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General introduction

"The Internet is a great resource, but it leads people in many directions, some of which are good and some of which are bad. If you suffer from health fears, it becomes a nightmare. You type in a symptom and it comes up with many disease possibilities. You learn about more subtleties and horrors. You go into a chat room and throw out your symptoms and people say you have lupus."

- Dr. Brian Fallon in Seligman (2004)

The quote above highlights in a nutshell what this dissertation is concerned with. There has been growing interest in the relationship between online health information seeking and anxiety about one's health, which is referred to as the phenomenon of 'cyberchondria'. It is often assumed that encountering online health information does not reassure individuals, but rather worsens health related fears. So far, however, there is little empirical evidence that underpins this assumption. This dissertation will make a contribution to the field by further examining the phenomenon of cyberchondria. The overall aim of this dissertation is to further study to what extent online health information seeking and health anxiety are related cross-sectionally and longitudinally.

Online Health Information Seeking

Nowadays, the Internet is a commonly used and preferred source of health information: Worldwide, approximately 50-70% of Internet users go online to find health information at least once a year (Andreassen et al., 2007; European Commission, 2013; European Union, 2014; Fox & Duggan, 2013; Krijgsman et al., 2016; Siliquini et al., 2011). It is not unlikely that you have searched the Web for health information one time or another, be it for yourself or to find

information for someone else. In general, online health seekers can be defined as “internet users who search online for information on health topics, whether they are acting as consumers, caregivers or e-patients” (Fox, 2006, part I, p. 1). In the Netherlands, the Internet is the most often used source for health information, followed by information provided by the general practitioner (van de Belt, Engelen, Berben, Teerenstra, Samson, & Schoonhoven, 2013).

Reasons for going online to find health information vary. People who search the Internet for health information tend to visit doctors more often (Lee, 2008; Singh & Brown, 2014). Seeking online health information may then, for example, serve as preparation for a doctor visit. Previous research has indeed shown that health seekers typically search for health information before visiting a doctor (Fox & Rainie, 2002). However, people may also seek for online health information because one is not satisfied with the information provided by their doctor (McMullan, 2006). Wanting to be better informed and looking for reassurance or alternative treatments are other reasons to search for health information online (McMullan, 2006; Rozmovitis & Ziebland, 2004). A study in the US furthermore revealed that people often go online to diagnose themselves. These online diagnosers often search for information about a specific medical treatment or procedure (Fox & Duggan, 2013). Previous research further revealed that people typically start their health search at a search engine, and mainly seek for information about diseases or medical problems, nutrition, exercise and how to lose weight (Fox & Duggan, 2013; Krijgsman et al., 2016).

Searching online for information about symptoms or illnesses has its benefits; e.g., information is always and easily accessible, people can easily find information that is tailored to their needs, costs are mostly low or non-existing, and important to note is that searching

can be anonymous. Furthermore, looking for health information online can empower people by giving them more control over their own health, provide for social support, and help patients cope with medical issues (Chung, 2013; Cline & Haynes, 2001; Korp, 2006; McMullan, 2006; Murray, Lo, Pollack, & et al., 2003; Rice, 2006; Starcevic & Berle, 2013; Tanis, 2008). Research also shows that people who search online for medical information experience positive consequences such as feeling more reassured to ask their doctor questions or more confident to make good health care decisions (Fox, 2006).

Hence, where one would normally consult a doctor in need for health information, online health information may just as well provide a satisfactory answer. But does it? Given the widespread reach of online sources and the fact that the Internet has become a new and important source of health information (Cline & Haynes, 2001; Fox & Jones, 2009; Hou & Shim, 2010; Lee & Hawkins, 2010), an understanding of the implications of online health information seeking and factors that influence these implications, is essential.

Despite numerous benefits of online health information, the wealth of readily available medical information also comes with negative implications. Negative consequences of using the Web for health-related purposes pertain, amongst others, to the comprehension of health information. People with low health literacy skills might misunderstand specific health-related information and therefore have problems with understanding and using the information they find (Chung, 2013; Korp, 2006; Lee, 2008; Meppelink, 2015; Norman & Skinner, 2006).

Another disadvantage of online health information pertains to the often poor quality, trustworthiness and credibility of the information (Korp, 2006; Lee, 2008). Websites may, for example, look professional

but lack evidence-based or peer reviewed content. At the same time, there is a lack of quality control of online health sources (Burkell, 2004; Cotten & Gupta, 2004), which makes it harder for consumers to estimate the quality and credibility of the information they find online (Cotten & Gupta, 2004; Korp, 2006; Lee, 2008). Furthermore, difficulties searching online due to information that is not clearly organized, technical language and information that can change at any time can hinder optimal use of online health sources (Cline & Haynes, 2001). Although access to a vast amount of medical information can empower people, it may thus just as well distress or misinform them. Studies indeed revealed that people feel confused and overwhelmed by the information found online (Ahmad, Hudak, Bercovitz, Hollenberg, & Levinson, 2006; Chung, 2013; Fox, 2006).

The potentially negative consequences of online health information can affect everyone. However, there seems to be a specific group of people who are more susceptible to negative consequences of online health information: people who are overly anxious about their health.

Health Anxiety

When referring to anxiety about one's health, the first 'diagnosis' that may come to mind is hypochondriasis. In the DSM-IV-TR, hypochondriasis is described as "the preoccupation with the fear of having, or the idea that one has, a serious disease based on the person's misinterpretation of bodily symptoms or bodily functions" (American Psychiatric Association, 2000, p. 445). An important aspect of hypochondriasis is that this preoccupation with health will remain present, despite medical evaluation and reassurance (Abramowitz & Braddock, 2011; American Psychiatric Association, 2000).

Abramowitz and Braddock (2011) point out two reasons for using the term *health anxiety* instead of hypochondriasis: the term health anxiety is clearer and more meaningful; health anxiety “is not a clinical diagnosis per se, but rather a phenomenon that can be present in a number of psychological conditions as well as medical diagnoses” (p. 2); and the term health anxiety is more value neutral compared to hypochondriasis. Therefore, in this dissertation the term *health anxiety* is used when referring to the phenomenon of anxiety or worries about one’s health. When referring to individuals who worry about or are anxious about their health, I use the term *health anxious* individuals or people.

It is easy to imagine that a complete lack of worry about one’s health might result in taking unnecessary health risks (e.g., ignoring signs of a heart attack). Hence, health anxiety is a form of worry that is in general beneficial but in extreme forms (either being too low or too high) may become harmful.

Taxometric analysis suggests that health anxiety can best be interpreted as a dimensional construct (Ferguson, 2009). This means that individuals should not be classified in distinct categories based on qualitative interpretations. Health anxiety should, instead, be interpreted on a continuum ranging from mild to severe. In that sense, individuals differ from each other in a quantitative perspective, and severe health anxiety then reflects one end of this continuum (Ferguson, 2008; Salkovskis, Rimes, Warwick, & Clark, 2002). Treating health anxiety as a dimensional construct, however, prohibits clinicians from diagnosing patients with (clinical) health anxiety. In light of this one might argue that, in particular for clinicians, it is useful to know whether online health information seeking poses a threat to those who are clinically health anxious.

Little is known about the prevalence of health anxiety. The DSM-IV-TR reports prevalence rates between 4% and 9% in general medical practice (American Psychiatric Association, 2000). In the DSM-Vⁱ prevalence rates of 1.3% to 10% are reported for illness anxiety disorder (based on community surveys and population-based samples) and 5% to 7% for somatic symptom disorder in the general adult population (American Psychiatric Association, 2013).

Maintaining Factors of Health Anxiety

Several factors may negatively affect health-related fears; instead of decreasing these fears, the health anxiety that is experienced is rather maintained. Based on a cognitive-behavioural model of health anxiety (Abramowitz, Schwartz, & Whiteside, 2002; Salkovskis & Warwick, 1986; Warwick and Salkovskis, 1989), maintaining factors of health anxiety can be subdivided in three systems based on behavioural, cognitive and physiological factorsⁱⁱ.

Behavioural factors pertain to avoidance and safety seeking behaviours that health anxious individuals perform with the goal to reduce health-related fears (Salkovskis and Warwick, 1986). Avoidance behaviours can result in, for example, not seeking medical treatment or avoiding TV-shows about illness (Salkovskis, 2002). Counterintuitively, however, this form of avoidance maintains the already present anxiety rather than decreases it, because information contradicting the belief that one is ill is avoided at the same time (Abramowitz et al., 2002; Warwick, 1989). Examples of safety seeking behaviours are recurrent checking of bodily symptoms and functions (e.g., repeatedly checking blood pressure), and taking preventative measures (e.g., taking medication). Reassurance seeking is the most prominent safety behaviour (Abramowitz et al., 2002). Overly health anxious individuals try to

find reassurance by talking about their symptoms to their doctor, but also relatives and friends, or by looking up information in medical textbooks or online (Abramowitz & Moore, 2007; Salkovskis et al., 2002; Salkovskis & Warwick, 1986; Warwick & Salkovskis, 1990). As with avoidance behaviours, the reassurance seeking seems to maintain the false beliefs or fears that symptoms are caused by a medical condition (Abramowitz & Moore, 2007; Asmundson, Abramowitz, Richter, & Whedon, 2010; Rachman, 2012).

Cognitive factors that maintain health anxiety are a constant focus on bodily changes (i.e., hypervigilance), preoccupation or rumination, helplessness, attention to negative or illness-confirming information and discounting positive information (Abramowitz et al., 2002; Warwick and Salkovskis, 1990). As the definition of hypochondria, as described previously in this chapter, already suggests, overly health anxious individuals are preoccupied with health and they misinterpret bodily symptoms and functions. By being very sensitive towards bodily changes and repeatedly thinking of the likelihood of being ill or imagining one is ill, existing anxiety about one's health is likely to be maintained rather than reduced. This is further reinforced by the fact that people who experience higher levels of health anxiety tend to exhibit an illness-related bias. This means that they selectively attend to stimuli, being it bodily symptoms or external information, which confirms their worries about being ill (Abramowitz et al., 2002; Warwick & Salkovskis, 1990). In addition, they tend to disregard information that might contradict their false thoughts about being ill (Abramowitz et al., 2002; Owens, Asmundson, Hadjistavropoulos, & Owens, 2004; Warwick & Salkovskis, 1990).

The third maintaining factor pertains to typical physiological changes as a result of the anxiety one experiences. By being more

sensitive towards bodily changes, one may also be more aware of these physiological changes. An example of physiological arousal due to anxiety is increased heart rate: the anxiety experienced due to an observed bodily symptom that is interpreted as being indicative of illness, results in stress which subsequently results in increased heart rate. This increase in heart rate is then also interpreted as being an indicator of something being wrong. Hence, the anxiety about one's health is maintained.

Searching for health information on the Internet is one way to achieve reassurance (Salkovskis et al., 2002) and may therefore play a key role in the maintenance of health anxiety. Furthermore, by (unintentionally) focusing on online health information that confirms rather than refutes irrational illness beliefs, health anxiety may perpetuate rather than diminish. The focus of this dissertation lies on these two specific maintaining factors of health anxiety, namely reassurance seeking through online health information seeking, and a bias toward illness-confirming online health information.

Cyberchondria: The Interplay between Health Anxiety and Online Health Information Seeking

“Health anxiety ruining my life looking for advice/help can't cope I'm 25 years old and for the past 3/4 weeks I think I've been suffering from health anxiety. First I was having night sweats and google made me think this was the start of a serious illness. Next I had chest pains which I thought were strained muscles but it lasted for a few weeks and I convinced myself this was serious. I now have a pain in my left breast and now I'm convinced I have breast cancer and I'm losing the plot. I have two small children (aged 2 and 10 weeks) this is ruining my life and my partner thinks I'm mad.

Every little symptom I get I google it and it makes me worry so much more. I've had my left breast checked and it's okay, also had an ECG and that was fine. I go from being fine one minute to panic and google searching the next. I don't know what to do. I'm so upset and keep thinking about my children not growing up with a mum. The pain I have is like a lingering pain from the back of my breast, sometimes it feels hot and the pain travels to my back. I'm also now worried about my other breast because the nipple has inverted tonight so I'm thinking this is serious. Please is anyone having the same symptoms. Please help me x"

Nicola, 2014

The quote above, derived from an online discussion board about anxiety disorders, reflects the maintaining or maybe even reinforcing role of online health information seeking as reassurance seeking behaviour in health anxious individuals. The 25-year old woman seeks for reassurance by not only asking her doctor but also by going online to find information about her symptoms. Instead of finding reassurance, however, her anxiety seems to perpetuate or even increase.

As pointed out earlier in this chapter, distressing effects of online health information seeking may affect everyone, but in particular health anxious individuals. Previous studies demonstrated, for example, that experiencing health anxiety is related to feeling more frightened (Baumgartner & Hartmann, 2011), tense (Singh & Brown, 2014), and anxious (Muse, McManus, Leung, Meghreblian & Williams, 2012) after online seeking. It thus seems that going online to find reassurance in the form of online health information does not work out for those who are already anxious about their health. Instead of finding reassurance, already present anxieties seem to be reinforced. This phenomenon of reinforced anxiety due to online

health information seeking has frequently been referred to as 'cyberchondria' (e.g., Doherty-Torstrick, Walton, & Fallon, 2016; Fergus, 2013; Loos, 2013; Muse et al, 2012; Starcevic & Berle, 2013; Starcevic, 2015; White & Horvitz, 2009).

The word 'cyberchondria' is derived from the words 'cyber' and 'hypochondriasis' and hence implies a link between cyberspace and health anxiety. The English Oxford dictionary describes a cyberchondriac as: "a person who compulsively searches the Internet for information about particular real or imagined symptoms of illness" ("cyberchondria", 1990) and coins its origin back to 1990. Starcevic & Berle (2013) refer to a 1999 article in the *Wall Street Journal*, in which the phenomenon was already described. And the word returns more often in popular media. For example, in a 2009 article on the website of *The Independent* (Usborne, 2009), in which the case of Catherine is described. Catherine experienced muscle twitching and looked up information about this symptom online. Results made her incorrectly believe she might have Creutzfeldt-Jakob disease, since muscle twitching is one of the symptoms. In a 2011 blog post of the *Huffington Post* written by a medical doctor (Senelick, 2011), a case study is described explaining how a systems engineer got extremely anxious because his search for information about headaches led him to belief, incorrectly, that he had a brain tumour.

The descriptions of cyberchondria in popular media often point in the direction of cyberchondria being a phenomenon resulting from online searches about health information. The most commonly used scientific definition of cyberchondria is the description introduced by Starcevic & Berle (2013), who define cyberchondria as "an excessive or repeated search for health-related information on the Internet, driven by distress or anxiety about health, which only

amplifies such distress or anxiety” (Starcevic & Berle, 2013, p. 206). In other words, the phenomenon pertains to a specific behaviour (i.e., online health information seeking) that is carried out by individuals who are anxious about their health (i.e., experience a form of health anxiety), and that reinforces this particular anxiety. Hence, according to this definition, there is more to it than merely online searching for health information about experienced bodily symptoms; the online searching originates from anxiety about health and is excessive.

Starcevic & Berle (2013) stress that cyberchondria is not an illness in itself but occurs as part of health anxiety. They furthermore point out that the anxiety one experiences due to the online health information seeking may induce further searches and hence even more anxiety. In other words, Starcevic & Berle seem to propose a reciprocal relationship between anxiety about one’s health and online health information seeking. However, they have not empirically tested this proposition. In fact, although often described as a deteriorating phenomenon in the literature, until now cyberchondria has only been described (Starcevic & Berle, 2013; 2015; Starcevic & Aboujaoude, 2015; Starcevic 2017) or explored in cross-sectional settings (e.g., Fergus, 2014; Loos, 2013; McElroy & Shevlin, 2014; Muse et al., 2012; Starcevic & Berle, 2013; White & Horvitz, 2009). Thus, empirical evidence for a reciprocal relationship, and therefore evidence for the phenomenon of cyberchondria, is lacking.

It is important to note that the definition of cyberchondria as introduced by Starcevic & Berle (2013) implies that this phenomenon pertains to individuals who experience heightened levels of health anxiety. In other words, individuals with hypochondrical traits, and who thus worry excessively about their health, consequently go online to find health information, but then feel even more anxious

about their health as a result. This definition, however, sheds no light on the consequences of online health information seeking for individuals with 'normal' levels of health anxiety. Is it possible that the proposed reciprocal relationship does not start with extreme worrying about health, but with online health information seeking in itself? One might expect that the downsides of online health information may result in heightened health anxiety for those who previously did not experience unfounded worries about their health. It is, for example, not unlikely that Nicola started her online health information search merely because she experienced night sweats and just wanted to know what she could do to prevent them from happening, and not because she was already health anxious. In the end, however, it seems that she became health anxious due to the information she encountered online.

So, does cyberchondria merely pertain to individuals who are overly anxious about their health (as suggested by Starcevic & Berle, 2013) or is it a phenomenon that may also pertain to the general public, being a negative consequence of online health information? Furthermore, does this relationship originate with an increase in worries about one's health, or by searching for health information online? In the current dissertation a multilevel longitudinal design is used in a first attempt to shed more light on this. By applying a multilevel approach, differences between individuals as well as changes in health anxiety and online health information seeking within individuals over time could be examined.

Aims and Outline of this Dissertation

The overall aim of this dissertation is to shed light on the relationship between health anxiety and online health information seeking and potential underlying mechanisms of this relationship, with the goal to gain more insight in the phenomenon of cyberchondria.

First, because valid and reliable measures are key to every survey based study, we conducted a psychometric evaluation of the Dutch Short Health Anxiety Inventory to examine whether the translated version of the widely used Short Health Anxiety Inventory (Salkovskis et al., 2002) is a valid instrument to measure health anxiety in the Dutch population. This validation study is described in Chapter 2.

A second goal of this dissertation was to examine to what extent online health information seeking is associated with feelings of distress after seeking. More specifically, we wanted to find out whether this relationship is stronger for individuals with higher levels of health anxiety. This study, described in Chapter 3, contributes to the literature by examining the expected relationships in a large, nation-wide sample, thereby aiming to replicate findings from studies with small (student) samples. If individuals, in particular those with health fears, experience more distress after online health information seeking, we may also expect them to be more health anxious after seeking online for health information. Moreover, if online health information seeking is a reassurance seeking behaviour, characteristic for individuals with health fears, this seeking may thus maintain or increase health anxiety levels. In a longitudinal follow-up study, described in Chapter 4, we therefore investigated whether online health information seeking and health

anxiety are reciprocally related. To further unravel the role of experiencing health fears, we examined this reciprocal relationship in individuals with clinical and non-clinical levels of health anxiety.

In Chapter 3 and 4 we focus on investigating the interplay between online health information seeking and experienced distress or anxiety after seeking. One factor that may explain this consequence of seeking online health information pertains to the selective perception of information. If overly health anxious individuals merely focus on online health information that confirms their health fears, then it seems likely that this information distresses them and maintains their already present anxiety. The final study, described in Chapter 5, therefore explored the relationship between health anxiety and a bias toward illness-confirming online health information.

In the final chapter of this dissertation an overall discussion is presented followed by methodological and practical implications and suggestions for future research.

Methodological Approach

In the next four chapters, four studies are presented based on two correlational data sets. The first three studies made use of data from the LISS (Longitudinal Internet Studies for the Social Sciences) panel administered by CentERdata (Tilburg University, The Netherlands; Scherpenzeel & Das, 2010). The LISS panel data (4 waves of data with two-month time lags) were collected by CentERdata through its MESS project funded by the Netherlands Organization for Scientific Research. The LISS panel is a representative sample of Dutch individuals (aged 16 years and older) who participate in monthly Internet surveys. The panel is based on a true probability sample of households drawn from the population register (Scherpenzeel &

Das, 2010; www.lissdata.nl). In total, 5,322 completed the survey at Wave 1 (December 2013), 4,642 (87%), 4,540 (86%) and 4,570 (86%) completed the questionnaires in Waves 2, 3, and 4, respectively. The study described in Chapter 3 is based on the data from Wave 1. Data from Waves 1 and 2 were used for the study described in Chapter 2. Data from all four waves were used for the third study, described in Chapter 4. The fourth study, described in Chapter 5 of this dissertation, made use of additional cross-sectional data derived from a survey study including a forced choice paradigm.

Notes

ⁱ In the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), hypochondriasis is replaced by illness anxiety disorder and somatic symptom disorder (American Psychiatric Association, 2013).

ⁱⁱ In the visualization of their model, Warwick and Salkovskis (1989) refer to a fourth maintaining factor, namely the affective factor. However, no rationale for this factor is provided, and therefore it is not included in the current discussion of maintaining factors of health anxiety.