WE CAN ONLY KEEP HOPING

Effects of News about Innovative Diabetes Therapies on Patients' Emotional and Cognitive Responses

Hans Vehof

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PhD thesis
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CHAPTER 1

Introduction and Thesis Outline

Introduction

We are living in an age in which patients are becoming more empowered and have nearly full access to scientific information. Patients with chronic illnesses have increasing access to information about new treatments. Information can be acquired from primary sources, scholarly journals, and edited news that may not always be trustworthy and that is disseminated to a broader audience. Reports on innovative treatments are frequently seen in traditional media, including newspapers and magazines—both print and online—as well as on social media. The following is an example of such a hopeful headline: 'Promising stem cell therapy for type 1 given green light to progress' (JDRF, 2022).

How does exposure to such news affect patients? The literature does not provide a clear answer concerning whether improved access and coincidental exposure to news messages serve all patients well. Messages about new (or existing) therapies for chronic diseases may affect patients either positively or negatively at the cognitive level (e.g., knowledge, informed decision-making), the emotional level (e.g., hope, optimism, impatience, anxiety), and the behavioural level (e.g., medication adherence). The research in this thesis was performed to generate insight into the actual effects of health-news exposure on chronically ill patients and how these effects may be moderated by specific characteristics of messages and patients.

News on Diabetes Therapy

In this thesis, diabetes mellitus (Types I and II) serves as a case for generating insight into complex relationships between (1) characteristics of media coverage of innovative diabetes treatments; (2) the cognitive and emotional responses of chronically ill patients; and (3) the adherence of these patients to their current medication. Diabetes mellitus is one of the most widespread chronic diseases, and it receives a large amount of attention in academic papers, newspapers, and social media (Foley, et al., 2020; International Diabetes Federation, 2021). A quick scan of scientific databases (e.g., PubMed) shows that over 20,000 academic papers were published in 2022 about diabetes mellitus Types I and II, from which authors of health news could potentially draw. Although significant progress towards a cure for diabetes has been reported in several publications, various promising innovative concepts have been covered for decades without clinically adaptable results. For example, as early as 1972, a glucose sensor was developed that purportedly sparked optimism about a 'self-contained totally implantable artificial organ that would continuously monitor sugar concentration in a body fluid of a diabetic patient and meter out insulin in proportion to need'

(Bessman & Schultz, 1972). Known as the 'artificial pancreas', this artificial organ is currently still under development (Boughton & Hovorka, 2020).

The population for whom diabetes news is written has increasingly found their way to digital news sources in recent years. Most patients with diabetes mellitus Type II—who constitute the largest group of patients with diabetes—are older adults. In the general population in the Netherlands, people older than 65 years of age are increasingly using the internet on a daily basis. In 2021, 79% of people between the ages of 65 and 75 years used the web daily, as compared to 63% in 2016 (Statistics Netherlands, 2022).

News media regularly report on the early stages of medical research that has innovative potential before there is any actual clinical evidence from patients and before the market potential for these developments is clear (Sena et al., 2010). This raises questions concerning the stage at which medical innovations should be covered in the media to serve the diabetes community best. In recent years, several media watchdogs have emerged to assess the quality of health-news articles and to educate news editors and the general public on interpreting health claims (especially early claims) and determining their actual value (Schwitzer et al., 2005).

Types of Diabetes Research

Research on characteristics of news relating to diabetes should consider the therapeutic aim of innovation. In the biomedical sciences at universities and in pharmaceutical clinical trials, many studies are conducted on the origin, prevention, and cure of diabetes. For example, internists and biologists are researching the insulin resistance of body cells and ways to improve protection for the islets of Langerhans in the pancreas (Ashimova et al., 2019). Epidemiologists are investigating links between the living environment of vulnerable groups and the risk of developing diabetes mellitus Type II (Dendup et al., 2018). Furthermore, physiotherapists, dietitians, and psychologists are conducting numerous joint scientific experiments with potent interventions aimed at safeguarding an optimal lifestyle and diminishing the incidence of diabetes Type II (Siaw & Lee, 2019). Finally, the food industry also bears responsibility for addressing overweight and diabetes (Popkin & Kenan, 2016).

In addition to cures, research is focusing on reducing the symptoms of diabetes. For example, medical scientists are working to achieve steady blood sugar levels (Al-Ishaq et al., 2019), to prevent problems relating to dry eyes (Yoo & Oh, 2019),

and to alleviate neuropathies (Feldman et al., 2019) and many other clinical manifestations.

Phases of Clinical Research

The conventional time frame for creating a new medication is 10 to 15 years. In contrast, it can take several decades to develop a treatment for a complex ailment—if it is feasible at all—as this can be accomplished only incrementally. The early stages of biomedical research for novel therapies take place during the fundamental phase, in which researchers engage in contemplative analysis of existing literature and research findings. This is followed by a trial-and-error approach aimed at the discovery of new biomedical therapies (Copeland, 2019; Pandit, 2007; Roy, 2011). In the pharmaceutical sciences, however, serendipitous discoveries often occur that contribute to the gradual advancement of research. Following peer discussion and the creation of new theoretical concepts, theory development alternates with *in vitro* testing (e.g., organs on a chip). Subsequently, when promising molecular reactions or mechanical techniques are discovered, *in vivo* studies (e.g., on rodents, pigs, or dogs) are performed to gather information on efficacy, adverse effects, pharmacokinetics, and toxicity levels as a foundation for human testing. Although the term 'pre-clinical research' is commonly applied to animal research, it is worth noting that fundamental research is also conducted in preparation for clinical trials (Rantanen & Khinast, 2015). The word 'clinical' refers to the monitoring of effects on humans in a clinical setting.

In the clinical phases of studies, safety and beneficial effects are measured in healthy humans (Phase I) and, later, in actual patients. In Phase II of clinical studies, dose-finding studies are conducted and, in most cases, followed by a search for a proof of concept. This 'clinical evidence' demonstrates the practical potential of a concept or theory. In other words, it shows an overall beneficial effect on at least a small group of actual human patients. Phase III studies, also known as pivotal trials, are clinical trials that evaluate the efficacy and safety of a drug or medical intervention. These studies are conducted after promising results have been obtained from previous Phase I and II studies.

In Phase III studies, the drug or intervention is tested on a larger group of patients, typically in the hundreds or thousands, to determine whether it effectively treats the targeted condition. These studies are designed to provide evidence of a drug's effectiveness and safety, as well as to compare it to existing treatments or a placebo. Phase IV studies, also known as post-marketing surveillance or post-approval studies, are clinical trials conducted after a drug or medical device has been approved by regulatory agencies and made available to the public. These

studies are designed to monitor the long-term safety and efficacy of a drug or device, as well as to identify any rare or long-term side effects that may not have been identified in earlier clinical trials. Phase IV studies typically involve large numbers of participants and can last for several years. In addition, for scientific areas other than pharmacology (e.g., human movement sciences, psychology), it is also essential to obtain clinical evidence in patient trials before identifying innovations as promising (Nery et al., 2017).

The impact of news messages on patients might be related to the developmental phase that an innovation is in, but literature on this topic is lacking. For this reason, the primary goals of the present thesis are to assess the developmental phases in which medical innovations concerning diabetes are covered by news media [regardless of the availability of clinical evidence] and to identify the effects of such media coverage on patients with diabetes (Chapter 2). In the present thesis, studies are classified as preclinical in terms of the type of evidence sought, specifically regarding preliminary effectiveness and safety. These studies support concrete product development, thereby enabling the initiation of patient trials in the short term.

The SMCR Model of Communication

David Berlo's Sender Message Channel Receiver (SMCR) model (Berlo, 1960) serves as a broad communication framework to guide the research in this thesis. The SMRC model represents how the four constituent components of the communication process work together in their effects on the receiver. The objects of the present thesis are presented in Table 1.1, categorised according to the SMCR model. In the following sections, the separate elements of the model are discussed in more detail, within the context of news about innovations relating to diabetes.

Sources and Channels of Diabetes News

The object of study for the current thesis—'news source'—is operationalised as all individuals (e.g., editors, moderators, journalists) or organisations (e.g., academic research groups, health organisations, newspapers, or patient associations) sending messages on traditional media channels (television, radio, print newspapers) and web-based media (world wide web, social media), regardless of their aim. This description is a generalisation of the definition for source provided by the Oxford Dictionary of Journalism (Harcup, 2014). Although different dictionaries provide different definitions, the concept of a source (i.e., the author of a first-hand document or primary reference work) is used interchangeably with that of a sender (i.e., the one causing a transmission by an agent). The latter is sometimes regarded as a secondary (i.e., second-hand) source.

Table 1.1: Objects of the present thesis, classified according to Berlo's SMCR communication model (Berlo, 1960).

SMCR model	Operationalization	Example
Source	Physical sender/provider of information	
	Primary source: Researcher/research institute, scientific journal	*Primary source:* (moderator at) University, pharmaceutical company, government health institute, *Journal of Pharmaceutical Sciences*
	Secondary source: Provides information about the primary source	*Secondary source:* Patient association, Dutch Diabetes Association DVN, newspaper *De Telegraaf*
Message	Scientific and non-scientific information on the future treatment of diabetes	Results of artificial pancreas trials, blood glucose lowering recipes, description of a lifestyle innovation
Channel	Media Platform: Web-based media and print newspapers	Article in *De Telegraaf* (print or online), diabetes-related Facebook groups, forum at a patient association
Receiver	News reading patient and environment	A person diagnosed with diabetes Type 1 or 2; a patient's parent or spouse
Message effect	Changes in sentiment, attitude, behaviour intention	Hopefulness, anger, intention to adhere to medications

The purpose of sending health information to the public differs slightly for each source. For journalists, accurate and transparent news reporting is generally a primary concern. At the same time, however, the attention that readers pay to an article and the subsequent clicks on article headlines generate money, possibly rendering any concern for the consequences of a story secondary at most (Lantz & Lanier, 2002). In the United States, a statement of principles was published to improve the quality of health-news stories. According to this statement, members of the Association of Healthcare Journalists should be aware that their viewers and readers make essential healthcare decisions based on their stories (Schwitzer et al., 2005). According to the same association, journalists should investigate and report any possible conflicts of interest between sources of health information and those who promote a new idea or therapy. Journalists should search for such conflicts as a routine part of researching a story.

In contrast to journalists, those who manage social media or patient platforms (e.g., editors, writers, administrators) may not necessarily be bound by any journalistic codes or have distinct roles. Their main objective is to act as a channel

for disseminating new advancements in research. Primary or academic sources often have an inherent drive to promote their relevancy and communicate early research results to the public. The publication of early results allows universities to share their findings with the broader academic community, potentially accelerating progress in their field. It also allows other experts in the field to review and critique their work, thereby helping to improve the quality of the research and ensuring its accuracy and reliability. Frequent publication can also help universities to attract funding from external sources, including government agencies, private foundations, and industry partners (Aagaard, et al., 2015; Moses et al., 2015).

Enthusiastic disseminators of research results may not always be aware of how early scientific information can be understood—or misunderstood (Schwitzer, 2010). This issue can be highlighted by a quick overview of posts to diabetes-related Facebook groups. In an attempt to provide patients with as much information as possible, a significant amount of academic health information is shared in its unedited form and without providing the necessary context.

Source Authority and Credibility

Given the current dominance of digital media, it is often difficult to determine the accuracy and reliability of health news in general, and this applies to diabetes-related information as well. The origin of health information is particularly relevant. Health-related behaviours and decisions by patients are likely to be based on the perceived credibility of a source. The characteristics of the source can enhance or detract from the potential of a message to achieve changes in attitudes or beliefs.

As a construct, credibility is as complex as it is multidimensional. Its operationalisation is therefore complicated, given the difficulty of measuring which source characteristics explain significant proportions of variance in persuasion (Wilson & Sherrell, 1993). In an early factor analysis, Perloff (1993) identifies four factors and subsequent measurements that explain perceived source credibility: (1) trustworthiness of the sender, measured as right vs. wrong, honest vs. dishonest, trustworthy vs. untrustworthy, and just vs. unjust; (2) professionalism or competence, measured as experienced (e.g., academics reporting in a journal) vs. inexperienced (e.g., non-specialists starting a Facebook Group), and possessing professional manners vs. lacking professional manners; (3) dynamism, measured as aggressive vs. meek, active vs. passive; and (4) objectivity, measured as open-minded vs. closed-minded and objective vs. subjective.

The credibility of a source can be expressed as the perceived level of truth and the validity of messages received, and it has a substantial impact on the persuasiveness

of these messages (Ismagilova et al., 2020). If the credibility of a source is perceived as high, people tend to believe and accept the message as accurate. In other words, credibility implies correctness (Zhang & Watts, 2008). Source credibility is particularly important when the receiver is unable or unmotivated to process the message systematically (Kang & Namkung, 2019). The current thesis proceeds from the assumption—as supported in previous research (Choi, 2020; Machackova & Smahel, 2018)—that high involvement (in diabetes research) leads patients who are exposed to such research to employ a systematic information-processing strategy in which message-based cognitions mediate persuasion and trust in the message. Low involvement leads readers to use heuristic processing strategies in which simple decision rules (e.g., about the authority of the news source) mediate persuasion and trust in the messages received.

In the current research, perceived online credibility may be determined by the professional authority of the digital sender of the messages. Most health-news messages reach the public through a broad array of selecting sources, ranging from governmental health institutes to information gatekeepers (e.g., news anchors, reporters, and journalists), who select and present health-news messages for the public. In the online context, technological interfaces, such as web-based search engines and social media (e.g., Facebook), function as selective sources, filtering and forwarding health-news messages from primary sources (Chambers et al., 2021; Lee et al., 2015). In Western societies, credibility is higher in expert-based, official sources (e.g., government health institutes) and lower in non-professional sources (e.g., Facebook groups). Message-source effects are examined in Chapter 4.

Channels

Health information, including messages about novel treatments, is traditionally available from mass media channels (e.g., television programmes, newspaper sections, health magazines, and radio documentaries) and targeted media, including published literature, books, pamphlets, and telephone advice lines (O'Malley et al., 1999). The internet allows patients to seek health information online (Wang et al., 2021). In recent years, intelligent web technologies have led to the emergence of new online platforms on which to share information with large groups easily. These platforms include social media and online patient (or other) communities, where people find information, share stories, and participate in discussions about healthcare (Eysenbach et al., 2004; Oh et al., 2012). For the recipients of news, misunderstanding may arise concerning channels and sources. Some receivers may be confused by the fact that the medium through which news is transmitted is not always the primary source, but that it sometimes stands apart from the primary source, thus possibly warranting further study or interpretation.

In the SMCR framework applied in the current thesis, the channels are operationalised as (1) traditional media; (2) the internet as a whole (which includes many newspapers, magazines, and endless other news sources); (3) specialised websites containing forums and moderated by patient organisations or medical institutions; and (4) social media (e.g., Facebook or Twitter), which are often moderated by academics, healthcare workers, or patient organisations. In this thesis, Chapter 2 focuses on traditional media newspapers, Chapter 3 examines the realm of social media (Facebook), and Chapter 4 explores the focus of Facebook in comparison to an authoritative webpage.

The Message: Content and Form

Health-related information (for short, health information) refers to any type of data, facts, or knowledge related to health and medicine (Lambert & Loiselle, 2007). It can thus encompass information about diseases, conditions, medications, anatomy and physiology, or healthy living, as well as about conventional and alternative therapies that may or may not be reimbursed. It also includes information relating to ground-breaking therapies in various stages of research that may or may not ultimately prove efficacious (Schwitzer, 2010). The present thesis focuses on this type of information (i.e., regarding innovative therapies), which may offer hope or disappointment to susceptible patients seeking improved treatments.

Language Intensification

Health-news messages regularly contain powerful language that authors use to make their messages more vivid and to enhance their attention value. Although such 'language intensification' is a complex concept (Liebrecht, 2015), a functional definition is as follows: *the use of language to deviate from neutrality* (Bowers, 1963). The present thesis focuses on deviations in the direction of the positive aspects of the scientific results presented. Strong words (e.g., 'breakthrough,' 'enormous,' 'very important,' or 'life-saving') in a sentence intensify a statement that would otherwise be more factual. This phenomenon is common in the coverage of medical news (Abola & Prasad, 2016), and it can potentially affect the reader. The persuasive power of a text extends beyond the intensity of the words used. Readers may also be influenced by the professional layout and appearance of the site, the framing of gain versus loss, or the use of professional image editing that supports the text (Seo et al., 2013). In the current thesis, however, only the effects of intensified language are assessed.

Although overall results are mixed, several studies have indicated that the use of language intensifiers increases the clarity of the message (Hamilton et al., 1990; McEwen & Greenberg, 1970). Another study reports that language intensification

leads to high message elaboration by receivers: after reading intensified language, patients could better distinguish stronger from weaker arguments (Craig & Blankenship, 2011). In experimental studies, high-intensity language has been shown to have a more positive influence on attitudes and intentions than low-intensity language does (Bankhead et al., 2003; Craig & Blankenship, 2011). Evidence from a study by Andersen and Blackburn (2004) suggests that language intensification may influence behaviour. A study on perceptions of health-news messages indicates that these messages are affected mainly by objective risk characteristics. More specifically, language intensification affects only the reader's perception of the severity of a health risk (Klemm et al., 2019). The latter findings suggest that readers of health news can correct for the impact of language intensification and remain focused on the objective part of the information. Although language intensification is common in health-news coverage, the specific effects that the addition strong words to health news can have on outcomes (i.e., attitudes and behavioural intentions) amongst patient populations are yet unknown. Language intensification is examined in Chapter 4.

The Patient as a Receiver of News

The focus of this thesis is on patients with diabetes mellitus Types I and II. Like the Dutch population in general, this population is heterogeneous, in that specific characteristics of patients with diabetes are not yet known. As such, anyone in the general population could be affected. Moreover, patients diagnosed with Type II differ from those diagnosed with Type I, in that the former patients are often at risk due to lifestyle or ethnicity (Kolb & Martin, 2017; Kou et al., 2018; Meeks et al., 2015). Taken together, the patient population diagnosed with diabetes is heterogenous and requires a selection of variables that could potentially moderate the effects of news exposure on emotions, attitudes, and behavioural intentions. A selection of key variables is described below.

Diabetes Type

In the Netherlands, approximately one of every 14 individuals is diagnosed with diabetes mellitus Type I or Type II at some point, with about 90% of this group having Type II. A set of typical physical symptoms has been identified for patients diagnosed with diabetes. To some extent depending on the type of diabetes, about one in three patients will develop problems with visual acuity, and have an highly increased risk of cardiovascular disease. Other conditions that are commonly diagnosed in patients with diabetes (all types) include kidney disease and respiratory, metabolic, and digestive problems. (Bharucha et al., 2015; Einarson et al., 2018; Fu et al., 2019; Nanayakkara et al., 2021)

In recent years, Type II diabetes has been becoming more common. The number of people diagnosed with Type II diabetes is increasing rapidly, possibly due to lifestyle. The risk of Type II diabetes is increased by genetic predisposition, severe obesity, excess abdominal fat, sedentary lifestyle, smoking, unhealthy nutrition (consuming high fat and added refined sugar), high levels of LDL (bad cholesterol), and low levels of HDL (good cholesterol), high blood pressure, liver disease, and kidney disease (Wu et al., 2014). These factors impact glucose levels in the blood, either directly or indirectly, as well as over time. Although the group of people with Type I is increasing, research has yet to generate full understanding of the causes of this type (Wang et al., 2017). Possible causes include viruses, nutrition, and—to a small extent—heredity (Hyöty, 2016; Norris et al., 2020; Wang et al., 2017). To date, it is not possible to prevent diabetes mellitus Type I.

Gender and Age

Studies suggest that, compared to men, women have higher rates of diabetes during youth and adolescence. In middle adulthood, however, the rate of diabetes is higher for men than it is for women (Huebschmann et al., 2019). While it is difficult to define an exact age for the onset of Type II diabetes in a specific individual, age considerably increases the risk of developing the condition. In the Netherlands, the mean age at diagnosis is 61 years for Type II. For Type I, the age is considerably lower, at 35 years (Nielen et al., 2020). According to the Centers for Disease Control and Prevention (2022), in the United States, about 11% of the adult population had diabetes in 2019 and about 29% of people older than 65 years of age in the U.S. may have diabetes, whether diagnosed or not. As reported in a 2016 meta-analysis, rates of Type II diabetes were up to seven times higher in Chinese adults between the ages of 55 and 74 years than they were in those between the ages of 20 and 34 years (Yang et al., 2016).

Individual Differences in Health-information Seeking

In the current thesis, I study the effects of patient exposure to health news. Exposure includes active health-information seeking (HIS) and passive confrontation. There are significant individual differences in the needs and behaviours of patients with regard to HIS. According to the academic literature, actively searching for information about one's own health condition has several positive and negative effects. For example, HIS can reduce negative emotions (e.g., anxiety connected with uncertainty), and reading about the many future treatment options can provide a certain extent of reassurance (Lambert & Loiselle, 2007; Shiloh et al., 1999). In coping with health-threatening situations, HIS behaviours can help patients manage the emotions that accompany these stressful situations, in addition to resolving at least part of the situation. By helping them to focus on

the threatening situation, HIS enables patients to become more engaged with and aware of their disease. Patients who are better informed (e.g., about resources available for managing stressors) are better able to understand the health threat and anticipate associated future difficulties (Lambert & Loiselle, 2007; Rees & Bath, 2001). In addition, HIS can increase patient participation in medical decision-making, as it enhances understanding of the possible treatment options and reduces doubt concerning alternatives (Lambert & Loiselle, 2007). Empirical studies have shown that informed patients conform to medical regimens better, thereby leading to better health outcomes (Sherman et al., 2020). Patient engagement in healthy lifestyles and preventive behaviours is significantly influenced by HIS. The information found through such searching can provide motivation to make positive changes in health practice. The HIS behaviours of patients influence knowledge about the advantages and disadvantages of various health actions, alternative courses of action, and resources for performing healthy behaviours (Lambert & Loiselle, 2007).

In addition to the widely recognised positive effects of HIS, some experts have expressed concern that exposure to an abundance of interim research results may lead patients to experience frustration and false hope (Leask et al., 2010). This effect is especially likely to occur when news messages lack such essential properties as reasonable interpretation of the evidence presented, the timeline for development, the ratio of costs to benefits, and future opportunities for reimbursement (Schwitzer et al., 2005). Given the potential variability in the quality of health-information content, patients may not always possess the skills necessary for interpreting the progress of developments or for predicting and discussing the future success of innovative therapies (Ahluwalia et al., 2010; Ahmad et al., 2006). Low-quality or complex health information can leave patients misinformed or distressed, and it could eventually increase the likelihood of poor self-diagnosis or self-treatment (Ahmad et al., 2006).

Studies have also indicated that patients' trust in physicians can be affected when patients find information (online or elsewhere) that does not align with the treatments proposed by their physicians. As noted by Starcevic (2017), excessive online health research is associated with health anxiety and distress. In addition, Newby et al. (2018) report a relationship with body hyper-vigilance (i.e., a state of heightened sensitivity to physical sensations in the body). The evidence that HIS-related behaviours have dual effects on patients exposed to health information emphasises the need to increase existing scientific knowledge on this issue. It is essential to understand associations between individuals diagnosed with a chronic disease and HIS-related behaviours (e.g., to customise the stream of

health information to personal needs). The search for health information has been documented as an essential coping strategy in health-promoting activities and psychosocial adjustment to illness. Despite the relatively large body of research on HIS, however, negative aspects of message exposure have received relatively little attention. Correlations between HIS and patient characteristics are examined in Chapter 5.

Illness Perceptions

Studies on illness perceptions tend to focus on how individuals experience and mentally frame the experience of living with a disease (Weinman & Petrie, 1997). This may include positive and negative illness beliefs that can influence a patient's ability to cope with the disease and perceive it as manageable or threatening (Bonsaksen, et al., 2015). This thesis examines the relationship between illness perceptions and exposure (particularly active exposure) to news messages. To improve the alignment of the stream of health information with the needs of the various personality types of patients with diabetes, it is essential to understand the antecedents of active news exposure—in other words, the characteristics of patients wishing to read more about diabetes research. Studies in general patient communities have reported that the cognitive representations that individuals have of a disease can directly influence their information-seeking needs (Figueiras & Alves, 2007; Johnson & Meischke, 1993). For this reason, the present research focuses on information-seeking frequency in relation to such illness perceptions. This study is the first to target a group of patients diagnosed with diabetes mellitus Types I and II. The illness perceptions addressed in this thesis are based on a model developed and later refined by Moss-Morris et al. (2002), including the following constructs: consequences, timeline-acute/chronic, identity, personal control, treatment control, illness coherence, and emotional representations.

The 'consequences' dimension describes a patient's perception of the potential effect of an illness. Patients who perceive the consequences of a disease to be more serious are likely to be more motivated to avoid these outcomes by seeking information that could help them better manage their conditions or that reveals new treatment options. Moreover, related emotions (e.g., stress and anxiety) can increase patient involvement in various treatment options (Czaja et al., 2003; Hu et al., 2012; Lambert & Loiselle, 2007). The 'timeline' dimension refers to the perceived chronicity of an individual's illness. Higher perceived chronicity (and thus greater consequences for the patient) is likely to be associated with more frequent online information seeking. The 'identity' dimension refers to the extent to which individuals associate symptoms with their illnesses. Patients who perceive many symptoms may feel a more urgent need to improve their circumstances by

seeking factual information from reputable sources. As demonstrated by Hu et al. (2012), the perception of many signs of disease motivates patients to seek online information in advance of medical appointments. The 'personal control' dimension pertains to the perceptions that individuals have of their ability to control the course of an illness. This dimension is similar to Bandura's (2004) construct of self-efficacy, which facilitates information seeking (Hu et al., 2012; Shaw et al., 2008).

The 'treatment control' dimension refers to beliefs about a treatment's effectiveness for a medical condition. Although it has been hypothesised that patients are likely to be more motivated to seek information when they believe that their current treatment is ineffective (Hu et al., 2012), this has not been confirmed by empirical evidence. The 'illness coherence' dimension represents an individual's overall understanding of an illness. Patients with limited understanding of their conditions are more likely to search for helpful information (Attfield et al., 2006). The 'emotional representations' dimension refers to the beliefs that patients have about their affective reactions to illness. One study reports weak evidence (due to selection bias) that patients who are concerned about and emotionally affected by their illness are more likely to take advantage of online health sources (Hu et al., 2012). As reported by Cotten and Gupta (2004), therefore, people with a positive affect are therefore more likely to seek more information online.

Researchers have yet to conduct a thorough examination of whether illness perceptions can predict an individual's search for news relating to diabetes. Mapping this issue could provide fundamental insight into the prediction of news preferences and the identification of patients who may be vulnerable due to exposure to such news. The relationship between illness perceptions and HIS is examined in Chapter 5.

Trait Optimism

Trait optimism refers to a stable tendency to have positive expectations about the future, even in the face of adversity or challenging circumstances. This personality trait is characterised by a belief that good things will happen, even during difficulties and setbacks. Optimistic individuals tend to focus on the positive aspects of situations and believe that their actions can have a positive influence on outcomes. They also tend to see setbacks as temporary and specific to particular situations, rather than permanent or pervasive. Trait optimism has been associated with many positive outcomes, including better physical health, greater psychological well-being, and increased success in achieving goals. Optimistic individuals may be more resilient in the face of stress, and they may be better able to cope with adverse life events (Carver et al., 2010. This thesis endeavours

to establish a correlation between trait optimism and the proactive exploration of information related to diabetes therapies (HIS). The relationship between trait optimism and HIS is examined in Chapter 5.

Potential Effects on Patients

The current thesis focuses on examining the possible effects that news messages about innovative treatments may have on patients. The news messages that are frequently published about innovations regarding diabetes may have a variety of effects—positive, negative, or mixed—on patients with diabetes who are exposed to news about diabetes. Amongst the positive effects, hope is a distinct sentiment that is considered essential to helping chronic patients cope with disease (Folkman, 2010). Having hope can be defined as perceiving a pathway from a negative situation to a more favourable situation. Higher levels of hope have been found to be associated with lower mortality in older people with diabetes (Moskowitz et al., 2008).

In addition to psychological well-being related to sentiments, it is crucial to consider the behavioural effects of media exposure on adapted behaviours (e.g., decreased adherence to current medical regimens) through mechanisms of altered attitudes, interest in medical science, and behavioural intentions. News messages may alter the perceived seriousness and threat of diabetes, as well as the perceived benefits of and barriers relating to current therapies. Together, these effects could potentially lead differences in attitudes and behavioural intentions. This potential mechanism is based on the theoretical health belief model (HBM), as first developed in the 1950s by the social psychologists Hochbaum et al. (1952) and updated decades later by other scientists (e.g., Janz & Becker, 1984).

The HBM is a theoretical framework developed to explain and predict health-related behaviours based on an individual's beliefs and attitudes (Jones et al., 2015). The model suggests that an individual's willingness to engage in healthy behaviours is influenced by several factors, including perceived susceptibility to illness, perceived severity of the illness, perceived benefits of and barriers to engaging in the recommended behaviour, and cues to action. It assumes that people will take action to prevent or treat an illness if they believe that they are susceptible to it, that the consequences of the illness are severe, and that the recommended action will effectively reduce the risk or severity of the illness. The HBM further suggests that individuals must perceive that the benefits of engaging in the recommended behaviour outweigh the disadvantages, and they must be prompted to take action by some cue or trigger. Overall, the HBM provides a valuable framework for understanding the various factors that influence health-

related behaviours, and it can be used to guide the development of programmes aimed at health education and promotion.

The psychological framework for this thesis, as based on the HBM, is presented in Figure 1.1. Media coverage triggers emotional and cognitive responses based on message characteristics. Responses are also influenced by demographic and psychosocial factors influence the responses. Altered emotions and attitudes may eventually lead to improved or worsened adherence (or intentions thereto) which is of great importance. The management of Type II diabetes involves a variety of therapies, depending on a patient's health status and disease duration. Changes in lifestyle, including physical activity and diet, may improve body mass index, insulin sensitivity and, ultimately, blood glucose levels. Unfortunately, most people with Type II diabetes will require pharmacotherapy to achieve metabolic control, as insulin secretory capacity declines over time (Krass et al., 2015). In the treatment of diabetes, optimal adherence to lifestyle advice and medication regimens is vital. The World Health Organization defines adherence to long-term therapy as 'the extent to which a person's behaviour—taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider' (Vrijens et al., 2012; World Health Organization, 2003, p. 3). Poor medication adherence is a complex problem that is associated with various risk factors (Brown et al., 2016). As reported in a review by Krass et al. (2015), the prevalence of adherence among patients with Type II diabetes ranged from 38% to 93% in 27 study populations, with depression and medication costs as potential predictors. The associations between adherence and other factors were inconsistent across the studies reviewed. For this reason, the present thesis aims to generate further insight into correlations between factors in diabetes-related news and adherence (or the determinants thereof).

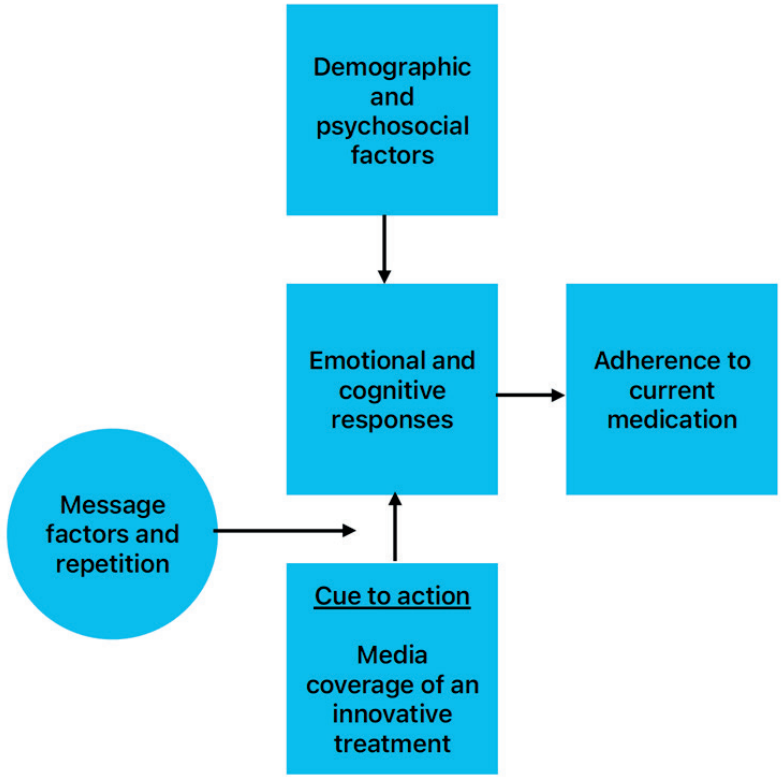

Figure 1.1: A modified version of the Health Belief Model developed by Janz and Becker (1984) was formulated and employed as the foundation for the current research inquiries.

Outline of the Thesis

The overarching question guiding this thesis project is as follows: *How are the characteristics of news about diabetes-related innovations related to cognitive outcomes (e.g., emotions, attitudes, intentions) in patients diagnosed with diabetes mellitus?*

To quantify aspects of news messages about innovative ways to treat diabetes, **Chapter 2** describes a quantitative corpus analysis of Dutch newspaper articles and the extent to which they contain clinical evidence on actual human patients. Evidence versus speculation ratios were assessed for a variety of relevant scientific fields (e.g., nutrition/diet, pharmacy, movement sciences). The study is guided by the following research question (**RQ1**): *To what extent do newspapers refer to clinical evidence when transmitting news about diabetes-related innovations?*

In **Chapter 3**, news posts to Facebook groups and subsequent user reactions are analysed for associations between characteristics of web-based diabetes-related news and reader sentiments. This quantitative corpus analysis of social media content is guided by the following research question (**RQ2**): *How are readers' sentiments associated with characteristics of news about diabetes-related innovations (phase, language intensity, treatment type) on Facebook?*

Chapter 4 describes an experimental study on the effects of characteristics of diabetes-related news on the perceptions and attitudes of patients concerning medical innovations and therapy adherence. This study was guided by the following research question (**RQ3**): *How are the treatment-adherence intentions and attitudes of readers associated with characteristics of news about diabetes-related innovations (phase, language, authority of the source).*

Chapter 5 reports on a quantitative survey investigating associations between the frequency of health-information seeking frequency and the characteristics of patients diagnosed with diabetes. This cross-sectional study was guided by the following research question (**RQ4**): *How is the frequency of health-information seeking by patients diagnosed with diabetes associated with their illness perceptions and trait optimism*?

Chapter 6 reflects on the key findings and contributions of the research, including an analysis of the results in relation to the research objectives. Furthermore, it discusses the implications, significance, and limitations of the research. Lastly, it offers insights into potential future directions for further investigation.

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CHAPTER 2

Clinical Evidence vs Preliminary Speculation in Newspaper Coverage of Diabetes Innovations: a Quantitative Analysis

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Abstract

Objectives

Researchers have discussed that journalistic reporting of medical developments is often characterised by exaggeration or lack of context, but additional quantitative evidence to support this claim is needed. This study introduces a quantitative approach to assessing coverage of medical innovations, by aiming at provided references to observed clinical effects. Although observed clinical effects reflect increased chances for future medical applications, it is unknown to which extent newspaper articles refer to it when spreading health information. We aimed to assess, over a 6-year period, newspaper publication characteristics of diabetes innovations, arising from all scientific areas of interest, regarding the total count and the proportion of articles that provide references to demonstrated clinical efficacy.

Study Design

Quantitative content analysis of newspaper articles covering innovative treatments for diabetes.

Methods

We performed a systematic review of newspaper articles between 2011 and 2016 printed in the largest six Dutch newspapers. By assessing in-article references, it was possible to quickly distinguish between (1) articles that referred to actual clinical efficacy demonstrated in a scientific setting and (2) articles that presented either predictions, fundamental research, preclinical research or personal experiences and recommendations. Proportion differences between scientific areas of interest were analysed using the chi-squared test.

Results

A total of 613 articles were categorised. Total newspaper publication frequency increased with 9.9 articles per year (P = .031). In total, 17% of the articles contained a reference to any proven clinical efficacy. Articles about human nutrition science (7%; P =.001) and (neuro)psychology (4.3%; P =.014) less frequently provided a reference to actual clinical efficacy.

Conclusions

Our findings show that less than one in five newspaper articles about diabetes research contains a reference to relevant clinical effects, while the publication count is increasing. These statistics may contribute to feelings of false hope and confusion in patients.

Diabetes innovations like the artificial pancreas receive extensive media coverage,[1] but the adequacy of media coverage is not always guaranteed. Medical scientists argue that news is often hampered by exaggeration and lacks context.[2,3] Regardless if health journalism is sloppy or intentionally fake, invalid claims pollute public health information and threaten individual decision-making.[4] Unrealistic expectations of treatment may evoke rejection of other modest but achievable goals.[5]

In media, also non-medical professionals recommend unusual ways to combat diabetes and its symptoms. Real examples are in economy sections ('We grow micro-vegetables that treat diabetes') and recipes ('Adding cinnamon lowers glucose levels'). A significant public interest in lifestyle improvements blurs the border between serious diabetes news and messages that lack scientific proof of their therapeutic concept.

Quantitative evidence regarding characteristics of diabetes coverage is lacking but is crucial to obtain an objective picture of news quality. We conducted a systematic review of Dutch newspaper articles published in a 6-year period. Our goal was three-fold. First, to find a possible trend in diabetes coverage, we quantified the number of articles that contained news, tips, speculations or predictions about innovative treatments for diabetes (all types). Second, to estimate the proportion of viable medical developments covered in the news, we assessed if claims were supported with in-article references to proven clinical efficacy in patients. Third, to explain a possible lack of references to clinical efficacy, we distinguished between scientific areas in the news reports.

We performed a quantitative content analysis of Dutch newspaper articles published between January 2011 and December 2016. The LexisNexis database was searched for paper-printed newspaper articles from the six largest national newspapers in the Netherlands. Keywords were 'diabetes' in combination with Dutch words, referring to the development of medical innovations: therapy, treatment, science, development, expectation, hope, optimism, breakthrough, innovation, revolutionary, life-saving, intervention or possibilities. This resulted in the extraction of 2699 articles that were manually scanned for describing (a) potential relationships of a substance, method, environmental condition, behaviour or medical device, with medical diabetes outcomes (e.g. insulin susceptibility, quality of life, weight) or with diabetes risk outcomes (e.g. 'stevia prevents diabetes'), (b) foreign treatments that were not registered or reimbursed in the Netherlands or (c) forecasts of future scientific developments. Articles solely describing an available standard therapy were not included. Duplicate articles

were removed, but different articles about one topic were assessed individually. Thus, 613 articles were included, ranging from news texts and background articles to interviews, columns and lifestyle features, covering diabetes innovations as the central topic or mentioning them in passing. The six newspapers were treated as a single group because of high similarities in genres, audience and self-proclaimed journalistic roles.

References to empirically demonstrated clinical efficacy were confirmed when two conditions were satisfied: (1) the article indicated that medical outcomes or biomarkers were positively affected in at least one patient; and (2) the article specified the scientific environment in which efficacy was measured in a systematic and controlled manner (i.e. name of a university, scientist, study, academic journal or industrial R and D department). The combined outcome measure distinguishes health claims with a reference to any proof of its theoretical concept[6] from earlier research (e.g. preclinical, observational) and speculation.

Approximately 90% of the articles fitted five scientific areas: (a) pharma, biomedical and genetics research; (b) human nutrition sciences; (c) human movement science; (d) medical devices and information and communication technology (ICT); and (e) (neuro)psychology. Furthermore, we created a group called 'other' to categorise the remaining topics, including surgical procedures. Statistical analyses were performed using SPSS software. Statistical significance was defined as $P < .05$. Frequency differences were tested with chi-squared calculations. Linear regression slope was calculated to find a possible increase or decrease in articles.

We found that, annually, the six largest Dutch newspapers together publish on average 102.2 (±21.7) articles about innovative ways to diagnose, treat or prevent diabetes (Table 2.1). This number increased by 9.9 articles per year ($P = .031$). Only 17.0% of the diabetes treatments were supported by references to clinical efficacy (Table 2.1).

Most reported innovations arose from 'human nutrition sciences' (30.3%) and 'pharma, biomedical and genetics research' (26.9%). Less contributing groups were 'medical devices and ICT' (12.7%), 'human movement sciences' (8.3%) and '(neuro)psychology' (7.5%).

Referencing differences between all scientific areas was significant ($P < .001$). Also, articles about nutrition less frequently referred to efficacious (diet)therapies (7.0%; $P < .001$) when compared with all other groups combined. Furthermore, also articles in the category (neuro)psychology less often contained references to

clinical efficacy (4.3%; P = .042) when compared with all other groups combined. No other differences were found.

Table 2.1: Publication count of innovative methods to treat Diabetes, and references to actual clinical efficacy (CER), in the largest six newspapers in the Netherlands: total, by year, and by scientific area.

Characteristics	Messages(%)	CER %
Total	613	17.0
Year		
2011	83	20.5
2012	72	27.8
2013	112	16.1
2014	107	14.0
2015	106	17.9
2016	133	11.3
Trend	**9.9**[a]	-2.2[b]
Scientific Area[c]		
Pharma, Biomedical, Genetics Research	165 (27)	25.5
Human Nutrition Science	186 (30)	**7.0**[d]
Human Movement Science	51 (8)	17.6
Medical Devices & ICT	78 (13)	28.2
(Neuro)psychology	46 (8)	**4.3**[e]
Other	87 (14)	18.4

[a] *P=.031; 2-sided*

[b] *P=.107; 2-sided*

[c] *Different CER between all groups ($x^2(5)=33.9;P<.001$)*

[d] *Different versus other groups combined ($x^2(1)=18.9;P<.001$; 2-sided)*

[e] *Different versus other groups combined ($x^2(1)=5.6;P=.014$; 2-sided)*

Statistical significance P>.05 is shown in bolt

The sheer number of diabetes publications is in line with the large quantity of diabetes information observed in US newspapers.[1] Its increase corresponds to the population's increasing interest in lifestyle-related information.[7] Regardless of content and tone, large news volumes about a topic affect immediate examples that come to patients' mind and influence risk perception.[8]

Our data show that the availability of empirical evidence for clinical efficacy is not conditional for communicating innovative diabetes treatments in Dutch newspapers. Less than one in five newspaper articles provided any references.

The lack of actual evidence may have undesirable consequences on patients' hope, confusion, and, perhaps, on health decisions.[4]

Especially, nutrition-related messages lacked reference to experimental evidence for diet modifications. The difference is explained by the frequent dissemination of observational study results demonstrating relationships between nutrition and health and unintentionally stimulating rumours about diets. The absence of references in articles covering (neuro)
psychology is, to a great extent, explained by fundamental research on sleeping patterns and stress.

Many journalists share a sense of responsibility to care for audiences and improve their well-being.[9] Reporting facts instead of disseminating opinion improves this.[10] However, the journalistic system is under pressure. Firm deadlines, together with increasingly sophisticated medical studies, compromise the correctness of health claims. Moreover, while specialist health journalists still emphasise interpretation over facts and, therefore, guide readers' understanding of medical numbers and figures, such contextualisation is often absent in generic journalism.[10] The resultant large amounts of fact-free news about diabetes may pollute public perceptions and people's trust in medical innovation.

More analyses are needed to assess trends in online media. Observational and experimental studies should examine the potential effects of factual and fact-free health claims on diabetic patients' emotions, cognition and behaviours.

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CHAPTER 3

Associations Between Characteristics of Web-Based Diabetes News and Readers' Sentiments: Observational Study in the Netherlands

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Abstract

Background
Although experts agree that Web-based health information often contains exaggeration and misrepresentation of science, it is not yet known how this information affects the readers' sentiments.

Objective
This study aimed to investigate whether specific aspects of Web-based diabetes research news are associated with positive or negative sentiments in readers.

Methods
A retrospective observational study of the comments on diabetes research news posted on Facebook pages was conducted as a function of the innovations' developmental phase, the intended treatment effect, and the use of strong language to intensify the news messages (superlatives). Data for the investigation were drawn from the diabetes research news posted between January 2014 and January 2018 on the two largest Dutch Facebook pages on diabetes and the corresponding reader comments. By manually coding these Facebook user comments, three binary outcome variables were created, reflecting the presence of a positive sentiment, the presence of a negative sentiment, and the presence of a statement expressing hopefulness.

Results
Facebook users made a total of 3710 comments on 173 diabetes research news posts that were eligible for further analysis. Facebook user comments on posts about diabetes prevention (odds ratio [OR] 0.55, 95% CI 0.37-0.84), improved blood glucose regulation (OR 0.68, 95% CI 0.56-0.84), and symptom relief (OR 0.31, 95% CI 0.21-0.44) were associated with less positive sentiments as compared with potential diabetes cures. Furthermore, comments on innovations supported by preclinical evidence in animals were associated with more positive sentiments (OR 1.46, 95% CI 1.07-1.99) and statements expressing hope (OR 1.47, 95% CI 1.01-2.14), when compared with innovations that have evidence from large human trials. This study found no evidence for the associations between language intensification of the news posts and the readers' sentiments.

Conclusions
Our finding that the attitudes toward diabetes research news on Facebook are most positive when clinical efficacy is not (or not yet) proven in large patient trials suggests that news authors and editors, as well as medical professionals, must exercise caution when acting as a conduit for diabetes research news.

Background

Patients who monitor online media for health information may experience frequent exposure to exaggeration and misrepresentation of medical science [1-5]. Two typical examples of such infelicitous reporting are the depiction of observed correlations as causal connections—for example, between lifestyle behaviours and disease outcomes—and the inflation of preclinical animal testing results, often followed by the inference of these to humans [6,7]. This is misleading when one considers that about 88% of the pharmaceutical developments that reach the first human trials will never reach the phase of market approval [8]. Such misrepresentations are present in numerous easily accessible health news sites and are spread freely on social media such as Facebook.

Earlier research by our group, on the media coverage of innovative diabetes therapies, found that 83% of Dutch newspaper reports about innovative diabetes treatments lack any reference to clinical trials in humans [9]. Similarly, in the United States, a study on health news appraisals found that most authors do not satisfactorily discuss the quality of the evidence [6].

Although, to our knowledge, there is no literature on the effects of news reporting on the patients' attitudes, it is highly plausible that messages about promising future treatments could affect the readers' sentiments such as enthusiasm and curiosity. Moreover, a patient's level of hope may increase, which is positive as having hope is associated with more favourable diabetes outcomes [10,11]. The effects may also turn out to be negative when, for example, feelings of impatience or disbelief are more prominent.

Overall, 3 aspects of Web-based reporting may influence attitudes. First, the tone of the reports, using intensified language (eg, revolutionary and breakthrough), a common phenomenon in health news coverage [12], may amplify these sentiments.

Second, attitudes may be affected by the references to an innovation's developmental phase. Important innovations are covered for many years and during different research stages. For the readers, it may remain unclear as to how long it would take for the innovation to be available in clinical practice. An example is the artificial pancreas, a concept for the treatment of diabetes that has been reported since 1972 [13]. Third, reports on future cure-focused innovations, such as pancreatic cell transplantation for diabetes, may potentially have a stronger impact on the readers' sentiments than news about non-cure-focused treatments.

Objectives

To increase the understanding of the associations between the characteristics of news about future treatments for chronic illnesses and the readers' sentiments, we assessed the posts about diabetes research on Facebook pages, together with the corresponding user comments.

Methods

Data Source

A retrospective observational study was performed on a corpus of diabetes news messages posted on publicly accessible Facebook pages between January 1, 2014, and January 1, 2018, and the associated reader comments. Facebook pages enable public figures and businesses to create a public presence on Facebook. Every person on Facebook can connect with these pages by liking them, after which they receive updates in their news feed and can interact with them [14]. The 2 most-followed publicly accessible diabetes pages in the Netherlands were selected: (1) Juvenile Diabetes Research Foundation (JDRF) Nederland [15], the Dutch division of an international type 1 diabetes research foundation, with over 27,000 Facebook followers and (2) Diabetes Fonds [16], a Dutch charity funding of research on all types of diabetes, with over 36,000 Facebook followers.

Data extraction and preparation comprised multiple steps (Figure 3.1). First, all news posts and associated readers' comments were extracted for the 4 years from January 1, 2014, to January 1, 2018. The Facepager tool, version 3.8.2., developed by Jünger and Keyling [17], was used to scrape the publicly available data from the Facebook pages, including all reader comments. Replies were excluded (i.e., comments on comments) as their content and sentiments are influenced by the initial comments on the news posts. Second, all nonscience news–related posts were identified and removed from the corpus. Furthermore, 3 criteria for diabetes research posts were applied: (1) it must contain information about the development of an innovative therapy, technique, product, instrument, or insights into preventive behaviours; (2) it must contain a reference to a traceable scientist or scientific institution (including medical companies); and (3) it must refer to an innovation which is not (or not yet) applied in the Dutch standard diabetes care. Therefore, nonmedical and nonscientific topics (eg, personal experiences, practical tips, travel stories, and fundraising) were excluded. The consensus between 2 raters in a subsample of 14.99% (271/1808) of the comments on initial Facebook posts was used to resolve disagreements. The third step was to extract the source

message (eg, Web-based newspaper item) whenever a hyperlink was available and to merge it with the post content.

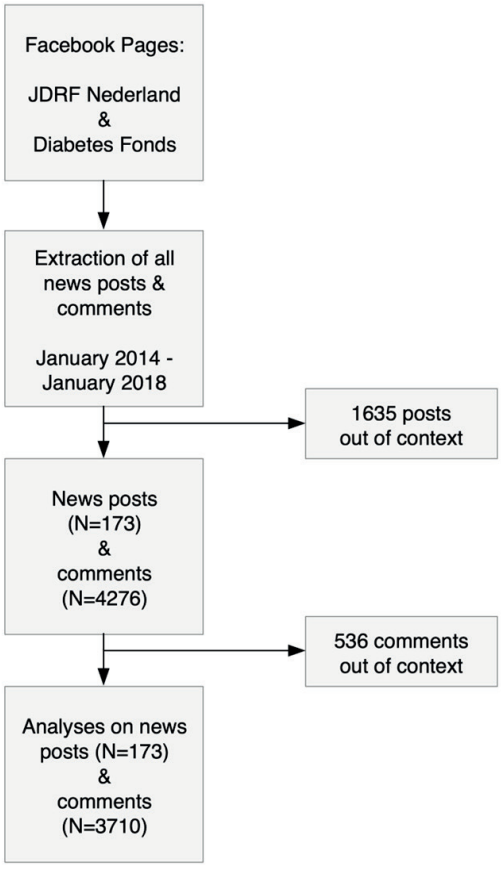

Figure 3.1: Overview of the Data Extraction and Preparation. JDRF: Juvenile Diabetes Research Foundation.

Data Classification

All user comments were evaluated by 2 raters as to whether they contained sentiments (positive, negative, or both). Focus was put on both textual expressions (ie, words and sentences) and the use of emoticons [18,19]. The initial interrater reliability in a subsample of 15% of the sentiments was high (kappa=0.80). For the remainder of the sample, any disagreements were resolved by consensus and, where uncertainties remained, by a third reviewer.

Dependent Variables: Positive Sentiments and Written Expression of Hopefulness

In the literature, sentiment analyses generally focus on a combined outcome: sentiment polarity (i.e., coding a single sentiment expression as either positive, negative, or neutral)[20]. As the readers' comments may include a combination of positivity (eg, enthusiasm and hopefulness) and negativity (e.g., frustrations about waiting for a long time), both positive and negative sentiments were detected and coded for this study. The binary dependent variable positive sentiment in a comment was manually detected and coded as present, when the following paraphrase described the utterance correctly: The Facebook user had the aim to express a positive emotion, attitude, or affective state in reaction to a corresponding post about innovative diabetes treatments. Signal examples were expressions of interest, curiosity, enthusiasm, attraction, desire, admiration, surprise, amusement, hope, excitement, gratitude, thankfulness, joy, elation, triumph, jubilation, patience, and contentment [21-23].

Individuals on the Facebook pages on diabetes frequently express that they have hopes or are very hopeful, or type let's hope so! Hope is a distinct positive sentiment that is considered essential for chronic patients to cope with their disease [24,25]. Having hope can be defined as perceiving a pathway from a negative situation to a favourable state of affairs [26]. Higher levels of hope were found to be associated with a lower prevalence of diabetes [10] and lower mortality in elderly people with diabetes [11].

A binary hopefulness-estimate was created to put a focus on hope as a distinct and essential positive sentiment. In all Facebook comments, the presence of the following Dutch and English conjugations and adjectives based on the verb to hope (Dutch: hopen) was programmatically detected by using Python programming language [27]: hoop, hoopt, hopen, hoopte, hoopten, gehoopt, gehoopte, hopelijk, hope, hoped, hoping, hopeful, and hopefully.

Dependent Variables: Negative Sentiments

The binary dependent variable negative sentiment in a comment was manually detected and coded as present, when the following paraphrase described the utterance correctly: The Facebook commenter had the aim to express a negative emotion, attitude, or affective state in reaction to a corresponding post about innovative diabetes treatments. Signal examples were expressions of indifference, habituation, boredom, aversion, disgust, revulsion, alarm, panic, fear, anxiety, dread, anger, rage, sorrow, grief, frustration, disappointment, discontentment, and restlessness [21-23].

The act of expressing and sharing these Facebook post–related emotions reveals an underlying negative sentiment toward the aspects of the innovation or the news message. Commenters sharing, for example, their boredom or indifference on the Web are unlikely to recommend other patients to try the innovation in the future, nor will they follow the news about the therapy actively; positive and neutral reactions would leave these latter 2 behaviour options open.

Independent Variables: Intended Therapeutic Effect

Overall, 2 raters identified the intended therapeutic effects of diabetes innovations through discussion and then specified the 5 major categories. These therapeutic effects yielded by diabetes research ranged from simple, practical solutions to a complete cure (Table 3.1).

Table 3.1: Six categories of intended diabetes research effects with examples.

Intended effect	Examples
Prevention	Research on a viral trigger for type 1 diabetes; effects of hygiene; nanotechnology; early diagnosis
Practical solution	Hypo alarm watch; an insulin temperature sensor; hypo watchdog; glucose monitoring app; diabetic shoe
Symptom control and relieve	Cognitive behavioural therapy; research on nephropathy; research on cardiomyopathy in type 2 diabetes
Glucose regulation	Artificial pancreas; inhalable insulin; Con-Ins G1; insulin delivery system
Diabetes curation	Beta cells encapsulation; viral gene transfer; the discovery of immature beta cells; transplanting pancreatic cells; effects of vitamin D

Independent Variables: Developmental Phase

Furthermore, the developmental phases of innovative diabetes therapies were identified. First, the references to research results in the Facebook posts itself were searched for. When a reference was missing, and a hyperlink was available, the source of the news message was examined. In a previous study, our research group distinguished the different research phases, or the levels of evidence, in health news [9]. Health news articles may contain a reference to positive results from (in the increasing order of reliability) (1) observational, often epidemiological, studies, (2) fundamental research on concepts and theories to improve understanding, (3) preclinical (eg, animal studies) and nonclinical studies to support concrete product development, and increasing the chances for clinical trials in humans to start soon, (4) clinical trials in a small sample of humans (eg,

phase II pharmaceutical trials), (5) clinical trials in a large population of humans (eg, phase III pharmaceutical trials), and (6) reports on near-market entry whenever a marketing registration has been or soon will be provided by domestic or overseas authorities. The developmental phase was labelled as not described, when the research phase was not recognizable either in the Facebook posts or the source message. In total, 2 raters independently scored a subset of 15% of the news posts (kappa=0.92). Consensus was used to resolve disagreement and indistinctness, and 1 rater subsequently coded the remaining 85%.

Independent Variables: Language Intensity

Language intensifiers were defined as words that are used to enhance and give emotional context to the other words that they modify. Literature also refers to such words as the pars pro toto superlatives [28,29].

By using Python programming code [27], all words in all Facebook posts were automatically counted and listed in the order of word usage frequency. First, after selecting 2 commonly used designations of the US Food and Drug Administration, breakthrough and promising [3] (Dutch: doorbraak and veelbelovend), 2 raters discussed and selected the following 15 most frequently used language intensifiers used in the diabetes research news posts: fabulous, beautiful, great, special, important, at last, lifesaving, discovery, dream, positive, powerful, truly, enormously, super, and happy (Dutch: geweldig, mooi, fijn, bijzonder, belangrijk, eindelijk, levensreddend, ontdekking, droom, positief, krachtig, werkelijk, ontzettend, super, and blij). Second, the 17 intensifiers were searched for and counted per Facebook post, and the number was converted into a 3-category variable: no text intensifiers, 1 or 2 intensifiers, and 3 to 9 intensifiers.

Analysis

The IBM SPSS Statistics program, version 25, was used to evaluate the differences in the probabilities that sentiments (positive, negative, and hopefulness) were reflected in the user comments, depending on the developmental phase, intended therapeutic effect, and the presence of language intensifiers in the text. Crude and mutually adjusted binary logistic regression models were used to calculate odds ratios (ORs) and 95% CIs. Furthermore, it was assessed whether Facebook pages ID, commenter ID, and gender data contributed to the logistic regression models.

Results

Innovative Methods

Table 3.2 shows that between January 1, 2014, and January 1, 2018, a total of 173 diabetes news messages about innovative methods to treat diabetes were posted on the 2 largest publicly accessible Facebook pages in the Netherlands. These posts evoked 3710 reader comments, containing a total of 2727 positive, 880 negative, and 363 neutral sentiments and 513 verbal expressions of having hope.

Sentiments and the Innovation's Intended Therapeutic Effect

First, it was tested whether the news messages about the innovative ways to cure diabetes were associated with different sentiments than the news messages related to other therapeutic effects. Table 3.3 shows that diabetes prevention (OR 0.55, 95% CI 0.37-0.84), improved blood glucose regulation (OR 0.68, 95% CI 0.56-0.84), and symptom relief (OR 0.31, 95% CI 0.21-0.44) were associated with less positive sentiments as compared with potential diabetes cures. Moreover, Table 3.3 shows that the analyses of negative sentiments show a similar pattern, although this was only significant in blood glucose regulation (OR 1.38, 95% CI 1.12-1.70; for being associated with more negative sentiments). Table 3.4 shows that, in line with the readers' positive sentiments, hopefulness was most frequently expressed when Facebook news reported on cure-focused therapies.

Table 3.2: The number of extracted news posts and user comments; by subgroups of three Facebook post characteristics.

	News Posts (n)	User comments n (%)	Comments per Post (n)
Total	173	3710	21
Intended therapeutic effect			
Disease prevention	16	211 (6)	13
Practical solution	14	250 (7)	18
Symptom relieve	11	182 (5)	17
Improved glucose regulation	56	1341 (36)	24
Curation	76	1726 (47)	23
Developmental phase			
Evidence from fundamental research	47	859 (23)	18
Evidence in pre-trial phases	32	758 (20)	24
Evidence in small human trials	33	712 (19)	22
Evidence in large human trial	10	434 (12)	43
(near)Market entry	14	259 (7)	19
Evidence in observational studies	12	185 (5)	15
Not described	25	503 (14)	20
Comment sentiments			
Positive only	-	2467 (66)	-
Negative only	-	620 (17)	-
Mixed positive and negative	-	260 (7)	-
Positive; incl. mixed	-	2727 (74)	-
Negative; incl. mixed	-	880 (24)	-
Neutral	-	363 (10)	-
Verbal expressions of ‘having hope’	-	513 (13%)	

Table 3.3: Logistic regression analysis of the association between three characteristics of diabetes science coverage in Facebook posts (mutually adjusted) and *positive and negative sentiments* in user comments on Facebook Pages.

		Positive sentiment			Negative sentiment		
	FB posts, N	Yes, n(%)	No, n(%)	OR (CI)	Yes (%)	No (%)	OR (CI)
Intended therapeutic effect							
Diabetes prevention	16	94 (1)	117 (10)	**0.55 (0.37-0.84)**	85 (10)	126 (4)	1.48 (0.98-2.25)
Practical solutions	14	196 (9)	54 (9)	1.01 (0.71-1.44)	52 (6)	198 (7)	1.01 (0.71-1.45)
Symptom relieve	11	86 (2)	96 (8)	**0.31 (0.21-0.44)**	49 (6)	133 (5)	1.24 (0.84-1.82)
Blood glucose regulation	56	970 (36)	371 (36)	**0.68 (0.56-0.84)**	343 (39)	998 (35)	**1.38 (1.12-1.70)**
Diabetes curation[1]	76	1381 (52)	345 (37)	1.0	351 (40)	1375 (49)	1.0
Developmental phase							
Observational evidence	12	61 (2)	124 (13)	**0.31 (0.15-0.66)**	79 (9)	106 (4)	**1.88 (1.17-3.02)**
Fundamental evidence	47	610 (22)	249 (25)	**0.71 (0.53-0.95)**	238 (27)	621 (22)	1.22 (0.92-1.63)
Preclinical evidence	32	639 (23)	119 (12)	**1.46 (1.07-1.99)**	112 (13)	646 (23)	**0.55 (0.41-0.76)**
Small Trial evidence	33	541 (20)	171 (17)	1.06 (0.80-1.42)	147 (17)	565 (20)	**0.75 (0.56-1.00)**
Large Trial evidence[1]	10	317 (12)	117 (12)	1.0	115 (13)	319 (11)	1.0
(Near) market entry	14	175 (6)	84 (9)	0.73 (0.52-1.04)	70 (8)	189 (7)	1.39 (0.90-2.14)
Not mentioned	25	384 (14)	119 (12)	1.03 (0.76-1.40)	119 (14)	384 (14)	0.96 (0.71-1.31)
Language intensifiers							
3 -9 intensifiers	21	380 (14)	156 (16)	0.97 (0.75-1.25)	132 (15)	404 (14)	1.12 (0.86-1.45)
1-2 intensifiers	55	1120 (41)	314 (32)	1.13 (0.94-1.35)	334 (38)	1100 (39)	1.18 (0.99-1.42)
0 intensifiers[1]	97	1227 (45)	513 (52)	1.0	414 (47)	1326 (47)	1.0

[1]*reference category*

Facebook page ID was entered and removed from this model.

Text intensifiers were a non-significant addition to this model but were left in the model to answer study questions.

Statistical significant ORs in bold

Table 3.4: Logistic regression analysis of the association between three characteristics of diabetes science coverage in Facebook posts (mutually adjusted) and *expressed hopefulness (e.g. hopefully; I hope)* in user comments on Facebook Pages.

		Textual expression of hopefulness		
	News posts N	Yes, n(%)	No, n(%)	OR (CI)
Potential therapeutic effect				
Prevention	16	15 (3)	196 (6)	0.92 (0.50-1.72)
Practical solution	14	10(2)	240 (8)	**0.18** (0.09-0.36)
Symptom relieve	11	4 (1)	178 (6)	**0.13** (0.05-0.36)
Glucose regulation	56	136 (27)	1205 (38)	**0.49** (0.38-0.64)
Diabetes curation[1]	76	348 (68)	1378 (43)	1.0
Developmental phase				
Observational evidence	12	2 (0)	183 (6)	**0.07 (0.02-0.33)**
Fundamental evidence	47	133 (26)	726 (23)	0.97(0.65-1.43)
Preclinical evidence	32	164 (32)	594 (19)	**1.47 (1.01-2.14)**
Small Trial evidence	33	96 (19)	616 (19)	1.26 (0.85-1.87)
Large Trial evidence[1]	10	46 (9)	388(12)	1.0
(Near) market entry	14	18 (4)	241 (8)	0.89 (0.49-1.59)
Not described	25	54 (11)	449 (14)	0.93 (0.61-1.43)
Language intensifiers				
3 -10 intensifiers	21	72 (28)	870 (37)	0.97 (0.62-1.52)
1-2 intensifiers	55	128 (50)	879 (37)	1.22 (0.80-1.86)
0 intensifiers[1]	97	54 (21)	620 (26)	1.0

[1]reference

Facebook page ID was entered and removed from this model.

Text intensifiers were a non-significant addition to this model but were left in the model to answer the study question.

Statistical significant ORs in bold

Sentiment and the Innovation's Developmental Phase

Furthermore, it was examined whether the commenters' sentiments were related to the covered innovations' developmental phases. Tables 3.3 and 3.4 show that, compared with the success in the larger patient trials, evidence from the preclinical phases led to more positive sentiments (OR 1.46, 95% CI 1.07-1.99). Earlier observational (OR 0.31, 95% CI 0.15-0.66) and fundamental findings (OR 0.71, 95% CI 0.53-0.95), however, led to less positive sentiments. Tables 3.3 and 3.4 also show that this sentiment pattern was, for the most part, confirmed in the analysis of

negative sentiments and the expressions of hopefulness. Sentiment and News Message Language Intensification It was examined whether the intensification of language was associated with sentiments and hopefulness. However, Tables 3.3 and 3.4 show that there were no significant relationships between the language intensification of Facebook posts about diabetes research and the sentiments (positive, negative, and hopefulness) of those who reacted to it on Facebook.

Controlling for Other Variables

To verify the robustness of our findings, additional variables and levels were tested for any effect on our regression analysis. It was found that the Facebook pages ID (JDRF Nederland vs Diabetes Fonds) did not contribute to the regression models. Furthermore, data on the commenters' gender were available for 71% (2634/3710) of the comments with identifiable sentiment (the first batch of 2 data extractions). Analysis of this sample showed that controlling for gender did not greatly alter the patterns and magnitudes of our results. In addition, the necessity to include commenter ID as a level in our regression model was rejected owing to the flat distribution of comments by the commenters in the same subsample: 80% (1495/1870) of the commenters commented once only.

Our final model only contained the 3 main independent variables: therapeutic effect, developmental phase, and language intensification.

Discussion

Principal Findings

In this analysis of 4 years of Facebook posts and comments on diabetes news and user sentiments, posts about potentially curative innovations were associated with more positive general sentiments than the posts not about potential cures, as expected.

However, unexpectedly, innovations supported by evidence from phases just before human clinical trials showed the strongest positive association with improved general sentiments. The observational research results were associated with the most negative general sentiments in the user comments. In addition, and contrary to our expectations, this study found no evidence for the associations between language intensity and the readers' sentiments.

Explanation of Findings

A strong positive association was found between cure-focused innovations and positive sentiments. The explanation for this finding is likely to be the absence of cure-focused therapies, to date, for the debilitating disease that diabetes still is. However, negative sentiments may also be provoked by cure-focused innovation, for example, when frustrations about perceived false promises have the upper hand. The strong negative association between the written expression of hopefulness and the news about non-cure-focused innovations suggests that the concept of hopefulness only plays a role regarding the desire for a cure.

When looking at the developmental phases, general sentiments were most positively associated with positive results in the preclinical phases closely before human trials. This finding conflicts with the scientific standard that the proof of concept is demonstrated by doing randomised clinical trials. Although it was not assessed by us, an explanation for the preclinical positivity may be the overly optimistic way in which news outlets frequently cover animal studies [30].

Negative associations of the fundamental research with positive sentiments can be explained using construal level theory [31]. First, as the success of therapies in the earliest research stages is far away in time, the patient's thinking about these innovations becomes more abstract and the consequent anticipation may decrease. Frequently, the medical applicability of very early stage therapies is indeed abstract. A second explanation may be that bad personal experiences, with waiting for other cure-focused innovations, affect the so-called experiential distance (ie, perception of the chance that treatment may become a reality, based on earlier experiences).

Specific research topics may explain the strong association between observational research and the less positive general sentiments. Both disbelief and powerlessness in readers may have arisen from Facebook posts that describe how patients should have behaved in the past to prevent their disease. Furthermore, the association between the less positive general sentiments and the news about near-market innovations may be related to fears and frustrations regarding low availability and the doubt on medical insurance coverage.

A possible explanation for the absence of associations between language intensifiers in the news content and the sentiments may have its origin in the characteristics of our target population. Patients and others interested in diabetes seemed to be able to distinguish between the objective content and the subjective use of language. People commenting on the investigated diabetes pages are

involved in the burdens of the chronic disease—enduring much and awaiting therapies for many years—and their emotions may not (or may no longer) be as affected by the subjective language.

Implications of This Study

Previous studies suggest that exaggeration of medical research is a problem [1-7]. Our study shows no evidence that language intensifiers are associated with the sentiments of the online diabetes populations. However, improved positive sentiments were found regarding the preclinical trials—just before evidence from humans—that give reason to suspect an undesired effect of health news exaggeration. The Facebook comments were enthusiastic and full of hope, despite the fact that about 88% of the pharmaceutical developments that reach the first human trials will never reach the phase of market approval [8].

These findings suggest that exaggeration is not limited to language intensification and other verbal inflation of research findings. It is the sheer coverage frequency of specific health research that may lead to positivity and hope, which is not always justified. The mental shortcut availability heuristic relies on the immediate examples that come to a person's mind, possibly putting too much weight on medical information when they read about it frequently [32]. At the same time, the importance of having hope when suffering from a chronic disease must not be underestimated. Hope mediates the relationship between psychological distress and health status and is an essential factor to cope with a disease [24,25]. High-quality health information is increasingly important. Responsible news authors must give context, interpret scientific findings, filter what is important to their target group, and act as an honest and valid conduit, especially as the role of social media is increasing every year [33]. Furthermore, the specific importance of social media to patients must be emphasised. Platforms such as Facebook or Twitter provide tailored information, increase the accessibility of news, and function as social and emotional peer supporters [34-36]. Being well-informed about scientific developments fulfils an essential need for the health information–monitoring patient [37], and it is known that the patients' subjective well-being also clearly and positively affects health and all-cause mortality [38].

Strengths and Limitations in Comparison With Other Studies

To our knowledge, our study is the first to quantitatively investigate the associations between the health news characteristics and the sentiments of readers dealing with chronic illnesses. Moreover, an extra focus was put on the written expressions of being hopeful, enabling the confirmation of general sentiment associations in 1 specific disease-related sentiment. By assessing common language intensifiers,

it was possible to differentiate between the objective characteristics of the news posts and a subjective language component. Our large sample size enabled us to mutually adjust the 3 news-related variables. Moreover, the validity of our sentiment outcome increased as offhand comments were observed, written down in an unforced situation. By using a Python regular expression search, the reliability of finding all language intensifiers was high. In addition, the kappa values for rating sentiments and coding message characteristics were high, and coding consensus was achieved regarding occasional discrepancies.

This study does, however, have limitations. First, it is not known what our population's exact proportion sizes are regarding the patients, their social context, and others who were perhaps only momentarily interested in diabetes and left a comment. Moreover, although the language intensifiers were included, other journalistic language elements, such as emotionalisation of news, were not included as a potentially predicting or modifying factor. One final limitation of the study may be the bias that theoretically occurs when readers with either very strong (rejecting) or neutral sentiments refrain from commenting owing to the sentiment itself.

Conclusions

By observing the news posts and comments on diabetes research on 2 large Dutch Facebook pages, we found that the readers' sentiments are associated with both the innovations' developmental phase and the intended therapeutic effect.
However, no evidence was found on the association between sentiments and the presence of commonly used language intensifiers in the health news texts.

Our finding that comments on diabetes news on Facebook have the most positive sentiment, and most frequently express hopefulness when clinical efficacy is not yet proven, suggests that the news authors and editors must exercise caution when acting as a conduit for medical research news. More experimental research is necessary, in various populations, to determine a healthy balance between being optimally informed and avoiding having false hope.

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CHAPTER 4

Effects of Diabetes News Characteristics on Patients' Perceptions and Attitudes towards Medical Innovations and Therapy Adherence

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Abstract

Patients have ever-increasing access to web-based news about hopeful scientific developments that may or may not cure them in the future. Science communication experts agree that the quality of news provision is not always guaranteed. However, literature does not clarify in what way users are actually affected by typical news characteristics such as the news object (described developmental phase of an innovation), the news source (degree of authority), and the news style (degree of language intensification). An online vignette experiment (N = 259) investigated causal relationships between characteristics of news about diabetes innovations and patients' perceptions of future success, their interest in the innovation, and attitudes regarding current therapy adherence. Findings show that descriptions of success in mice led to higher estimations of future success chances than earlier and later developmental phases. Furthermore, news from a nonauthoritative source led to an increased interest in the innovation, and a more negative attitude towards current lifestyle advice. Lastly, the intensification of the language used in news messages showed slight adverse effects on the readers' attitude. These findings, combined with their small effect sizes, support the optimistic view that diabetes patients are generally critical assessors of health news and that future research on this topic should focus on affected fragile subgroups.

Introduction

In the present digital era, patients with a chronic condition frequently encounter news messages about the potential healing of their disease. No matter if the person is an active health news seeker, or perhaps is trying to avoid such information, exposure to some extent seems likely for many. A large number of digital platforms actively spread scientific research results, with varying goals [1, 2]. For example, web-based newspapers present readers with quality interviews with scientists or patient organisations [3] acting as an information conduit for their communities; social media platforms provide members with daily news updates often from a highly personal perspective; academic and governmental news platforms and scientific libraries often the actual primary source of new scientific results. This online news on scientific health developments differs widely in important news characteristics such as news objects (i.e., fragments of content that receive a focus of the editor, such as the scientific developmental phase of an innovation in the news), the news source (with a degree of authority), and the news style (e.g. degree of language intensification). Given the unrestrained expansion of web-based news sources, essential questions arise that yet require empirical answering in the scientific literature: In what way do typical characteristics of news about innovative treatments affect patient perceptions? The present study aims to obtain new insights into this topic in the context of a chronic disease that receives a lot of media attention worldwide: diabetes mellitus.

Diabetes Research in the News

Diabetes mellitus is one of the most widely spread chronic diseases and it receives much attention in academic papers as well as in newspapers and social media [4–6]. A quick scan in scientific databases such as PubMed shows that, annually, tens of thousands of academic papers are published about both diabetes mellitus type 1 and type 2, from which authors of health news could potentially draw. Although significant progress towards a cure for diabetes is reported in several publications, various promising innovative concepts have been covered for decades without clinically adaptable results. Already in 1972, for example, a glucose sensor was developed that purportedly gave rise to optimism about a so-called '*self-contained totally implantable artificial organ that would continuously monitor sugar concentration in a body fluid of a diabetic and meter out insulin in proportion to need*' [7]. The whole organ is presently referred to as the artificial pancreas and is still under development. News media regularly report early stages of medical research with innovative potential while remaining unclear about actual clinical evidence from patients and thus about market potential. In fact, a study showed that less than 1 out of 5 Dutch newspaper articles reporting innovative treatments for diabetes

were supported by an in-article reference to proven effects in actual patients [8].

Nonetheless, even the holy grail in research, the randomised controlled trial on actual patients, may lack reliability and still reach media headlines. Weaker human trials have small sample sizes or include patients with narrow inclusion criteria. It may also happen that they detect evidence for effectivity, despite the fact that risk-benefit ratios of the treatment are unfavourable due to high costs or side effects. Fortunately, several examples of media watchdogs have arisen in the world to assess the quality of health news articles and to educate news editors and the general public on interpreting the value of health claims [9, 10].

News Object: Developmental Phases in Medical Science

Developing new drugs or other medical therapies is a complicated and time-consuming process. In addition to the lengthy process of discovering new molecules or refining smart techniques and testing their effectiveness in laboratory settings, the subsequent clinical research phase, involving experiments on smaller and larger groups of actual patients, can last years and is not always successful. For example, innovations in the endocrine disease area that are promising enough to be tested for safety on humans (i.e., phase 1 clinical research) have a chance of about 14% to be eventually approved for the market, which is between 6 and 9 years later [11]. The development of new medical applications can take decades and follows distinct phases, from first ideas to actual market access. In the earliest stages of research, evidence from observational studies (e.g., correlations with food) or evidence from fundamental research may lead to animal-testing, clinical testing in small groups of humans, or encourage investments in innovative technologies. Randomised clinical trials in patient populations provide the most valuable type of evidence: proof of effectiveness and a probability that the new therapy will be applicable in large populations in the future largely increased.

The academic literature shows no indication that choices regarding the dissemination of diabetes news are affected by the research phase of the presented innovation. Innovations in all stages of research are discussed in news media. Although lay readers might not be able to differentiate between evidence from different clinical phases, such messages may still affect treatment perceptions and emotions. This assumption is supported by research findings showing that the preclinical phase (e.g., research on animals) elicited the most positive emotions among diabetes patients on Facebook [12]. Persons with knowledge of clinical research may presumably perceive a qualification like ‘successful in patients’ as news with higher actual success chances. However, overly optimistic perceptions might potentially harm treatment adherence. Literature by Mann et al. [13] showed

that disease and medication beliefs that were inconsistent with a chronic disease model of diabetes were significant predictors of poor medication adherence.

News Source: Authority of the News Source

The accessibility of the internet and the low cost to spread information has led to increased access to and dissemination of health information. Patients seeking health information encounter large quantities of information from various sources and of varying quality and accuracy. The new digital era entails a significant challenge in assessing the credibility of health news [14]; and this is also true for diabetes news [15]. Particularly relevant is the source of health information since important health-related behaviours and decisions are based on the perceived credibility of the source [16]. On the internet, perceived credibility is determined by the authority of the administrator of a website or platform, representative of the expertise, and the trustworthiness of its writers of health information [17, 18].

The primary source of a health message frequently is a research institute or academic press release. Nonprofessional websites without authority repeatedly are selecting sources of health information [19]. Most health news messages reach the public through a broad range of selecting sources, varying from governmental health institutes to information gatekeepers such as news anchors, reporters, and journalists who select and present health news messages for their public. In the online context, technological interfaces such as web-based search engines and social media like Facebook function as selective sources, filtering and forwarding health news messages of primary sources [20].

Interestingly, online networks also enable receivers of health information to select and transfer health news messages themselves (whether or not assisted by technological interfaces). Examples of such receiving sources are moderators and members of online support groups, Facebook groups, chat rooms, and discussion forums. Online users of health news information may establish the selecting sources' credibility based on the perceived degree of expertise in these sources. In Western societies, credibility will be estimated higher in expert-based, authorised sources such as government health institutes, and lower in nonprofessional sources such as Facebook groups. In line with the Elaboration Likelihood Model of Persuasion [21], it is expected that sources with a clear scientific origin–such as universities or governmental institutions– will, by rule of thumb, lead to higher perceptions of a message's credibility and accuracy. News messages coming from authoritative sources may therefore increase estimations that the innovation will eventually be successful and personally useful. Further, it can be hypothesised that the authority of the source plays a

crucial role in opinion formation and change especially to those (patients) who are less inclined to seek news on the topic and thus are less likely to take the time to elaborate on the actual arguments in the message through the central route.

News Style: Language Intensification

Health news regularly contains powerful language that is used by the author to increase its vividness and attention value. Although this so-called language intensification is a complex concept [22], a functional definition is the use of language that is used to deviate from neutrality [23]; in the present case, that is deviating towards the positive aspect. Strong words such as breakthrough, enormous, very important, or lifesaving in a sentence intensify, by inserting pars pro toto' superlatives', a statement that otherwise would be more factual; this phenomenon is not strange to coverage of medical news [24] and may affect the reader. Although overall results are mixed, several studies show that the use of language intensifiers increases the clarity of the message [25, 26]. In another study, language intensification led to high message elaboration by receivers: after reading intensified language, patients were better able to distinguish stronger from weaker arguments [27]. In experimental studies, the high-intensive language had a more positive influence on attitudes and intentions than low-intensive language [28]. Also, some studies suggest that language intensification may influence behaviour [29].

In contrast, a study on perceptions of health news messages showed that these were mostly affected by objective risk characteristics; language intensification only affected readers' perceptions of the severity of a health risk [30]. These findings suggest that readers of health news have the ability to correct for language intensification and see the objective part of the information. Although the use of language intensification is common practice in health news coverage, specific effects of adding strong words to health news, on outcomes (i.e., attitudes, and behavioural intentions) among patient populations are yet unknown. The present study compared intensified with factual text versions, to assess effects on the value that diabetes patients attach to the news message content, and thus on their estimations that the presented innovation will be successful. Furthermore, the study assessed effects on interest in the given innovation and attitudes towards current lifestyle advice and therapy adherence attitudes and intentions.

Despite excessive media attention for clinically unproven innovations and existing worries about this phenomenon among experts [8, 31, 32], the actual effects of such media coverage on patients have not been established in empirical research. It is known that characteristics of news messages are associated with emotions

[12, 33, 34], but empirical evidence on patients' attitudes and behaviours to continue a challenging lifestyle programme or medication regimen is lacking. The current study aims to gather first insights into the possible impact of reading about promising medical research, varying the typical characteristics of scientific health news. Focus is put on dependent outcomes that represent perceptions and attitudes regarding the presented innovation in the news, and regarding the current treatment that the patients receive. The outcomes may be considered determinants of actual therapy adherence behaviour [35].

To measure news effects on these outcomes, we present fictional innovations in short messages that are systematically manipulated on three news dimensions; object, source, and style, that is: (a) the developmental phase of a particular innovation; (b) the type of authority of the source on the innovation news message; and (c) the degree of language intensification by intext presence of strong words to emphasise the innovative research results. Based on the literature and the guidelines outlined above, the research questions that guided the current research were as follows:

Research Question

When patients diagnosed with diabetes read news messages about innovative ways to treat their disease in the future: to what extent do news message characteristics (i.e. developmental phase of the innovation, authority of the news source, and language intensification) affect patients' (**i**) expectations of the innovation's success, (**ii**) interest to gain additional information, and intentions towards currently prescribed (**iii**) lifestyle advices and (**iv**) medication regimens?

Materials and methods

Participants and Design

Human participants were involved in an online vignette experiment. The local review board *UPPER (Utrecht University)* approved our study protocol (September 28th, 2018; UPF1806) and declared that the study did not fall under the scope of the "Medical Research Involving Human Subjects Act". Prior to start of the actual digital survey, patients were informed about the aims and burden of the study and consent was given by a click to accept principle. Because, no names and other identifying information was requested, a signed consent form was not required. Diabetes patients for the present online vignette study were recruited both on social media and in pharmacies. Patients were invited by posting a link on three Dutch diabetes-related forums and 14 diabetes Facebook groups (October 2018 –January 2019). With the approval of the website owners or moderators, a

recruitment text with a request to participate in an online questionnaire about Diabetes News and Reader's Mood was posted together with the survey link. In the same period, 25 Dutch pharmacies agreed to contribute to our research by handing out flyers containing a recruitment text and a weblink to customers treated for diabetes mellitus type 1 or 2. All participants were volunteers and remained anonymous. To include sufficient patients in our experiment, we determined a clinically significant increase of interest in an innovation of 0.5 on a 5-point Likert scale (with a standard deviation for the population of 1.0). A sample size calculation for an exploratory study with alpha 0.05 and power 0.80 predicted a necessary sample size of 63 per experimental group. To detect differences between two authority types, two language intensity types or three developmental phases, we needed a total of 126 to 189 participants. The present experiment consisted of a three-factor between-subjects design, using vignettes, i.e., short descriptions of imaginary situations. Participants were randomly assigned to one vignette that varied on three different dimensions: (1) three levels of the developmental phase that the presented innovation could be in, (2) two types of authority of the source, and (3) two degrees of language intensification (see Measures section). This design resulted in a total of twelve (3x2x2) unique text combinations and the messages were matched on diabetes type (type 1 and 2). Although a within-subjects design may result in more power to detect differences, it would come at the potential costs of a lower external validity and a higher dropout rate. Moreover, the present research anticipated that reading the second vignette in a short period of time may have led to decreased emotional responses.

Materials and Procedure

Our data was collected in Lime Survey and was exported to a protected University network environment. No data was saved that can lead to tracing individual participants of the study. After giving consent for participating, all participants indicated their age and whether they were diagnosed with either type 1 or type 2 diabetes mellitus. Those not diagnosed with diabetes, or having an age under 18 years, were thanked for their interest, and the questionnaire automatically ended. There were no other in- or exclusion criteria. The remaining participants were then asked to read one of 12 experimental news texts that were shown in visual frames (Figures 4.1 and 4.2). The survey software matched the fictional news messages to typical innovations for either diabetes mellitus type 1 or type 2. Thus, the messages were matched to specific diabetes mellitus type, but this matching was not a factor (or: manipulation) in the vignette research design.

Figure 4.1: The visual frame surrounding the news message suggests that the news message is published in an online diabetes Facebook group.

Figure 4.2: The visual frame surrounding the news message suggests that the news message is published on the website of an authority: Netherlands National Institute for Public Health and the Environment (RIVM).

To experimentally manipulate the presented scientific evidence for the innovation's success, we varied the developmental phases in the vignettes. Table 4.1 shows the three simplified stages of diabetes research (levels of presented evidence) that we used. For the fundamental phase, we presented the following statement: the innovation is soon ready to be tested in animals. Next, to indicate that preclinical evidence (in animals) had already been found, we stated that the therapy showed positive results in mice. Lastly, to indicate that actual clinical evidence in patients was gathered, we stated that the treatment proved successful in 22 patients.

Table 4.1: Factors and levels used in the construction of the vignettes

Factor	Level
Developmental phase	Reported success in fundamental research stages: '*the therapy is soon ready to be tested in mice*'
	Reported success in preclinical research on mice: *'In the last year, the therapy showed positive results in mice'*
	Reported success in clinical research on patients: 'In the last year, *the therapy showed positive results in a group of 22 patients'*
Source authority	Source with authority: simulated website of the Dutch National Institute for Public Health and Environment (RIVM)
	Source without authority: a not further specified '*Diabetes Facebook Group*' simulation
Language intensification	No intensified news content; base texts
	Intensified news content; four common intensifiers added (*special, discovery, important, and promising*)

To suggest that the message was either visible on the website of (1) an authoritative governmental source (i.e., Dutch National Institute for Public Health and Environment), or (2) from a nonprofessional non-authoritative source (i.e., a Facebook group named Diabetes Facebook Group without specified author).

To experimentally manipulate language intensification, we added four language intensifiers (special, discovery, important, and promising) that are frequently used in Dutch medical news to 50% of the presented vignettes, and this was added in combination with degree indicators very, a lot, much, and many; all of these intensifiers were absent from the other 50%. The four chosen intensifiers were identified after programmatically counting all words and identifying potential

text intensifiers that were written in 173 web-based news articles about diabetes that we selected for earlier research. After reading the experimental message, participants filled out a web-based baseline questionnaire that assessed four dependent outcomes (see Measures section): (1) perception of successfulness of the innovation; (2) interest in the innovation; (3) attitude towards advised lifestyle changes; (4) attitude towards adhering to medication regimes.

Measures

Factor analysis was conducted for 8 items measuring (1) estimations of future successfulness and (2) interest in gaining additional information 3) intentions regarding the usefulness of previously received lifestyle advices (4) intentions regarding adhering to current medication regimens. A principal component analysis was used to generate the factors. The Kaiser-Meyer- Olkin (KMO) test was used for determining the sample adequacy. A value of more than 0.5 has been considered adequate to perform factor analysis [36]. The Bartlett test of Sphericity was used to determine the homogeneity of the data. A Bartlett test p-value of less than 0.05 is considered significant and useful for factor analysis [36]. Oblimin rotation was used after the initial factor solution. The optimal number of factors was assessed from the scree plot. Findings showed that the following four 2-item (5-point Likert) scales represented the four components of our interest:

1. Two items assessed the patient's expectations of the innovation's success on a 5-point Likert scale (strongly disagree–strongly agree): "The treatment I just read about will be successfully used against diabetes in 10 years", and "The message I just read exaggerates the success of the new treatment (reverse coded)" (Cronbach's alpha = 0.69). The average score on this 2 item scale was used to answer research questions.

2. Two items assessed the patient's interest to gain additional information on a 5-point Likert scale (strongly disagree–strongly agree): "I will look up more information about this new treatment", and "I will discuss this treatment with my health professional" (Cronbach's alpha = 0.83). The average score on this 2 item scale was used to answer research questions.

3. Two items assessed the patient's intentions regarding received lifestyle advice: "It is wise to follow lifestyle advice in the coming month", "I will follow the lifestyle advice that I received in the coming month", (strongly disagree–strongly agree) (Cronbach's alpha = 0.80). The average score on this 2-item scale was used to answer research questions.

4. Two items assessed the patient's intentions regarding current medication adherence: "It is wise to take prescription medication in the coming month" I will take my own medication as prescribed in the coming month" (strongly disagree–strongly agree) (Cronbach's alpha = 0.91). The average score on this 2-item scale was used to answer research questions.

Statistical Analysis

Data were analyzed with SPSS Version 25.0 (SPSS, Inc, IL, USA) using unifactorial analyses of variance with developmental phase, source platform, language intensification as independent factors, and 3x2x2 ANOVA to assess interactions between independent variables. Effect sizes were calculated with partial eta squared, with effect sizes of .01–.06 considered as small, .06–.14 as medium and above .14 as large [37]. Descriptive analysis was carried out using mean and standard deviation with the range for continuous variables, while frequency and percentages were used for discontinuous ones. The present study did not use corrections for multiple testing based on the exploratory nature of the research, with research questions but without a prespecified key hypothesis. In exploratory studies multiple test adjustments are not strictly required [38]. Moreover, corrections such as the Bonferroni correction may come at the cost of missing a novel point of departure for studying new associations between independents and clinical outcomes [39].

This study was part of a larger research project that aims to assess the effects of health news characteristics on patient well-being; associations between patient characteristics and health seeking preference will be reported elsewhere. To secure the outcomes of a random vignette distribution, and possibly correct for unequal patient characteristics in the various vignette groups, we were able to verify the equal distribution of different baseline characteristics: age, gender, the estimated number of years since diabetes diagnosis, and current medication.

Results

We collected data on independent and dependent variables from 259 participants. Table 4.2 shows the participant characteristics. Table 4.3 shows the random allocation to the vignette manipulations. since a small number of the participating patients did not complete the full questionnaire, the total number of patients in the various analyses shows a small variation between 235 and 259 (see results section). Sensitivity analyses with these patients showed no relevant differences in outcome between the subgroups (data available upon request).

Table 4.2: Characteristics of the participants

	N=259	Range
Age, mean (*SD*)	50.6 (15.5)	18 - 80
Gender, *n* (%)		
Female	176 (68.0)	
Male	78 (30.1)	
Other	5 (1.9)	
Diabetes Type, *n* (%)		
T1DM	110 (42.5)	
T2DM	149 (57.5)	
Education, *n* (%)		
High	107 (41.3)	
Middle	106 (40.9)	
Low	46 (17.8)	

Table 4.3: Distribution of vignette manipulations.

	N= 259
Developmental phase, n (%)	
Reported success in fundamental stage	88 (34.0)
Reported success in mice	84 (32.4)
Reported success in 22 patients	87 (33.6)
Language intensification, n (%)	
Intensified	138 (53.3)
Not intensified	121 (46.7)
Source platform, n (%)	
Expert	132 (51.0)
Laymen	127 (49.0)

Developmental phase

The ANOVA on patients' expectations of the innovation's success, entering the manipulation of developmental phase as a fixed factor, showed a difference between the manipulated phases with a small effect size ($F(2, 258) = 3.81$, $p < .05$, $\eta p 2 = .029$). The highest success chances were perceived when success in mice was reported ($M = 1.93$, $SD = 0.42$). See Table 4.4.

No statistically significant main effects of the developmental phase were found on the other dependent variables: interest in the presented innovation, and intentions regarding current lifestyle and medication therapy adherence.

Table 4.4: Results one-way ANOVA: between group differences as filled in on a 5 point likert scale 0–4; mean/neutral = 2.0 (Developmental phase).

	Developmental phase, expressed by Success			
	1: 'Soon ready for research on mice'	2: Success in mice'	3: Success in 22 patients'	*F* statistic P value
	Mean(*SD*)	Mean(*SD*)	Mean(*SD*)	η_p^2=
expectations of the innovation's success	1.74(0.44) n=88	1.93(0.42) n=84	1.78(0.52) n=87	*F*(2,258) = 3.81 *p* <.05* η_p^2=.029
interest to gain additional information	1.72(1.17) n=87	1.70(1.18) n=83	1.40(1.04) n=87	*F* (2,256) = 2.25 *p* = .11 η_p^2=.017
lifestyle intention	3.05(0.89) n=83	3.03(0.74) n=75	2.84(0.97) n=77	*F* (2,234) = 1.42 *p* = .25 η_p^2=.012
medication adherence intention	3.40(1.07) n=82	3.21(1.05) n=74	3.46(0.75) n=81	*F* (2,236) = 1.38 *p* = .25 η_p^2=.012

**statistically significant (p<.05)*

Source Authority

The ANOVA on patients' information intention, entering the manipulation of developmental phase as a fixed factor showed that patients' information intention was higher when the source was not authoritative, (F(1, 256 = 4.79 p < .05, ηp 2 = .018). In contrast, patients' medication adherence intention was higher when the source condition was authoritative (F(1, 236) = 8.52, p < .005, ηp 2 = .035). A similar pattern was observed for lifestyle intentions, but this effect was not statistically significant. See Table 4.5 for Means and SDs.

Table 4.5: Results one-way ANOVA: between group differences as filled in on a 5-point Likert scale 0–4; mean/neutral = 2.0 (Source authority).

	Source authority		
	Authority	No authority	*F* statistic P value η_p^2=
expectations of the innovation's success	1.81(0.50) n=132	1.83(0.42) n=127	*F* (1,258) = 0.12 *p* = .73 η_p^2=.000
interest to gain additional information	1.45(1.09) n=131	1.76(1.16) n=126	*F* (1,256) = 4.79 *p* <.05* η_p^2=.018
lifestyle intention	3.08(0.83) n=117	2.87(0.90) n=118	*F* (1,234) = 3.24 *p* = .073 η_p^2=.014
medication adherence intention	3.54(0.77)* n=118	3.18(1.11*) n=119	*F* (1,236) = 8.52 *p* <.005* η_p^2=.035

**statistically significant (p<.05)*

Language Intensification

The ANOVA on patients' expectations of the innovation's success, entering the manipulation of language intensification as a fixed factor, showed no significant effect. Patients' information intention was higher in the no intensification condition, compared with the intensification condition ($F(1,255) = 3.93$, $p < .05$, $\eta p\ 2 = .015$), with a small effect size. Furthermore, patients had a higher lifestyle intention in the condition without language intensification, $F\ (1,234) = 5.74$, $p < .05$, $\eta p\ 2 = .014$. No significant effect was observed on the medication adherence intention. See Table 4.6.

Table 4.6: Results one-way ANOVA: between group differences as filled in on a 5-point Likert scale 0–4; mean/neutral = 2.0 (Language intensification).

	Language intensification		
	No intensification	Intensification	*F* statistic P value η_p^2=
expectations of the innovation's success	1.83(0.48) n=121	1.80(0.45) n=138	*F* (1,258) = .34 *p* = .56 η_p^2=.001
interest to gain additional information	1.75(1.21) n=120	1.47(1.06) n=137	*F* (1,256) = 3.93 *p* < .05* η_p^2=.015
Attitude/intention received lifestyle advices	3.12(0.85) n=112	2.85(0.87) n=123	*F* (1,234) = 5.74 *p* < .05* η_p^2=.024
Attitude/intention medication adherence	3.29(1.07) n=111	3.42(0.87) n=126	*F* (1,236) = 1.03 *p* = .31 η_p^2=.004

**statistically significant (p<.05)*

Interaction Effects

To assess interactions between the independent variables, 3(developmental phase) x 2(source authority) x 2(language intensification) ANOVAs were conducted on the dependent variables. The analyses revealed no statistically significant ($p < .05$) interaction effects.

Discussion

Previous studies reported an abundance of accessible online health messages, frequently lacking clarity regarding their therapeutic potential [8, 40, 41]. The present study assessed whether such news characteristics affected diabetes patients' expectations, interests, and attitudes regarding the presented innovation and their current therapies. For the first time, a particular focus was put on the persuasive effects of the reported developmental phase of the innovation on perceptions and intentions. In biomedical research on innovative therapies, the evidence for clinical effects in actual patients is vital, and earlier successes must be celebrated with restraint. Only when therapeutic results are confirmed in actual patients, so-called proof of concept is reached, which indicates that in this

stage, innovations have improved chances to succeed [11]. However, journalists frequently report about earlier developmental phases, which may affect patients' perceptions and adherence intentions different from situations where better evidence is available.

This study found that, on average, patients estimate the future success chances of a presented diabetes innovation the highest when success in mice is shown and not when success in patients is presented. Note that the power of the effects was limited and, remarkably, that patients' interest in gaining additional information did not increase by stating success in actual patients. Apparently, patients are already quite convinced by the value of laboratory medicine, unaware of the challenging translation from such inventions to healthcare innovations. [42] In other words, it may be that patients did not carefully interpret essential signals about the level of scientific evidence due to a lack of medical and healthcare knowledge. This may have induced peripheral argument processing, following the so-called expert heuristic ("these scientists can be trusted") rather than following the central route of full argument processing [43]. Especially in experimental settings such as our study, such an expert heuristic may eliminate developmental phase-related persuasive effects that require more cognitive elaboration. In addition, for laymen (such as our participants), the reference to 'mice' in the laboratory evidence may function as a rather prototypical cue that the evidence is indeed scientific evidence, and this 'mice' reference may thus in fact have reinforced, rather than diminished, the aforementioned expert heuristic.

Additional support for the explanation that at least some patients may have processed information via the peripheral route, comes from the effects of the manipulating factor source authority: results showed that when the news was brought by an authoritative professional source, it increased patients' intention to adhere to current medication regimens, in comparison to reading the same message when brought by a non-authoritative, nonprofessional source. The improved adherence intentions in the authoritative source version may be explained by the persuasive power that authorities such as the National Institute for Public Health and the Environment (RIVM) in the Netherlands have. The positive cues that participants received from recognizing this authority may have led to simple merit conclusions and quick information processing in the peripheral route [43]. However, our study also showed that specifically the nonprofessional, non-authoritative source increased patients' interest in the innovation, which seems not directly in line with this theory. One possible explanation may be that the interest is in fact a need to receive additional information which results from

a lower trust in non-authoritative message sources: information brought by such sources is in need of further elaboration and verification.

Remarkably, our findings suggest that intensifying medical news with strong language such as promising, very, or breakthrough, is counterproductive when trying to serve a patient community. Although effect sizes were small, they indicate that using intensified language decreases rather than increases patients' interest in the presented innovation and even slightly lower patients' intentions to follow current lifestyle advice. This unexpected, reversed, effect of language intensification in our study may be explained when taking into account that intensified language in the context of our study may have been perceived as an expression of subjectivity. Linguistically, intensification foregrounds the involvement, or stance, of the author and as such, it contributes to the emotive and subjective dimension of discourse [44, 45]. Subjective intensification may therefore be perceived–either consciously or subconsciously—as framing bias, in which the author or speaker takes a particular position on arguable topics such as anticipating a better future [46]. In a context in which patients are expectant of trustworthy, factual descriptions of future treatment options, this non-neutral position of the author may thus weaken the persuasiveness of the news message. Note that in the context of news stories on research, language intensification must be distinguished from spin, which was found to increase readers' estimates of future success of the presented therapy [47]. However, spin, i.e. the conscious or unconscious misrepresentation of study results that overemphasise the efficacy or safety of the treatment; in the current study, was not included in the current study.

Limitations and Future Directions

The current study has some limitations. First, anonymous patients were recruited online, and it was not possible to verify their self-reported medical information. Second, a large part of the online recruitment was performed in Facebook groups. This may have led to bias regarding Facebook-related perceptions and opinions since these patients are more used to this social media platform than the whole diabetes population may be. Possibly, participating patients that were recruited from Facebook put more trust in non-authoritative sources while holding a relative distrust towards official authorities. Yet, most of the cooperating Facebook Groups were either linked to large diabetes patient associations that do not oppose science nor medical authorities in any way, or were acting as a conduit for scientific news from universities and other scientific authorities. Moreover, it is this specific population that is most frequently online and reading news on Facebook groups, and can, therefore, be considered as our primary target population. Another

limitation may be the absence of a control group that did not read the news at all. The implication of not including this third group is that questions with respect to reading versus not reading news, remain unanswered. However, the odds are low that in a real-world situation, patients will never read health news messages. The last limitation may be the use of parametric tests on data from 5 point Likert scales. Although it has become common practice to perform parametric tests on 5-point scales, some researchers oppose the idea that differences between neutral, agree, and strongly agree are equal and linear steps [48]. Future research should aim at effects on emotional wellbeing as well as on determining specific vulnerable patient groups that are more susceptible to effects than our general population on average was. This can preferably be done by using a longitudinal observational design containing actual media exposure measures on patients from susceptible groups. Furthermore, it may be important to understand if, and how, patients are affected by news on social media accounts of professionals in the medical fields, specifically physicians and scientists. Another limitation is the power of our study. The number of patients that we included was large enough to detect 0.5 point differences on the 5p Likert scales. However, for detecting such a difference in two-way interactions (e.g. source authority x developmental phase) the eventual number of participants was about fifty per cent too low. This is a possible explanation for the absence of interaction effects. Hence, we recommend future studies to repeat our experiments with higher power since clinical relevant differences may still exists in diabetes groups. Lastly, research needs to be performed on patients' understanding and perceptions of medical developments and on possible education: what do patients comprehend, and how much knowledge of current diabetes research is necessary to optimise information provision and quality of life.

Conclusions

The present experimental study presented diabetes patients with news about relevant medical innovations, to assess whether specific news characteristics, i.e., the developmental phase of an particular innovation; the authority of the source; and the language intensification degree of the message, affect patients' perceptions of the presented innovation and their current therapy adherence intentions. Large effects were not found. A small but significant effect that was established is an increase of the intention to adhere to medication after reading news from an authoritative source. Though limited, this effect is may yet be of importance, given the large and greatly varied diabetes population that encounters an ever increasing amount of online health news. From an overarching viewpoint, the results of our study support an optimistic view that patients diagnosed with

diabetes, as they are generally critical assessors of health news. Future research on this topic should above all focus on affected fragile subgroups.

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CHAPTER 5

Associations between Patient Characteristics and Information Seeking on Diabetes-related Research Information: A Cross-sectional Study in the Netherlands

Abstract

This study aimed to examine the associations between health-information seeking (HIS) behaviours and demographic factors, perceptions, and disease characteristics among Dutch patients with diabetes mellitus Types I and II. By exploring these relationships, the study intends to contribute to a better understanding of HIS and facilitate the provision of tailored news and information to meet individual needs.

This cross-sectional observational study utilised survey data, collected at baseline of the experiment described in Chapter 4. It included 246 participants, primarily female (70%) and diagnosed with diabetes mellitus Type I (42%) or II (58%), with a mean age of 50.7 years. The participants' frequency of seeking news about diabetes innovations was assessed, along with demographic factors, disease characteristics, illness perceptions, and trait optimism. Bivariate logistic regression analyses were conducted to examine the associations between these variables and the probability of being a high-frequency health information seeker. Several models were created to explore the relationships, including demographic variables, disease characteristics, illness perceptions, and trait optimism. SPSS Version 25.0 was used for data analysis.

HIS frequency was positively associated with female gender, age older than 40 years, and a diagnosis of diabetes mellitus Type II. Furthermore, HIS frequency was negatively related to time since diagnosis. Bivariate associations with HIS frequency were found for comorbidities and several illness perceptions (i.e., consequence, identity, illness coherence, and emotional representations), but these associations were not robust when controlling for other predictors. One overall implication based on the results of this study is that, when disseminating news about diabetes, it is important to consider the gender and age of patients, as well as time since diagnosis.

Introduction

In biomedical sciences, improved research transparency makes it possible for patients to monitor the development of innovative therapies that may improve their lives (Andreassen et al., 2007). Academic articles are widely available, and news editors often translate them for broader audiences. This is especially true for diseases that have a major impact on a large part of the population, including diabetes, heart disease, cancer, and Alzheimer's disease (Adelman & Verbrugge, 2000). Patients can engage in health-information seeking (HIS; the act of seeking information about medical topics) on various news websites, forums, patient platforms, academic libraries, and social media (Pew Research Center, 2021; Vehof et al., 2018). In many cases, stakeholders accelerate the dissemination of research results. Examples include academic institutions promoting their research and patient associations seeking to inform their members (JDRF, 2023; Stichting DON, 2023). Although the intention to serve as a conduit for promising research results is positive, studies have indicated that patients with chronic conditions have varying, and often negative attitudes towards news about innovative research (Vehof et al., 2019). Moreover, as a coping mechanism to reduce stress and anxiety, a proportion of the patient population avoids reading any health information (Ek & Heinström, 2011).

The existing body of knowledge does not provide clear characteristics to identify which diabetes patients are 'information monitors' and which are 'information avoiders'. Enhancing current understanding of fundamental relationships between HIS and demographics, perceptions, and disease characteristics may be a next step towards improving the provision of news customised to individual needs. The present research aims to assess these associations within a sample of Dutch patients diagnosed with a chronic disease: diabetes mellitus Types I and II.

Effects of HIS on the Patient

According to the academic literature, actively searching for information about one's own health condition is associated with several positive and negative effects. For example, HIS can reduce negative emotions (e.g., anxiety connected with uncertainty), and reading about the many future treatment options can provide a certain extent of reassurance (Lambert & Loiselle, 2007; Shiloh et al., 1999). In coping with health-threatening situations, HIS behaviours can help patients manage the emotions that accompany these stressful situations, in addition to resolving at least part of the situation. By helping them to focus on the threatening situation, HIS enables patients to become more engaged with and aware of their disease. Patients who are better informed (e.g., about resources

available for managing stressors) are better able to understand the health threat and anticipate associated future difficulties (Lambert & Loiselle, 2007; Rees & Bath, 2001). In addition, HIS can increase patient participation in medical decision-making, as it enhances understanding of the possible treatment options and reduces doubt concerning alternatives (Lambert & Loiselle, 2007).

Empirical studies have shown that informed patients conform to medical regimens better, thereby leading to better health outcomes (Rossmann & Stehr, 2019, p. 405; Sherman et al., 2020). Patient engagement in healthy lifestyles and preventive behaviours is significantly influenced by HIS. The information found through such searching can provide motivation to make positive changes in health practice. The HIS behaviours of patients influence knowledge about the advantages and disadvantages of various health actions, alternative courses of action, and resources for performing healthy behaviours (Lambert & Loiselle, 2007). In addition to the widely recognised positive effects of HIS, some experts have expressed concern that exposure to an abundance of interim research results may lead to patients to experience frustration and false hope (Leask et al., 2010). This effect is especially likely to occur when news messages lack essential properties, such as reasonable interpretation of the evidence presented, the timeline for development, the ratio of costs to benefits, and future opportunities for reimbursement (Schwitzer et al., 2005). Given the wide potential variability in the quality of health-information content, patients may not always possess the skills necessary for interpreting the progress of developments or for predicting and discussing the future success of innovative therapies (Ahluwalia et al., 2010; Ahmad et al., 2006; Berland et al., 2001). As an important outcome, low-quality or complex health information can leave patients misinformed or distressed, and it could eventually increase the likelihood of poor self-diagnosis or self-treatment (Ahmad et al., 2006). In a study of emotional responses to diabetes-related news in Facebook groups, Vehof et al. (2019) assess the negative emotions that arise when reading about promising future treatment options. One in four of the observed reactions of readers to the research findings presented reflected negative emotions (e.g., 'They promised this 10 years ago'; 'This will come too late for me'; 'They'll never reimburse this').

Studies have also indicated that patients' trust in physicians can be affected when patients find information online that does not align with the treatments proposed by their physicians. As noted by Starcevic (2017), excessive online health research is connected to health anxiety and distress. The evidence that HIS-related behaviours have dual effects on patients exposed to health information emphasises the need to increase existing scientific knowledge on this issue. It is essential to understand

associations between individuals diagnosed with a chronic disease and HIS-related behaviours (e.g., to customise the stream of health information to personal needs).

Disease Characteristics, Trait Optimism, and Illness Perceptions

The frequency of searching for hopeful new therapies might depend on disease-related characteristics, but indications specific to the context of diabetes are limited. Previous studies on HIS and seeker characteristics have focused on the general population. In a random sample of the general population in Australia, people with multiple comorbidities sought more health information than did adults with less severe or no diseases, although this was the case only amongst women (Nikoloudakis et al., 2018). Based on a sample of ethnically diverse young adolescents, another study identifies immediate needs (i.e., for diagnosis and short-term treatment) amongst a general group of young adults. The authors conclude that understanding existing needs for better-designed health-information technology will require much additional research (Okoniewski et al., 2014). In a study conducted in a group of Chinese WeChat users, Zhang et al. (2020) observe that the perceived susceptibility and severity of a condition are not significantly related to HIS.

The following research question was constructed to guide the present study:

RQ1: Is the probability of high-frequency information seeking for diabetes-related research associated with diabetes characteristics (type, time since diagnosis, and comorbidity)?

Other characteristics that may influence the frequency of HIS include the perceptions that patients have concerning their diseases. Perceived disease risk (high vs. low) and the perceived efficacy of using health information (effective vs. non-effective) play a central role in many HIS studies (Hastall & Knobloch-Westerwick, 2013). Along these two axes, previous research has identified four types of information seekers (Grasso & Bell, 2015; Rimal & Real, 2003). Studies conducted in general patient communities have reported that cognitive representations of a disease can have a direct influence on the HIS needs of patients (Figueiras & Alves, 2007; Johnson & Meischke, 1993). In a questionnaire developed and later revised by Moss-Morris et al. (2002), illness perceptions comprise the following dimensions: consequences, timeline (acute/chronic), identity, personal control, treatment control, illness coherence, and emotional representations. The *consequences* dimension describes a patient's perception of the potential effects of an illness. Patients who perceive the consequences of a disease to be more serious are likely to be more motivated to avoid these outcomes by

seeking information that could help them better manage their conditions or that reveals new treatment options. The *timeline* dimension refers to the perceived chronicity of an individual's illness. Higher perceived chronicity (and thus greater consequences for the patient) is likely to be associated with more frequent online HIS. The *identity* dimension refers to the extent to which individuals associate symptoms with their illnesses. Patients who perceive many symptoms may feel a more urgent need to improve their circumstances by seeking factual information from valuable sources. As demonstrated by Hu et al. (2012), the perception of many signs of disease motivates patients to seek online information in advance of medical appointments. The *personal control* dimension pertains to the perceptions that patients have of their ability to control the course of an illness. This dimension is similar to Bandura's (2004) construct of self-efficacy, which facilitates HIS (Hu, et al., 2012). The *treatment control* dimension refers to beliefs about a treatment's effectiveness for a medical condition. Although it has been hypothesised that patients are likely to be more motivated to seek information when they believe their current treatment is ineffective (Hu et al., 2012), this has yet to be confirmed by empirical evidence. The *illness coherence* dimension represents an individual's overall understanding of an illness. Patients with limited understanding of their conditions are more likely to search for helpful information (Attfield et al., 2006). The *emotional representations* dimension refers to patients' beliefs about their affective reactions to illness. One study reports weak evidence (due to selection bias) that patients who are concerned about and emotionally affected by their illness are more likely to use online health sources (Hu et al., 2012). Moreover, the emotions of stress and anxiety related to the severe effects of disease have been shown to increase patient involvement in treatment options (Czaja et al., 2003; Hu et al., 2012; Lambert & Loiselle, 2007).

In addition to illness perceptions, the present research includes trait optimism as a determinant of frequently searching for health information. Optimism is the attitude (or perception) that good things will happen and that one's wishes or aims will eventually be fulfilled (Carver et al., 2010). Optimists are confident in attaining desired goals. Most individuals tend to demonstrate relatively stable situational tendencies in one direction: either pure optimism or pure pessimism. To date, no research has been performed on associations between the more general concept of trait optimism and HIS (Aspinwall & Brunhart, 1996).

The following research question was constructed to guide the present study:

RQ2: Is the probability of high-frequency information seeking for diabetes-related research associated with illness perceptions or trait optimism?

Demographic Patient Characteristics

Previous research on HIS behaviours has identified that HIS is positively related to education (Johnson & Meischke, 1993; Rains, 2007; Tian & Robinson, 2008). Individuals with more education may have the material resources and the cognitive skills to seek health information more frequently (Maslow & Lewis, 1987). Studies have also indicated that education is associated with increased skills for using digital technologies (van Deursen et al., 2011).

Previous research on associations between the demographic characteristics of patients and HIS has generated inconclusive findings. In a study on a Web2.0 application, the HIS of women was three times greater than that of men (Tennant et al., 2015). Female gender has also been identified as a predictor of using eHealth applications (Kontos et al., 2014). Furthermore, Nikoloudakis et al. (2018) report that women are more likely to search for health information online, and Sherman et al. (2020) conclude that men are less engaged in their healthcare. In contrast, in an earlier study on online HIS behaviours, Baumann et al. (2017) report that men are more likely to seek information. Likewise, Robinson et al. (2006) report that male cancer patients engage in more online HIS than female cancer patients do.

The results of HIS research are also inconclusive regarding associations with age. In a study on internet usage as a source of health information, Lee et al. (2015) report that people between the ages of 25 and 34 years had a greater need to seek information than others did, and that those between the ages of 45 and 54 years exhibited less need to seek information. Studies by DeLorme et al. (2011), by Rains (2007), and by Zhao and Cai (2009) report negative, albeit small, correlations between age and HIS. In another study, Miller and Bell (2012) suggest that older adults might benefit from special instruction to enhance their trust in information found on the internet and to help them distinguish between high-quality and low-quality websites. This proposition is supported by the results of studies by Johnson and Meischke (1993), by Rains (2007), and by Tian and Robinson (2008), which indicate that older adults have a greater need to search for health information.

In the present study, demographic factors are posited to be related to HIS in patients with diabetes. The following research question was constructed to guide the current study:

RQ3: Is the probability of high-frequency health-information seeking for diabetes-related research associated with a patient's essential demographic characteristics (i.e., gender, age, and education)?

Method

Participants and Design

The present study uses cross-sectional observational survey data obtained at the baseline of a broader online experiment on the effects of news characteristics on medical-adherence intentions (Vehof et al., 2021). The data used in the present study are unique and not reported elsewhere.

In all, 246 participants had completed the questions that were necessary for this study. About 70% of the participants were female, and 58% had been diagnosed with diabetes mellitus Type II. The mean age was 50.7 years (SD = 15.3). About 40% of the participants had completed education equivalent to a Bachelor's degree or higher (i.e., high education). An overview of selected characteristics of the participants is presented in Table 5.1.

Materials and Procedure

Patients with diabetes were recruited on social media and in pharmacies. Patients were invited by posting a link on three Dutch diabetes-related forums and 14 diabetes-related Facebook groups (October 2018–January 2019). With the approval of the website owners or moderators, a survey link and a recruitment text with a request to participate in an online questionnaire were posted. In the same period, 25 Dutch pharmacies agreed to contribute to our research by distributing flyers containing a recruitment text and a web link to patients being treated for diabetes Type I or II.

The data were collected in Lime Survey (university account) and exported to a protected university network environment. Our local institutional review board (UPPER Institutional review board) approved the study protocol (28 September 2018; UPF1806). All participants were volunteers and remained anonymous, and no data were saved that could lead to the tracing of individual study participants. No signed consent forms were required, as no identifying information was requested.

After opening the survey link, participants were presented with a general introductory text explaining the objectives of the survey. This was followed by the first filter question, in which participants indicated whether they had been diagnosed with Type I or Type II diabetes. Those who had not been diagnosed with diabetes were thanked for their interest, and the questionnaire automatically ended.

The research described in this chapter was part of a larger study (see Chapter 4). The associations assessed for the present study have not been described or published elsewhere.

Table 5.1: Participant characteristics

N = 246	Value
Age	
Mean (SD)	50.7 (15.3)
Range	18-80
Gender, n (%)	
Female	173 (70.3)
Male	73 (29.7)
Education, n (%)	
High	99 (40.2)
Middle	106 (43.1)
Low	41 (16.7)
Diabetes type	
Type I	104 (42.3)
Type II	142 (57.7)
Years since diagnosis, mean (SD)	14.4 (11.9)
Comorbidities, n (%)	
No	144 (58)
Yes, DM greatest concern	70 (28)
Yes, other comorbidities greatest concern	32 (13)
Illness perception, mean (SD)	
Consequences	5.88 (2.57)
Timeline	8.76 (2.50)
Personal control	6.37 (2.22)
Treatment control	6.93 (2.22)
Identity (symptoms)	4.93 (2.44)
Illness coherence	7.33 (2.05)
Emotional representations	5.40 (2.47)
Trait optimism, mean (SD)	14.20 (4.04)
Health-seeking frequency, n (%)	
High	97 (39)
Low	149 (61)

Measures

Health Information Seeking Frequency

One item was used to assess HIS frequency: *How often do you search for information about medical research on diabetes in the media? Choose the answer that matches your situation best: Daily, weekly, monthly, yearly, less often than yearly.* This question was adapted from the one used by Renahy et al. (2010), who used the response options *weekly, monthly, less often*.

Due to the non-linear nature of the response options (1, 12, 52, 365 times per year), we distinguished two broad groups that were visible in the data: *high-frequency*, referring to 12 or more searches per year (daily, weekly, monthly; n = 97); and *low-frequency*, referring to one or fewer searches per year (annually or less often n = 149).

Independent Variables

Age was assessed and divided into five categories (18-39, n = 61; 40-49, n = 43; 50-59, n = 62; 60-69, n = 57; 70+, n = 23), as the association between HIS and age was not assumed to be linear. The highest level of *education* completed was assessed, and the answers were divided into three categories: *High:* Bachelor's, Master's; *Middle*: senior general secondary education (HAVO), university preparatory education (VWO), vocational education and training (MBO 2,3,4); *Low*: primary school, preparatory vocational secondary education (VMBO), vocational education and training (MBO1).

The variable Diabetes mellitus type (I or II) was assessed because the impact and course of a disease may lead to varying needs for health information. It was assumed that the insulin-dependent form of diabetes mellitus (Type 1) would have a more significant life-long impact on an individual than the other type would. Participants were asked to indicate the time since diagnosis. Because linearity was not assumed, the answers were divided into five-year categories, starting with 0-4 years and ending with 25 years or longer. Finally, we assessed comorbidities as follows; (1) no comorbidities; (2) comorbidities that are of less concern to the patient than diabetes; and (3) comorbidities that are of more concern to the patient than diabetes. This distinction was made, as the presence of more troublesome conditions could potentially lead to less diabetes-related HIS.

The illness perceptions of respondents were measured using the Dutch-language version of the Brief Illness Perception Questionnaire (de Raaij et al., 2007). Responses to the questionnaire items—one per sub-dimension—were made along bipolar scales (0-10) and worded as follows:

1. Consequences: 'How much does your illness affect your life?'
2. Timeline: 'How long do you think your illness will continue?'
3. Identity: 'How much do you experience symptoms from your illness?'
4. Personal control: 'How much control do you feel you have over your illness?'
5. Treatment control: 'How much do you think your treatment can help your illness?'
6. Illness coherence: 'How well do you feel you understand your illness?'
7. Emotional representations: Two items on emotional representations were averaged to a single scale: 'How concerned are you about your illness?' and 'How much does your illness affect you emotionally (e.g., does it make you angry, scared, upset, or depressed)?'

Trait optimism was assessed using the 10-item Revised Life Orientation Test (LOT-R) questionnaire (Herzberg et al., 2006), which produced one composite outcome for use in our analyses. Cronbach's alpha was calculated (Gliem & Gliem, 2003) and the LOT-R was found to have acceptable internal reliability ($\alpha = 0.73$).

Statistical Analysis

Data were analysed with SPSS Version 25.0 (SPSS Inc., IL, USA). Bivariate logistic regression analyses were conducted to assess the crude relationships between (a) the probability of being high-frequency health-information seeking and (b) demographic characteristics, diabetes characteristics, illness perceptions, and optimism. The examination of associations began with a (1) bivariate analysis. Then a model was created that included (2) demographic variables. Next, another model was created that included (3) only the disease characteristics. In the next step, (4) a model showing illness perceptions and trait optimism was used. Finally, (5) a full model was used that included all previous variables.

Results

Bivariate Analysis

Binary logistic regression analyses were performed to assess relationships between HIS frequency and demographic, disease, and perception-related variables. The results are presented in Table 5.2. There was no significant crude relationship between HIS and gender, education, time since diagnosis, and trait optimism, but HIS was significantly related to age. Patients between the ages of 40 and 49 years had a significantly higher frequency of HIS frequency (OR 2.41 [1.08-5.36]), as compared to those in the reference range (18-39 years). Patients diagnosed with diabetes mellitus Type II had a significantly lower crude probability

of high-frequency diabetes-related HIS (OR 0.57 [0.34-0.96]). In addition, having 'comorbidities of less concern than diabetes' increased the likelihood of high-frequency diabetes-related HIS (OR 1.93 [1.08-3.45]), as compared to those without comorbidities. No difference was found between 'no comorbidities' and 'comorbidities of more concern than diabetes'. Finally, crude associations between illness perceptions and HIS indicated that participants with high-frequency diabetes-related HIS reported that their lives were more affected by diabetes (OR 1.19 [1.07-1.33]), that they experienced more symptoms (OR 1.20 [1.07-1.34]), that they understood diabetes better (OR 1.15 [1.01-1.32]), and that they were more concerned and emotionally affected (1.17 [1.05-1.31]).

Multivariate Analyses

Model 1: Demographic Characteristics of Patients

The first regression model, which includes the three demographic variables (gender, age, and education), accounted for 6.2% of the variance in the outcome variable (HIS frequency). Age between 40 and 49 years increased HIS frequency, as compared age younger than 40 years (OR 2.86 [1.25-6.52]). No other associations were found in the demographics model.

Model 2: Disease Characteristics

Model 2 included the three disease characteristics (diabetes type, years since diagnosis, and comorbidities), which together accounted for 9.7% of the variance in HIS frequency. Diabetes mellitus Type II decreased self-reported HIS frequency, as compared to Type I (OR 0.53 [0.29-0.97]). Furthermore, patients who had received their diagnosis 0-4 years before the time of the survey reported significantly lower HIS frequencies than did patients who had been diagnosed 15-19 years before the survey (OR 0.30 [0.10-0.94]). See Table 5.2.

Model 3: Illness Perceptions and Trait Optimism

Model 3 included illness perceptions and trait optimism, which together accounted for 11.3% of HIS variation. Although it explained more of the variance than previous models, the results for this model indicate that none of the illness perceptions and neither level of trait optimism was significantly related to HIS frequency.

Table 5.2: Bivariate and multivariate logistic regression analyses

N=246 Explanatory variables	n	Bivariate logistic regressions	Model 1 0.062 318.502	Model 2 0.097 311.694	Model 3 0.113 308.481	Model 4 0.236 282.876
Gender						
Female	173	-	-			**-**
Male	73	0.62 (0.35-1.10)	0.58 (0.32-1.07)			**0.49 (0.25-0.97)**
Age						
18-39[1]	61	-	-			-
40-49	43	**2.41 (1.08-5.36)**	**2.86 (1.25-6.52)**			**4.48 (1.70-11.78)**
50-59	62	1.12 (0.54-2.35)	1.28 (0.60-2.72)			2.47 (0.91-6.74)
60-69	57	1.03 (0.48-2.20)	1.28 (0.58-2.82)			**3.85 (1.17-12.75)**
70+	23	1.22 (0.46-3.30)	1.94 (0.65-5.75)			3.82 (0.90-16.23)
Education						
High[1]	99	-	-			-
Middle	106	0.61 (0.28-1.30)	0.54 (0.23-1.23)			0.69 (0.26-1.87)
Low	41	0.82 (0.47-1.43)	0.79 (0.44-1.40)			0.80 (0.41-1.56)
Diabetes						
Type I[1]	142	-		-		**-**
Type II	104	**0.57 (0.34-0.96)**		**0.53 (0.29-0.97)**		0.43 (0.17-1.05)
Time since diagnosis (y)						
0-4[1]	58	-		-		**-**
5-9	38	0.65 (0.28-1.55)		0.69 (0.29-1.66)		0.66 (0.25-1.73)
10-14	51	1.16 (0.54-2.49)		1.20 (0.55-2.61)		0.94 (0.40-2.21)
15-19	25	0.35 (0.12-1.08)		**0.30 (0.10-0.94)**		**0.25 (0.07-0.87)**
20-24	31	1.51 (0.63-3.63)		1.19 (0.48-2.96		1.10 (0.39-3.13)
25+	43	0.93 (0.41-2.07)		0.59 (0.25-1.43)		**0.30 (0.10-0.89)**
Comorbidities						
None[1]	144	-		-		-
Yes, DM most worries	70	**1.93 (1.08-3.45)**		**2.01 (1.09-3.72)**		1.43 (0.70-2.92)
Yes, other morbidities most worries	32	0.83 (0.36-1.89)		0.99 (0.42-2.36)		0.93 (0.35-2.49)

Table 5.2: Continued

N=246 Explanatory variables	n	Bivariate logistic regressions	Model 1 0.062 318.502	Model 2 0.097 311.694	Model 3 0.113 308.481	Model 4 0.236 282.876
Illness perceptions						
Consequences		**1.19 (1.07-1.33)**			1.11 (0.95-1.29)	1.07 (0.90-1.28)
Timeline		1.04 (0.94-1.16)			0.94 (0.83-1.06)	0.95 (0.83-1.08)
Personal control		1.03 (0.92-1.16)			1.05 (0.91-1.22)	1.07 (0.91-1.27)
Treatment control		1.09 (0.97-1.23)			1.10 (0.95-1.27)	1.10 (0.93-1.29)
Identity (symptoms)		**1.20 (1.07-1.34)**			1.10 (0.94-1.29)	1.07 (0.89-1.29)
Illness coherence		**1.15 (1.01-1.32)**			1.15 (0.98-1.36)	1.16 (0.97-1.38)
Emotional representations		**1.17 (1.05-1.31)**			1.08 (0.91-1.28)	1.15 (0.95-1.39)
Trait optimism		1.00 (0.94-1.06)			0.98 (0.91-1.06)	0.98 (0.90-1.07)

Model 1: multivariate analysis of demographics

Model 2: multivariate analysis of disease characteristics

Model 3: multivariate analysis of illness perceptions and trait optimism

Model 4: multivariate analysis of the full model

Statistically significanct results (P<.05) in bold

[1] *reference group*

Model 4: Full Model Entered into Logistic Regression

As shown in Table 5.2, Model 4 accounted for 23.6% of the HIS variation. The results indicate that, when all variables were entered into the binary logistic regression, three variables remained statistically related to HIS frequency. Male gender was associated with 50% less need to search for health information (OR 0.49 [0.25-0.97]). Age younger than 40 years was also associated with a large decrease in the need to search for health information, and time since diagnosis was negatively related to HIS frequency in the categories of 15-19 years (OR 0.25 [0.07-0.87]) and 25+ years (OR 0.30 [0.10-0.89]), as compared to 0-4 years.

Discussion

Information about diabetes research is becoming increasingly available to patients (Vehof et al., 2018). Nevertheless, few studies have investigated relationships between the frequency of HIS and characteristics of patients diagnosed with diabetes mellitus in the Netherlands. The objective of this study is to identify which patients diagnosed with diabetes mellitus have a more substantial tendency to read about innovative diabetes-related research. Possible relationships with self-reported HIS frequency for the demographic characteristics of patients diagnosed with diabetes, their disease characteristics, and their illness perceptions.

According to the results of this study, HIS frequency is positively associated with female gender, age older than 40 years, and a diagnosis of diabetes mellitus Type II. Furthermore, HIS frequency is negatively related to time since diagnosis. Bivariate associations with HIS frequency were found for comorbidities and several illness perceptions (i.e., consequence, identity, illness coherence, and emotional representations), but these associations were not robust when controlling for other predictors.

In accordance with previous literature (Nikoloudakis et al., 2018; Sherman et al., 2020; Tennant et al., 2015), Dutch women diagnosed with diabetes were more likely to search for health information than men were. The results nevertheless did not replicate the negative association between HIS and age that has been reported in most existing literature. In the present study, patients younger than 40 years of age had a lower frequency of HIS. Given that we corrected for illness perceptions and trait optimism, this finding is more likely due to HIS skills, time management, or leisure activities, and not solely to emotions or attitudes. We found no evidence that patients with higher levels of education searched for information more frequently as a result of higher levels of online search skills. The absence of this

relationship is not in accordance with the literature (Johnson & Meischke, 1993; Maslow & Lewis, 1987; Rains, 2007; van Deursen et al., 2011),

According to our results, diabetes type is related to HIS frequency. The HIS frequency of patients with Type I diabetes was twice as high as it was for those with Type II. Although the literature says nothing on this topic, the cause is arguably related to perceptions of efficacy to improve one's health situation. More specifically, Type II diabetes is often associated with a high prevalence of smoking and heavy alcohol use, as well as with high intake of refined carbohydrates, and dramatically decreased levels of physical activity (Hu, 2011). As such, patients diagnosed with Type II have more tools for improving their health situations (thus through lifestyle changes) than do those with Type I, whose treatment depends entirely on scientific breakthroughs.

Our findings suggest that having received a medical diagnosis more than 15 years in the past is associated with a decreased likelihood of frequent HIS. Despite the tendency of long-term patients to face increasing medical requirements, the decrease in the frequency of HIS for these patients could possibly be explained by their resignation and habituation to the chronicity of the disease, to current treatment, and to the long-standing absence of alternative treatments. The role of information seeking extends beyond merely finding practical solutions (e.g., medication for symptoms or curation). It also serves an emotional function, namely, to alleviate anxiety regarding long-term consequences. Once these long-term consequences are known by or familiar to patients, the need for information decreases (Case et al., 2005).

Comorbidities were related to an increase in the frequency of HIS. This result might possibly be explained by an increased urge for treatment that a patient might feel. In our sample, however, patients with comorbidities that were of more concern to them than diabetes were less likely to search for diabetes-related information. It may be that these patients were searching for health information, but about the other condition.

Although some literature (Attfield et al., 2006) argues that a limited understanding of diabetes is associated with a higher frequency of HIS (i.e., patients search for information to enhance their understanding), analysis of the full model did not yield evidence of this pattern. Although this possibility was not evaluated in this study, a subset of patients with a deeper understanding of the biology of their disease may have been more motivated to seek out, read, and comprehend additional health-information articles. They may also have had more avenues for initiating

searches (e.g., in scientific libraries). A second explanation for the absence of the finding may have to do with to the cross-sectional character of the study design. More specifically, patients who had searched more frequently might have already learned more about their disease and therefore perceived that they understood their chronic condition better. According to some studies, patients who perceive more consequences and symptoms and who are more affected emotionally are likely to seek information frequently (Czaja et al., 2003; Hu et al., 2012; Lambert & Loiselle, 2007). Although this relationship became statistically insignificant in our corrected logistic regression models, our crude bivariate analyses provide some support for this premise.

To date, no research has investigated associations between the concepts of perceived chronicity and HIS frequency. In our study, the absence of a positive relationship between perceived chronicity and HIS may be explained by the idea that having an optimistic view (e.g., about the chronicity of diabetes) triggers a search for new therapies. However, we found no indication that patients with a high level of trait optimism sought information more frequently. Further studies on this topic should focus on effect modifiers or, in other words: *Who are the low-frequency HIS optimists?*

The strengths of this study include the fact that it is based on data from a large number of actual patients who varied in age, diagnosis (diabetes mellitus Types I and II), gender, and educational background. The results may therefore be extrapolated to the whole population of people diagnosed with diabetes in the Netherlands. Another strength is that this is the first study to assess HIS in Dutch patients diagnosed with diabetes. Limitations of this study include the absence of any follow-up data, the fact that the subjects were only known from an anonymous web-survey, and the self-reported, rather crude, primary outcome *high information seeker*.

One overall implication based on the results of this study is that, when disseminating news about diabetes, it is important to consider the gender and age of patients, as well as time since diagnosis are important when disseminating diabetes news. We also identified promising avenues for additional studies on predictors of interest in diabetes-related information. In a society with an ever-increasing stream of information (and misinformation) about novel treatments, and in which reading news messages is known to lead to frustration amongst persons affected by the disease (add reference), it is important exercise caution with regard to those who are exposed to health information. The need for well-designed digital libraries customised to the needs and conditions of patients is becoming more evident.

The first step towards such customisation could simply be to ask the members of a given community how often they like to read information or to use scientific knowledge to predict the average needs in groups according to the available basic (e.g., demographic) or more extensive (e.g., psychometric) information about the members. Another step is to safeguard the optional character of reading further information (e.g., by placing it on an additional webpage) and to avoid acting as a direct conduit of research results for all viewers. A more comprehensive step could be to provide readers with essential information in online interactive tools that return the exact information that individual patients wish to read.

Future research on this topic should focus on different diseases and discrepancies between needs for and actual exposure to health information and their effects on patients, as well as on practical applications related to the customisation of information.

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CHAPTER 6

General Discussion

The objective of this thesis has been to determine whether specific characteristics of health-news coverage influence how news about diabetes-related innovations affects the sentiments, therapy-related attitudes, and intentions of chronic patients. The relevance of this research goal is illustrated by the commonly asked questions posted by patients on social media regarding diabetes-related news, such as: "What will the cost of the new therapy be?", Will the treatment be reimbursed in the future? How far away is that future? What are the possible side effects? How many times have we already heard about this therapy?

The project is multi-disciplinary (involving communication science, linguistics, and pharmacology) and based on a diverse methodological approach. To assess the influence of news about diabetes-related innovations on patients, the research focuses on various aspects of typical news messages about future treatments for diabetes (i.e., sources, media platforms, language uses, and aspects of scientific evidence for the treatment). The studies presented in this thesis examine (1) the variety of news messages relating to diabetes research in classical news media and the evidence presented for success; (2) associations between essential characteristics of diabetes-related news and user sentiment on Facebook; and (3) the effects of diabetes-related news on the emotional, cognitive, and behavioural responses of patients. The studies also address (4) associations between trait characteristics of patients with diabetes and the frequency with which they seek health-related news.

This concluding chapter presents a summary of and reflection on the principal discoveries presented throughout this thesis, along with their theoretical and practical ramifications.

Summary of Findings

Clinical Evidence in Newspapers

Key finding: *Only 17% of Dutch newspaper articles about innovative diabetes treatments, as found in all sections (e.g., national news, economy, entertainment) include clinical evidence on patients, with reference to an academic institution, study, or researcher.*

Chapter 2 presents the results from a quantitative examination of the background characteristics of news messages about innovative treatments for diabetes mellitus Types I and II in Dutch newspapers. During the period of investigation, six prominent national newspapers in the Netherlands published between 83 and 133 articles per year discussing innovative options for treating diabetes. Only 17% of these articles, however, referenced actual clinical evidence by naming an academic institution, study, or researcher. The articles often lacked clinical evidence or provided no reference to a scientific source. Nutrition-related articles about diabetes treatments were even less likely to reference clinical evidence, with 93% lacking such evidence. Articles about pharmaceutical products were slightly more likely to include clinical evidence, with 75% of articles supported by references to patient studies.

Overall, the high number of news articles discussing diabetes-related innovations without clinical evidence is a point of concern for patients who are exposed to these messages. While journalists often aim to provide accurate information, the pressure of deadlines and the complexity of medical studies can compromise the accuracy or contextualisation of health claims. Although specialised health journalists typically provide more context and interpretation of medical findings, this information is often lacking in general journalistic products (Klemm et al., 2019). The lack of proper contextualisation in diabetes-related news may eventually erode public trust in medical innovation.

Sentiments vs. News Characteristics

Key finding: *Positive study results from pre-clinical studies, such as those conducted on animals, trigger the most positive sentiments amongst readers of Facebook groups hosted by patient organisations.*

Chapter 3 focuses on identifying possible relationships between the characteristics of news messages and the valence of sentiments in comments on Facebook groups hosted by patient organisations. These groups serve as a conduit for sharing academic research results, and they allow patients and others interested in diabetes

to join and post comments in response to the news messages. Results of the study indicate that language intensification (e.g., using words like 'breakthrough' or 'excellent') did not affect the sentiments of readers either positively or negatively. Reader sentiments tended to be positive, however, and the word 'hope' was more frequently articulated in readers' comments when the treatment presented was a potential cure for the disease. The most striking finding reported in Chapter 3 is the correlation of positive sentiments with news about good results in pre-clinical studies (often: animal studies). In terms of clinical development, studies on animals are far removed from the scientific standard of demonstrating proof of concept through randomised clinical trials. The positive reactions to this type of study might have been due the fact that news outlets sometimes present animal studies in an overly optimistic manner or do not provide enough context for readers to understand the various development phases of innovations.

Roles of Source Authority, Language Intensification, and the Phase of Development

Key finding: *The impact of news about innovative diabetes therapies on patients varies marginally depending on the developmental phase, the authority of the source, and the use of intense language.*

Chapter 4 reports on an online experiment using vignettes with systematically modified aspects of diabetes news. One aim of the study was to assess the role of the relative authority of the news source and the role of language intensification in influencing the attitudes of patients with diabetes towards a novel therapy and their intention to adhere to current medical regimens. The results from this study confirm those reported in Chapter 3: patients with diabetes have higher expectations for innovative treatments when news messages report promising results from preclinical (animal) studies. In addition, the source of diabetes-related news matters. More specifically the novel therapy garnered greater interest but reduced intentions to adhere to current medication when news from a not further specified *diabetes-related Facebook group*, which holds little authority, was compared to news from the RIVM (the Dutch National Institute for Public Health and the Environment), a high-level news authority. Notably, the modification of news messages to use more intense language decreased patient interest in the innovation and their intentions to follow lifestyle advice.

Who Monitors Health News?

Key finding: *Male gender and age younger than 40 years were negatively associated with the frequency of diabetes-related news seeking. However, no correlation was observed between illness perceptions or trait optimism and such news-seeking behaviour.*

Chapter 5 presents results from a cross-sectional survey investigating the mechanisms behind the effects of news characteristics on patients. Connections were investigated between independent patient characteristics gathered at baseline and searching for diabetes-related news at least once a month (i.e., high-frequency news seeking). High-frequency news seeking was found to be positively associated with female gender and negatively associated with age younger than 40 years. In addition, evidence was found for a decrease in HIS frequency for patients who had received their diagnoses 25 years in the past, even after controlling for age.

The data revealed no significant relationship between illness perceptions, as measured by the IPQ (de Raaij et al., 2007) and the frequent monitoring of innovative therapies. There was also no relationship between trait optimism and the frequent monitoring of diabetes-related news. These results suggest that the general or specific views that patients have about their lives and illness do not influence their desire to read about diabetes.

Conclusion

This thesis was guided by the following overarching research question: How are the characteristics of news about diabetes-related innovations related to cognitive outcomes (e.g., emotions, attitudes, intentions) in patients diagnosed with diabetes mellitus?

The data reveal that various news and source characteristics (including phase of development, language intensification, therapy characteristics, and source authority) are associated (albeit with small effect sizes) with patient attitudes towards novel therapies and their intentions to adhere to current medication regimens. Future research should focus on identifying vulnerable subgroups of patients, such as those with a lower survival rate, and further investigate associations (or the absence thereof) with patient emotions. Such studies could provide insight into the effectiveness of editorial strategies on news platforms that serve as conduits for research results.

Theoretical Reflections

This thesis addresses several initial questions about the role of crucial news characteristics in reactions to reports about diabetes-related innovations. The findings also raise new questions and call for the re-evaluation of our conceptualisation and methodological approach to responsible health-news coverage.

Fit with the Health Belief Model

The research inquiries presented in this thesis are guided by the Health Belief Model (Janz & Becker, 1984). Within the context of the thesis, this psychological and behavioural model assumes that patients with diabetes want to get well and believe that adhering to lifestyle changes and medication will prevent diabetes symptoms. The model asserts that the effectiveness of behavioural alteration is influenced by perceived barriers, advantages, self-efficacy, and threats. Communication is one of the cues to action (i.e., stimuli) needed to trigger the decision-making process relating to accepting a medical or lifestyle recommendation.

The key findings of the thesis concerning the Health Belief Model are presented in Figure 6.1. Chapters 2 and 3 report that patients with diabetes may encounter a plethora of information in newspapers, websites, and social media that can function as a stimulus to eventual action. As shown in Chapters 3 and 4, characteristics of news about diabetes-related innovations have an impact on the sentiments, attitudes, and intentions of patients. No correlation was detected between psychological factors and the pursuit of diabetes-related news. This result diverges from the findings reported by Johnson and Meischke (1993) in a study conducted within population of patients with cancer. Nevertheless, a negative association was established between seeking diabetes-related news frequently and gender (male) or age (< 40 years).

To achieve a thorough comprehension of the correlation between patient responses and news about diabetes-related innovations based on the tenets of the Health Belief Model, future studies should seek to substantiate existing findings and shed additional light on the theory. For example, studies could explore the link between emotional and cognitive reactions and behaviours or examine additional attributes of diabetes-related news messages, the effects of repeated exposure, intricate demographic factors, and patient populations with varying degrees of disease severity.

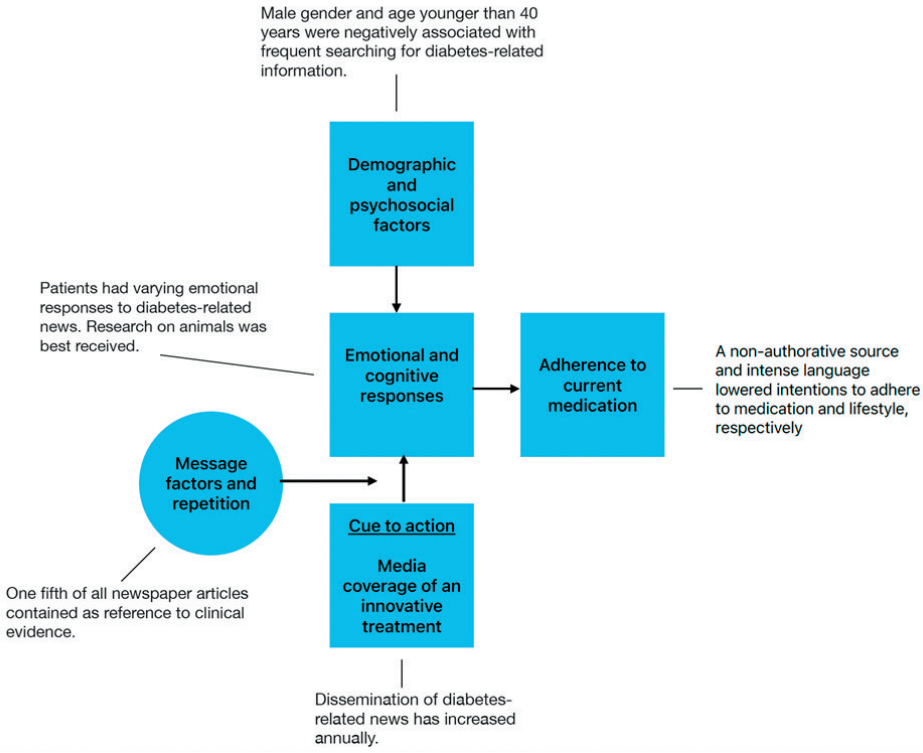

Figure 6.1: Principal findings of the current thesis concerning the Health Belief Model

News Media and Transparency in Reporting

The transparency of health reporting in media is determined by many factors, some of which have been confirmed in this thesis. Previous research has identified medical and academic experts as essential primary sources of health information (De Dobbelaer et al., 2017; Dunwoody, 2014). Experts help to clarify and contextualise complex and technical health topics and increase the authority and credibility of reporters' stories. According to the results reported in Chapter 2, however, augmenting a news narrative with appropriate references to clinical evidence provided by actual experts is not a ubiquitous phenomenon: only 20% of the news articles on innovative concepts for mitigating diabetes were substantiated by such references (computed across all disciplines).

The interviews conducted by De Dobbelaer et al. (2017) suggest that, in Belgium, pharmaceutical PR services influence health coverage in a subtle and often unperceived manner. For example, this is done by offering additional services, such as bringing journalists in contact with patients, offering illustrations, or

clarifying statistics. In the same interviews, it was suggested that the editors-in-chief of certain Belgian magazines try to anticipate the needs and preferences of advertisers by placing editorial and commercial content on specific health issues together. Although this particular topic is not addressed in the current thesis, future research endeavours should focus on the identification and quantitative evaluation of this matter in Belgium and beyond.

As emphasised in several studies on health-related media content, information about benefits, risks, and costs is often incomplete or inadequate, and financial conflicts of interest are seldom described. Many journalists feel that, when covering health news stories, their primary role is to inform the public by providing accurate and precise reports. The consequences of patient exposure to health information (e.g., in terms of therapy adherence) are of lesser concern (Schwitzer et al., 2005). Such findings raise questions concerning the extent to which popular media could be harmful rather than helpful to public health (Arif & Ghezzi, 2018; Iaboli et al., 2010; Schwitzer, 2003). The potential harm of popular media is underscored by the large share of low-evidence articles found in this thesis, especially about nutrition and diabetes, as well as by the overly optimistic perceptions that news messages about early developments may induce among readers with diabetes.

Principles of Health News Communication

Health news does not always reflect the needs and issues of patients, as the logic of news media differs from that of health communication (Kovach & Rosenstiel, 2021, pp. 6-7; Schwitzer et al., 2005). To bridge this gap, Schwitzer (2005) formulated a statement of principles for effective and transparent communication of medical research by any medium involved. The list frequently appears in expert recommendations. In many cases, however, little if any good research is available on the precise adoption of these principles. The results of our research highlight the importance of some of these principles.

First, the results confirm that, instead of having a positive effect on readers, the use of vague and sensational language (e.g., using words like *miracle*, *breakthrough*, or *promising*) has a mild negative effect. Sensational language should therefore be avoided. Second, our finding that readers do not fully comprehend the various developmental phases of medical innovations reinforces the need to quantify the extent of any benefits portrayed in a story. The meaning of results should be identified and explained, and not merely correlations between factors in a study (e.g., observation of a link between curcuma and diabetes outcomes; see Chapter 2). It is also essential to identify and describe any areas of uncertainty that remain in the developmental process. Third, ensuring objectivity and credibility in health

news calls for vigilance in selecting sources and investigating the relevant interests of the manufacturers. Despite the lack of focus on manufacturers' interests, the results reported in this thesis confirm the significance of opting for trustworthy and authoritative sources. Finally, it is important to evaluate claims and the actual evidence (clinical or otherwise) that is presented, especially when side effects are not mentioned. The need to pay attention to this is highlighted in Chapter 2.

Understanding the Phases of Research

Building on insights from pharmacological studies, the patients in this thesis's studies expressed a more positive outlook towards pre-clinical animal studies, as compared to earlier and later research stages. More specifically, readers viewed success reported in the pre-clinical stages as more promising than success in later stages involving human subjects. These findings warrant contemplation on the phases of innovation in drug development (and communication relating to these developments). As asserted by Dowden and Munro (2019), when all indication areas (with their high level of variability) are considered together, only approximately 7% of successful pre-clinical projects advance from Phase I trials to the actual launch stage, whereas 62% of successful Phase II trials go on to be introduced to the market following subsequent Phase III trials (i.e., extensive and versatile group effects).

The unexpected preference for pre-clinical on animal trials needs further investigation. Additional literature on this topic is needed, as the present study is the first to present evidence of this preference. It would be logical to posit that patients who possess knowledge of the pharmaceutical industry may not be easily excited about early news messages concerning novel therapies, given that the period required for development can still be extensive. As suggested by the results of this research, awareness of development time may outweigh enthusiasm for actual progression in research. It is more complicated to explain why people react more positively to pre-clinical research than they do to positive patient results. It may be that the complex metabolic, chemical, or cellular processes that lead to beneficial effects in laboratory animals appeal to the imagination of readers more than studies conducted with human participants do. Another possible explanation could be that the underutilisation of research evidence in media, as found by the study in Chapter 2 and confirmed by Walker and Viaña (2023), impedes readers from understanding the value of clinical results.

Pre-clinical research also tends to make headlines relatively often. The repetition of messages through such headlines may make this particular type of research more memorable and, therefore, more likely to be perceived as positive. Known as the 'availability heuristic', this mechanism has been described by Schwarz et al. (1991) and, more recently, by Zimand-Sheiner, Kol et al. (2021) in relation to COVID-19. It is based on the idea that the mind uses mental shortcuts to immediate examples (e.g., frequent headlines about pre-clinical research) when evaluating a specific medical topic. For example, future research should investigate whether pre-clinical trials are perceived as more typically scientific.

Practical Implications

The results reported in Chapter 3 of this thesis reflect a significant share of negative patient sentiments surrounding the provision of news about diabetes-related innovations. This is partly due to factors that are amenable to change by the authors or distributors of news articles. Currently, many experts are already working on improving the transparency of health news. For example, several suggestions for guidelines or rules have been proposed with regard to reporting new pharmaceutical (or other) therapies for various diseases.

The suggestions presented in Table 6.1 have been confirmed in the studies included in this thesis, and I wish to emphasise them as recommendations for any person writing, editing, or disseminating news about innovative treatments (e.g., for diabetes).

As beneficial adaptations of future diabetes-related news, the implications presented in this thesis may initially be perceived as demanding to some. I acknowledge that time and additional studies will be required in order to map the potential drawbacks of providing sub-optimal information and to adjust the flow of information based on those findings to an audience that is apparently highly welcoming of news. In this digital age, in which mouse clicks on headlines, the imperative to publish, and the pursuit of research grants are more crucial than ever, it has become increasingly challenging for content creators to restrain their enthusiasm about novel advancements and to refrain from disseminating them to patients they care about.

Table 6.1 Transparency advice for journalists, editors, and moderators

Evidence Be transparent about the evidence for a therapy's success. Did the researcher only theorise about future options, or is pre-clinical or clinical evidence available? Are references to academic institutions available? Especially for nutritional research, it is essential to highlight evidence (or the lack thereof) from observational studies, as such results have often not yet been repeated in clinical trials and are still a long way from being incorporated into therapeutical applications or prevention guidelines. Journalists should also recognise the complexity of differing viewpoints regarding the successful development of therapies.
Context Proper contextualisation also requires highlighting potential opposing sides of developments. What will a new therapy cost? Will the treatment be reimbursed in the future? How far away is that future? What are the possible side effects? The absence of answers to these questions is a major source of negative sentiment.
Neutral stance Patients value transparency and objectivity. In the attempt to persuade the reader, a writer may think that it would be ineffective to proceed from a neutral stance, as it would decrease emotional involvement. The use of intensified language in an article is not recommended, however, given that the use of words like *great*, *very*, or *excellent* was not found to have any positive effect on the interest, attitudes, or health-related intentions of patients with diabetes.
Developmental phase Provide more context about the significance of the phase of the scientific development of new therapies. Some patients are likely to think that pre-clinical trials (animal studies) are the most crucial moment in development. Patients may need help understanding the difference between effects on humans and effects *in vitro* (laboratory) or *in vivo* (animals). This presents an opportunity for journalists to inform patients by providing more context in their reports.
Primary source Always refer to the primary source of health information in order to allow the reader to look up more information and be better informed about actual evidence. Readers may have a subconscious idea that social media messages are relatively incomplete and that, as a rule, additional information should be sought elsewhere. A significant challenge remains for journalists and scientists to investigate how to raise interest in the innovations they describe to a higher level. Scientific findings emphasise that robust and professional science communication is beneficial to reader attitudes towards diabetes.
Message repetition Avoid over-repeating news messages on the same subject. If there is a slight improvement in specific research, it is essential to determine whether it is worth mentioning. If this decision favours publishing, the author of the piece should provide context about the strength of new evidence and the new place of innovation within the long developmental process. Alternatively, reader annoyance could be reduced to some extent by including a statement indicating that the author clearly understands that the development has been going on for a long time and that the article is reporting on only a minor scientific improvement. Moreover, if it would serve a broad public interest, it would be good to follow up with stories on negative findings and other failures in subsequent research.

Methodological Considerations and Future Directions

This thesis provides initial insight into the extent to which patient perceptions of medical innovations are linked to the characteristics of news reporting. The current results reveal that characteristics of news can have minor moderating effects on news reactions within a large group of patients with diabetes mellitus Types I and II. The patients involved were not selected primarily for typical characteristics (e.g., frailty, disease status, disease burden, health literacy, or interest in innovations). Future research could potentially identify variables related to disease severity that might modify some of the relationships reported here. To patients with terminal illnesses, who often participate and put their hopes in experimental trials, hope plays a particularly significant role (Pattison & Lee, 2011). To customise news to the preferences of such fragile individuals, it would be advisable to conduct follow-up research within these sub-populations. This type of analysis could be performed according to a short-term longitudinal observational design and measures of actual media exposure from patients in susceptible groups.

The current thesis reports on the quantitative investigation of sentiments that news evokes and the situations in which this occurs. The analysis is limited to a few essential news characteristics (e.g., strong language and the phases of research). Future research should also include the qualitative examination of unknown and unexplored effects (e.g., insomnia, beliefs about medicine, religion) and their frequencies in several novel situations. Proposed situations could include doctor visits, loneliness, acute anxiety, the well-meaning sharing of diabetes-related news messages by friends and family, or palliative end-of-life situations in which hope is—or perhaps should—no longer be applicable. Another concrete recommendation for research is to conduct a more detailed assessment of the relationship between language usage and sentiments, attitudes, and behaviour (or behavioural intentions). The scarce literature on the associations evaluated in this thesis project and the questions that remain after its conclusion indicate the existence of a knowledge gap concerning the actual impact of exposure to news about promising therapies.

A further important direction for future research involves understanding the short-term and long-terms effects of news on the social media accounts of medical professionals—and specifically physicians and scientists—on patients. Finally, studies are needed on the understanding and perceptions of patients with regard to medical developments and the impact of relevant educational interventions: what do patients comprehend, and how much knowledge of current diabetes-related research is necessary for patients to optimise information provision and, ultimately, quality of life?

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SUMMARY
NEDERLANDSE SAMENVATTING

SUMMARY

Due to the accessibility of a wide variety of media, nowadays patients with chronic diseases can stay informed about scientific developments and possible new treatments for their medical conditions. Exposure to such news can benefit patients in several ways. For example, if news reports offer patients hope for a cure or improvement, this can have a positive impact on their disease progression. Knowledge about scientific developments can also lead to better-informed discussions with physicians about newly available treatments. Frequent exposure to news about future treatments may also have disadvantages such as giving false hope, but to date, research on this topic is scarce.

Reports about new treatment methods are published frequently in mainstream media. Such news reports about innovations may be based on very early (laboratory) research with a high degree of uncertainty regarding when a treatment will (ever) be successfully tested in humans, and lead to so-called clinical effects in patients. Developments in laboratory (or other) research can stagnate, in which case a continuous stream of news on this topic has little news value and may give false hope to patients. Furthermore, the use of language intensification (sometimes incorrectly referred to as superlatives) in news offers the writer an opportunity to emphasize a message. It is unclear what impact such language use has on patients who are seeking clues to remain hopeful. Another characteristic of news that may play a role in evoking (false) hope, which this dissertation also focuses on, is the authority of the news source. What are the effects of a news source on patients' cognitive responses to hopeful or non-hopeful news?

The studies in this thesis aim to increase understanding of the effects of various characteristics of scientific news about a common chronic disease, i.e., diabetes, on the cognitive responses (e.g., emotions, attitudes, intentions) of diabetes patients. The research questions presented in this thesis are guided by the Health Belief Model, a theoretical framework developed to explain and predict health-related behaviours based on an individual's beliefs and attitudes. The model asserts that perceived barriers to a recommended health behavior, advantages of the behavior, self-efficacy in executing the behavior, and disease severity and personal susceptibility to the disease are important predictors of a health behavior. Communication is one of the cues to action (i.e., stimuli) that may trigger the decision-making process relating to accepting a medical or lifestyle recommendation.

The first objective was to provide insight into the amount of news messages on new diabetes-related treatment methods that is published in mainstream media, and determine how often these reports refer to actual clinical effects on patients. The second objective was to determine the ratio of positive and negative sentiments on social media to reading diabetes news, and to assess a relationship between sentiments and news characteristics. The third objective was to assess causal relationships between treatment news characteristics and patients' cognitive and emotional responses to news about diabetes innovations. Lastly, the fourth objective was to gain insight into patient characteristics associated with the motivation to frequently seek information on new diabetes treatments.

Chapter 2 describes a corpus analysis of reports in the six largest Dutch national newspapers between 2011 and 2016. Although actual clinical effects on patients reflect increased chances for future medical applications, it is unknown to what extent newspaper articles refer to such clinical effects when reporting health information. The study's objective was to assess, over a 6-year period, newspaper publication characteristics of innovative methods to treat diabetes from all scientific areas of interest regarding the total count and the proportion of articles that provide references to demonstrated clinical efficacy. The study introduces a quantitative approach to assessing coverage of medical innovations by analyzing in-article references to clinical evidence. The LexisNexis database was searched for newspaper articles from the six largest national newspapers in the Netherlands. Keywords were 'diabetes' in combination with the following words referring to the development of medical innovations: therapy, treatment, science, development, expectation, hope, optimism, breakthrough, innovation, revolutionary, life-saving, intervention or possibilities.

By assessing the presence of references to science, we could distinguish between articles that referred to actual clinical efficacy demonstrated in a scientific setting and articles that presented either predictions, fundamental research, preclinical research or personal experiences and recommendations. Proportion differences between scientific areas of interest were analysed. A total of 613 articles describing an innovative method to treat diabetes were found and categorised. Findings showed that the number of articles about diabetes innovations in these six newspapers increased per year. In total, 17% of the articles referenced any proven clinical efficacy. This percentage varied between the scientific areas. Articles containing a new method to treat diabetes related to human nutrition science and (neuro)psychology less frequently provided a reference to actual clinical efficacy. We conclude that less than one in five newspaper articles about an innovative method to treat diabetes contains a reference to relevant clinical effects despite

an upward trend in overall publications about innovative treatments. These findings highlight the potential impact of such statistics in fostering misguided expectations among patients.

Chapter 3 presents a social media corpus analysis that assesses the sentiment polarity of readers reacting to news about diabetes innovations.

While there is consensus among experts that Web-based health information often contains exaggeration and misrepresentation of science, it is unclear how this information affects readers' sentiments. The study aimed to investigate whether specific aspects of Web-based diabetes research news are associated with positive or negative sentiments in readers. A retrospective observational study of the comments on diabetes research news posted on Facebook pages was conducted as a function of the innovations' developmental phase, the intended treatment effect, and the use of strong language to intensify the news messages (e.g. fabulous, beautiful, great, special, important). Data for the investigation were drawn from diabetes research news posted between January 2014 and January 2018 on the two largest public Dutch Facebook pages on diabetes and the corresponding reader comments. By manually coding these Facebook user comments, three binary outcome variables were created, reflecting the presence of a positive sentiment, the presence of a negative sentiment, and the presence of a statement expressing hopefulness (e.g., 'I hope', 'Let's hope'). These sentiments could also occur together in one comment (mixed sentiments).

Facebook users made 3710 comments on 173 diabetes research news posts eligible for further analysis. Findings showed that Facebook user comments on posts about diabetes prevention, improved blood glucose regulation, and symptom relief were associated with less positive sentiments as compared with posts about potential diabetes cures. Furthermore, comments on innovations supported by preclinical evidence in animals were associated with more positive sentiments and more statements expressing hope when compared with innovations with clinical evidence from large human trials. The study found no evidence for the associations between language intensification of the news posts and the readers' sentiments. The finding that attitudes toward diabetes research news on Facebook were most positive when clinical efficacy was not (or not yet) proven in large patient trials suggests that news authors and editors, as well as medical professionals, must exercise caution when acting as conduit for diabetes research news.

Chapter 4 describes a vignette experiment (i.e., a presentation of short hypothetical scenarios) to assess causal relations between news characteristics and patients'

cognitive and emotional responses. Patients diagnosed with diabetes mellitus type 1 or 2 (N=259) were asked to read news reports about medical developments in diabetes that differed in the degree of language intensity, the degree of authority of the news source, and the research stage that was reported. The effects of these characteristics of diabetes news on patients' emotions, attitudes, and intended behaviours were measured, with a particular interest in adherence to treatment therapy. This aim was chosen since the literature did not clarify in what way users are affected by typical news characteristics such as the news object (described developmental phase of an innovation), the news source (degree of authority), and the news style (degree of language intensification).

To experimentally manipulate the presented scientific evidence for the innovation's success, the developmental phases in the vignettes were varied: (1) positive results from fundamental/laboratory research, (2) preclinical trials on animals, or (3) clinical trials on patients. To manipulate the news message's source authority, the message was either visible on the website of (1) an authoritative governmental source (i.e., Dutch National Institute for Public Health and Environment) or (2) from a nonprofessional non-authoritative source (i.e., a Facebook group named Diabetes Facebook Group without a specified author). To experimentally manipulate language intensification, we added four language intensifiers (special, discovery, important, and promising) that are frequently used in Dutch medical news to 50% of the presented vignettes, and this was added in combination with degree indicators: very, a lot, much, and many.

Findings showed that patients expected the highest success chances for news reports on mice studies, and that the patients' interest in gaining additional information about the treatment, by searching information or discussing the innovation with a health provider, was higher when the source was not authoritative. In contrast, patients' medication adherence intention was higher when the source condition was authoritative. Language intensification in the news reports had no significant effect on patients' expectations of the innovations' success and medication adherence intention. Patients' information intention was higher in the no intensification condition, compared with the intensification condition, and patients had a higher lifestyle intention in the condition without language intensification.
The findings in this study suggest that diabetes patients might not be fully aware of the challenging translation from early studies to actual healthcare innovations. Moreover, they may have an increased need for additional information or experience a diminished feeling of trust when reading from a non-authoritative

source. Lastly, the findings suggest that patients with diabetes seem mostly unaffected by subtle linguistic cues.

Chapter 5 describes a secondary analysis that was conducted the baseline data from the vignette experiment. These analyses aimed to determine whether patients' need to search for diabetes news is related to demographic factors, illness perceptions, and disease characteristics. The study was cross-sectional observational and reported secondary analyses on survey data additionally collected at the baseline of the experiment described in Chapter 4, for the purpose of gaining a better understanding of Health Information Seeking (HIS) and facilitating the provision of tailored news and information to meet individual needs.

Participants' frequency of seeking news about diabetes innovations was assessed, along with demographic factors, disease characteristics, illness perceptions, and trait optimism. Data from a total of N=246 participants were eligible for the subsequent analyses. Several models were assessed to explore the relationships between health seeking behavior (HIS) demographic variables, disease characteristics, illness perceptions, and trait optimism.

HIS frequency was negatively associated with male gender and age younger than 40. Time since diagnosis was negatively related to HIS frequency in the categories of 15-19 and 25+ years, as compared to 0-4 years since diagnosis. Bivariate associations with HIS frequency were found for comorbidities and several illness perceptions (i.e., consequence, identity, illness coherence, and emotional representations), but these associations were not robust when controlling for other predictors.

One overall implication of this study is that, when disseminating diabetes news, it is important to consider the gender and age of patients, as well as time since diagnosis.

Theoretical and practical implications and future research directions

Patients with diabetes may encounter a plethora of information in newspapers, websites, and social media that can function as a stimulus to eventual action, as described in the Health Belief Model. This thesis adds to the literature by showing that several characteristics of news about diabetes-related innovations have an impact on the sentiments, attitudes, and intentions of patients. Previous research has identified medical and academic experts as essential primary sources of health information. According to the results reported in Chapter 2, however, augmenting a news narrative with appropriate references to clinical evidence provided by

actual experts is not a ubiquitous phenomenon: only 20% of the news articles on innovative concepts for mitigating diabetes were substantiated by such references (computed across all disciplines).

Earlier research has raised questions about the extent to which popular media could be harmful rather than helpful to public health. This potential harm of popular media is underscored by the large share of low-evidence articles found in this thesis, especially about nutrition and diabetes, as well as by the overly optimistic perceptions that news messages about earlydevelopments may induce among readers with diabetes.

The thesis also highlights the importance of using principles for effective and transparent communication of medical research as the logic of news media differs from that of health communication. The results in this thesis confirm existing advice proposed by health information experts: Sensational language should be avoided; The meaning of results should be identified and explained; Identify and describe areas of uncertainty in the developmental process; Be vigilant when selecting sources and investigate the relevant interests of the manufacturers; Evaluate claims and the actual evidence that is presented.

Currently, many experts are working on improving the transparency of health news. Several of their recommendations have been confirmed in this thesis:

- Be transparent about the development's actual success.
- Describe the context of opposing sides of a development.
- Refrain from attempting to persuade the reader with strong language.
- Provide context about the developmental phase of an innovation.
- Refer to the primary source of health information.
- Avoid over-repeating news messages.

Future research could identify disease-related variables that modify some of the relationships reported in this thesis. In order to tailor news to the preferences of fragile individuals, such as patients with a terminal illness, it is recommended to conduct further research within subgroups using a short-term longitudinal observational design and measures of actual media exposure from patients from susceptible groups.

NEDERLANDSE SAMENVATTING

Dankzij de toegenomen toegankelijkheid van (online) nieuwsmedia kunnen patiënten met chronische ziekten continu geïnformeerd worden over wetenschappelijke ontwikkelingen en mogelijke nieuwe behandelingen. Nieuws kan patiënten op verschillende manieren beïnvloeden. Positieve nieuwsberichten kunnen bijvoorbeeld bijdragen aan een beter ziekteverloop, vooral als ze hoop bieden op genezing. Bovendien kunnen patiënten dankzij meer kennis beter geïnformeerde gesprekken voeren met artsen over nieuwe behandelopties. Echter, frequente blootstelling aan nieuws over toekomstige behandelingen kan ook nadelige effecten op het welzijn van de patiënt hebben, maar tot op heden is er weinig onderzoek naar dit onderwerp gedaan.

Berichten over nieuwe behandelmethoden worden regelmatig gepubliceerd in verschillende traditionele massamedia. Dergelijke nieuwsberichten over innovaties kunnen gebaseerd zijn op zeer vroeg (laboratorium)onderzoek met een hoge mate van onzekerheid over wanneer een behandeling succesvol zal worden getest op mensen en leiden tot zogenaamde klinische effecten bij patiënten. Ontwikkelingen in laboratorium- (of ander) onderzoek kunnen stagneren. In die gevallen kan een continue stroom van nieuws over het onderwerp weinig nieuwswaarde hebben en wellicht tot valse hoop bij patiënten leiden. Daarbij biedt het gebruik van krachtige woorden in het nieuws (soms onterecht aangeduid als 'superlatieven') de schrijver de mogelijkheid om een boodschap te benadrukken. Het is onduidelijk wat voor impact een dergelijk taalgebruik heeft op patiënten die op zoek zijn naar hoopvolle berichten. Een andere eigenschap van nieuws die mogelijk een rol speelt bij het oproepen van (valse) hoop, waarop deze thesis zich ook richt, is de autoriteit van de nieuwsbron. Wat zijn de effecten van de nieuwsbron op de cognitieve respons van patiënten op hoopvol of niet-hoopvol nieuws?

De onderzoeksvragen die voor deze thesis zijn opgesteld, worden geleid door het Health Belief Model, een theoretisch kader ontwikkeld om gezondheids-gerelateerd gedrag te verklaren en te voorspellen op basis van de overtuigingen en attitudes van een individu. Het model stelt dat de effectiviteit van gedragsverandering wordt beïnvloed door waargenomen barrières, voordelen, zelfeffectiviteit en bedreigingen. Communicatie is een van de stimuli die nodig zijn om het besluitvormingsproces te activeren met betrekking tot het accepteren van een medische of leefstijl-aanbeveling.

Het eerste doel van het huidige thesis onderzoek was het vergroten van inzichten in de publicatiefrequentie van berichten over diabetesbehandelingen en te bepalen hoe vaak deze berichten een verwijzing bevatten naar klinische effecten op patiënten. Het tweede doel was om de hoeveelheid, en verhouding van, positieve en negatieve sentimenten in reactie op gelezen online diabetesnieuws vast te stellen. Het derde doel was om na te gaan of er sprake kan zijn van causale verbanden tussen kenmerken van nieuws over diabetes en cognitieve en emotionele reacties van patiënten op het nieuws. Het vierde doel was het verkennen van mogelijke verbanden tussen patiëntkenmerken en het frequent zoeken naar informatie over innovatieve diabetesbehandelingen.

Hoofdstuk 2 is het startpunt van deze thesis en beschrijft een corpusanalyse van berichten in de zes grootste Nederlandse landelijke kranten van 2011 tot 2016. Hoewel het vooral de klinische effecten bij patiënten zijn die een verhoogde kans op toekomstige medische toepassingen voorspellen, is het onbekend in hoeverre krantenartikelen aan dit klinische bewijs refereren bij het verspreiden van nieuws over innovaties. Het doel van het onderzoek was om gedurende een periode van zes jaar kenmerken van krantenartikelen over innovatieve methoden om diabetes te behandelen, uit alle wetenschappelijke interessegebieden, te beoordelen. De studie gebruikt een kwantitatieve benadering om de berichtgeving over medische innovaties te beoordelen door te streven naar verwijzingen naar klinisch bewijs binnen de artikelen. De LexisNexis-database werd doorzocht naar papieren krantenartikelen uit de zes grootste landelijke kranten in Nederland. Trefwoorden waren ‘diabetes’ in combinatie met Nederlandse woorden die verwijzen naar de ontwikkeling van medische innovaties: therapie, behandeling, wetenschap, ontwikkeling, verwachting, hoop, optimisme, doorbraak, innovatie, revolutionair, levensreddend, interventie of mogelijkheden. Het totaal aantal artikelen over innovatieve behandelingen is geteld en het percentage artikelen is bepaald dat in de tekst verwijst naar een klinische werkzaamheid gemeten door een met naam genoemd wetenschappelijk instituut of wetenschapper. Er is daarmee onderscheid gemaakt tussen artikelen die verwezen naar (1) een daadwerkelijke klinische werkzaamheid aangetoond in een wetenschappelijke setting en artikelen die (2) voorspellingen, fundamenteel onderzoek, preklinisch onderzoek of persoonlijke ervaringen en aanbevelingen presenteerden. Daarbij werden verschillen in proporties tussen wetenschappelijke interessegebieden – zoals humane voeding of farmacologie- geanalyseerd met behulp van een chi-kwadraattoets. Er werden in totaal 613 artikelen gevonden die een innovatieve methode beschreven om diabetes te behandelen en deze werden gecategoriseerd. De resultaten lieten zien dat het aantal artikelen over diabetesinnovaties in deze zes kranten per jaar toenam. In totaal verwees 17% van de artikelen naar enige bewezen klinische

werkzaamheid. Dit percentage varieerde per wetenschappelijk domein. Artikelen gerelateerd aan voedingswetenschappen en (neuro)psychologie verwezen minder vaak naar daadwerkelijke klinische werkzaamheid. De genoemde resultaten benadrukken een mogelijke impact van berichten over diabetes op verkeerde verwachtingen bij patiënten.

Hoofdstuk 3 beschrijft de tweede empirische studie: een corpusanalyse van sociale media om de tendens van sentimenten te beoordelen van lezers die reageren op nieuws over diabetesinnovaties.

Hoewel experts het erover eens zijn dat op internet gebaseerde gezondheidsinformatie vaak overdrijving of een vertekende voorstelling van wetenschap bevat, is het onduidelijk hoe deze informatie van invloed is op de sentimenten van de lezers. De studie had als doel te onderzoeken of kenmerken van nieuws op sociale media over diabetesinnovaties geassocieerd zijn met positieve en negatieve sentimenten bij lezers. Er is een retrospectieve observationele studie uitgevoerd naar de sentimenten die aanwezig zijn in commentaren die door gebruikers geplaatst zijn bij nieuws over diabetesinnovaties in Facebookgroepen. De onafhankelijke variabelen die hierbij werden onderzocht waren de ontwikkelingsfase van de innovaties, het beoogde behandeleffect en de aanwezigheid van taalintensificatie om de boodschap van nieuwsberichten te versterken (bijv. fantastisch, mooi, geweldig, speciaal, belangrijk). De data die gebruikt zijn voor het onderzoek komen uit nieuwsartikelen die tussen januari 2014 en januari 2018 op de twee grootste openbare Nederlandse Facebook-pagina's over diabetes geplaatst zijn. Deze zijn samen met de bijbehorende opmerkingen van de lezers in een analyseerbare database gezet. Door vervolgens deze opmerkingen van Facebook-gebruikers handmatig te coderen, werden drie uitkomstvariabelen gecreëerd, die (1) de aanwezigheid van een positief sentiment, (2) de aanwezigheid van een negatief sentiment en (3) de aanwezigheid van een woordelijke uitdrukking die het (willen) hebben van hoop weerspiegelden ('ik hoop', 'hopelijk', 'laten we het hopen', etcetera). Deze drie sentimenten konden ook samen voorkomen in een commentaar.

Bij 173 berichten over diabetesonderzoek plaatsten Facebook-gebruikers 3710 opmerkingen die geschikt waren voor verder onderzoek. De bevindingen lieten zien dat Facebook-gebruikersreacties op berichten over diabetespreventie, verbeterde bloedglucoseregulatie en symptoomverlichting geassocieerd waren met minder positieve sentimenten in vergelijking met berichten over mogelijke diabetesgenezingen. Bovendien waren reacties op innovaties met preklinisch bewijs bij dieren geassocieerd met meer positieve sentimenten en

meer uitingen van hoop in vergelijking met innovaties met klinisch bewijs uit grootschalige menselijke proeven. De studie vond geen bewijs voor de verbanden tussen taalversterking in de nieuwsberichten en de sentimenten van de lezers. Deze bevinding dat de houding ten opzichte van nieuws over behandelingen het meest positief is wanneer klinische effecten in patiënten niet (of nog niet) zijn aangetoond in grootschalig onderzoek op mensen, benadrukt dat nieuwsauteurs en redacteuren, evenals medische professionals, voorzichtig moeten zijn wanneer ze, zonder de context te verduidelijken, alleen optreden als doorgeefluik voor nieuws over diabetesonderzoek.

Het derde onderzoek, gepresenteerd in **Hoofdstuk 4**, was een vignetten-experiment om causale verbanden te meten tussen kenmerken van nieuws over diabetesinnovaties en de cognitieve en emotionele reacties van patiënten. Patiënten gediagnosticeerd met diabetes mellitus type 1 of 2 (N=259) kregen fictieve nieuwsberichten (gebaseerd op werkelijke ontwikkelingen in onderzoek) te zien over ontwikkelingen in diabetesonderzoek die systematisch verschilden op drie kenmerken: (1) de fase van het onderzoek, (2) de autoriteit van de bron en (3) de mate van taalintensiteit van de tekst. De afhankelijke variabelen in de studie hadden betrekking op emoties, attitudes en gedragsintenties van patiënten, met bijzondere aandacht voor therapietrouw (medicatie en leefstijl).

Om effecten van het wetenschappelijke bewijs in de nieuwsberichten te kunnen bepalen, varieerden de ontwikkelingsfases in de vignetten systematisch per deelnemer: (1) positieve resultaten uit fundamenteel/laboratoriumonderzoek, (2) preklinische proeven op dieren, of (3) klinische proeven op patiënten. Verder werd de autoriteit van de bron systematisch gevarieerd door het nieuws te presenteren alsof het op een webpagina stond van: (1) een autoriteit (in deze studie: het Rijksinstituut voor Volksgezondheid en Milieu) of (2) een niet-professionele niet-gezaghebbende bron (een fictieve Facebook-groep genaamd Diabetes Facebook Group zonder gespecificeerde beheerder). Om taalintensivering systematisch te manipuleren, kreeg de helft van de deelnemers vier taalversterkers in de tekst te lezen (speciaal, ontdekking, belangrijk en veelbelovend) die vaak worden gebruikt in Nederlandse medische nieuwsberichten en dit werd toegevoegd in combinatie met graadindicatoren: zeer, erg, heel.

De resultaten lieten zien dat patiënten de hoogste kans op succes verwachtten bij nieuwsberichten over muizenstudies, en dat de intentie van de patiënten om aanvullende informatie te verkrijgen over de behandeling, door informatie op te zoeken of de innovatie met een zorgverlener te bespreken, hoger was wanneer de bron geen autoriteit was. De intentie van patiënten om medicatietrouw

te zijn was hoger wanneer de bron een autoriteit was. Taalversterking in de nieuwsberichten had geen significant effect op de verwachtingen van de patiënten over het succes van de innovaties en de intentie om medicatietrouw te zijn. De intentie van patiënten om meer informatie over te therapie te verkrijgen was hoger in de groep zonder taalintensificatie, in vergelijking met de groep met taalintensificatie, en patiënten hadden een hogere intentie op het gebied van leefstijl in de conditie zonder taalversterking. De bevindingen in dit onderzoek suggereren dat diabetespatiënten mogelijk onvoldoende op de hoogte zijn van de uitdagingen die gepaard gaan met het doorontwikkelen van vroege studieresultaten naar daadwerkelijke innovaties in de gezondheidszorg. Bovendien hebben patiënten een grotere behoefte aan aanvullende informatie wanneer ze berichten lezen van een niet-autoritaire bron, die zij mogelijk iets minder vertrouwen, en lijken ze grotendeels ongevoelig te zijn voor subtiele linguïstische signalen.

Hoofdstuk 5 beschrijft een secundaire analyse die is uitgevoerd op de baselinedata van het vignetten-experiment uit hoofdstuk 4. De analyses hadden als doel om te bepalen of de behoefte van patiënten om naar diabetesnieuws te zoeken gerelateerd is aan demografische factoren, ziektepercepties, ziektekenmerken en het hebben van een algemeen optimistische levenshouding. De studie was een cross-sectioneel observationeel onderzoek met secundaire analyses op enquêtegegevens die waren verzameld bij de aanvang van het eerder beschreven vignetten-experiment, met als doel het beter begrijpen van zoekgedrag met betrekking tot gezondheidsinformatie waarmee in de toekomst nieuwsvoorzieningen op maat gemaakt kunnen worden van de wensen van individuen.

De frequentie waarmee deelnemers op zoek gingen naar nieuws over diabetesinnovaties werd geëvalueerd. In statistische modellen werden verbanden onderzocht tussen zoekfrequentie (binair: jaarlijks of minder versus maandelijks of vaker) en patiënteigenschappen. Gegevens van in totaal N=246 deelnemers waren geschikt voor de analyses.

Zoekfrequentie hing negatief samen met het mannelijk geslacht en leeftijd jonger dan 40. De tijd sinds de diagnose hing negatief samen met zoekfrequentie in de categorieën 15-19 en 25+ jaar, in vergelijking met 0-4 jaar sinds de diagnose. Er werden bivariate associaties met zoekfrequentie gevonden voor comorbiditeiten en verschillende ziektepercepties (gevolg, identiteit, ziektecoherentie en emotionele representaties), maar deze associaties waren niet robuust toen werd gecorrigeerd voor andere voorspellende variabelen.

Een belangrijke implicatie van de onderzoeksresultaten is dat wanneer diabetesnieuws wordt verspreid, het belangrijk is om rekening te houden met het geslacht, de leeftijd en de tijd sinds diagnose van de patiënten die het lezen.

Theoretische en praktische implicaties en toekomstige onderzoeksrichtingen

Patiënten met diabetes kunnen een overvloed aan informatie tegenkomen in kranten, op websites en op sociale media die kunnen fungeren als een stimulus om tot gedragsverandering over te gaan, zoals beschreven in het Health Belief Model. Deze scriptie draagt bij aan de literatuur door aan te tonen dat verschillende kenmerken van nieuws over diabetesgerelateerde innovaties invloed hebben op de gevoelens, attitudes en intenties van patiënten. Eerdere onderzoeken hebben medische en academische experts geïdentificeerd als essentiële primaire bronnen van gezondheidsinformatie. Volgens de resultaten die worden gerapporteerd in Hoofdstuk 2 is echter het verrijken van een nieuwsbericht met passende verwijzingen naar klinisch bewijs, verstrekt door daadwerkelijke experts, geen alomtegenwoordig gebruik: slechts 20% van de nieuwsartikelen over innovatieve concepten ter vermindering van diabetes werd onderbouwd door dergelijke referenties (berekend over alle disciplines).

Eerder onderzoek heeft vragen opgeworpen over de mate waarin populaire media schadelijk kunnen zijn in plaats van bij te dragen aan de volksgezondheid. Dit potentiële schadelijke effect van populaire media wordt benadrukt door het grote aandeel van artikelen met een laag bewijsniveau die in deze thesis zijn gevonden, vooral over voeding en diabetes, evenals door de relatief optimistische percepties die nieuwsberichten over vroege ontwikkelingen kunnen teweegbrengen bij lezers met diabetes.

De thesis benadrukt ook het belang van het gebruik van richtlijnen voor effectieve en transparante communicatie van medisch onderzoek, aangezien de aanpak van nieuwsmedia veelal verschilt van die van gezondheidscommunicatie. De resultaten in deze scriptie bevestigen bestaand advies dat is voorgesteld door gezondheidsinformatie-experts: Sensationele taal moet worden vermeden; De betekenis van resultaten moet worden geïdentificeerd en uitgelegd; Identificeer en beschrijf onzekerheden in het ontwikkelingsproces; Wees waakzaam bij het selecteren van bronnen en onderzoek de relevante belangen van de fabrikanten; Beoordeel claims en het daadwerkelijke bewijs dat wordt gepresenteerd.

Op dit moment werken veel experts aan het verbeteren van de transparantie van gezondheidsnieuws. Verschillende van hun praktische aanbevelingen zijn bevestigd in deze scriptie:

- Wees transparant over het werkelijke succes van de ontwikkeling.
- Beschrijf de context van tegengestelde kanten van een ontwikkeling.
- Probeer de lezer niet met sterke taal te overtuigen.
- Geef context over de ontwikkelingsfase van een innovatie.
- Verwijs naar de primaire bron van gezondheidsinformatie.
- Vermijd het overmatig herhalen van nieuwsberichten over hetzelfde onderwerp

Toekomstig onderzoek kan ziektegerelateerde variabelen identificeren die enkele van de relaties modificeren die in deze scriptie worden beschreven. Om nieuws af te stemmen op de voorkeuren van kwetsbare individuen, zoals patiënten met een terminale ziekte, wordt aanbevolen om verder onderzoek te doen binnen subgroepen met behulp van een kortdurend longitudinaal observationeel design en met metingen van de daadwerkelijke mediablootstelling van patiënten uit vatbare groepen.

APPENDICES

APPENDIX A

News Message Texts and Variations for Chapter 4

A study participant detailed in Chapter 4 received a virtual news report via their web browser. Two reports were designed for each type of diabetes (T1DM, T2DM). A participant diagnosed with type 1 diabetes mellitus read one message about T1DM, while a participant diagnosed with type 2 diabetes mellitus read one message relevant to T2DM. The reports were randomly manipulated on three aspects: the subjects received a text with either no language intensification or considerable language intensification. In the latter vignettes, the following four words are added to the text: *veelbelovend, belangrijk, ontdekking*, or *bijzonder*, in combination with *zeer, heel,* or *erg* (degree indicators).

Text 1 for T1DM

Nieuw: [veelbelovende] productie van bètacellen bij diabetes type 1.
Voor mensen met diabetes type 1 wordt gewerkt aan een [erg belangrijke] nieuwe behandeling. Die [Deze grote ontdekking] moet ervoor zorgen dat er weer voldoende insuline-producerende cellen in het lichaam aanwezig zijn. Dr. Petra Bergman (AMC) heeft met haar team een [zeer bijzondere] techniek ontwikkeld onder de naam Lipostemm. Tijdens een Lipostemm-behandeling worden eerst lichaamseigen vetcellen veranderd in zogeheten 'stamcellen'. Deze stamcellen worden op kweek gezet en vermenigvuldigd tot een groot aantal insuline producerende bètacellen. Genezing door een transplantatie van de bètacellen lijkt mogelijk voor mensen met diabetes mellitus type 1.

Text 2 for T1DM

[Veelbelovende] Capsule met insuline producerende bètacellen ontwikkeld voor diabetes type 1.
Dr. Ulrike Beindorf (Leiden UMC) werkt aan een nieuwe behandeling [of: grote ontdekking] voor Type 1-diabetes. In de afgelopen jaren ontwikkelde zij een [zeer bijzondere] capsule die insuline-producerende bètacellen bevat. De capsule geeft insuline af aan het bloed en 'omzeilt' problemen met de eigen afweer. De [erg belangrijke] techniek moet het overbodig maken dat mensen met diabetes type 1 injecties met insuline krijgen of een insulinepomp bij zich dragen. Deze capsule-methode lijkt op het zogeheten 'inkapselen', een onderzoekspad waar andere onderzoekers al enkele jaren mee bezig zijn.

Text 1 for T2DM

[Grote ontdekking:] Macrofagenbehandeling verhoogt de insulinegevoeligheid bij diabetes type 2.
Het is al langer bekent dat overgewicht leidt tot een lichte ontstekingen in vetcellen. Dit maakt het lichaam minder gevoelig voor insuline en dat leidt tot een hoge kans op diabetes type 2. Het is dr. Chris Keller (UMC Groningen) nu gelukt een [erg belangrijke] behandeling te ontwikkelen waarbij ontstekingen worden voorkomen. In zijn [zeer veelbelovende] onderzoek richt hij zich op zogeheten macrofagen en iNKT-cellen. Na een zogenaamde [of: heel bijzondere] 'macrofagenbehandeling' zijn bepaalde onderdelen van het afweersysteem niet langer overwerkt en raken lichaamscellen weer gevoelig voor insuline.

Text 2 for T2DM

Nieuw[e ontdekking]: virale gentransfer ook bij diabetes type 2.
Dr. Anika Breedveld (VUmc) heeft een bestaande [erg bijzondere] techniek genaamd 'virale gentransfer' verbeterd. Bij mensen met diabetes worden de bètacellen vernietigd door het immuunsysteem, maar de andere cellen in de alvleesklier blijven vaak "gespaard". Deze cellen werden door de onderzoekers gebruikt om nieuwe insuline producerende cellen te maken. Met behulp van een virus werden insuline producerende genen ingebouwd in de overgebleven alvleesklier cellen. Zo wordt de insuline aanmaak weer op gang gebracht, echter zonder het risico op afsterving van de nieuwe cellen. De [zeer veelbelovende] nieuwe techniek biedt ook [heel belangrijke] ondersteuning bij het genezen van mensen met type 2diabetes.

Research Phase Variation

The news messages were manipulated by randomly assigning the innovation's developmental phase. One of the following three sentences was added as a part of the news message content:

1 "De nieuwe techniek is bijna gereed voor eerste testen in proefdieren."
2 "Onderzoek in muizen liet het afgelopen jaar positieve resultaten zien."
3 "Onderzoek in een groep van 22 patiënten liet het afgelopen jaar positieve resultaten zien."

(English translation)

1 The novel technique is nearly ready for initial testing in experimental animals.
2 Research in mice exhibited encouraging outcomes during the past year.
3 Research in a cohort of 22 patients revealed favourable findings during the previous year.

Source Variation

Two conditions: the news message is shown in a visual frame suggesting that the message is published on either a not further specified "Diabetes Facebook Group", or on the RIVM website.

Figure C1: Version 1 of the Source Manipulation The visual frame surrounding the news message suggests that the news message is published in an online diabetes Facebook group. Neither the primary source nor characteristics of the Facebook group will be further specified.

Figure C2: Version 2 of the Source Manipulation The visual frame surrounding the news message suggests that the news message is published on the website of the RIVM (Netherlands National Institute for Public Health and the Environment).

APPENDIX B

Author Contributions and Research Data Management

Author contributions

Chapter 1 Introduction
HV wrote the general introduction of this thesis. His PhD supervisors commented on earlier manuscript drafts, and HV implemented their feedback.

Chapters 2, 3, 4, and 5
HV designed the studies described in these chapters; he collected and analyzed the data, interpreted the results, and wrote the manuscript. All authors contributed to and provided commentary on these aspects. HV implemented their feedback.

Chapter 6 General Discussion
HV wrote the general discussion of this thesis. His PhD supervisors commented on earlier drafts of the manuscript and gave advice.

RESEARCH DATA MANAGEMENT

The current thesis comprises data from three collections. For the first study, using a LexisNexis account from the Hogeschool Utrecht (HU), 2699 news articles from Dutch national print newspapers were downloaded from a database (LexisNexis). These news articles were stored in a secure cloud environment called Surf Drive and analyzed from a HU computer. A file containing the publication dates and headlines of all relevant 613 newspaper articles used for the final analysis in Chapter 2 can be accessed through this link to a Mendeley data repository: https://data.mendeley.com/datasets/b5prd7t3vz

For the second study, Facebook posts and subsequent comments were downloaded from publicly accessible Facebook group pages. The news messages from Facebook group administrators and the related posts from Facebook users were stored on a secure server at the HU and analyzed on a HU PC. The names of the posters in the comments were immediately removed and permanently deleted and replaced with numbers to allow for the correction of repeated comments from a single Facebook user. Those interested in utilizing the final dataset of Facebook posts, anonymous comments, and coded emotions may contact the authors of Chapter 3 at lectoraatizf@hu.nl.

For the third and fourth studies, a quantitative vignette experiment containing different hypothetical news messages presented to individuals with type 1 diabetes was conducted, and data were collected using the survey program HU-survey. Data has been collected regarding age, educational level, gender, diabetes type, time since diagnosis, medication use, the perceived success rate of the innovation, illness perceptions, trait optimism, perception of news exaggeration, adherence intentions, interest in the innovation, and intention to discuss the innovation with a healthcare provider. The University of Utrecht's ethical committee, UPPER, granted ethical permission. The file number for this permission is UPF1806, dated September 28th, 2018. HU survey is a licensed variant of the Lime Survey software, which has been reviewed and deemed safe by the HU. Initially, HU survey internally stored the data in their cloud, which can be accessed with an HU account. Subsequently, the data was downloaded with an HU PC and stored on a secure HU server for analysis. The data stored here does not contain identifiable information about the participants (i.e., people with type 1 or 2 diabetes). The data provide insufficient information for identification purposes. No names, pharmacy names, or residence names were requested. The data and codebook from the experiment in Chapter 4 are publicly accessible on the Mendeley repository at the link https://data.mendeley.com/datasets/jr2y88gzdp/1. Appendix C contains an overview of the news articles and manipulations used for Chapter 4.

Those interested in utilizing the data (gender, age, education, diabetes type, time since diagnosis, presence of a comorbidity, illness perceptions, trait optimism, HIS frequency) collected at baseline of the vignette experiment (Chapter 5) may contact the authors of Chapter 5 at lectoraatizf@hu.nl.

The collections of data acquisition, research documentation, and data sharing are kept for at least 10 years in the research data archive of the HU Knowledge Centre for Healthy and Sustainable Living. These collections are accessible upon request by the HU Department of Innovation of Healthcare Processes in Pharmacology or by contacting lectoraatizf@hu.nl.

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Mijn proefschrift is afgerond. Dat maakt me vrolijk, trots en opgelucht. De weg ernaartoe was buitengewoon leerzaam en leuk. Het voelde in het begin enigszins complex door de verschillende onderzoekdomeinen die we in de studies lieten samenkomen. Gelukkig heb ik een geweldige begeleiding gehad en zijn uiteindelijk alle hybride puzzelstukjes op de goede plaats terechtgekomen.

Dit promotietraject is succesvol door de belangrijke personen die mij erbij hielpen. Ik wil daarom mijn promotoren prof. dr. Enny Das en prof. dr. José Sanders en copromotor dr. Rob Heerdink enorm bedanken. Jullie expertise, vertrouwen en altijd positief-kritische feedback hebben me niet alleen als onderzoeker, maar ook als analytisch denkend mens enorm veel completer gemaakt.

Graag wil ik ook de leden van de manuscriptcommissie, prof. dr. Jos Hornikx, prof. dr. Bart van den Bemt, dr. Gert-Jan de Bruijn, prof. dr. Sandra van Dulmen en prof. dr. Hans Hoeken, bedanken voor het kritisch beoordelen van mijn thesis. Veel dank ook aan dr. Hanneke Hendriks voor het plaatsnemen in de corona. Ik zie uit naar een mooie discussie tijdens mijn verdediging.

Dit proefschrift kon niet tot stand kon komen zonder de medewerking van vrijwilligers. Een groot aantal betrokken en geïnteresseerde mensen, vaak zelf met de diagnose diabetes, heeft meegedaan aan voorbereidende gesprekken en interviews en aan pilots. Daarnaast ben ik ook de vele deelnemers aan het vignettenexperiment zeer erkentelijk.

Mijn bijzondere dank gaat uit naar de beheerders van de Facebook-groepen die hielpen bij de werving en naar de coördinatoren van het instituut UPPER van de Universiteit Utrecht die mij ondersteunden om deelnemers via apotheken te bereiken. Hartelijk dank, allen, dat jullie enthousiast meedachten met mij.

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je fijne begeleiding bij het opzetten van het promotietraject en je input voor hoofdstuk 2 van deze thesis. Dankjewel ook Hans Merkx voor alle steun die je me gaf toen je directeur van het Instituut Paramedische Studies was. Daarnaast hebben mijn collega's van het Lectoraat Innovaties van Zorgprocessen in de Farmacie van de HU mij van fijne feedback voorzien tijdens mijn presentaties van protocollen en studieresultaten. Dank daarvoor! Ook ben ik de medewerkers van het Departement Taal en Communicatie van de Radboud Universiteit dankbaar voor de onderzoeksoverleggen die ik heb mogen bijwonen en de feedback die ik op mijn ideeën heb gekregen. Het was daarbij erg motiverend en effectief voor mijn productiviteit dat ik een lange tijd wekelijks bij jullie in het Erasmusgebouw heb mogen werken.

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- Vehof, H., Sanders, J., van Dooren, A., Heerdink, E., & Das, E. (2018). Clinical evidence vs preliminary speculation in newspaper coverage of diabetes innovations: a quantitative analysis. *Public Health*, 160, 49–51. https://doi.org/10.1016/j.puhe.2018.03.022

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ABOUT THE AUTHOR

Hans Vehof was born in 1977 in Deventer, the Netherlands, and grew up in Beekbergen. He earned his Bachelor's degree in Nutrition and Dietetics from HAN University of Applied Sciences, Nijmegen, in 2004. In 2006, he completed his Master of Science in Nutrition and Health at Wageningen University & Research. During his professional career, he conducted research at the Danish Cancer Society in Copenhagen, Denmark, and Radboudumc in the Netherlands. From 2013 to October 2023, Hans worked as a lecturer in research methods and human nutrition, as a graduate supervisor, and as a course coordinator at the University of Applied Sciences Utrecht, the Netherlands (HU).

He conducted his PhD research at Radboud University (RU), within the Department of Language and Communication, and the HU Research Group for Process Innovations in Pharmaceutical Care, under the supervision of prof. dr. Enny Das (RU), prof. dr. José Sanders (RU), and dr. Rob Heerdink (HU). In November 2023, Hans began a new role as a Senior Advisor in Food Safety at the Netherlands Food and Consumer Product Safety Authority (NVWA).