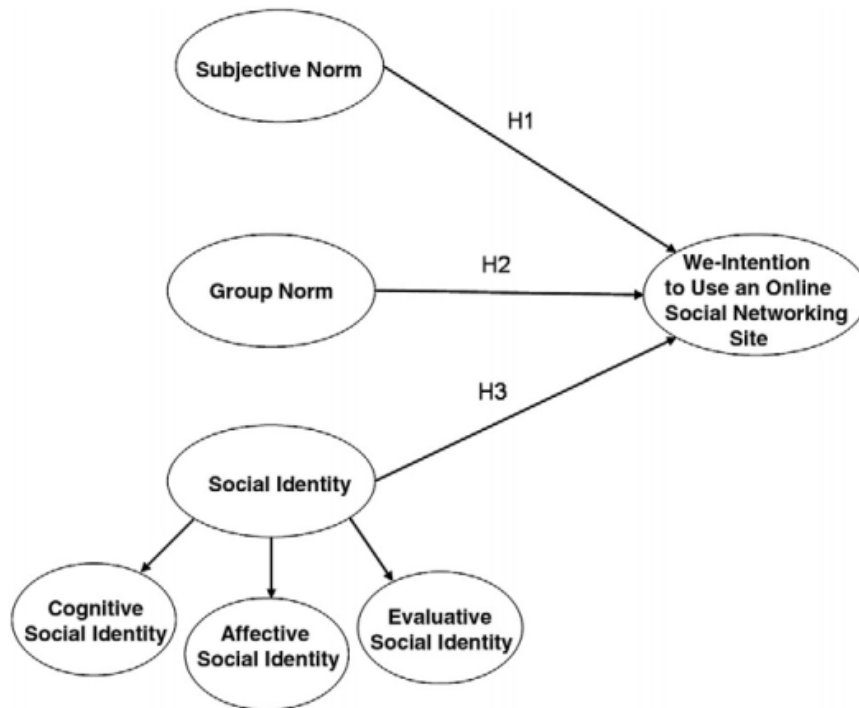


Figure 9.1. Model describing the intention to use an online social network [16].

#### 9.2.4 Ethical Considerations

This study was submitted to and approved by the ethical committee of the Faculty of Science of the Vrije Universiteit (VU), Amsterdam. Informed consent was obtained from questionnaire respondents and interviewees prior to participation. Confidentiality of the data was ensured by storing data on a password protected database.

## 9.3 Results

In this section, results from content analysis, questionnaire and interviews are reported as integrated with each other, following a who-what-why structure: first, an overview of questionnaire and interview samples, and their characteristics, is provided (who); followed by an exploration of the type of ON-related content shared on Instagram (what); last, motivations to share ON-related content on Instagram are presented (why).

### 9.3.1 Who Shares Orthorexia Nervosa-Related Content on Instagram?

#### 9.3.1.1 Questionnaire Sample

In total, 248 individuals filled out the questionnaire; 63 responses were excluded because users did not meet inclusion criteria, leaving 185 participants. Among those, 124 claimed to post about ON on Instagram; therefore, the majority of the calculations were performed on this sub-sample. Most of participants who posted about ON on Instagram were female (95.2%), with a mean age of 26.2 years. Among 30 different nationalities, American (45.2%) and British (14.5%) were reported most frequently. A full overview of the sample's demographics is reported in Table 9.1.

Table 9.1. Demographics of questionnaire participants and of sub-group of people posting about ON on Instagram

Variables		All participants (n=185)	Posters (n=124)
Sex at birth*	Male	8 (4.3%)	6 (4.8%)
	Female	177 (95.7%)	118 (95.2%)
	Intersex	-	-
	Prefer not to answer	-	-
Gender at birth*	Male	8 (4.3%)	6 (4.8%)
	Female	177 (95.7%)	118 (95.2%)
	Intersex	-	-
	Other	-	-
	Prefer not to answer	-	-
Age (in years); mean (SD)		25.3 (8.1)	26.2 (8.1)
Nationality*,**	American	63 (34.1%)	56 (45.2%)
	Australian	8 (4.3%)	7 (5.6%)
	British	42 (22.7%)	18 (14.5%)
	Canadian	11 (5.9%)	11 (8.9%)
	Dutch	13 (7.0%)	2 (1.6%)
	Russian	5 (2.7%)	4 (3.2%)
	Other	53 (28.6%)	34 (27.4%)
Highest level of education*	Primary school	-	-
	Some high school	26 (14.1%)	14 (11.3%)
	High school diploma or equivalent	23 (12.4%)	14 (11.3%)
	Some college education	26 (14.1%)	20 (16.1%)
	Trade/vocational school/MBO	2 (1.1%)	1 (0.8%)
	Associate's degree/HBO	10 (5.4%)	7 (5.6%)
	Bachelor's degree/WO	49 (26.5%)	36 (29.0%)
	Master's degree	42 (22.7%)	28 (22.6%)
	Other professional degree (e.g. NP, LSW)	3 (1.6%)	2 (1.6%)
Doctoral degree (e.g. MD, PhD, JD)	4 (2.2%)	2 (1.6%)	
Occupation*, **	Employed full-time	60 (32.4%)	46 (32.6%)
	Employed part-time	48 (25.9%)	34 (24.1%)
	Unemployed	11 (5.9%)	9 (6.4%)
	Unpaid/voluntary work	7 (3.8%)	5 (3.5%)
	Student	76 (41.1%)	41 (29.1%)
	Retired	1 (0.5%)	- (0%)
	Unable to work	7 (3.8%)	6 (4.3%)

\* Number (%), \*\* multiple answers were possible.

### 9.3.1.2 Interview Sample

Nine individuals participated to the interviews. These were all individuals self-identify as having (had) ON who posted about ON on Instagram, all female, with a mean age of 28.4 years. American (66.7%) was the most prevalent nationality encountered. A full overview of sample's demographics is reported in Table 9.2.

Table 9.2. Demographics of interviewees

<b>Variables</b>		<b>Participants (N=9)</b>
Gender	Female	9
	Male	-
Age (in years); mean (SD)		28.4 ± 13.0
Country of residence	United States of America	6
	Switzerland	1
	United Kingdom	1
	Canada	1
Employment status	Student	4
	Employed	4
	Unemployed	1

### 9.3.1.3 Knowledge and Opinions about Orthorexia Nervosa

When asked about the source for learning about ON, 33.3% of questionnaire respondents reported social media, followed by health professionals (27.4%). The majority of participants (79.8%) knew that ON is not an official diagnosis, 87.9% believed ON should become an official diagnosis, 87.1% self-identified as having (had) ON, and 91.1% knew someone who might have ON (Table 9.3).

Table 9.3. Knowledge and opinion of the participants of the questionnaire about ON (N=124)

Variables	Participants (N=124); N (%)	
First source of ON knowledge*	News(paper)	2 (1.7%)
	Social media	39 (33.3%)
	Blog	7 (6.0%)
	Website	16 (13.7%)
	Book	4 (3.4%)
	Health professional	32 (27.4%)
	Friend/family	3 (2.6%)
	Television	4 (3.4%)
	Other	10 (8.5%)
Know that ON is not an official diagnosis	Yes	99 (79.8%)
	No	25 (20.2%)
ON should be an official diagnosis	Yes	109 (87.9%)
	No	6 (4.8%)
	I am not sure	9 (7.3%)
Self-identify as having (had) ON	Yes	108 (87.1%)
	No	16 (12.9%)
Know someone who might have ON	Yes	113 (91.1%)
	No	11 (8.9%)

\* N=117

#### 9.3.1.3.1 Definition of orthorexia nervosa.

Questionnaire respondents sharing ON-related content on Instagram were asked to describe what ON was to them in one or two sentences. The analysis shows that 66.9% defined ON as an *obsession*. Adjectives used to emphasize the behavior were *unhealthy* (24.0%) and *extreme* (7.4%). The obsession was described as directed towards *eating healthy* (38.0%), *eating clean* (20.7%), *healthy food* (19.8%), or *purity* (9.1%), with 14.9% reporting *being healthy* as the ultimate goal. *Restricting* the range of foods was mentioned by 17.4% of respondents, and *exercise* was associated to ON by 14.9% of respondents. Among the negative consequences of ON were *anxiety* (10.7%), *interference with daily life* (9.9%), and *psychological impairment* (8.3%). Notably, 8.3% of people called ON an *eating disorder*, while 9.1% did not use any terms related to eating when describing ON. Definitions provided by people who self-identified as having (had) ON and those provided by people who did not were similar, except for the fact that the terms *extreme*, *psychological impairment* and *interference with daily life* were only mentioned by those who self-identified as having (had) ON.

### 9.3.1.4 Social Media Use

For questionnaire respondents, Instagram was the mostly used social media platform (96.2%) and the highest ranked platform according to the time spent on it. Respondents spent a considerable amount of time on social media: 47.6% spent 1-3 hours a day, and approximately one in four participants used social media more than 3 hours a day. No significant differences were found in hours of social media use between people who did and who did not self-identify as having (had) ON (Table 9.4).

Table 9.4. Social media use of participants of the questionnaire

Variables	Participants (N=124); N(%)	
Age starting social media use (in years); mean (SD)**		16.2 (6.0)
Social media platforms used*,**	Facebook	105 (84.7%)
	Instagram	124 (100.0%)
	Twitter	33 (26.6%)
	YouTube	81 (65.3%)
	Snapchat	50 (40.3%)
	Flickr	-
	LinkedIn	33 (26.6%)
	Pinterest	64 (51.6%)
	Tumblr	17 (14.5%)
Ranking social media platforms used (scale 1-8); mean (SD)**	Facebook	2.6 ± 1.1
	Instagram	1.2 ± 0.5
	Twitter	3.9 ± 1.5
	YouTube	2.8 ± 1.1
	Snapchat	3.6 ± 1.4
	Flickr	-
	LinkedIn	4.8 ± 1.4
	Pinterest	4.0 ± 1.2
	Tumblr	5.4 ± 1.5
Hours of social media use per day**	< 30 minutes	2 (1.6%)
	30-60 minutes	28 (22.6%)
	1-3 hours	59 (47.6%)
	> 3 hours	35 (28.2%)

\* multiple answers were possible, \*\* these questions were only asked to people who use social media.

#### 9.3.1.4.1 Influence of Instagram on the Development of Orthorexia Nervosa.

Influence of other people's posts on the development of ON was investigated in the interviews. Two interviewees were not on Instagram when they developed ON. The majority of interviewees having an Instagram account at the time of developing ON said that it affected this development to a certain extent, however it was not the main cause. Content that was seen as most harmful concerned diets, especially clean eating: *"There are some really triggering ones [accounts], because people think it is just a diet. Maybe you heard about those pro-ana groups, there is also some people that are pro-orthorexia and I think it is really triggering so I don't look it up myself because I don't want to get triggered."* (P2, 17 years). Instagram use also had positive effects, through problem realization for example: *"I think Instagram actually helped me because it helped me realize what I was doing wasn't normal."* (P3, 19 years).

#### 9.3.2 What Type of Content is Shared on Instagram about Orthorexia Nervosa?

The type of ON-related content on Instagram was investigated through content analysis. Of 3027 pictures analyzed, 42.5% contained food, 18.1% people, 34.8% text, and 4.6% were categorized as 'other.' In the category 'food,' pictures of savory and unprocessed food were shared most frequently. Most pictures in the category 'people' depicted an individual whose face and other body parts were visible. Art pictures were most highly represented in the category 'other' (Table 9.5).

Table 9.5. Content analysis of a subsample of #orthorexia pictures (n=3027)

<b>Main code</b>	<b>Detailed code</b>	<b>N (%)</b>
Food (n=1287; 42.5%)	Drink	48 (1.6%)
	Food	554 (18.3%)
	Food and drink	58 (1.9%)
	Fruit and vegetable	58 (1.9%)
	Pizza/pasta	72 (2.4%)
	Salad	54 (1.8%)
	Sweet food	443 (14.6%)
People (n=548; 18.1%)	Body parts	22 (0.7%)
	Exercise	15 (0.5%)
	Face	71 (2.3%)
	Group	74 (2.4%)
	Individual	231 (7.6%)
	Individual without face	23 (0.8%)
	Mirror selfie	71 (2.3%)
	Multiple photos individual	41 (1.4%)
	Text	1054 (34.8%)
Other (n=138; 4.6%)	Art	63 (2.1%)
	Art exhibition	1 (0%)
	Cat	2 (0.1%)
	Dishware	5 (0.2%)
	Dog	3 (0.1%)
	Horse	1 (0%)
	Map	2 (0.1%)
	Multiple photos other	5 (0.2%)
	Object	32 (1.1%)
	Room	6 (0.2%)
	Scenery	18 (0.6%)

Chi-squared test was used to compare the results of the content analysis with self-reported type of pictures obtained from the questionnaire (Table 9.6). Triangulation showed that content regarding ‘food’ and ‘text’ occurred significantly more in the content analysis compared to what was self-reported in the questionnaire ( $p < .001$ ). Contrarily, pictures of people and ‘other’ were significantly more self-reported in the questionnaire than in the content analysis ( $p < .001$ ).



Table 9.6. Frequency of occurrence of content of Instagram posts about ON, comparing results from the content analysis and the questionnaire using chi-squared test.

	<b>Content analysis</b>	<b>Questionnaire</b>	<b>P-value</b>
<b>Food/recipes</b>	42.5%	24.0%	< 0.001
<b>People</b>	18.1%	30.4%	< 0.001
<b>Text</b>	34.8%	21.6%	< 0.001
<b>Other</b>	4.6%	24.0%	< 0.001

The interviews investigated the type of ON-related content posted on Instagram. Many interviewees posted about food. Pictures of people were also posted by the majority of interviewees, and these were primarily pictures of the ‘poster’ themselves. The interviews also shed light on captions used underneath the pictures. The majority of captions were personal stories of the development of ON. In addition, informative captions about ON were shared.

Chi squared test was used to assess differences between questionnaire respondents who self-identified as having (had) ON and those who did not in regard to their ON-related Instagram use. People who self-identified as having (had) ON were significantly more likely to post about ON on Instagram ( $p < .001$ ), to search for #orthorexia ( $p = .006$ ), and to follow ON-related accounts ( $p = .008$ ). They were also significantly more likely to post content belonging to the categories ‘food’, ‘people’ and ‘text,’ as compared to people who did not self-identify (all  $p < .05$ ); the latter group was significantly more likely to post content in the ‘other’ category ( $p < .05$ ) (Table 9.7).

Table 9.7. Crosstabulation of Instagram use related to ON with self-identification

Variable		Self-identify as having (had) ON; N(column %)			P value
		Yes	No	Total	
Posted about ON on Instagram	Yes	108 (76.2%)	16 (45.7%)	124 (70.1%)	<0.0001
Posted with #orthorexia on Instagram**	Yes	103 (95.4%)	16 (100%)	119 (96%)	1.000
Content posted about ON on Instagram**,***	Food	49 (45.4%)*	0 (0%)*	49 (39.5%)*	0.001
	People	59 (54.6%)*	3 (18.8%)*	62 (50.0%)*	0.007
	Text	42 (38.9%)*	2 (12.5%)*	44 (35.5%)*	0.04
	Other	35 (32.4%)*	14 (87.5%)*	49 (39.5%)*	<0.0001
Intended audience Instagram posts about ON**,***	Followers with a specific interest in ON	75 (69.4%)*	8 (50.0%)*	83 (66.9%)*	0.123
	Followers without a specific interest in ON	46 (24.6%)*	10 (62.5%)*	56 (45.2%)*	0.135
	People who look for #orthorexia	53 (49.1%)*	5 (31.2%)*	58 (46.8%)*	0.182
	Other	33 (30.6%)*	4 (25.0%)*	37 (29.8%)*	0.650
Look for #orthorexia content on Instagram	Yes	73 (51.4%)	9 (25.7%)	82 (46.3%)	0.006
Follow #orthorexia on Instagram****	Yes	11 (15.1%)	1 (11.1%)	12 (14.6%)	1.000
Follow ON-related Instagram accounts	Yes	63 (44.4%)	7 (20.0%)	70 (39.5%)	0.008

\*% of cases, \*\* only answered by participants who posted about ON on Instagram, \*\*\* multiple answers were possible, \*\*\*\* only answered by participants who looked for #orthorexia on Instagram

### 9.3.3 Why Do People Share Orthorexia Nervosa-Related Content on Instagram?

#### 9.3.3.1 Reasons to Start Posting

The most frequently mentioned reason to start posting ON-related content on Instagram was the drive to recover, because sharing content related to recovery stimulated a sort of ‘peer-pressure’ to continue recovering: *“I really needed to talk about this to make myself accountable for my recovery. Now people know I am doing this, so I have to keep doing it.”* (P8, 55 years). Another reason was the urge to share knowledge about ON. Notably, one interviewee mentioned to have started posting about ON because other people were doing so: *“In my Instagram explore page I started seeing posts about it [ON] and I wanted to create my own.”* (P9, 17 years).

#### 9.3.3.2 Intentions to Post Content about Orthorexia Nervosa on Instagram

Intentions for posting ON-related content have been classified according to Cheung and Lee’s model of intention to engage in online social networking (2010) (Figure 1).

#### 9.3.3.2.1 Social identity.

Social identity refers to the self-awareness of one's membership in a community (Cheung & Lee, 2010). The feeling of belonging to a certain 'orthorexia community' is found to be an important driver for posting about ON on Instagram. According to all interviewees there is a community around ON: "I: *'Do you think there is some sort of community on Instagram talking about these kinds of things?'* R: *'Yes, absolutely. Absolutely. I found some really amazing people through Instagram. It is fantastic.'* (P8, 55 years). Communities that were mentioned as associated with ON revolved around body positivity, intuitive eating, mental health and wellness. The three dimensions of social identity, i.e. cognitive, affective and evaluative social identity (Cheung & Lee, 2010), were all found to contribute to the intention to post about ON on Instagram.

Cognitive social identity concerns a perception that members of the community are distinct from people outside, who do not understand what ON encompasses: "*As a society, this is not something we talk about or are aware of, so when I am able to read [ON-related content on Instagram] I realize I am not the only one that feels that way.*" (P3, 19 years).

Affective social identity refers to the emotional involvement in the community, and was mentioned by the majority of interviewees in the form of positive feelings deriving from belonging to the community: "*It makes me feel good. I enjoy it.*" (P4, 41 years). With regard to evaluative social identity, it emerged that membership of a community around ON is validating and reinforces self-worth: "*Not only I feel I am being validated for the work that I do, but also if I am having a bad body day, or I am having doubts about recovery, I can talk about that with these people. That really boosts me up a lot, that is great.*" (P8, 55 years).

#### 9.3.3.2.2 Group norm.

Group norm indicates the similarity of a person's values to those of other community members (Cheung & Lee, 2010). All interviewees perceived that there are shared values within the community: "*I just really felt I could relate to what they shared and I thought I could contribute to that.*" (P9, 17 years). Interestingly, it emerged that, although people felt less alone because others experienced the same 'journey,' they also noted how behaviors and experiences might differ from one person to the other, thus identifying a sort of individualization of experiences: "*Behaviors are expressed so differently. Sometimes I learn about somebody else's behavior and be like 'I never thought of that.' I think they [ideas and behaviors] are shared by most but not by all.*" (P8, 55 years).

#### 9.3.3.2.3 Subjective norm.

The subjective norm is the need for approval from other members, which is most often expressed in the form of likes and comments on Instagram. The majority of interviewees mentioned that appreciation of other people is important to them: "*If I see significant less likes I start to wonder why. Do people not like me as much, or why do people like this person more? I start thinking those negative thoughts.*" (P5, 28 years). On the contrary,

a few participants mentioned not to care about approval from others: *“I don’t need a certain number to feel good about the post. If it doesn’t hit a certain number, I am not going to delete it.”* (P9, 17 years).

#### 9.3.3.3 Aim of the Posts about Orthorexia Nervosa

Besides intentions and motivations, interviewees also mentioned the drive to reach a certain goal with posting about ON on Instagram. Two major goals were found: to raise awareness on how the pursuit of health can become harmful once it turns into an obsession, and to support other people who are struggling with or recovering from ON: *“I wanted to show other people that even if it is hard, you can get out of it. It needs some hard work, you need to face your fears to get out of It, but it is worth it and you can do it.”* (P2, 17 years). Another goal mentioned by a few interviewees was to help themselves with recovery: *“It keeps me accountable and reminds me of why I want to stay healthy and not go back down on an eating disorder path.”* (P9, 17 years).

#### 9.3.3.4 Intended Audience

Two main target audiences for ON-related Instagram posts were identified: (1) people who are actively struggling with or recovering from ON, with the intention to support them in their journey, and (2) people who are interested in ON, with the intention to provide more information about ON, as well as making them aware that healthy eating can become an issue.

## 9.4 Discussion

By using mixed methods, this study collected information on conversations about ON on Instagram. The findings of this study, which followed a who-what-why structure, allow obtaining a composite overview of these conversations.

*Who shares ON-related content on Instagram?* Predominantly female, around their mid-20s. These are heavy social media users and favor Instagram over other platforms. Approximately, one in three came to know about ON through social media. Their definition of ON is in line with literature [12], though those who self-identify as having (had) ON are more likely to use words like *‘psychological impairment’* or *‘interference with life’*. Those who self-identify as having (had) ON believe that Instagram might have an impact on ON, but it is not the primary cause. Instead, Instagram is considered to promote problem realization.

*What type of content is shared on Instagram about ON?* The phenomenon of ON is encoded into pictures of food, people, text and other. Personal story captions and informative captions accompany the pictures.

*Why do people share ON-related content on Instagram?* People started posting to recover, to share information and to help others. Individuals feel inspired to post by other accounts, shedding light on a ‘peer emulation’ process. An overall sense of belonging to the #orthorexia community emerged, where people share values and ideals, and seek validation from each other. People use Instagram as a tool for helping themselves and others.

By sharing stories, values, and advices people aggregate around #orthorexia, thus creating CoPs. These are ‘safe spaces’ where to share sensitive content and personal stories. Within these CoPs, individuals tell their stories with ON and therefore contribute to the social construction of it. Furthermore, individuals share common beliefs and ideals, which seem to reveal an ideological ‘rebellion’ against diet culture and clean eating more broadly. These spontaneous aggregations resemble a primate stage of peer support groups, since individuals feel empowered in talking about their health and providing help to others [17].

While interacting on Instagram about ON, individuals seem to emulate and imitate each other; e.g. one individual shares ON-related content because inspired by another user. This hints to a sort of social contagion, where community members would imitate each other’s online behavior. While in this case the contagion is positive, most of the studies investigating social contagion reveal a negative contagion. For example, evidence suggests that social contagion contributes to the spread of EDs among young women, with social media intensifying this process [18]. Negative social contagion happens for suicide too, to the point that the WHO warns against the dangers of social contagion propagated by traditional and social media [19]. Given that social media have become increasingly prominent in young people’s lives, we encourage future research to further assess the potential positive and negative effects that these platforms might have on EDs.

Our findings are in line with those of Santarossa, et al. (2019) [15], who found a small supportive community, mostly composed of females, interacting on Instagram about ON. However, our results go one step further, by exploring motivations and intentions to share such supportive content, thus painting a more comprehensive picture. Our results also corroborate those of Turner and Lefevre (2017) [14]. Although we found a predominantly positive conversation around the topic of ON, respondents agreed that diet- and clean eating-related content is instead dangerous for ON. Similar to the supportive communities around #orthorexia, Andalibi and colleagues (2017), in their investigation into #depression on Instagram, shed light on the presence of great social support, a strong sense of community and little sharing of pro-disease behaviors [20].

A methodological reflection should be dedicated to the incongruence we found regarding frequencies of types of pictures between content analysis and questionnaire results. This incongruence could originate from the different samples involved: the majority of the questionnaire participants self-identified as having (had) ON, whereas the content analysis might consist of a more equal distribution of people who did and did not self-identify. These different samples, and the fact that different content is posted by people who do and do not self-identify, could clarify the discrepancy. Another possible explanation is the potential difference in

interpretation of codes between content analysis and questionnaire. As an example, every picture including any form of text was coded as ‘text’ in the content analysis, whereas pictures with more than just text could have been categorized differently by questionnaire respondents.

We would like to provide some recommendations for meaningful research directions. Future research should be conducted on the role of CoPs on recovery from EDs. Although we found a positive community around ON, our findings shed light on a search for validation from other community members. Thus, it may be useful to understand if these communities could be harmful in stimulating mechanisms of peer pressure. A second hint for future research concerns the topic of identity. What we noticed is that individuals seemed to ‘melt’ their identities to that of the community. What helped them recover was the shift from a ‘orthorexia identity’ to a ‘communitarian identity’. Going deeper into the role of identity during recovery from ON can inform treatment strategies.

While this study has strengths (e.g. the use of three methodologies, an in-depth qualitative investigation), it also has some limitations, namely the relatively small sample size of the qualitative sample and the plausible use of different codes for pictures analyzed during content analysis and those self-reported in the questionnaire.

In conclusion, this study found that conversations around #orthorexia on Instagram generate supportive communities that aid recovery from ON. Individuals use Instagram as a tool for helping others and themselves recovering from ON. Understanding how people help each other, manage their health, cope with ON symptoms and undertake recovery can inform implementation of therapeutic interventions.

#### *Data Availability Statement*

The data that support the findings of this study are available from the corresponding author upon reasonable request.

#### *Conflict of Interest*

No conflict of interest to declare.

## References

- [1] American Psychiatric Association, “Diagnostic and Statistical Manual of Mental Disorders,” 2013.
- [2] E. V. Eikey and K. M. Booth, “Recovery and Maintenance: How Women with Eating Disorders Use Instagram,” *iConference*. 2017.
- [3] C. M. Shisslak, M. Crago, and L. S. Estes, “The spectrum of eating disturbances,” *Int. J. Eat. Disord.*, vol. 18, no. 3, pp. 209–219, 1995.
- [4] J. E. Mitchell and S. Crow, “Medical complications of anorexia nervosa and bulimia nervosa,” *Curr. Opin. Psychiatry*, vol. 19, no. 4, pp. 438–443, 2006.
- [5] J. Arcelus, A. J. Mitchell, J. Wales, and S. Nielsen, “Mortality rates in patients with anorexia nervosa and other eating disorders: A meta-analysis of 36 studies,” *Arch. Gen. Psychiatry*, vol. 68, no. 7, pp. 724–731, Jul. 2011.
- [6] H. W. Hoek, “Review of the worldwide epidemiology of eating disorders Article in Current Opinion in Psychiatry,” 2016.
- [7] S. B. Austin, “Accelerating Progress in Eating Disorders Prevention: A Call for Policy Translation Research and Training,” *Eat. Disord.*, vol. 24, no. 1, pp. 6–19, Jan. 2016.
- [8] H. Gulec, M. Moessner, A. Mezei, E. Kohls, F. Túry, and S. Bauer, “Internet-based maintenance treatment for patients with eating disorders,” *Prof. Psychol. Res. Pract.*, vol. 42, no. 6, pp. 479–486, Dec. 2011.
- [9] H. Sharpe, P. Musiat, O. Knapton, and U. Schmidt, “Pro-eating disorder websites: Facts, fictions and fixes,” *Journal of Public Mental Health*, vol. 10, no. 1. Emerald Group Publishing Limited, pp. 34–44, Mar-2011.
- [10] T. Bellander and M. Landqvist, “Becoming the expert constructing health knowledge in epistemic communities online,” *Inf. Commun. Soc.*, vol. 23, no. 4, pp. 507–522, 2018.
- [11] W. Stommel and T. Koole, “The online support group as a community: A micro-analysis of the interaction with a new member,” *Discourse Stud.*, vol. 12, no. 3, pp. 357–378, Jun. 2010.
- [12] H. Cena *et al.*, *Definition and diagnostic criteria for orthorexia nervosa: a narrative review of the literature*, vol. 24, no. 2. Springer International Publishing, 2019.
- [13] C. Hanganu-Bresch, “Orthorexia: eating right in the context of healthism,” *Med. Humanit.*, p. medhum-2019-011681, 2019.
- [14] P. G. Turner and C. E. Lefevre, “Instagram use is linked to increased symptoms of orthorexia nervosa,” *Eat. Weight Disord.*, vol. 22, no. 2, pp. 277–284, 2017.
- [15] S. Santarossa, J. Lacasse, J. Larocque, and S. J. Woodruff, “#Orthorexia on Instagram: a descriptive study exploring the online conversation and community using the Netlytic software,” *Eat. Weight Disord.*, vol. 24, no. 2, pp. 283–290, 2019.
- [16] C. M. K. Cheung and M. K. O. Lee, “A theoretical model of intentional social action in online social networks,” *Decis. Support Syst.*, vol. 49, no. 1, pp. 24–30, Apr. 2010.
- [17] J. A. Naslund, K. A. Aschbrenner, L. A. Marsch, and S. J. Bartels, “The future of mental health care: Peer-To-peer support and social media,” *Epidemiol. Psychiatr. Sci.*, vol. 25, no. 2, pp. 113–122, 2016.
- [18] S. Allison, M. Warin, and T. Bastiampillai, “Anorexia nervosa and social contagion: Clinical implications,” *Aust. N. Z. J. Psychiatry*, vol. 48, no. 2, pp. 116–120, 2014.
- [19] Who, “Preventing suicide: A resource for media professionals,” *Geneva World Heal. Organ.*, p. 18, 2017.
- [20] N. Andalibi, P. Ozturk, and A. Forte, “Sensitive self-disclosures, responses, and social support on instagram: The case of #depression,” *Proc. ACM Conf. Comput. Support. Coop. Work. CSCW*, pp. 1485–1500, 2017.

