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2020

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citation for published version (APA)

Valente, M. (2020). *“Healthy” When the pursuit of health turns into a mental disorder: the case of orthorexia nervosa.*

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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
ten overstaan van de promotiecommissie
van de Faculteit der Bètawetenschappen
op woensdag 21 oktober 2020 om 9.45 uur
in de aula van de universiteit,
De Boelelaan 1105

door

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CHAPTER 3. Research Design

3.1 Transdisciplinary Approach

The methodology of this study was informed by transdisciplinary research (TDR). Although a single working definition of TDR would end up being reductionist [1], we can broadly refer to TDR as “a process of collaboration between scientists and non-scientists on a specific real-world problem” [2]. TDR has various defining principles, which were not all been implemented by this project. For this reason, we refer to ‘transdisciplinary approach’, rather than TDR.

The principles of transdisciplinarity [1] that inspired this project are: (i) holistic approach; (ii) focus on a real-world problem; (iii) consultation of non-academic actors; (iv) involvement of different types of knowledge; and (v) consideration of the societal perspective.

Holistic Approach. One of the central features of TDR is adopting a holistic approach to the problem being studied, meaning transcending spatial and temporal restrictions in understanding a problem and aspiring to a ‘synthesis’ at a time of increasing fragmentation of knowledge [1], [3]. Accordingly, our approach to ON aimed to transcend the narrowness of disciplinary approaches that have been employed by most research to date, in order to obtain an understanding of ON that is comprehensive, encompassing of all its psychopathological, clinical, social and cultural aspects.

Focus on a Real-World Problem. Another important feature characterizing TDR is that it addresses real-world, societal problems (i.e. problem orientation) [1], [3]. This feature also applies to our study, since we aimed to address a real-world, complex problem, namely the rise of ON (experienced in individuals as a disorder and in society as a phenomenon), which is extremely ingrained in societal forces and trends that characterize our world.

Consultation of Non-Academic Actors. Perhaps the most central feature of TDR concerns the involvement of non-academic actors in research, as these have experiential knowledge essential to unpack the complexity of problems. It follows that TDR implies dialogue between science and society, which enhances heterogeneous knowledge co-creation, and which ultimately leads to a holistic understanding of the phenomenon being studied [1], [3]. In this research, different perspectives (i.e. health practitioners, people with ON, and lay people with an interest in ON) were consulted and integrated to conceptualize and understand ON and its development.

Involvement of Different Types of Knowledge. Another important feature of TDR is the adoption of knowledge paradigms and models belonging to different disciplines. This broader perspective to understanding complex

problems is necessary, since today's societal problems cannot be solved by relying on a narrow approach of one specific discipline [1], [4]. Accordingly, our research project borrowed models and theories from different disciplines (e.g. medical sociology, health communication, prospective health).

Consideration of the Societal Perspective. The last TDR feature implemented in the present research concerns a change of perspective in considering science - society communication. Scientists are used to assuming that science is supposed to communicate results and achievements to society. Yet, it is rarely taken into account that communication can also take place in the other way around, meaning that society can have a say on scientific issues [4]. Following this last principle, the present study decided to explore societal views on ON, through an analysis of social media conversations.

In the following sections, the three perspectives involved in this research project (i.e. practitioners' perspective, insiders' perspective and lay people's perspective) are presented in more detail, by outlining the strategies used for recruiting participants and the inclusion criteria.

3.1.1 Health Practitioners' Perspective

Health practitioners and professionals, such as dieticians, psychologists and ED experts, are important stakeholders, whose experiential knowledge is of primary importance for understanding ON and how it develops. For this project, we involved two types of health practitioners and professionals: physical and mental health practitioners working with ED patients in the Netherlands, to trace the developmental pathway of ON; and practitioners working with EDs in Italy, together with international experts in ON, to jointly reflect upon definition and diagnostic criteria for ON. Health practitioners in the Netherlands were primarily recruited through email, social media, and ED- or health professional-related websites. Health practitioners in Italy were recruited through convenience sampling and their voluntary participation to a workshop held at a dedicated session at the National Congress of the Italian Society for the Study of Eating Disorders (SISDCA). International experts were members of the ON task force and were recruited through email. Ideally, it would have been better for all the practitioners involved to have experience with treating a patient with symptoms of ON. However, in the absence of an official diagnosis, this could not be ensured for all practitioners participating in the study. Therefore, we also involved practitioners without direct experience with ON, as we believed their contribution was still valuable for understanding ON as an ED.

3.1.2 Insider Perspective

People experiencing, or having experienced, ON are a valuable source of information about past experiences triggering ON, symptomatology, and effectiveness of treatment strategies. In this project, we involved people declaring to follow a healthy diet, to explore if and how certain factors leading to eat healthy could potentially

be implicated in developing ON; and people who self-identify as having (had) ON, to retrace their development of ON, and thus identify contributing factors, triggering events, symptoms and effective treatments. The first group of people, i.e. people following a healthy diet, was made up of young women in the Netherlands who self-declared they were following a healthy diet. This group was recruited by sharing an announcement on Facebook groups and pages. The second group of people, i.e. people who have/had ON, was recruited via Instagram, specifically by reaching people using the hashtags #orthorexiannervosa or #orthorexiarecovery. Both samples were recruited by relying on their self-reported healthy eating or ON symptomatology. Although we did not assess if individuals were truly following a healthy diet or manifesting ON-like symptoms, the purpose of our investigations was to explore the perspectives of people self-identifying with what they considered to be a healthy diet or ON.

3.1.3 Lay Perspective: The Role of Social Media

Not only does ON develop as a psychopathology in individuals, but it also develops as a concept in society [5]. According to *social constructivism*, a phenomenon takes shape and acquires meaning via the meaning people attribute to it [6], [7]. Through *symbolic convergence* [8] people contribute to the creation of phenomena by communicating with each other. Social constructivism is particularly important for ON, as it is a new and emerging phenomenon, which is created day by day by people who interact with each other. Nowadays, the role of social media is particularly crucial in this regard, as it allows online conversations among different users. Thus, we turned to social media to analyze conversations related to ON to understand the perspective of lay people who express an interest in or opinion about ON. Social media platforms that were explored in this project were Instagram and Twitter. With regard to Instagram, images using the hashtag #orthorexia were downloaded through the command line application Instagram-scraper (<https://github.com/arc298/instagram-scraper>) and subsequently analyzed. Regarding Twitter, tweets using the keyword 'orthorexia' were downloaded through the Twitter Archiving Google Sheet TAGS (<https://tags.hawksey.info/>) and subsequently analyzed.

3.2 Data Collection

The majority of the studies of this project used mixed methods, with sequential exploratory or explanatory designs. A more detailed overview of the methods used is reported in Table 2. Although quantitative and qualitative techniques were always used in an integrated way, in the following sections these two data collection strategies are presented in separate paragraphs, for the sake of clarity.

3.2.1 Qualitative Data Collection and Analysis

Semi-structured interviews (n = 41) and focus group discussion (n = 1) were used to collect qualitative data. Interviews were conducted face-to-face, with people residing in the Netherlands, and online through multiple videoconferencing tools, with international participants. In the case of Dutch health practitioners, interviews were held in Dutch, the focus group discussion (FGD) and interviews with Italian professionals were held in

Italian. For all the other respondents, interviews were conducted in English. Prior to the conduction of interviews, interview guides were developed and piloted with samples of students. All interviews guides relied on the theoretical framework(s) on which the specific study was based. Face-to-face interviews allowed for the deployment of visualization techniques enhancing participatory activities. For example, to gain insights into respondents' perceptions of healthy eating, they were asked to write on a board all the words that came to their mind when thinking at 'healthy eating', and these words worked as a starting point for broader discussions. Interviews and the FGD were transcribed verbatim, translated when necessary, and analyzed through the software *Atlas.ti*. Open and axial coding, or thematic analysis [9], were performed. In studies with sequential explanatory designs, qualitative data were used to explore the quantitative findings in greater depth; in studies with sequential exploratory designs, qualitative data were used to inform the quantitative phase. Qualitative analysis was also used to explore social media content, such as tweets downloaded from Twitter. In this case, thematic analysis [9] was used to identify main themes characterizing the online conversation around ON.

3.2.2 Quantitative Data Collection and Analysis

Self-administered questionnaires (total respondents, n = 368) and social media content analysis were the primary sources of quantitative data. Questionnaires were delivered via email and through social media groups and pages, while social media content was downloaded through specific open-source applications. The questionnaire for health practitioners in the Netherlands was written in Dutch, while all the other questionnaires were written in English. Prior to the official dissemination, questionnaires were piloted on samples of students. In the same way as for the interviews, the questionnaires were always constructed following a theoretical framework. Questionnaires were made up of several sections, one of which always inquired about demographic information, while the others aimed to acquire information that was useful to answer the respective research questions. Questionnaire data were analyzed through the software *SPSS* and, in some instances, *Stata*. In the case of the study conducted on Twitter, quantitative descriptive information was obtained through software *Tableau* and *Gephi*. Quantitative analysis predominantly relied on the book '*Discovering Statistics Using IBM SPSS Statistics*' 5th edition [10].

3.2.3 Literature Review

One literature review was conducted in the context of this project. It consisted of a review of the literature obtained through a systematic search. Specifically, two routes were used to collect relevant studies to be analyzed: first, important databases were systematically searched; second, a manual search of grey literature was undertaken. Procedures described in the PRISMA statement were followed [11].

3.3 Validity

Validity of data collected in this project has been ensured through various strategies:

- (1) This study consulted the perspectives of those who suffer from ON, and of professionals who have met orthorexic patients. In the absence of a diagnostic category for ON, it was difficult to be sure that individuals truly had ON, or that professionals truly met patients with ON. In this regard, it is worth saying that we were interested in understanding what ON was for them, or what information they relied on to consider that what they suffered from was ON. In order to ensure there was some sort of baseline understanding of ON, participants were shown a general description of ON. This allowed to ensure that participants were able to recall all experiential knowledge they had on ON, but at the same time to give them freedom to express what ON was for them personally.
- (2) Triangulation occurred between different methodologies in the same study, and between different studies – for example, triangulating data from a questionnaire with those from an interview and *vice versa*, or triangulating data obtained from consulting health professionals with those obtained from consulting individuals who self-diagnose with ON. This ensured generalizability and validity of findings.
- (3) Another measure to preserve validity was to avoid using the diagnostic tools provided in literature as much as possible, since these have been widely criticized and not yet validated. In one instance we used the ORTO-15; this was not used as a diagnostic tool, however, but rather as a scale that allowed obtaining different ranges of concern towards a healthy diet.
- (4) Interviews were always conducted until reaching saturation; after receiving consent, interviews were recorded and always transcribed verbatim. Data analysis was performed in a reflexive manner, consulting the research team at any important stage.

3.4 Ethical Considerations

Two out of seven studies (chapters 8 and 9) required ethical approval from the Ethical Committee of Athena Institute, within the Faculty of Science, Vrije Universiteit Amsterdam. The other studies (chapters 4, 5, 6, 7, 10) did not require approval from the ethical committee. Participation in the research was voluntary. Written and/or verbal informed consent was obtained from all participants. Privacy, confidentiality and anonymity were ensured and participants were made aware that they may discontinue participation at any time, for any reason. Participants were not subject to harm in any way. Communication with regard to the research aim and methodology was always performed with transparency and honesty. With regard to material downloaded from social media (i.e. Tweets and Instagram pictures), which was already of public domain, attention was paid to preserve users' anonymity. This material was managed following the recommendations from the AoIR Ethics Working Committee on Ethical Decision-Making and Internet Research (version 2.0) [12]; hence, social media content was anonymized, rephrased when possible, and stored in a password secured university cloud. The data management plan of this project can be found as an Appendix (Appendix 1).

Table 3.1 Overview of methods, designs, and number of interviewees and questionnaire respondents

	Methods	Designs	Numbers
Chapter 4	Mixed-methods	Sequential exploratory	Interviews = 10 Questionnaire = 101
Chapter 5	Participatory methodology		Focus Group & Email round n.1 = 14 Email round n.2 = 7 Interviews = 5
Chapter 6	Review of the literature		N. of articles = 70
Chapter 7	Mixed-methods	Sequential exploratory	Interviews = 12 Questionnaire = 82
Chapter 8	Mixed-methods	Sequential explanatory	Questionnaire = 185 Interviews = 10
Chapter 9	Mixed-methods	Concurrent triangulation & Sequential explanatory	Content analysis = 3.027 Questionnaire = 185 Interviews = 9
Chapter 10	Mixed-methods	Sequential explanatory	Content analysis = 522 Qualitative analysis = 234

3.5 Outline of the Thesis

Chapter 1 introduced the topic of ON, provided an overview of current knowledge gaps, and presented the research objective and question. Chapter 2 explored the theoretical frameworks that were used in this research. Chapter 3 explained the methodological approach of the research.

Chapters 4 to 10 refer to the studies that were conducted in this research project. These are divided into three parts, which refer to the three perspectives that were investigated.

Part 1 is concerned with the *practitioner* perspective on the conceptualization of ON and on how it develops. Chapter 4 explores Dutch practitioners' perspective to trace the developmental pathway of ON and contributing factors. Chapter 5 presents practitioners' and experts' involvement in co-developing definition and diagnostic criteria for ON. Chapter 6 reviews the diagnostic instruments developed and used to assess ON over the years.

Part 2 is concerned with the *insider* perspective (i.e. perspective of people who eat healthily or self-identify with having ON) on how this complex condition develops in time. Chapter 7 explores the factors responsible for the transition from healthy eating to ON. Chapter 8 explores the developmental pathway of ON from the perspective of people who self-diagnose.

Part 3 is concerned with the *lay people's* perspective (e.g. people with an interest in ON and joining the conversation about ON on social media) on ON. Chapter 9 unpacks the relationship between ON and Instagram, exploring who shares ON-related content on Instagram, what ON-related content is shared on Instagram, and why people share this content. Chapter 10 explores how do Twitter conversations about ON reveal the discursive process of medicalization.

Lastly, Chapter 11 discusses main results and reflect on those findings with social relevance, elaborating recommendations for future research, and clinical and therapeutic practice.

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