ADVOCACY IN MENTAL HEALTH SOCIAL INTERACTIONS

ON PUBLIC SOCIAL MEDIA

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DEDICATION

Papy et Mamie, on a réussi!

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Victor P. Cornet

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Health advocacy is a social phenomenon in which individuals and collectives attempt to raise awareness and change opinions and policies about health-related causes. Mental health advocacy is health advocacy to advance treatment, rights, and recognition of people living with a mental health condition. The Internet is reshaping how mental health advocacy is performed on a global scale, by facilitating and broadening the reach of advocacy activities, but also giving more room for opposing mental health advocacy. Another factor contributing to mental health advocacy lies in the cultural underpinnings of mental health in different societies; East Asian countries like South Korea have higher stigma attached to mental health compared to Western countries like the US. This study examines interactions about schizophrenia, a specific mental health diagnosis, on public social media (Facebook, Instagram, and Twitter) in two different languages, English and Korean, to determine how mental health advocacy and its opposition are expressed on social media.

After delineation of a set of keywords for retrieval of content about schizophrenia, three months' worth of social media posts were collected; a subset of these posts was then analyzed qualitatively using constant comparing with a proposed model describing online mental heath advocacy based on existing literature. Various expressions of light mental health advocacy, such as sharing facts about schizophrenia, and strong advocacy, showcasing offline engagement, were found in English posts; many of these expressions were however absent from

the analyzed Korean posts that heavily featured jokes, insults, and criticisms. These findings were used to train machine learning classifiers to detect advocacy and counter-advocacy. The classifiers confirmed the predominance of counter-advocacy in Korean posts compared to important advocacy prevalence in English posts. These findings informed culturally sensitive recommendations for social media uses by mental health advocates and implications for international social media studies in human-computer interaction.

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LIST OF ABBREVIATIONS

CBD: cannabidiol
EN: English
FB: Facebook
HCI: Human-Computer Interaction
IN: Instagram
LNG: Language
KO: Korean
MCC: Matthews Correlation Coefficient
MH: mental health
SMP: social media platform, such as Facebook, Twitter, or Instagram.
TW: Twitter

CHAPTER ONE. INTRODUCTION

Health advocacy is a social phenomenon in which individuals and collectives attempt to bring social and policy change about health-related causes (Laverack, 2013b), such as the rights of people living with HIV (Gamson, 1989; Gould, 2002) and Mad Pride activists defending the rights of individuals with mental illnesses (Lewis, 2013). These advocates do so through various activities ranging from education, stating their public support on online social media platforms (SMPs) like Instagram or Twitter, to petitioning politicians to improve awareness, stigma reduction, funding, and laws for health-related causes (Brown et al., 2004; Laverack, 2013b; Prakash & Gugerty, 2010; Zoller, 2005). Mental health advocacy, the branch of health advocacy focusing on mental health issues, has emerged to advocate for people with mental illnesses against policies, laws, and private interests fostering stigma and deprivation of rights (Grob, 1994; Heijnders & Van Der Meij, 2006; Tomes, 2006). Advocacy does not exist without opposition; advocates challenge existing policy and social constructs brought by "perpetrators of social injustice" (Laverack, 2013b) who can be governmental institutions, private companies, non-profit organizations, or even individuals (Laverack, 2013b; Prakash & Gugerty, 2010). Opposition can have many representations, such as misinformation about scientific facts, a lack of resources to address problems, conflicting interests (e.g., satisfying voters, religious motivations), unwillingness to relinquish privileges, among others (Laverack, 2013b; Prakash & Gugerty, 2010). The prime mission of advocates is to overcome opposition and the status quo.

The rise of the Internet has altered who performs advocacy, how it is performed, and how opposition responds to it (Illia, 2003; Rotman et al., 2011; Vegh,

2013). The pervasiveness of the Internet eases advocate participation as online advocacy can be performed remotely, requires less time and effort than offline advocacy, and enables people physically distant from each other to contribute to the same cause (Dimond et al., 2013; Hara & Huang, 2011). Moreover, the Internet has become the starting point of some advocacy campaigns, on both general-purpose SMPs (e.g., the Guatemalan justice movement; Harlow, 2012) and specific platforms (e.g., Change.org; Huang et al., 2015); in some cases, the Internet has even allowed offline advocacy to move online (Cornet et al., 2017). In this new online advocacy context, the Internet has emerged as a new avenue for health advocacy (Parker, 2013; Parker et al., 2012) and, more specifically, mental health advocacy (Koteyko & Atanasova, 2018). Besides advocacy, the Internet has also offered new ways to talk and share about mental health, for example by asking questions to groups of friends about post-partum depression (De Choudhury et al., 2014) or by sharing self-harm pictures (Cornet, 2019; Pater & Mynatt, 2017). It has also opened the door to opposing talks about mental health advocacy. The Internet is poised to affect mental health advocacy like it has been affecting advocacy in other domains such as racial justice (Mundt et al., 2018) or the rights of LGBT people (Blackwell et al., 2016).

As the advent of the Internet has changed mental health advocacy, an updated global understanding of mental health advocacy is needed. This updated understanding will allow designing or revising online tools and platforms to facilitate the organization and diffusion of health advocacy. It will also contribute to existing online health advocacy research (e.g., Parker, 2013; Parker et al., 2012) as the field of HCI potentially moves towards “embracing activism at all levels”

(Ashby et al., 2019). This dissertation reports on the changes to mental health advocacy Internet brought, through the analysis of English and Korean-language advocacy posts about schizophrenia, a specific mental health diagnosis.

Because mental health advocacy is a global phenomenon as much as the Internet is a global platform for communication, it is crucial to approach online mental health advocacy with a global perspective. Asian countries stand as interesting comparison points for mental health activism. Asian cultures are inherently different from Western ones, translating into different experiences of illness (Nilchaikovit et al., 1993) and stigma regarding mental health (Ng, 1997). South Korea, an East Asian OECD country, is an interesting case study because of the important stigma attached to mental health (Jang et al., 2009; Park & Jeon, 2016) and a relative lack of access to community mental health services and high suicide rate compared to other OECD countries (Kahng & Kim, 2010; Lee, 2017). Korean people tend to use the Internet differently than Americans, in line with their high-context culture (Kim et al., 2011; Lewis & George, 2008). As the OECD country with the highest Internet penetration rate (99.5%, (OECD, 2020)), South Korea has many SMP users who are potential mental health advocates (Korea Information Society Development Institute, 2019) but use the Internet to the same end. Studying online mental health advocacy through the lens of schizophrenia for English and Korean posts is particularly relevant because the prevalence of schizophrenia is similar around the world and schizophrenia is a well-defined psychiatric diagnosis. This dissertation explores the presence of mental health activism on the Internet through a qualitative analysis of Twitter and Instagram posts about schizophrenia, a serious mental illness, in both English and Korean.

This dissertation aims to *understand online health advocacy by studying social interactions about mental health on public social media platforms using English and Korean data.* To fulfill this aim, I will treat the following research questions in this dissertation:

RQ1: What are the manifestations of schizophrenia advocacy and counter-advocacy in English and Korean Facebook, Instagram, and Twitter content?

RQ2: How prevalent are advocacy and counter-advocacy among English and Korean Facebook, Instagram, and Twitter SMP posts and comments?

Overview

The rest of this dissertation is structured as follows:

In Chapter 2, I introduce related work from human-computer interaction and social sciences upon which this dissertation builds.

In Chapter 3, I introduce a theoretical model of online mental health advocacy based on existing research.

In Chapter 4, I present the overall dataset used to answer RQ1 and RQ2.

In Chapter 5, I answer RQ1 by a qualitative analysis of SMP content and a description of patterns seen in the dataset, such as top users and most frequent hashtags (see definition in Appendix H). The chapter ends with the generation of hypotheses for RQ2.

In Chapter 6, I answer RQ2 by presenting a machine-learning classification of advocacy and counter-advocacy constructs in SMP posts that I used to compare advocacy and counter-advocacy between language and SMPs.

In Chapter 7, I present a revision of the online mental health advocacy model based on Chapters 5 and 6's findings and discuss contributions to HCI and social sciences.

CHAPTER TWO. BACKGROUND

In this chapter, I first introduce what advocacy is and its origins. I then present health advocacy as a continuation of advocacy and introduce the complements of health advocacy as well as existing research on mental health advocacy. To show how advocacy has played out since the advent of the Internet, I present existing research on online advocacy. The chapter closes on a presentation of schizophrenia and South Korea and its language.

Advocacy and Activism

Definition and Classification

Advocacy and activism are the actions of using various means to bring about political or social change (Oxford University Press, 2016a, 2016b). These means range from "conventional and indirect" actions (e.g., "vote at a local or national election," send a letter of protest") to "unconventional direct actions" (e.g., "take part in a riot"), and from non-violent to violent (Della Porta & Diani, 2006; Laverack, 2013b). The difference between advocacy and activism resides in how "uncommon" or "unconventional" the means used are; if the means are deemed "uncommon," the action is considered activism, if not, advocacy (Laverack, 2013b; Oxford University Press, 2016a). Advocacy and activism thus belong to a continuum of involvement to bring about change. Consequently, classifying an action as advocacy or activism is not straightforward, especially in changing environments such as the Internet (e.g., signing an online petition is not as uncommon as it was before) (Laverack, 2013b; Martin, 2007). Furthermore, the qualification of these actions as activism and advocacy is contextually relevant to the period studied and may change over time (Martin, 2007). For these reasons and added simplicity, the rest of

this proposal refers to advocacy and activism as advocacy, which thus denotes the entire continuum of actions to bring about political or social change.

Relevance of Activism Research

Advocacy, as defined in this proposal, is a powerful enabler for social and policy change (Staggenborg, 2011). This desire for change stems from inadequacies in the current social or policy context, which perpetuate inequalities. The inadequacies are not necessarily a byproduct of reforms but can be a result of an unwillingness to change the status quo (Prakash & Gugerty, 2010; Zoller, 2005) (e.g., marriage between people of the opposite sex).

In earlier advocacy and activism research, advocates tended to be the direct recipients of the equality they were fighting for, e.g., in the class warfare in the 1920s, as informed by collective behavior theory (Buechler, 2016). As social movements evolved over the years, advocates have emerged among people who do not necessarily have a direct stake in the movements they are advocating for, such as straight allies becoming LGBT advocates to fight for equality and rights (Grzanka et al., 2015). The motivation for these people comes from a desire to help others or a belief in fighting inequalities. In short, advocates can but do not have to be the direct recipient of the cause they are advocating for.

The fundamental reason for advocacy is the existence of inequalities maintained (status quo) or brought by (e.g., Indiana's RFRA) by opponents. The nature of opponents to change varies; government organizations, for-profit companies, advocacy organizations with different interests, and individuals (e.g., NIMBY, "Not In My BackYard") (Laverack, 2013b; Prakash & Gugerty, 2010). Reasons for opponents to oppose change include misinformation, lacking resources

to correct the problem, conflicting interests (e.g., satisfying voters, religious motivations), a refusal to relinquish privileges (Laverack, 2013b; Prakash & Gugerty, 2010). Simply put, advocacy does not exist without opposition. Advocacy is an enabler for large-scale social and policy change, as illustrated in the following section.

Social Movements; the Origins of Activism and Advocacy

The origins of advocacy and activism can be found in social movements (Della Porta & Diani, 2006) which are "informal collective of people who seek to enact a common political or social goal" (Cornet et al., 2017). Two popular examples of social movements are the women's suffrage movement and the civil rights movement (Staggenborg, 2016, pp. 58-59; 72). These social movements emerged as people were fighting for their rights in a way that conflicted with the establishment (Staggenborg, 2016, p. 6). Over the last century, social movement theories have been formulated to explain the formation and organization of social movements. Theories of *collective behavior* started to emerge in the 1920s to explain the class warfares of that decade (Buechler, 2016). Around the 1960s, *resource mobilization theory* emerged to explain how social movements are tied to political processes and preexisting organizations (Olson, 2009). *New social movement theory*, the most recent major social movement theory, uses social attitudes instead of political and economic motives as the basis to explain social movements (Staggenborg, 2016). This theory posits movements are not centered around an organization but involve people with weaker, more informal ties around their shared interest in a cause (Staggenborg, 2016). While the lens of each theory can be used to analyze a

movement, some movements are better characterized by certain theories (Cornet et al., 2017).

Health Advocacy

Definition of health advocacy

Health advocacy is the branch of advocacy that brings change that has direct or indirect implications on the health of society members. Health advocates fight against social injustice already existing or brought by "perpetrators of social injustice" using a wide range of means, some of which "[go] beyond the conventional" (Laverack, 2013b, p. 149). Several scholars have defined health activism as a simple combination of activism for health causes, in other words challenging the status quo, or "existing order" (Laverack, 2013b, pp. 19-20; Zoller, 2005), if it impedes people's health or health promotion (Zoller, 2005). In this definition, the "existing order" can refer to the social context, the policy context, or even the power relationships in place (Zoller, 2005). Health activism is thus not only limited to patient activism but also includes various health-related topics such as disease prevention, public safety, and health inequalities among races and sexual orientations, as pointed out by Zoller (2005)[1].

[1] "actions related to patient activism, health care reform, disease prevention, illness advocacy, physical disability, environmental justice, public safety, and health disparities in populations such as women, minorities, gays, and lesbians, among others." Zoller, H. M. (2005). Health Activism: Communication Theory and Action for Social Change. *Communication Theory, 15*(4), 341-364.

In health advocacy (as in advocacy in general), health advocates are not necessarily the direct recipients of the change they are trying to bring forward. Scholarly definitions of health activism rightly omit to specify who the actual advocates are (Brown & Zavestoski, 2004; Laverack, 2013b, pp. 19-20; Zoller, 2005). In fact, advocates can be advocating either for themselves (*self-directed advocacy*) or on behalf of other people (*other-directed advocacy*) (Stewart et al., 2012). In the latter case, advocates do so to address inequalities in society, usually because the people they are advocating for cannot advocate for themselves (e.g., bed-ridden people) (Stewart et al., 2012; Zoller, 2005).

Components of Health Advocacy

Based on existing health social movement (HSM) research (the study of social movements aiming at societal and policy change influencing health; Brown & Zavestoski, 2004), Zoller proposed a two-dimensional classification of health activism (2005). This classification intended to remedy problems with earlier classifications that were omitting advocacy to help the health and lives of others (i.e., not the patients themselves or people acting on behalf of patients; Brown et al., 2004; Zoller, 2005). The first dimension in Zoller's classification, issue focus, corresponds to a three-class classification of issues targeted by health activism: "medical care access and improvement, … illness and disability activism, … [and] public health promotion and disease prevention activism" (Zoller, 2005). The second dimension advanced by Zoller is political orientation, from movements attempting to fundamentally change individuals and society to movements bringing only partial change to individuals and society (2005). For both dimensions (issue focus and political orientation), the categories are not necessarily mutually

exclusive and may evolve and be subject to interpretation. For example, the fight against the defunding of Planned Parenthood (medical care access) could be interpreted as the evolution of the Women's health movement (illness advocacy).

Mental Health Advocacy

Mental health advocacy is the branch of health activism that brings about change to mental health issues in society and policy. Several mental health movements have taken place in modern history. Tomes described the evolution of advocacy in a movement led by people with mental illness (the "consumer/survivor movement"; Tomes, 2006). While the movement in the 50s to 70s was initially led by "professionals (psychiatrists, lawyers, and academics)," the movement evolved in the 70s as patients and ex-patients took the lead and advocated for themselves; they argued for a focus on recovery and independent living rather than medication taking and hospitalization (Tomes, 2006). Tomes interestingly noted that different organizations existed within the movement (2006). They were not all composed of patients or ex-patients; some organizations accepted professionals and lay people's support, while some organizations were created and operated by family members of people with mental illness, sometimes with conflicting interests (Tomes, 2006). This consumer activism led to tangible changes in mental health care and support institutions, such as the creation of the Substance Abuse and Mental Health Services Administration (SAMHSA). Some patient-focused movements that emerged since the 1960s include Mad Pride and MindFreedom International (Laverack, 2013a).

Online Advocacy

Advocacy and activism have undergone significant reassessment in recent years due to the advent of the Internet (Tan et al., 2013). More specifically, the

emergence of the “Web 2.0”, which reinforced social ties between users compared to the original Web (Murugesan, 2007; Newman et al., 2016), created direct connections between actors of a movement and bystanders, consequently accelerating the expansion of online advocacy. As societies have become more developed, new concerns have emerged in social and political movements (new social movement theory (Buechler, 2016)), such as the fight against the defunding of Planned Parenthood (Silver & Kapadia, 2017). The influence of the Internet for advocacy is beginning to emerge in scholarly research, especially for political or human rights purposes (Hara, 2008; Hara & Huang, 2011; Harlow, 2012; Huang et al., 2015; Tan et al., 2013; Vegh, 2013).

Researchers have used several terms to refer to what this proposal calls *online advocacy.* Brady, Young, and McLeod (2015) mention that “terms such as digital advocacy, digital activism, online social movement, cyber-activism, and e-advocacy” as terms to designate all the advocacy work happening online. Fitzgerald and McNutt (1999) defined “electronic” advocacy in 1999 as “the use of technologically intensive media to influence stakeholders to effect policy change.” While this definition omits “social change” as one of the elements that advocacy is attempting to effect, by construct it includes online advocacy (with the set of “technologically intensive media” restricted to the Internet).

Brady et al. (2015) mention the different online platforms that can be used for online advocacy: “email, Facebook, Twitter, Google +, YouTube, … cloud-based applications, … Change.org,” among others. Below are examples of HCI studies about online advocacy that have been conducted on these platforms.

Facebook

Harlow (2012) studied Facebook groups created after the death of a prominent lawyer, allegedly orchestrated by the then president of Guatemala. Through interviews and analyzing user-generated Facebook content, she found that people belonging to these groups used the Internet to get alternative news, share their support online, effectively contributing to this online movement. She also pointed out that, while less frequent posters in these groups shared and commented more about the movement's values (sustaining online action), more frequent posters tended to organize offline action instead. In fact, there might be two classes of users in online social movements, mirroring the leaders and followers in offline social movements and traditional social movement theories (Harlow, 2012).

Instagram

Research conducted on Instagram shows that users manifest their participation in social movements differently on the online platform than in the real world (Afnan et al., 2019; Cornet et al., 2016; Cornet et al., 2017). This participation varies depending on the individuals, from weaker forms of involvement such as resharing content to stronger calls to action. Specifically, people shared pictures that could be classified into one of five categories, such as rally pictures or user-created art.

Specific Advocacy Platforms

HCI researchers have also explored the use of specific platforms to bring about social and policy change. Huang et al. (Huang et al., 2015) studied the platform Change.org on which people can support various causes by signing e-

petitions. Through two studies, one qualitative (semi-structured interviews) and one quantitative (statistical analysis of a small sample of the platform's users), the researchers were able to show that as users get more engaged with the platforms, they are likely to participate more and to sign more petitions that will be successful. While offline actions of Change.org users were not explored during the interviews, petitions that get enough signatures online get sent to the offline organization or person directly concerned by the petition, another example of how online advocacy transcends the Internet. Despite not studying specific advocacy platforms in this proposal, (Huang et al., 2015) is nonetheless relevant as an illustration of what dedicated platforms afford. These previous studies also show the value that this dissertation work can bring to SMPs.

Health and Mental Health in online advocacy research

Scholars have studied various manifestations of online health communication, such as reaching out for advice or getting help (De Choudhury et al., 2014), or joining communities for people with rare diseases (MacLeod et al., 2015). HCI researchers have called for more research in online advocacy as a means to bring social change, and specifically online health advocacy (Parker, 2013; Parker et al., 2012). Specifically, understanding the dynamics of health advocacy in large SMPs would enable researchers to develop tools to facilitate health advocacy more efficiently (Parker et al., 2012). This is important, as advocacy occurring on the web can help reduce cyberbullying (Sabella et al., 2013; Snakenborg et al., 2011) and stigma by complementing offline interventions. It can also bring significant changes to health matters, such as helping change legislation, or potentially assisting in the

organization of offline protests, as it has been shown for other types of social movements (Cornet et al., 2017).

In their paper *Health Promotion as Activism: Build Community Capacity to Effect Social Change*, Parker et al. detailed the evaluation of a platform (built by the researchers) that enables users to promote healthy eating habits within their community (Parker et al., 2012). They designate "heath activism" as "collective efforts to counter local and cultural challenges to healthy living." With this definition, health advocates are still working on bringing about change, but with results on a more micro-scale than the macro-scale advocacy and activism as defined by Laverack and Zoller (Laverack, 2013b; Zoller, 2005). While Parker et al.'s study is interesting for its analysis of their own platform to explain how to build for health advocacy, it does not address the essential question of how health advocacy is performed on existing Internet platforms. The study also 'forces' advocacy onto its participants (adequate in this case because of the nature of the purposed change, namely healthy habits) instead of studying health advocates emerging naturally in existing online platforms like SMPs.

Zoller (2005) calls for researching the effects of Internet-based methods on health activism organizing, but such deep analysis has yet to occur. Searches on the Association for Computing Machinery's Digital Library [2] among prime HCI conferences (CHI, CSCW) for the terms "health advocacy" and "health activism" returned few results at the time of writing (Parker et al., 2012)(Ammari &

[2] The Association for Computing Machinery's Digital Library indexes journals, papers, books, and theses relevant to computing and human-computer interaction.

Schoenebeck, 2015; Herrick, 2003; Loue et al., 2013; Talhouk et al., 2016), illustrating the scarcity of research on online health activism in HCI. Current analyses of online posts about mental health have been limited to stigma analysis or prediction of mental health diagnoses from SMP posts (Atanasova et al., 2019). Few were the analyses of mental health activism online (Koteyko & Atanasova, 2018), and none have looked at mental health activism on an international scale despite the Internet being a global platform and calls for doing so (Atanasova et al., 2019).

Computer-Mediated Communication

Computer-mediated communication (CMC) is the use of computer systems by people to communicate with each other. Computer-mediated communication has been increasingly studied with the advent of the Internet, especially as SMPs such as Facebook have taken off and augmented the ways people interact. CMC brought along computer-mediated discourse (CMD) that Herring and Androutsopoulos (2015) define as:

The communication produced when human beings interact with one another by transmitting messages via networked or mobile computers, where "computers" are defined broadly to include any digital communication device.

Computer-mediated discourse provides theories and methods to analyze online interactions, such as posts and comments left by people on SMPs.

Researchers have looked at the modifications in character that are induced by computer-mediated communication. These changes are induced by some of the inherent features that online SMPs offer, such as anonymity. Computer-mediated communication notably encourages online disinhibition (Suler, 2004) that can range from slight changes in characters to obsessive trolling, as observed on

Wikipedia (Shachaf & Hara, 2010) and on Twitter (Synnott et al., 2017) for example. Trolling behavior may appear in online posts about mental health activism, and if so, should be reported accordingly.

South Korea

Asian countries stand as interesting comparison points for mental health activism. Asian cultures are inherently different from Western ones, translating into different experiences of illness (Nilchaikovit et al., 1993) and stigma regarding mental health (Ng, 1997). South Korea, an East Asian OECD country, is an interesting case study by the important stigma attached to mental health (Jang et al., 2009; Park & Jeon, 2016) and a relative lack of access to community mental health services and high suicide rate compared to other OECD countries (Kahng & Kim, 2010; Lee, 2017). As the OECD country with the highest Internet penetration rate (99.5%, OECD, 2020), South Korea has many SMP users who are potential mental health activists (Korea Information Society Development Institute, 2019).

The Korean language is interesting to use in comparisons of online mental health advocacy as it is spoken predominantly by South Korean users online. Indeed the number of Korean first-language speakers was 77.3 million in 2019 (*Summary by language size*, 2019), of which 25.7 million live in North Korea thus deprived of widespread Internet access (*North Korea*, 2021). As such, most Korean speakers worldwide live in South Korea, a country with 50.2 million Korean speakers out of 51.8 million inhabitants (*South Korea*, 2021). SMP users posting in Korean are therefore more likely to have a cohesive Eastern culture and potentially exhibit different characteristics such as increased stigma (Krendl & Pescosolido, 2020; Turvey et al., 2012) in their online communication from English speakers, of

whom most first-language speakers (379 million globally, *Summary by language size*, 2019) live in Western countries. Additional comparisons between South Korea and the US as a proxy for western countries can be found in Appendices A through C.

Schizophrenia

Schizophrenia is a chronic mental illness with low global prevalence but unproportionate high direct and indirect costs to individual countries (Chang et al., 2008; Charlson et al., 2018; Chong et al., 2016). Symptoms of schizophrenia include delusions, hallucinations, and disorganized speech and behaviors (*Diagnostic and Statistical Manual of Mental Disorders, 5th Edition*, 2013). People with schizophrenia, who receive treatment primarily as outpatients of community mental health centers in the US, are still mainly receiving treatment in hospitals in South Korea (Chang et al., 2008). South Korea had, in fact, an unclear legal framework in place that had led to many "medically unjustified" involuntary hospitalizations until lawmakers passed the Mental Health Act in 2017 (Kim, 2017). While the act added additional safeguards, it failed to create adequate structures for improved treatment of schizophrenia and other severe mental illnesses in the community (Heo et al., 2019).

Given the mental health activist movements that brought social and policy reforms in America (Tomes, 2006), such activism would have reason to exist in South Korea. This activism manifested for example in 2012 with a new term coined to designate schizophrenia, trading the old stigmatized word 정신분열증 (*jeongshinbunyeoljeung;* lit. mind split disorder) for the new term 조현병 (*johyeonbyeong*) (Lee et al.; Lee et al., 2014), and with the recent reform of the Mental Health Act (Heo et al., 2019).

CHAPTER THREE. CONCEPTUAL MODEL

While theories exist describing general advocacy and health advocacy in general (Brown & Zavestoski, 2004; Laverack, 2013b; Zoller, 2005), no theory focuses specifically on online mental health advocacy despite the specificities brought by mental health as a health domain as well as the Internet as an advocacy medium. As such, I propose a conceptual model describing the actions that advocates, as well as counter advocates, undertake when advocating for mental health online and the tension that results from these actions. This model, drawing from health advocacy literature (Brown & Zavestoski, 2004; Laverack, 2013b; Zoller, 2005) and previous studies on online advocacy and social movement research, is depicted in Figure 1 and described in further detail hereafter.

An online mental health advocacy model would help entities like nonprofit organizations allocate resources for mental health advocacy. Such a model can suggest the prevalence of advocacy and counter advocacy actions, whether they should be supported or inhibited, and the levels of dialogue about the issue on SMPs. With the rise of corporations' environmental, social, and corporate governance goals (Gillan et al., 2021), SMP companies trying to make social change a priority can also benefit from such a model. They can indeed limit very negative counter advocacy actions occurring on their platforms, akin to how Twitter banned former President Donald Trump's account ("The expulsion of Donald Trump marks a watershed for Facebook and Twitter," 2021). Beyond SMPs, online platforms supporting social change, such as Change.org, can also benefit from an online

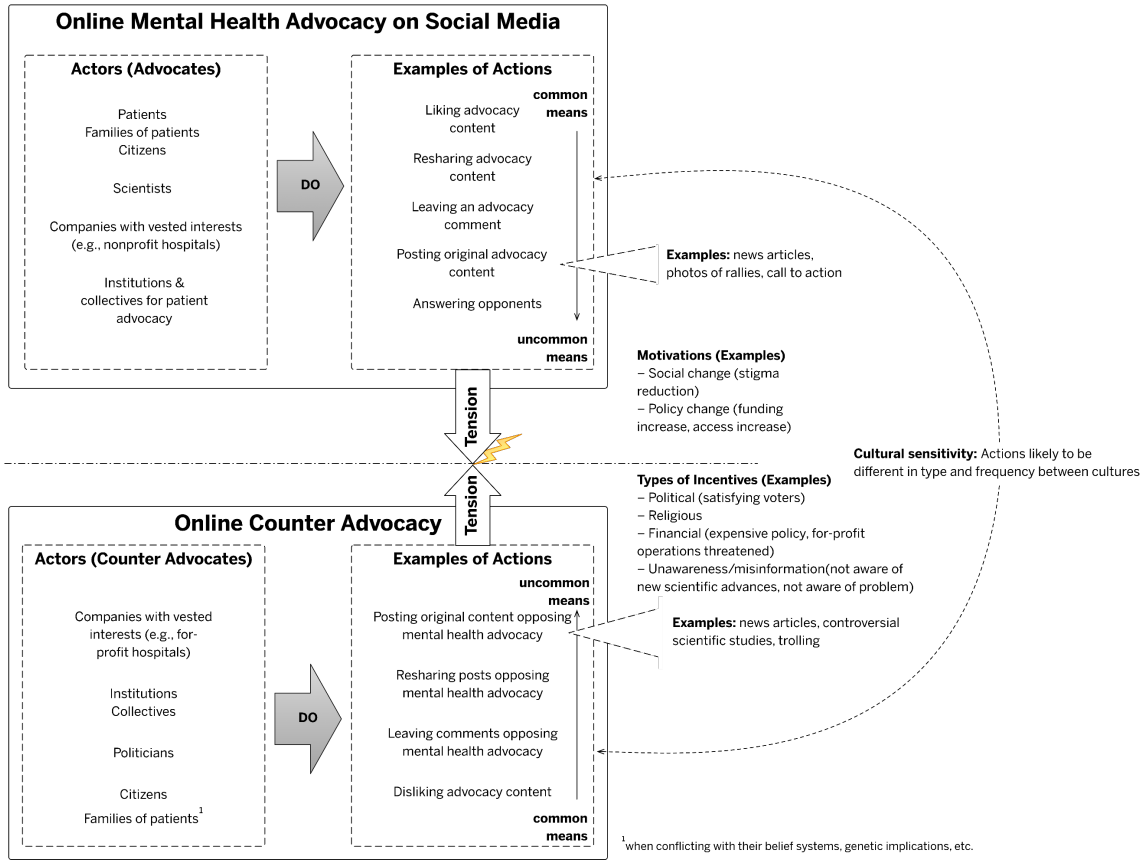

Figure 1. Proposed online mental health advocacy model.

mental health advocacy model. They could facilitate new campaigns around mental health by providing advice to campaign leaders on what works and does not work when leading such online campaigns; for example, these online platforms supporting social change could provide tips and keywords that could boost online presence.

An online mental health advocacy model that factors in cultural differences can help social movement organizers or organizations spending resources advocating for these issues better target different populations. This can be particularly useful in some contexts, especially in countries where different communities speak several languages (Sheldon et al., 2017). For example, if

considering the United States and its minorities, an effective social media campaign advocating for mental health rights, promoting treatment options, or fighting against stigma would seek to communicate in English as well as in languages commonly spoken in US homes (for example, 37 million Spanish, 2.9 million Chinese, and 1.6 million Tagalog speakersGary, 2005; United States Census Bureau, 2015). As there can already be major cultural differences within a single country (Taras et al., 2016), these minorities are indeed likely to have different needs, taboos, preconceived notions about mental health, and less likely to receive adequate treatment (Breslau et al., 2017; Hsu et al., 2008; Rastogi et al., 2012). Researchers have indeed shown that differences in cultures can lead to differences in online behaviors, such as hashtagging (Sheldon et al., 2020), and called for more investigations of pluricultural contexts on SMPs (Sheldon et al., 2020; Sheldon et al., 2017).

Description

Online mental health advocacy and counter advocacy. These two concepts are characterized by the actions performed by advocates and counter advocates. Health advocacy and counter advocacy are fundamentally opposed, and this opposition is the source of tensions between advocates and counter-advocates. The model frames the opposition between health advocates and opponents who both perform actions detrimental to the other camp, consciously or unconsciously dictated by their respective motives.

Actors. In this conceptual model, actors are either advocates or counter advocates. Previous research has shown that online advocates and counter advocates are Internet user accounts that could represent individual people,

governmental or nongovernmental organizations, businesses, or collective of people regrouped behind a social media account with a specific theme (e.g., sharing memes, advocating for a social issue) (Cornet et al., 2017; Laverack, 2013b). When looking at these actors through the lens of health advocacy, the individual Internet users could be specified further as patients, family members, or regular citizens; research scientists and doctors; politicians; companies with vested interests such as nonprofit hospitals or for-profit treatment centers; or institutions and collectives for patient advocacy. Actors usually perform actions in line with their nature; for example, a nonprofit organization may create and share a social media campaign aiming to spread awareness around mental health issues, and patients may comment on such campaign by sharing their personal stories in order to reduce stigma. Some types of actors may be more or less present in the various SMPs; politicians may be more active on Twitter, while patients may have a more important Instagram presence. Actors will not be studied in this dissertation because of the complexity of accurately assessing the type of social media users behind posts in three different SMPs and two languages.

Actions. Health advocacy and social movement theory advance that actions performed to help further a movement can be placed on the spectrum ranging from common means to uncommon means (Laverack defines them as "conventional" and "unconventional", respectively; Laverack, 2013b). Common means include arguing with peers during informal discussions, education campaigns, writing letters to politicians asking for change (e.g., increasing funding for mental health causes). Uncommon means include participating in peaceful rallies, helping organize protests, vandalizing public and private property during violent protests,

etc. Common and uncommon means can also be assimilated to ease of advocating and how demanding the action is on the advocate; for example, sending a letter to a politician is evidently than organizing a protest.

As antagonists to advocates, counter advocates perform actions that go against health advocacy. Such actions include inaction, or not changing the status quo (thus perpetuating unfair or unjust situations), protesting the funding of agencies helping vulnerable populations, the instauration of policies and actions that maintain or increase stigma around a population or diagnosis, or taking away rights of people with a particular health diagnosis. Online, these counter advocacy actions may take the form of using terminology that stigmatizes people with a specific diagnosis, re-sharing posts opposing mental health advocacy, and advocating in comments or posts for depriving people with mental health issues of their rights, such as forcing admission to specialized care structures without the person's consent. Some of these actions may be performed as a direct answer to advocacy actions, resulting in tensions between advocacy and counter advocacy.

Tensions. Tensions emerging from advocacy and counter advocacy actions may mostly emerge in SMP content through users (online advocates and counter advocates) arguing in comment/reply sections about a specific advocacy or counter advocacy action. Tensions may show escalation between users by an important number of replies contradicting each other or quick resolution through concession or giving in. Trolling, or personal attacks towards advocates or opponents, may also be found as its presence has been established for Internet platforms like Twitter (Synnott et al., 2017) and Wikipedia (Shachaf & Hara, 2010).

Cultural dimension. Online mental health advocacy ought to cover the impact that cultural differences have on advocacy and counter advocacy in order to address cultural disparities in the perception of mental health issues. Eastern and Western cultures have, for example, different regards on stigmas attached to mental health concepts (Krendl & Pescosolido, 2020). Online, SMP users with an Eastern cultural background may be using counter advocacy actions more, such as mental health-related words for derogatory purposes (e.g., “you’re just a schizophrenic”), than users with a Western cultural background.

While mental health has been studied in the context of post-partum depression, eating disorders, general depression, no studies have been specifically looking at the activism aspect of such posts on popular SMPs. Online advocacy and activism have been studied in previous studies (e.g., Hara, 2008; Harlow, 2012; Huang et al., 2015; LaFrance & Nathan, 2012; Savage & Monroy-Hernández, 2015; State & Adamic, 2015; Tan et al., 2013), but online health activism remains a seldom-studied field.

CHAPTER FOUR. CONSTITUTION OF A DATASET OF SCHIZOPHRENIA-RELATED CONTENT

I built a dataset of English and Korean SMP posts and comments to answer the two overarching research questions of this dissertation:

RQ1: What are the manifestations of schizophrenia advocacy and counter-advocacy in English and Korean Facebook, Instagram, and Twitter content?

RQ2: How prevalent are advocacy and counter-advocacy among English and Korean Facebook, Instagram, and Twitter SMP posts and comments?

This chapter describes the reason and process behind the creation of the dataset, its usage to answer RQ1 and RQ2 is reported in Chapter 5 and 6.

Background and Motivation

The collection of a bi-lingual, multi-platform dataset appears necessary to answer RQ1 and RQ2. I was unable to find any existing public dataset of SMP content about schizophrenia in both languages, or general-purpose datasets in both Korean and English content from popular SMPs that would include such content.

The dataset also needs to be as equivalent as possible for both English and Korean, i.e., there should be limited variation in the date ranges of collected posts and other data collection methods in order to avoid bias. For the same reason, the data collection methods should also be similar between SMPs. One platform that helps alleviate such bias is Netlytic, an online platform that can crawl social media content (Gruzd et al., 2017). Popular among researchers, Netlytic allows users to fetch data related to specific search terms (such as phrases and hashtags) from

Facebook, Instagram, and Twitter at regular intervals, thus getting around the limitations of the platforms' respective programming interfaces (Gruzd et al., 2017).

Process

Term Expansion

I conducted a preliminary study to retrieve hashtags that would be relevant to the project. Netlytic, a social media mining platform developed for and used by researchers (Gruzd et al., 2017), was used to collect historical Twitter and Instagram posts using two seeding hashtags, #schizophrenia and #schizophrenic, and similar Korean hashtags #정신분열증 (#jeongshinbunyeolcheung) and #johyeonbyeong); see Appendix G for the complete list. The data collection happened in the first half of 2018. I extracted these hashtags from the collected posts' metadata (tweet for Twitter, and caption for Instagram posts) using MathWorks' MATLAB R2018b. For Twitter, 5,141 and 107 hashtags were extracted from 36,236 unique English posts and 2,222 unique Korean posts, respectively; for Instagram, 15,970 and 5,142 hashtags were extracted from 7,941 English and 928 Korean posts, respectively. The resulting hashtags were then manually and qualitatively analyzed to retain hashtags and terms that had a direct link with schizophrenia; as such, hashtags containing character sequences such as "schizo," "조현병," "정신분열" were retained. I retained 27 and 16 hashtags for English and Korean Twitter posts, and 26 and 9 hashtags for English and Korean Instagram posts, respectively.

Data Collection – Methods for the main dataset

The paid tier of the platform Netlytic was used to get three months (May 2018 – August 2018) of posts and comments related to schizophrenia on Facebook,

Twitter, and Instagram. Three months were selected to have enough content for data analysis.

Platform selection. Platforms to be used for such analysis need to be adequately represented among SMP English and Korean speakers. Instagram, Twitter, and Facebook were among the dominant SMPs in the United States and the United Kingdom in recent years (as a proxy for English speakers) (Hashemi, 2018), and among the top 5 SMPs in South Korea in 2018 (Korea Information Society Development Institute, 2018). Netlytic (as of 2018) conveniently supported all three social networks, thus making data capture more consistent rather than using a different application programming interface for each SMP. Specific methods used for each dataset are described below.

Instagram. Posts retrieved had one or several hashtags in either the caption of the post or in one of the comments left by the author of the post. Comments were also retrieved for each post matching the inclusion criteria. Cf. Appendix D for the data points captured for each post, and Appendix G for a list of the keywords used.

Twitter. Posts retrieved had one or several hashtags or keywords in their were retrieved using the keywords in Appendix G. Retweets and comments were treated by Netlytic as posts at that time, so I performed post-processing in MATLAB 2018a Academic Edition to associate each comment and retweet with the posts that were in the dataset. Replies that did not contain any hashtag or keyword from the inclusion criteria could not be retrieved (limitation of the Netlytic platform at that time). For each query, Netlytic returns up to 1,000 posts per 15 minutes.

Facebook. An alternative data collection strategy was used to collect Facebook posts as the social media platform does not allow the direct retrieval of

posts for any given search word. Posts from popular English and Korean news outlet pages were captured using similar methods as Ha et al. (2017). The news outlets selected are listed in Appendix F. These news outlets were chosen based on their popularity (Pew Research Center, 2015), their type (broadcast network, newspapers, Internet-only source), and the traditional political and religious orientation of their readership (Pew Research Center, 2014). The final set was restricted by keeping all posts with at least one mention of any of the inclusion search terms and their corresponding comments and keeping all posts with at least one comment mentioning any of the inclusion search terms. Cf. Appendix D for the data points captured for each post.

Data Collection – Results and Discussion.

Table 1 breaks down the counts of posts and comments retrieved through Netlytic for each language and SMP.

For each SMP, the number of English posts and comments retrieved was more important than the number of Korean posts and comments retrieved, an unsurprising fact given the worldwide prevalence of English speakers versus Korean speakers (respectively 370 million native speakers and 82 million speakers; *English*, 2021; *Korean*, 2021).

For both languages and out of the three SMPs, Twitter was the SMP with the highest number of posts retrieved (89,697 English posts, 6,427 Korean posts), while Facebook was understandably trailing Twitter and Instagram with the lowest number of posts for each language (133 English posts, 84 Korean posts). This is not surprising as Facebook posts were limited to the ones of news outlets that had one of the inclusion keywords in their posts, or that had at least one comment including

one of the inclusion keywords. Comments outnumbered posts for both languages on Instagram and Facebook, but not on Twitter (where comments were fetched only if including a keyword or hashtag from the inclusion criteria). Another notable fact is that the number of Korean Facebook posts and comments is comparable to its English counterpart (3,168 versus 5,861), especially when considering the larger difference between the number of Korean and English posts and comments on Instagram and Twitter. This can partly be explained by the comparable number of news outlets used to fetch Korean and English posts on Facebook (respectively 10 and 15), as well as a reported appetite by South Korean Internet users for news content (Singh et al., 2012).

Interestingly, the number of Korean comments on Instagram is greater than the number of Korean posts on Instagram, a relationship that does not hold true for English Instagram content. This likely points to Korean Instagram posts garnering more responses per post, possibly indicating more personal posts.

Conclusion

I conducted qualitative and quantitative analyses of this dataset, respectively described in Chapter 5 and Chapter 6, to study mental health advocacy on SMPs and, more specifically, answer the two research questions RQ1 and RQ2. Using both quantitative and qualitative methods in this particular study allows for triangulation of the results, making the study results more robust (Clark & Ivankova, 2015).

Table 1. Counts of retrieved posts and comments for English and Korean content on Instagram, Twitter, and Facebook.

		English	Korean	Total
Total	Total (excl. retweets)	177,564	11,113	188,677
	Posts	121,098	7,076	128,174
	Comments/Replies	56,466	4,037	60,503
Instagram	Total	78,194	1,363	79,557
	Posts	31,268	565	31,833
	Comments	46,926	798	47,724
Twitter	Total (incl. retweets)	200,194	26,567	226,761
	Posts	89,697	6,427	96,124
	Replies	3,812	155	3,967
Facebook	Total	5,861	3,168	9,029
	Posts	133	84	217
	Comments	5,728	3,084	8,812

CHAPTER FIVE. QUALITATIVE STUDY OF SOCIAL MEDIA POSTS RELATED TO SCHIZOPHRENIA

To see if the health activism model presented in Figure 1 applies to mental health advocacy and activism online, I qualitatively analyzed the positive and negative discussion about schizophrenia that occurs on online social media. Several public-facing social media platforms were chosen to retrieve relevant posts about mental health advocacy. Public-facing social media platforms are chosen as a) by being public, they foster conversational interactions, both positive and negative, b) they are fundamentally not biased toward a certain point of view, and c) they are not exclusive (not restricted to members sharing a unique vision). To be able to conduct a comparative analysis of the two countries, three of the most popular social media websites common to both countries were be selected: Facebook (public posts only), Instagram (public accounts only), and Twitter (public accounts only).

To attempt to sample broadly through the different layers of the model, posts and responses about a specific diagnosis, schizophrenia, were collected and analyzed qualitatively in order to answer the following research question:

RQ1: What are the manifestations of schizophrenia advocacy and counter-advocacy in English and Korean Facebook, Instagram, and Twitter content?

The research objectives were:

- Determining the type of content shared on posts with advocacy or counter-advocacy content on SMPs
- Determining how advocacy and counter-advocacy are carried out in SMP comments.

- Determining the popular keywords shared in posts with a schizophrenia-related hashtag or keyword.

Methods

The dataset was collected between May 2018 and August 2018 (3 months), feeding the keywords obtained from the preliminary study to the Netlytic web app (Gruzd et al., 2017). 89,697 English and 6,427 Korean Twitter posts, 31,268 English and 565 Korean Instagram posts, and 133 English and 84 Korean Facebook posts were collected. For each post, responses were also collected through the Netlytic platform. The results were parsed and organized using MATLAB 2018b Academic Edition (Mathworks).

Qualitative analysis.

I qualitatively analyzed the dataset by initially performing affinity diagramming on SMP content (Haskins Lisle et al., 2020) in both languages (1,215 and 1,200 English Instagram and Twitter posts respectively, 122 and 300 Korean Instagram posts respectively, and 3,389 and 694 Facebook posts and comments in English and Korean, respectively; the posts were analyzed chronologically starting from the first post), looking specifically at the types of content shared on SMP and markers of advocacy and counter-advocacy. I derived a codebook from recouping the results of the affinity diagramming process with concepts from health advocacy and activism theories (Zoller, 2005). I then used this codebook to code posts and replies using the constant comparing method (Corbin & Strauss, 2014; Strauss & Corbin, 1994).

I coded subsets of content for each language and SMP. The initial subsets attempted to cover all the posts in a specific date range when possible; additional

subsets of top or random content were coded to gain additional understanding of the dataset and improve coverage as resources allowed (Gentles et al., 2015). Table 2 lists the different subsets that were coded for each language/SMP pair.

I single-handedly determined the codebook and coded the posts (see Appendix E for full codebook). The outcome of the qualitative study was also not generating codes to be used for any quantitative analysis but instead augmenting the model of online mental health advocacy with findings from the grounded theory approach used; an inter-rater reliability score would have been appropriate had that not been the case (McDonald et al., 2019).

Table 2. Subsets of the dataset coded for given language/SMP pairs.

LNG/SMP	**Subset**	**N (% of total posts of the pair)**	**Notes (All temporal subsets start on 5/17/2018)**
EN/IN	2 days of posts	618 (2.0%)	
KO/IN	11 days of posts	52 (9.2%)	
EN/IN	Random 200 posts	200 (0.6%)	Posts already in the "2 days of posts" subset were skipped and not recoded.
KO/IN	Random 54 posts	54 (10%)	Posts already in the "10 days of posts" subset were skipped and not recoded.
EN/IN	Top 50 posts by likes	50 (0.2%)	
KO/IN	Top 50 posts by likes	50 (8.8%)	
EN/TW	Random 300 posts within 2 days of posts	300 (0.3%)	Random posts were selected within the two-day period as the number of posts to code (1,693) exceeded coding resources
KO/TW	4 days of posts	269 (4.1%)	
EN/TW	Top 50 posts by retweets	50 (0.1%)	
KO/TW	Top 50 posts by retweets	50 (0.7%)	
EN/FB	2 months of posts	83 (61%)	
KO/FB	1 month of posts	22 (26%)	Korean posts took longer to code than English posts;

I paraphrased quotes with personal details to preserve anonymity, and translated Korean quotes to English. Specific categories of action were coded based

on Zoller's categorization of health activism issues (Zoller, 2005). Individual comments were not coded; codes regarding comments were added at the post level. Microsoft Excel was used for coding.

Exploratory Quantitative Analysis.

Data cleaning. I found multiple posts in languages other than English and Korean while coding for the qualitative analysis that needed to be removed for additional analyses. I first attempted to use computer libraries for automatic language detection of posts in the dataset (MATLAB 2021a, Lingua[3]), but upon manual review both were unsatisfactory as English or Korean posts were frequently misclassified as other languages – unsurprising given the short length or unusual syntactic nature of many posts (e.g., only hashtags). After this unsuccessful attempt, I manually filtered the dataset to keep only English and Korean content; English content was kept only when captured using the English hashtags and keywords, and Korean content when captured using the Korean hashtags and keywords. Replies and comments on posts that were neither in English nor Korean were also deleted, as well as replies and comments not in English or Korean on an English and Korean post. A total of 24,054 entries were removed; a detailed breakdown is available in Table 3.

[3] https://github.com/pemistahl/lingua

Table 3. Counts of entries in the dataset after removal of entries in a foreign language (number in parentheses: original number of entries)

		English		Korean		Total	
Total	Total	153,542	(177,564)	11,081	(11,113)	164,623	(188,677)
	Posts	106,973	(121,098)	7,056	(7,076)	114,029	(128,174)
	Comments/ Replies	46,569	(56,466)	4,025	(4,037)	50,594	(60,503)
Instagram	Total	67,563	(78,194)	1,337	(1,363)	68,900	(79,557)
	Posts	28,218	(31,268)	551	(565)	28,769	(31,833)
	Comments	39,345	(46,926)	786	(798)	40,131	(47,724)
Twitter	Total	182,568	(200,194)	26,561	(26,567)	209,129	(226,761)
	Posts	78,643	(89,697)	6,421	(6,427)	85,064	(96,124)
	Replies	2,574	(3,812)	155	(155)	2,729	(3,967)
Facebook	Total	4,762	(5,861)	3,168	(3,168)	7,930	(9,029)
	Posts	112	(133)	84	(84)	196	(217)
	Comments	4,650	(5,728)	3,084	(3,084)	7,734	(8,812)

Hashtag Analysis. I then performed a hashtag analysis on the resulting dataset for English and Korean, Twitter and Instagram content. I used a MATLAB regular expression to extract all the hashtags within posts, comments, and replies. The hashtags were then counted by social media platform and language. I calculated their frequency among the dataset by dividing the number of occurrences of a given hashtag by the number of posts (and not comments or replies) for that data slice; this denominator was used as replies on Instagram and Twitter do not usually have hashtags, except on Instagram when the author of the post replies to their own content with hashtags that actually promote the original post rather than the reply. The hashtags were finally ranked by the number of occurrences in their respective data slice. I did not perform a hashtag analysis for Facebook content as it mostly consists of replies that are not used for content discoverability.

Frequent Terms. I performed several preprocessing steps on the dataset using MATLAB 2021a to collect the frequent terms used on Instagram, Facebook, and Twitter. The documents (individual units of content, such as posts, comments, or replies) were first stripped of all URLs and hashtags and were then tokenized (i.e., broken down into ordered collections of words) using MATLAB's `tokenizedDocument` function. The `tokenizedDocument` function accepts both Korean and English inputs and, based on the language of the document, uses the MeCAB tokenizer and ICU tokenizer, respectively. Punctuation and stop words were then removed using MATLAB's functions that support both languages, and words were finally lemmatized (i.e., transformed into dictionary form) using MATLAB's `normalizeWords` function that also supports both English and Korean. The `normalizeWords` function does not affect words that are not in the internal dictionary, limiting the risk of transforming Internet lingua that does not always reflect standard English or Korean. The tokens resulting from this processing were counted as words using `topkwords`, excluding any web address, email address, and hashtag tokens.

Results

Advocacy Content Shared on SMPs

Multiple types of advocacy content were shared across the dataset's SMPs and languages. These types are listed below in order of engagement, from least engaged to most engaged.

Positive Messages and Art (EN = 16% of coded posts, KO = 2%). Positive quotes were widely shared in English Instagram posts. Content shared included photos featuring positive messages, such as "the pain in your life is not stronger

than you." The messages did not always have a connection to mental health, such as this quote from Eleanor Roosevelt: "Beautiful young people are accidents of nature, but beautiful old people are works of art." These quotes were however accompanied by narratives or, in many cases, simply hashtags that tied back the quote to mental health. Some posts included poetry or philosophical quotes from books.

Other posts only featured abstract art, often paintings or drawings, for which the link to mental health and schizophrenia was less apparent. These messages and captions, while not directly related to schizophrenia, included "#schizophrenia" in the captions that, like with positive quotes, were often accompanied by hashtags supporting mental health awareness ("#mentalhealthawareness") and multiple mental illness diagnoses.

Some posts featured more concrete photos or art where the meaning of schizophrenia was clearer. These posts also often had the same activist hashtags but only a few mental illness hashtags, the central one being #schizophrenia.

Cultural References. Several posts mentioned schizophrenia through cultural references, such as movies and video games. Usually, these references featured characters with schizophrenia or mental health problems, such as *A Beautiful Mind* relating the life of mathematician John Nash who was diagnosed with paranoid schizophrenia, and the South Korean drama TV show *It's Okay, That's Love* featuring a lead character with schizophrenia.

Posts Promoting Mental Health Awareness (EN = 24%, KO = 6%). Partly because of Mental Health Awareness Week overlapping the beginning of the dataset timeframe, several posts shared facts, personal journeys, and positive

messages to raise awareness. Some posts recommended specific actions that readers should undertake, such as resharing a post or posting specific pictures to raise awareness. Posts referencing mental health awareness week were not seen in Korean posts.

Posts Promoting Mental Health Facts, Tips, and Education (EN = 8%, KO = 2%). Several posts shared facts and education about mental illnesses to spread awareness about mental health. On Instagram, these posts often had infographics with information such as prevalence rates or statistics (for example, "Schizophrenia ranks among the top 10 causes of disability in developed countries worldwide"), definitions of mental illnesses (e.g., "bipolar disorder: a mental condition marked by alternating periods of elation and depression"), or myth debunking (see Figure 2). On Twitter, simple figures were usually shared; for example: "What is the employment rate percentage for people with Schizophrenia? Just 8% #EndTheStigma #MentalHealthAwarenessWeek." When such content was shared on Twitter, simple figures were usually shared, most likely due to the limited character space that authors have for expressing themselves. Several posts were specifically sharing statistics about schizophrenia only, especially on Twitter where character limits prevent sharing information about multiple diagnoses. On

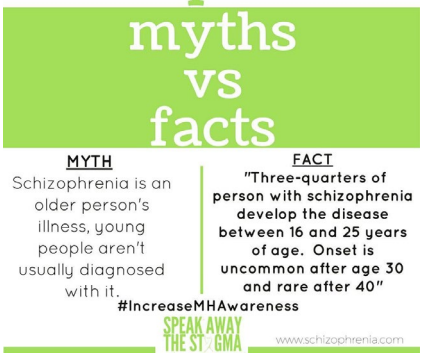

Figure 2. Example of an Instagram infographic mentioning a fact about schizophrenia.

Instagram, some posts also promoted wellness and wellbeing practices that are often embedded in therapies, such as mindfulness, for example:

> Take a deep breath! Check in with your breathing throughout the day. Practice mindfulness: feel the cool air slide past your nose and the heat of your breath as you exhale from your mouth. (Instagram post)

In many instances, especially on Instagram, this type of content was relayed through a list of hashtags describing various mental illness diagnoses (the above quote's hashtags included, for example, #anxiety, #depression, #bipolar, #schizophrenia, and #psychosis). These posts, especially on Instagram, were sometimes accompanied by advocacy hashtags, such as #endthestigma. Posts promoting mental health facts, tips, and education were seldom found in Korean content.

> Some people take medication for their mental health, some people seek therapy for treatment, and some people use a combo of both. What works for you doesn't necessarily work for everyone else, so be kind and don't judge. There's no shame in taking medication for you mental illness! Happy Friday everyone!!... *(English Instagram post)*

> Using mental disorders such as autism, bipolar disorder…, schizophrenia, OCD, PTSD, depression as insults or jokes are not okay. They are real and should not be stereotyped. *(English Twitter post)*

> The rate of crimes committed by people with a mental illness is statistically very low, but every time a brutal crime occurs, the criminal claims suffering from a mental illness so that his sentence is commuted. The media then reports such claim without verification. This gives a very bad perception of mental illnesses in our country. *(Korean Twitter post)*

> Formulas like "insanity = schizophrenia" can fuel prejudice against people with schizophrenia. In fact, people with schizophrenia are severely mentally disabled, and are more likely to be victims than perpetrators of violence. [link]. (Korean Twitter post)

Promotion and Recommendation of Medical Services or Treatment (EN = 1%, KO = 2%). Whether free or paid, medical services were advertised on both

social media platforms; on Twitter by sharing links, and on Instagram by including pictures and lengthy descriptions about one or several mental illnesses diagnoses and how the service can help. For example, an addiction recovery center advertised its services on Instagram:

> Whether you are seeking help for yourself or a loved one, we know how lonely and overwhelming this process can feel.... A phone call, email or in-person consultation gives you the opportunity to get your questions answered privately and confidentially, learn more about your treatment options, and understand the culture of our program....Our staff is here to listen, help, and meet you wherever you are in recovery. Contact us: 📱Phone: (XXX) XXX-XXXX ✉Email:info@abc.com (Instagram)

A few Korean posts advertised paid services delivered by individuals or treatment facilities, as seen for example on Instagram (translated from Korean):

> Hello. I am healer XXX. Is your Monday morning commute going well? I am going to upload a sample lecture video [about the relationship between physical illness and emotions, phobia, leadership and confidence]... Please call 010 0000 0000 for a consultation. #depression #familyviolence #sexualassault #familycounseling #schizophrenia #pasthealing #alcoholaddiction #borderlinepersonalitydisorder... *(Note: 30 hashtags were present on this post, the limit on Instagram at that time)*

Some English posts advertising new products approved for the treatment of schizophrenia were seen on Facebook and Twitter, for example:

> Alkermes Scores FDA Approval for Potential Game-Changing Schizophrenia Treatment [link] (Twitter)

Posts Relating Mental Health Journey of Poster or Close One (EN = 6%, KO = 2%). Some content authors, rather than sharing general facts about mental health, shared about their own personal experience of mental health or the experience of somebody they know or knew. The content shared was not necessarily about schizophrenia; in many cases, posters shared about their experience of depression or bipolar disorder, for example:

> I was diagnosed with BPD (Borderline Personality Disorder) when I was 29 (I'm now 39). BPD is a misunderstood illness. I believe that it resulted from childhood trauma… (Instagram post)

Hashtags representing other mental health diagnoses were commonly added at the end of these posts or as comments, especially on Instagram where space is not an issue. Other hashtags included support for raising mental health awareness (e.g., #mentalhealthawareness) and ending stigma (e.g., #endthestigma) surrounding mental illnesses. Some of these uploads were also triggered by Mental Health Awareness Week that took place late May 2018.

Comments on the English posts usually indicated support. In some cases, commenters also shared personal stories of themselves or their friends or family struggling with mental illness, usually with a positive twist. In some instances, and this was more frequent with severe mental illnesses, narratives of people's lives intertwined with mental illness were shared on organizational accounts, such as support groups for people with severe mental illnesses.

> I wish people would include disorders like bpd, schizophrenia, halsey stans, ed's and more when they decide to speak up about mental health all people ever care about is anxiety and depression as if those are the only two mental illnesses. (Twitter user)

More engaged posts (EN = 3%, KO = 1%). A few posts were more engaged, showing offline involvement of the author or inviting other SMP users to take part in online or offline activities to help further MH causes. For example, a pharmaceutical company posted the following call to online action, which was then relayed by several users:

> I CAN! Help reduce stigma by joining us in spreading the #ICanWithSchizophrenia message to support individuals living w/ schizophrenia pursuing their personal goals. For every RT of this video, we'll donate $1 to @[mental health organization] (min. $10K, max. $30K; thru 7/31) [link] (English Twitter post)

Ironically, many of these users were English-speaking fans of BTS, a popular Korean music band.

Counter-advocacy Content Shared on SMPs

Jokes, Exaggeration of daily life events (EN = 2%, KO = 26%). Many Korean users, especially on Instagram, used the old term for schizophrenia, jeongshinbunyeol ("정신분열"), to exaggerate their frequent change of opinion, emotion, or switching between contexts. These uses of the old term for schizophrenia in Korean were usually for trivial things such as what artist to vote for in a music competition, as seen on Twitter:

> I think I'm going to have schizophrenia because I keep moving between my primary account and secondary accounts. Was this what it was like to vote in the 21st *[sic]* century… #iVote[Boy band name followed by music competition name] *(Korean Twitter post)*

Korean users also frequently used the term jeongshinbunyeol (정신분열) when talking about academic tests or diet, with once again little relevance to schizophrenia as a mental illness, but instead representing the user's personal state of mind. The term was frequently seen in hashtags or phrases detached from the main message, as shown in the two examples below:

> I'm really confident I messed up this test…! (Schizophrenia *(Korean Twitter post)*

> I want to get rid of exams #Korea #[Korean region name] #[High school name] #Instagram #Studygram #jeongshinbunyeol #English #Alotof #Stress… (Korean Instagram user)

In these instances, the newer term "johyeonbyeong" (조현병) was never used, possibly because the term sounds more medical and is yet to be commonly used.

Pejorative Uses of "Schizophrenia" and "Schizophrenic." The terms "schizophrenia" and "schizophrenic" were used rather liberally on many Twitter

posts as opposed to Instagram posts. “Schizophrenic” was used as an insult by English users in contexts unrelated to mental health, in general to describe people that, according to them, exhibit characteristics of schizophrenia such as hallucinations or changing their mind all the time, sometimes in elaborate analogies:

> *(About Kim Jeong Eun)* "Dealing with this guy is like trying to get back together with your schizophrenic, crazy ex girlfriend. One minute you're all hugging and all seems well, the next she's trying to stab you to death in your sleep." *(English Facebook comment)*

> @[username of other Twitter user] You clearly have mental issues. I would say paranoid schizophrenic. My advice is to seek medical attention ASAP. Take your pills, today is Saturday *(English Twitter)*

> @[username of other Twitter user] Talking to yourself? #schizo *(English Twitter)*

These insults were frequently directed to politicians such as former President Donald Trump:

> Something is definitely wrong with Donald Trump. According to him, everything is rigged. Paranoid, schizophrenic? A good reason to remove him from office. 25th Amendment will work in this instance. (Twitter user)

“Schizophrenic” was also used to describe things that are inconsistent, like the following post from a major US newspaper and on which several comments pointed out the inappropriateness of the word in this context:

> Past winners of the 7.5-mile "topographically schizophrenic romp" include an 8-year-old girl (barely beating a 68-year-old woman) and a 72-year-old man. (English Facebook post)

> I suggest following the Diversity Style Guide suggestions for the use of “schizophrenic” – [Link] (English Facebook reply)

> C'mon, [Newspaper name]. I've run this truly amazing race before and know what your author is trying to say, but that's not what "schizophrenic" means, and your otherwise excellent editors should have corrected it. (English Facebook reply)

In these instances, English Twitter users sometimes corrected the poster in responses to their tweets by disapproving of the use of the term for pejorative purposes. These commenters sometimes self-disclosed their own or a close one's mental health diagnosis (not necessarily schizophrenia), with discussions either stopping their order continuing towards more negative argumentation. In Korean posts, this was seen in only two cases.

Political comments on Twitter. Korean Twitter users have used the term "jeongshinbunyeol" (mind split, former term for "schizophrenia") to attack political figures, like President Moon Jae-in or politician Lee Jae-myung (이재명), who allegedly forced his brother into an involuntary hospitalization in a mental health hospital (before the application of the new Mental Health Act).

> Something is definitely wrong with Donald Trump. According to him, everything is rigged. Paranoid, schizophrenic? A good reason to remove him from office. 25th Amendment will work in this instance. (Twitter user)

Comments on Facebook news articles featured pejorative uses of words related to schizophrenia. Common usages were to describe politicians' actions or behaviors when responding to news articles about politics, and labeling criminals "schizophrenic" without any mention of any diagnosis in response to news articles about crime. For example, on a post about President Donald Trump's insinuation that a spy infiltrated his 2016 presidential campaign, a user posted the following:

> Admission of guilt or paranoid schizophrenia? Either way totally unfit to be in office, that part has been obvious since before the election… (English Facebook comment)

Reactions on news stories. Many reactions to news stories were vehement, especially when people with schizophrenia were included in the news.

Korean Twitter users shared many articles about news stories and added their opinion, often negative, about male perpetrators who were allegedly diagnosed with schizophrenia, often about hate crimes against women.

> "Assault without asking" and wielding brick… 4 victims in 17 minutes [link]. (Korean Facebook post)

> If you commit a crime, you should be punished. There's a victim, but there is no perpetrator! Does this make any sense?! (Korean Facebook reply)

Posters commented on how schizophrenia is used as an excuse in these highly mediatized court cases, and female posters expressed fear toward people with schizophrenia.

A few posts perpetrated stigma around schizophrenia by warning other users about people with schizophrenia and criminals "roaming free," without assuming that they could have received adequate treatment:

> Everybody living in [city name]!! A schizophrenia patient with a history of murder has just escaped. Please proceed with caution just in case! (Korean Twitter post)

More pronounced counter activism was also noted, such as Facebook users advocating for people with schizophrenia to be deprived of their rights to "keep the public safe." Some Facebook users alluded to their alleged familial circumstances and clearly stated their stance on the rights of people with schizophrenia, despite being in a public forum:

> "Most schizohprenic are gentle souls. They should either take their meds or be committed. We made our family member take his meds or go back in hospital. There should be no other option." *(English Facebook comment)*

Korean Facebook replies exhibited even more virulent vocabulary, such as calls to “kill all people who have schizophrenia.”

Other Content

These posts were tagged with the hashtag schizophrenia but did not have any apparent mental health connection beyond lyrical content. Notably, these posts rarely featured content, such as text or pictures, that promoted mental health in a positive light or shared about schizophrenia for its mental health value.

Alternative Cultures. Some posts shared on Instagram were tagged with #schizophrenic or #schizophrenia but did not have any apparent relation to mental health or schizophrenia. These posts were referring to subcultures, mostly Satanist, metal, and emo subcultures, and sometimes referred to song lyrics that depicted schizophrenia in songs (like Metallica’s *The Frayed Ends of Sanity*, 1988). These alternate culture posts were not seen among the studied Korean posts.

Name of bands or products’ linguistically close to schizophrenia (EN = 0%, KO = 7%). Several Korean Twitter posts mentioned a Japanese videogame called Unlight: Schizo Chronicles (ウンライト：スゾクロニクル in Japanese, 언라이트: 스키조크로니클 in Korean)[4] whose only apparent relation with schizophrenia is that the main characters hear voices telling them where to go. This game was discontinued on August 24, 2018 during the study period; several posts on Twitter

[4] Unlight: SchizoChronicle on Namu Wiki: https://namu.wiki/w/%EC%96%B8%EB%9D%BC%EC%9D%B4%ED%8A%B8:%20%EC%8A%A4%ED%82%A4%EC%A1%B0%ED%81%AC%EB%A1%9C%EB%8B%88%ED%81%B4

were commenting (mostly venting) about the discontinuation. Schizo is also the name of a Korean rock band popular in the early 2010s.

Business Promotion. There were instances of product or service promotion in both Instagram and Twitter posts. Some Korean posts advertised clinics offering mental health services to their clients. English Instagram and Twitter posts advertised cannabidiol (CBD)-based products, herbal complements, or books as tools to help with treating schizophrenia symptoms, among other mental illnesses (1% of English posts coded). In these posts, schizophrenia was rarely singled out and was instead mentioned along with other mental illness diagnoses; and frequently with other ailments unrelated to mental health, especially when CBD products were advertised. These posts featured limited engagement in the comment section. Comments typically encouraged the business or were asking to be followed back for promotion, and rarely were the comments about mental health or schizophrenia. There were no Korean posts about CBD, an unsurprising fact given that the medical use of marijuana-derived products was approved in 2019 ("S. Korea to allow imports of medical cannabis starting in March," 2019), i.e., the year following the data collection period.

News Articles. All social media platforms featured posts sharing news. News articles shared on Twitter ranged from positive scientific advancements, such as pharmaceutical companies trying new drugs for schizophrenia, to more negative news, for example, Pres. Trump misappropriating the term “schizophrenic” or crimes committed by people with alleged or confirmed schizophrenia. For example, this Korean post shared a news article about a recent event:

> Ex-convict in his 40s escapes from psychiatric hospital [link]
> In the past, he was sentenced to three years in prison for assaulting

> and killing a fellow patient for being noisy when he was hospitalized in a mental ward, and was currently being treated for schizophrenia at a hospital. [link] (Korean Twitter post)

On Twitter, posts sharing news articles usually contained a simple title explaining the outcomes of a research article recently published accompanied with a link pointing to the article. The articles referred to were either news articles published in mainstream media outlets or academic journals. For the English dataset, these articles were often positive, sharing advancements in medical research for the treatment of schizophrenia either through medication research or more alternative medicine, such as marijuana. In some cases, tweets were referring to articles about alleged triggers of schizophrenia, such as how milk consumption can be a factor in developing schizophrenia.

On Instagram, news articles shared were often linked to a business purpose like the promotion of CBD products as improving outcomes among people with schizophrenia.

Positive mentions of schizophrenia on Facebook included comments on news articles about new drugs, push for increased public funding regarding services for people with schizophrenia, and users correcting misusages of "schizophrenia" and related words.

> (On research linking pregnancy complications to schizophrenia) Schizophrenia needs to be paid attention to because it affects a persons's ability to think,feel and behave clearly.just to educate everyone,it can never be cured but can be treated and sometimes it last for years or lifelong *(English Facebook comment)*

Posts in Languages Other Than English or Korean. 10% (134 posts) of the posts collected with English hashtags were not written in English; languages included Arabic, Spanish, and French. These posts were not analyzed.

Advocacy and counter advocacy in SMP comments

Comments were the most frequent on Instagram and Facebook because of the limitations in collecting related responses in Twitter. On English Instagram advocacy content, many comments were positive albeit not quite involved, for example by containing only heart-shaped or thumb-up emojis. On posts sharing personal stories to raise mental health awareness, users sometimes commented with their own stories to provide additional insight or just to relate with the author of the post.

As Instagram Korean posts had many posts unrelated to mental health, Korean comments predominantly featured language indicating familiarity between commenters and authors.

In both languages there were a few posts (1 in English, 3 in Korean) containing argumentative language countering counter-advocacy comments on Facebook. In English it was the example mentioned previously of a well-regarded US newspaper using “schizophrenic” to describe a bike race; in Korean, users criticized the negative light that news reports or other commenters shed on schizophrenia. A Facebook Korean user notably added that most people with schizophrenia are regular people if they receive appropriate treatment and criticized the journalist for perpetrating stigma around mental illness.

Frequent Terms and Hashtags in Content Shared. Table 5 provides descriptive statistics on the hashtag repartition across English and Korean content for Instagram and Twitter, while Table 4 and Table 6 rank the most popular hashtags on Instagram and Twitter, respectively, and Table 7 the most frequent words in Twitter content. For English content, on both Twitter and Instagram,

#schizophrenia was unexpectedly the most popular hashtag, being on 80.1% of Instagram posts, as it was one of the terms used to fetch the study dataset. #정신분열 (#schizophrenia, old term) was the most popular Korean Instagram hashtag for similar reasons; being on 35.2% of the posts, it was interestingly more popular than #조현병 (#schizophrenia, new sanctioned term) that ranked third (17.8% of the posts). When adding similar term 정신분열증 (former term for schizophrenia with a postposition meaning symptoms, affixed to many mental health diagnoses), the hashtag root 정신분열 was on 53% of the posts, making it a more popular hashtag in the dataset than #조현병 (schizophrenia, new term).

For both languages, other notable popular hashtags on Instagram included terms related to specific mental health diagnoses—for example #depression or #우울증 *(#depression),* both ranking second among English and Korean hashtags, respectively. For both English and Korean Instagram posts, 8 hashtags in the top 10 represent mental health diagnoses, suggesting that these diagnoses may frequently appear together; such posts may thus not be fundamentally about schizophrenia but may be about general mental health.

Notable hashtags representing more engaged forms of advocacy were present in English content, such as #mentalhealthawareness (appearing on 30.8% of Instagram posts and 0.5% of Twitter content) and #endthestigma (appearing on 6.8% of Instagram posts and 0.3% of Twitter content). Korean content did not have similar hashtags among their most frequent hashtags.

Some of the most frequent Instagram and Twitter Korean posts were unrelated to mental health, especially when seen without any additional context. Examples for Instagram include #일상 (#dailylife) and #daily, and #모바일상품권매입

(#mobileGiftCardPurchase). Most hashtags in the top 30 for English Instagram posts were related to mental health; notable exceptions include #art (9.4% of posts) and #love (7.8%). As for English Twitter content, several hashtags related to recreational drugs were present in the top 30 such as #cbd (0.4%), #cannabis (0.3%), and #cannabis (0.3%).

Table 4. Top 30 English and Korean hashtags on Instagram

Rank	English	Korean	Translation
01	#schizophrenia (22,599; 80.1 %)	#정신분열 (194; 35.2%)	*#schizophrenia (old term)*
02	#depression (13,770; 48.8%)	#우울증 (109; 19.8%)	*#depression*
03	#anxiety (13,195; 46.8%)	#조현병 (98; 17.8%)	*#schizophrenia (new term)*
04	#mentalhealth (12,723; 45.1%)	#정신분열증 (77; 14.0%)	*#schizophrenia (old term, with additional. suffix)*
05	#bipolar (10,575; 37.5%)	#공황장애 (64; 11.6%)	*#panicdisorder*
06	#mentalillness (9,515; 33.7%)	#자해 (45; 8.2%)	*#selfharm*
07	#mentalhealthawareness (8,682; 30.8%)	#일상 (39; 7.1%)	*#dailylife*
08	#ptsd (7,744; 27.4%)	#분노조절장애 (34; 6.2%)	*#angermanagementproblem*
09	#ocd (5,165; 18.3%)	#조울증 (31; 5.6%)	*#bipolardisorder*
10	#bpd (4,720; 16.7%)	#소통 (29; 5.3%)	*#communication*
11	#recovery (4,389; 15.6%)	#알콜중독 (27; 4.9%)	*#alcoholaddiction*
		#자살 (27; 4.9%)	*#suicide*
12	#suicide (4,233; 15.0%)	#섭식장애 (26; 4.7%)	*#eatingdisorder*
		#성폭행 (26; 4.7%)	*#sexualassault*
		#섹스중독 (26; 4.7%)	*#sexaddiction*
		#자폐증 (26; 4.7%)	*#autism*
13	#anorexia (4,048; 14.3%)	#adhd (25; 4.5%)	
		#심리상담 (25; 4.5%)	*#psychologycounseling*
		#아동폭력 (25; 4.5%)	*#childviolence*
14	#psychosis (3,738; 13.2%)	#자녀상담 (24; 4.4%)	*#childrencouseling*
15	#adhd (3,473; 12.3%)	#가족관계치유 (23; 4.2%)	*#familyrelationsrecovery*
		#데이트폭력 (23; 4.2%)	*#dateviolence*
		#성폭력 (23; 4.2%)	*#sexualabuse*
		#역기능가정 (23; 4.2%)	*#dysfunctionalfamily*
		#폭력가정 (23; 4.2%)	*#violenthousehold*
		#폭식증 (23; 4.2%)	*#bulimia*
16	#bipolardisorder (3,248; 11.5%)	#거식증 (22; 4.0%)	*#anorexia*
		#비행청소년 (22; 4.0%)	*#juveniledelinquents*
		#이혼후상처 (22; 4.0%)	*#postdivorcehurt*
17	#depressed (3,244; 11.5%)	#단도박 (21; 3.8%)	*#stopgambling*
18	#schizophrenic (2,958; 10.5%)	#daily (20; 3.6%)	
19	#bulimia (2,932; 10.4%)	* Hashtags present on less than 20 posts redacted	
20	#art (2,645; 9.4%)		

21	#selfharm (2,527; 9.0%)
22	#eatingdisorder (2,255; 8.0%)
23	#love (2,197; 7.8%)
24	#suicidal (2,158; 7.6%)
25	#socialanxiety (2,065; 7.3%)
26	#personalitydisorder (1,940; 6.9%)
27	#endthestigma (1,929; 6.8%)
28	#suicideprevention (1,869; 6.6%)
29	#eatingdisorders (1,857; 6.6%)
30	#selfcare (1,834; 6.5%)

Table 5. Instagram and Twitter hashtag representation for English and Korean content

		Unique hashtags	**Mean (STD) hashtag count of…**	
			all content	**posts and self-replies only**
Instagram	All	42,177	8.15 (11.47)	17.46 (10.89)
	English	39,748	8.23 (11.52)	17.62 (10.85)
	Korean	2,573	3.86 (07.50)	9.01 (09.30)
Twitter	All	13,805	0.60 (02.18)	0.61 (02.21)
	English	13,367	0.63 (02.21)	0.64 (02.24)
	Korean	452	0.22 (01.65)	0.22 (01.67)

Table 6. Top 30 English and Korean hashtags on Twitter

Rank	English	Korean	Translation
01	#schizophrenia (6129; 7.8%)	#조현병 (113; 1.8%)	*#schizophrenia (new term)*
02	#mentalhealth (1612; 2.0%)	#소액결제현금화 (27; 0.4%)	*#micropaymentCashRedemption*
03	#depression (1048; 1.3%)	#모바일상품권매입 (25; 0.4%)	*#mobileGiftCardPurchase*
		#실검 (25; 0.4%)	*#topTrendingSearches*
04	#mentalillness (862; 1.1%)	#네이버 (24; 0.4%)	*#Naver (Korean Google)*
05	#bipolar (797; 1.0%)	#임성진 (23; 0.4%)	*#LimSungJin (volleyballer)*
06	#anxiety (781; 1.0%)	#구글정보이용료 (21; 0.3%)	*#GoogleInformationUsageFee*
07	#ptsd (452; 0.6%)		
08	#mentalhealthawareness (423; 0.5%)		
09	#health (403; 0.5%)		
09	#psychosis (403; 0.5%)		
10	#autism (333; 0.4%)		
11	#schizophrenic (323; 0.4%)		
12	#ocd (303; 0.4%)		
13	#cbd (286; 0.4%)		
14	#bipolardisorder (273; 0.3%)		
15	#cannabis (266; 0.3%)		
15	#endthestigma (266; 0.3%)		
16	#bpd (250; 0.3%)	* Hashtags present on less than 20 posts redacted	
17	#psychology (245; 0.3%)		
18	#psychiatry (244; 0.3%)		
19	#mentalhealthmatters (239; 0.3%)		
20	#adhd (204; 0.3%)		
21	#cbdoil (195; 0.2%)		
22	#schizoaffective (185; 0.2%)		
23	#marijuana (184; 0.2%)		
24	#brain (180; 0.2%)		
25	#cancer (177; 0.2%)		
26	#sicknotweak (175; 0.2%)		
27	#suicide (174; 0.2%)		
28	#insomnia (169; 0.2%)		

29	#pain (167; 0.2%)
30	#neuroscience (163; 0.2%)

Table 7. Most frequent words in Twitter content.

Rank	English	Counts	%	Korean	Counts	%
1	schizophrenia	38362	47.2	하다	5469	49.4
2	schizophrenic	25897	31.9	이다	4838	43.7
3	s	18888	23.3	은	3558	32.1
4	nt	11659	14.4	도	3339	30.1
5	like	9213	11.3	조현병	3116	28.1
6	people	8630	10.6	는	3030	27.3
7	mental	7299	9.0	있다	2400	21.7
8	amp	6343	7.8	되다	2355	21.3
9	just	6317	7.8	거	2165	19.5
10	disorder	6266	7.7	다	1961	17.7
11	get	6257	7.7	보다	1913	17.3
12	m	6097	7.5	정신분열	1896	17.1
13	#schizophrenia	5818	7.2	크크크	1740	15.7
14	think	5464	6.7	한	1717	15.5
15	know	4961	6.1	같	1531	13.8
16	schizo	4730	5.8	사람	1432	12.9
17	bipolar	4627	5.7	안	1387	12.5
18	go	4537	5.6	게	1361	12.3
19	paranoid	4319	5.3	적	1269	11.5
20	make	4277	5.3	크크	1158	10.5
21	illness	4228	5.2	없	1153	10.4
22	re	3731	4.6	스키조	1058	9.5
23	up	3632	4.5	환자	1055	9.5
24	depression	3317	4.1	정신분열증	1026	9.3
25	help	3293	4.1	만	999	9.0
26	take	3243	4.0	내	933	8.4
27	good	3197	3.9	정신	923	8.3
				뭐	923	8.3
28	need	3174	3.9	진짜	908	8.2
				수	908	8.2
29	time	2942	3.6	주다	891	8.0
30	thing	2890	3.6	좋	872	7.9

Discussion

This analysis of English and Korean Instagram and Twitter posts shows that activism around schizophrenia goes from slacktivism consisting of resharing simple posts with a plethora of hashtags (Lane & Dal Cin, 2018; Rotman et al., 2011) to more involved online actions, including correcting other Internet users' misuses of the term schizophrenia and sharing personal mental health journeys to start a conversation about mental health. The results align with quantitative studies of English schizophrenia posts on Twitter (Alvarez-Mon et al., 2019; Joseph et al., 2015; Passerello et al., 2019; Robinson et al., 2019), and confirm that online activism exhibits different facets on Instagram and Twitter. Schizophrenia is, however, rarely the prime focus of Internet posts and is rather added to other mental illness diagnoses as a hashtag, especially on Instagram.

This analysis also illustrates the differences between Korean and English Internet posts about mental health, with Korean posts less concerned about mental health and still contributing to stigma around the term "schizophrenia." This work breaks ground for an international quantitative analysis of Instagram and Twitter posts in both Korean and English to uncover differences in mental health activism between South Korea and the West. It also opens the door for further discussion about culturally-sensitive social media platforms which have historically been developed primarily by and for Western audiences (Reinecke & Bernstein, 2007, 2011).

Advocacy on English and Korean content posted on Twitter, Facebook, and Instagram has many representations and many facets. Content seen ranged from light engagement, such as sharing content supporting the cause with hashtags, to

more engaged advocacy, such as correcting people for the use of schizophrenia-related words,

Conversations on advocacy content were found to be very disengaged, in many cases supporting the poster for their person rather than commenting on the content shared. Exceptions were however seen, such as on posts posted by mental organizations supporting mental health issues.

On Korean posts, dialogues about mental health were rarely seen in the posts reviewed. When conversation happened, the topics were often negative, such as crime reports, and the comments on them were also negative. This tends to support the hypotheses put forward of Korean posts being more negative than English posts when it comes to mental illness.

The hashtag counts show that the Instagram posts in the dataset have more posts on average than Twitter, and the difference is significant (t-test) whether all content types are considered or only original posts and self-responses. The predominance of the former terms designating schizophrenia in the Korean Instagram and Twitter posts seems to confirm that Korean users may be more prejudiced towards using the word to discuss their own mental state instead of subjects dealing with the actual psychiatric diagnosis. The identical frequency of some of the hashtags in Korean content can be attributed to a few entities (mostly selling healthcare-related services) uploading multiple posts with the same hashtags, such as #심리상담 (#psychologycounseling) posted frequently by a mental health treatment center.

The repartition of hashtags present on both Instagram and Twitter for English and Korean implies very subdued forms of advocacy as stronger advocacy

hashtags like #endthestigma seldomly appear among the top hashtags. Further, the top hashtags in Korean Instagram and Twitter content did not include any hashtag supporting advocacy besides the mention of mental health diagnoses or promoting for-profit treatment options. The absence of strong advocacy forms based on hashtags supports that advocacy online appears to be limited to weak support for causes.

Multiple Types of MH Activism and Counter-Activism on SMPs.

This study proves the existence of MH advocacy and counter advocacy on the SMPs studied. It also highlights the variety of advocacy and counter-advocacy types, from very light advocacy (e.g., sharing a picture and a few hashtags) to stronger advocacy (e.g., calls to action), and from unconscious counter-advocacy to vehement verbal bashing and calls for taking away rights of people with schizophrenia. This confirms the spectrum of advocacy and counter advocacy described in the model and allows mapping out the different types of advocacy and counter advocacy content to this spectrum.

Some forms of advocacy and counter advocacy content were rarely or not found in some SMPs (for example, discussion of crimes committed by people with schizophrenia was not seen in Instagram content), while some forms of expression, like insults using words derived from “schizophrenia,” were commonly seen on Twitter for example. This may speak to the difference in communication styles between SMPs.

The rarity of some forms of advocacy, like calls to action, may also speak to the status of schizophrenia advocacy online. If considering “schizophrenia advocacy” as a social movement, the online presence of the movement may well be

in its infancy, judging by the lack of engagement of users sharing about schizophrenia. This lack of engagement is also in spite of real-world MH activist movements like (give some examples), MH associations, and governmental bodies and institutions promoting mental health care. As studies have pointed out, more engaged forms of activism and counter-activism do exist online (e.g., the Arab Spring; Bruns et al., 2013) and can translate to offline advocacy with calls to join events, such as what has been seen in the Black Lives Matter movement (Mundt et al., 2018). SMPs can indeed be used to mobilize and build coalitions between several organizations within a movement (Mundt et al., 2018), something that was not evident in the SMP content analyzed in this study.

Schizophrenia as an advocacy movement could also be the issue. Schizophrenia is often mentioned peripherally together with other mental illnesses, often less severe. In the posts and comments seen, people who were disclosing a mental illness to raise awareness were not necessarily people with schizophrenia but often were people with bipolar disorder, post-traumatic stress disorder, or other diagnoses. While some users did report having schizophrenia, they also did so to raise awareness about the illness but not necessarily to make a profound change to policies or funding for MH. Other mental illnesses may have these more engaged advocates, but schizophrenia appears not to have many active advocates online. There may also be advocates of general MH, advocating for the right of all people with a mental illness, that could be using different hashtags from the ones selected for this study, but in this case their posts are unlikely to mention schizophrenia directly.

This implies that the theory for online schizophrenia advocacy may evolve over time. As “schizophrenia advocacy” plays out online, new forms of advocacy and counter-advocacy may emerge, following the course of social movements. New types of advocates, as well as counter-advocates, may emerge as well, illustrating the ever-changing nature of the model. This evolution is unlikely to be unpredictable; other studies of social movements with online components have shown what to expect. Despite advocates and counter-advocates present, schizophrenia advocacy may be waiting for one or several determining events, such as the killing of Trayvon Martin followed by Michael Brown and Eric Garner that catalyzed membership to the Black Lives Matter movement (Leach & Allen, 2017). Scale can however be a problem, for example in the US the number of people with schizophrenia pales in comparison to the number of Black people (between 0.25% and 0.64% for the former compared to 13.4% for the latter (NIMH, 2016; United States Census Bureau, 2019); such movement centered on schizophrenia advocacy would need to quickly gather engaged advocates outside people with schizophrenia to become visible.

Blurred Boundaries of MH Advocacy and Counter-Advocacy. Delineating what constitutes mental health activism and counter-activism is challenging in the context of SMPs. Sentences and words seemingly anodyne at first sight could be judged derogatory when viewed in the context of schizophrenia advocacy and counter-advocacy. For example, many Korean posts did not have a direct association with mental health other than using the word 정신분열증 (jeongshinbunyeol, former word for schizophrenia), but instead describing a mental stat in a light tone. Because the official word for schizophrenia has now

changed to 조현병 (johyeonbyeong), the use of the former word on social media can be debated as being advocacy or counter-advocacy.

It may be argued that the use of the former word does not constitute a form of counter-advocacy because the authors do not necessarily have ill intentions behind their posts. Nonetheless, the fact that several posts about schizophrenia do use the word 정신분열 (jeongshinbunyeol) leads to the conclusion that jeongshinbunyeol must be classified as a form of counter advocacy, albeit very light, because using the word in online posts actually does a disservice to people posting about schizophrenia as it requisitions the search term, making it impossible to search for content about schizophrenia without using the johyeonbyeong (조현병; new term for schizophrenia) search term. Similar to how slacktivism is a very light form of activism (Henrik Serup, 2011), very light forms of counter activism should not be discounted and instead considered as such.

What would not be considered advocacy or counter-advocacy offline is not necessarily equivalent to what should not be considered advocacy or counter-advocacy online (Henrik Serup, 2011). Online methods of expression—although gradually improving with videos, dynamic feeds, and others—are not equivalent to offline, face-to-face expressions. When words and pictures are the main means of expressions in the text- and image-driven SMPs studied (especially at the time of data collection), the terms and representations used in these media intrinsically carry more weight. Online advocacy can also lead to increased offline advocacy; further, some SMP users may perform online advocacy because they cannot participate otherwise (Smith et al., 2019). Discounting weak forms of advocacy and counter-advocacy thus appears unwise.

Implications for SMPs. The SMPs studied are used as media for sharing content about mental health, yet do nothing to help promote advocacy topics or disparage counter advocacy content regarding schizophrenia. This is puzzling as many of these SMPs offer some kind of content analysis and content policing when posting about certain MH topics. For instance, Instagram blocks the main hashtags related to self-harm (Pater & Mynatt, 2017), and Facebook shows warnings and suicide hotline numbers to users posting content with potential suicidal undertones (D'Hotman & Loh, 2020). In the context of schizophrenia, SMPs could display an alert to the user when words related to schizophrenia (or any other mental illness) are misused, such as when the user starts replying to another user with an insult including a schizophrenia-related word ("you must definitely be schizophrenic").

As SMPs become more socially engaged – a great example of which played out in 2021 with Twitter banning President Donald Trump from its platform ("The expulsion of Donald Trump marks a watershed for Facebook and Twitter," 2021) – SMPs could provide portals and tools destined to people and organizations advocating for mental health causes. For example, SMPs could promote posts that feature MH advocacy themes or provide guides on how to tailor content to best utilize their platform (Bossetta, 2018). Progress has been made in recent years, such as Facebook allowing frames published by external organizations on profile pictures (Facebook for Government, 2021); ease of access to such tools make users also more likely to support causes dear to them (Oeldorf-Hirsch & McGloin, 2017) (although support for multiple causes may backfire for users; see Wilson & Cohen, 2019).

Limitations

This qualitative analysis was conducted on a set of posts that may not have included all the themes of the data set. Several measures were however undertaken to limit the risk of missing major themes; namely, the purposive sampling used by looking at different slices of data by popularity and temporality. A rapid review of all the posts to remove posts that were in languages other than English and Korean also did not unearth any other major theme that had not been found in this phase; the next chapter details the motivations behind this search.

While this rich qualitative work uses some quantifiers to describe the themes, no real quantification of the phenomena observed could be done in this phase as some themes are highly dependent on current events, such as news items (crimes, quotes of public figures, suicides, etc.)

Very similar posts, such as bot-generated messages or advertisement messages, were not removed from the dataset and may have thus inflated some hashtag counts. This could potentially explain the presence of hashtags far removed from mental health topics in the top 30 hashtags in Korean Twitter content, such as #소액결제현금화 (#micropaymentCashRedemption) or #실검 (#topTrendingSearches).

Conclusion

This chapter showed that schizophrenia advocacy and counter-advocacy on SMPs are present and range from light to engaged advocacy and counter-advocacy, although engaged advocacy seems to be less frequent. This chapter discussed the ever-changing nature of online advocacy in the context of schizophrenia advocacy, the blurred boundaries of what constitutes schizophrenia advocacy and counter-

advocacy on SMPs, and design implications for SMPs. Because of the dataset samples used in this chapter, there was no means of addressing how prevalent advocacy or counter-advocacy were on these SMPs in the period covered by the dataset. Knowing this prevalence and detecting such posts would however be valuable for many stakeholders. For example, mental health advocacy organizations could estimate what SMPs to prioritize for advocacy posts, and engaged SMPs could push forward features to help advocates advocate and at least warn of schizophrenia-derived term misuse. The next chapter focuses on that by addressing RQ2: **How RQ2: How prevalent are advocacy and counter-advocacy among English and Korean Facebook, Instagram, and Twitter SMP posts and comments?**

CHAPTER SIX. QUANTITATIVE STUDY OF SOCIAL MEDIA POSTS RELATED TO SCHIZOPHRENIA

Chapter 5 showed the various forms of advocacy and counter advocacy present on SMPs. While the presence of advocacy and counter advocacy on SMPs was established, the amount of advocacy and counter advocacy that the different SMPs exhibits for each language has not yet been investigated. This chapter does so by answering the following research question:

RQ2: How prevalent are advocacy and counter-advocacy among English and Korean Facebook, Instagram, and Twitter SMP posts and comments?

The objectives of this chapter are:

- Measuring advocacy and counter-advocacy in English and Korean content on SMPs with reasonable accuracy, precision, and recall

- Comparing the proportion of advocacy content between English and Korean posts for each SMP, and for all SMPs combined.

- Comparing the proportion of counter-advocacy content between English and Korean posts for each SMP, and for all SMPs combined.

- Comparing advocacy and counter advocacy happening in comments on Instagram and Twitter advocacy and counter advocacy posts.

I decided to use machine learning classification techniques to achieve these objectives. Machine learning is more desirable than statistics in an online social media context as data is constantly evolving. As such, statistical analyses would need to be performed frequently to estimate the evolution of advocacy or counter-advocacy trends, whereas reliable machine learning classifiers trained on known data could be used for predictions on unseen SMP content (Bzdok et al., 2018).

Statistical methods would also require more resources to code enough content for each SMP-language pair to ensure correct sampling, whereas machine learning classifiers can use different approaches, such as coding across SMPs for a given language. One benefit of using statistical methods for inference of advocacy and counter-advocacy proportions in SMP content is that the well-known error metrics are simpler to interpret as they do not have the added complexity of factoring machine learning validation metrics such as accuracy or F1 scores. However, practitioners may find value in the ability to predict advocacy and counter-advocacy in new batches of SMP content through machine learning classifiers and can certainly trade off a bit of added error for ease of use and not coding a batch of new content to infer advocacy and counter-advocacy.

Methods

Data Coding. Each piece of content was first tagged with different outcome variables representing constructs of the health advocacy framework proposed in Chapter 3. A few outcome variables were added to help with subsequent analyses, such as whether a piece of content had several mental health diagnoses present. A subset of the data was manually tagged for each outcome variable. Each post was manually given a score between 0 and 3 for each outcome variable, with a score of 0 being an absence of the variable's concept and 1-3 the presence of that concept, with 1 being a weak presence (e.g., in just hashtags) and 3 a strong presence (e.g., the author of the post/comment elaborating on the concept). For the rest of this chapter, scores between 1-3 were converted to 1, simplifying the classification problem into a binary one.

I derived a simplified codebook based on the qualitative analysis of only advocacy and counter-advocacy codes, with a few additional codes added to broadly identify posts unrelated to schizophrenia, such as using the term *schizophrenia* for a musical project or to talk about "스키조" ("Schizo"), a popular Korean band. All content with weak to strong forms of advocacy or counter-advocacy were covered with the established codes. Two variables, *any advocacy* and *any counter-advocacy*, were automatically created by aggregating all the variables representing advocacy or counter advocacy, respectively. The codebook with the automatically generated variables can be found in The best classifiers retained for each variable and their validation metrics are presented in Appendix I.

Given limited resources to code large swaths of content, I selected 765 posts and comments at random and 742 posts and comments from the different topics generated by a simple Latent Dirichlet Allocation topic model approach[5] in an attempt to code content as diverse as possible and representing different topics. The coding process was realized using an Excel spreadsheet that was then processed in MATLAB Academic Edition 2021a.

Data Preparation. I then processed the datasets using MATLAB 2021a. I created one unique data table by aggregating all content (posts, comments, replies) for all three SMPs and languages; while doing so I also added three variables distinguishing the content type, the language, and the SMP used. This table contained unique study identifiers for each piece of content; comments and replies

[5] https://www.mathworks.com/help/textanalytics/ug/analyze-text-data-using-topic-models.html

also held a reference to their parent post in an additional variable. I kept variables that were present for only specific SMPs, like the number of retweets or the number of followers of a user for Twitter; for SMPs without these variables, I set the values as missing. I then converted posts and comments into tokenized documents to which I added sentence and part-of-speech information, types and lemma forms; I also erased punctuation and stopwords, and lemmatized the remaining words. I performed these preprocessing steps using relevant MATLAB 2021a functions from the Text Analytics Toolbox[6], a text analytics software suite that supports both English and Korean input text.

Training and prediction. I split the data table into two data tables containing English content in one and Korean content in the other. Different strategies were then applied to find the best classification models and best data representations of the data table to predict each outcome variable as accurately as possible. For each strategy, the data tables were first partitioned so that 30% of the coded rows were reserved for a validation set; a balanced set was created within the 70% left comprising of all the rows coded with the least frequent class, and a random selection of as many rows coded with the most frequent class. Table 10 contains a breakdown of the number of posts and comments used for training and validation.

Data representations. Classification models were trained on different data representations as some data representations may be more appropriate to predict certain outcome variables. The chosen data representations only rely on features

[6] https://www.mathworks.com/products/text-analytics.html

determined from the actual content of the post and not its metadata, such as number of likes or number of comments, in order to avoid introducing bias into the classification models that could lead to false predictions. For example, as seen in Chapter 5, Instagram posts have on average more replies than Twitter posts; if most Instagram posts exhibit advocacy-related outcomes, the classification models could potentially wrongly explain advocacy by the number of replies on a post instead of focusing on the actual content of the post. The data representations that were used for classification are listed in Table 8. One dimensionality reduction technique, chi-square tests for feature ranking (keeping features with $p<0.05$), was separately applied on the transformed data and trained separately.

Table 8. Content representations used for classification training and prediction.

Representation and Description	**Dimension**	
	English	**Korean**
Mean word vectors trained on the dataset Word vectors derived from word embeddings created on the data table's tokenized documents. 25-, 50-, 100-dimension word embeddings were created for each language; the two approaches competed with the other representations. Word vectors were averaged to obtain one vector for each piece of content.	25, 50, 100	25, 50, 100
Mean words vectors trained on the dataset and augmented with additional metadata: content has URL, number/ratio of hashtags/length, number/ratio of mentions, word count, specific text patterns (e.g., "스키조," "schizo" by itself, "schizophrenic," etc.	50	50
Mean word vectors derived from FastText word embeddings Word vectors derived from pre-trained word embeddings provided by the FastText project. These vectors were used as they exist both in Korean and English. The dimension of the vectors was reduced to 100. Word vectors were averaged to obtain one vector for each piece of content.	100	100

Classification Models. Common classification algorithms (SVM, KKN, and Ensemble trees) were trained on the data representations listed in Table 8. Each classification algorithm ran twice, once with the full predictor variables and once with dimensionality reduction using chi-square tests (MATLAB's fscchi2 function, kept variables with p-values<0.05). Non-categorical data were standardized. Hyperparameters were optimized using MATLAB 2021a's optimization parameters for each respective model (as listed in Table 9). All optimizers used 5-fold validation, Bayesian optimization and ran for 50 iterations before stopping to allow all the models to run within a reasonable timeframe.

Table 9. Optimized Hyperparameters.

Model (MATLAB function)	**Optimized Hyperparameters**
SVM (fitcsvm, fitcauto). Support vector machine.	Kernel function (gaussian or linear) Box constraint Kernel scale
Ensemble (fitcensemble). Tree ensembles.	Method (Bag, AdaBoostM1) NumLearningCycles ([10,500]) LearnRate MinLeafSize
KNN (k-nearest neighbors) (fitcauto)	Distance Number of nearest neighbors to find

For each variable, accuracy, F1 score, and Matthews Correlation Coefficient (MCC) were computed on the validation dataset, and the model with the highest MCC was kept and used for predicting the variable for the whole dataset as MCC is more reliable for unbalanced binary variables (Boughorbel et al., 2017; Chicco & Jurman, 2020). Accuracy and F1 score are metrics between [0 1], while MCC is between [-1 1]. Accuracy lesser than 0.5 and MCC lesser than 0 indicates predictions worse than a random guess. For the rest of the analyses, the predictions were used with the underlying assumption that there was no error in the predictions. The best

classifiers retained for each variable and their validation metrics are presented in Appendix I.

Analysis of Predictions. Chi-square analyses were computed on each variable to compare English and Korean content overall and by social media. To understand how the conversations differ between social media and language, Kruskal-Wallis one-way analyses of variance were conducted on the ratio of the number of times a variable was true among the post and all its replies. Kruskal-Wallis analyses were used as normality of the distributions of the dependent variables could not be guaranteed (McKight & Najab, 2010). Pairwise comparisons were then performed using MATLAB's multiple comparison test (`multcompare`).

Results

Table 10. Counts of coded content used for training and validation.

Social Media	Post Type	English	Korean	Total
Facebook	Post	24	16	40
Facebook	Reply	81	61	145
Facebook	Total	108	77	185
Instagram	Post	247	138	385
Instagram	Reply	279	104	383
Instagram	Total	526	242	768
Twitter	Post	333	171	504
Twitter	Reply	12	3	15
Twitter	Total	345	174	519
All	Post	604	325	929
All	Reply	375	168	543
All	Total	979	493	1472

Table 11. Advocacy (Any advocacy)

Ln	Content Type	n_{train}	n_{val}	Acc.	F1 Score	MCC	Predicted Count (%)	Instagram	Twitter	Facebook
en	all	588	293	0.88	0.87	0.76	55,699 (36.27%)	22,138 (32.8%)	33,021 (40.7%)	540 (11.3%)
	posts						49,233 (46.02%)	17,308 (61.3%)	31,901 (40.6%)	24 (21.4%)
	replies						6,466 (13.88%)	4,830 (12.3%)	1,120 (43.5%)	516 (11.1%)
ko	all	148	147	0.88	0.75	0.68	2,255 (20.35%)	267 (20.0%)	1,472 (22.4%)	516 (16.3%)
	posts						1,620 (22.95%)	184 (33.4%)	1,427 (22.2%)	9 (10.7%)
	replies						635 (15.77%)	83 (10.6%)	45 (29.0%)	507 (16.4%)

Table 12. Counter Advocacy (Any counter-advocacy)

Ln	Content Type	n_{train}	n_{val}	Acc.	F1 Score	MCC	Predicted Count (%)	Instagram	Twitter	Facebook
en	all	216	293	0.90	0.73	0.68	58,433 (38.05%)	4,127 (6.1%)	52,973 (65.2%)	1,333 (28.0%)
	posts						53,994 (50.47%)	2,496 (8.8%)	51,450 (65.4%)	48 (42.9%)
	replies						4,439 (9.53%)	1,631 (4.1%)	1,523 (59.2%)	1,285 (27.6%)
ko	all	234	147	0.80	0.74	0.60	5,232 (47.21%)	403 (30.1%)	3,979 (60.5%)	850 (26.8%)
	posts						4,265 (60.44%)	345 (62.6%)	3,904 (60.8%)	16 (19.0%)
	replies						967 (24.02%)	58 (7.4%)	75 (48.4%)	834 (27.0%)

Table 13. Counter Advocacy: using schizophrenia as a joke.

Ln	Content Type	n_{train}	n_{val}	Acc.	F1 Score	MCC	Predicted Count (%)	Instagram	Twitter	Facebook
en	all	74	293	0.95	0.62	0.62	14,318 (9.32%)	3,693 (5.5%)	10,153 (12.5%)	472 (9.9%)
	posts						10,799 (10.09%)	943 (3.3%)	9,850 (12.5%)	6 (5.4%)
	replies						3,519 (7.55%)	2,750 (7.0%)	303 (11.8%)	466 (10.0%)
ko	all	126	147	0.93	0.84	0.81	2,224 (20.07%)	404 (30.2%)	1,769 (26.9%)	51 (1.6%)
	posts						2,092 (29.64%)	344 (62.4%)	1,747 (27.2%)	1 (1.2%)
	replies						132 (3.27%)	60 (7.6%)	22 (14.2%)	50 (1.6%)

Predicting Advocacy and Counter-advocacy Concepts.

Table 19 in Appendix I introduces the validation metrics (accuracy, F1 score, and MCC) for the predicted variables, and Appendices J and K the results of the Kruskal Wallis and Chi-square analyses, respectively.

The variables any advocacy and any counter advocacy have both high accuracies, both over 0.8. This tends to suggest that advocacy and counter advocacy as general concepts can be reliably detected within the dataset, contingent on validation samples being representative enough of the entire dataset.

Many variables, such as “Supporting people with mental health issues” and “Raising awareness about treatment options for mental health,” could not reliably be predicted for Korean content (low accuracy, F1 score, or MCC), likely because training samples were too small (under <100) to guarantee appropriate training given the dimensionality of the data representations used.

Comparison between Languages.

Across SMPs, advocacy was predicted more frequently in English content (36%) than Korean content (20%) (see Table 11), but the difference was negligible ($\Phi = 0.08$). Counter-advocacy was detected less frequently in English content (38%) than Korean content (47%) (see Table 12), and the effect size was very weak ($\Phi = -0.05$).

On Instagram, advocacy was predicted more frequently in English content (32%) than in Korean content (20%), but the effect size was negligible ($\Phi = 0.03$). Counter-advocacy was predicted more frequently in Korean content (30%) than in English content (6%), and the effect size was very weak ($\Phi = 0.15$). When only considering posts, advocacy was also predicted more frequently in English content

(61%) than in Korean content (33%), but the effect size was negligible (Φ = 0.07). Counter-advocacy was predicted more frequently in Korean content (62%) than in English content (8%), and the effect size was negligible (Φ = 0.05). The high frequency of predicted counter-advocacy in Korean posts can be explained by the high frequency of predicted incorrect use of schizophrenia-related words in Korean posts (66%), mostly using 정신분열 (jeongshinbunyeol) as a joke (62%) on Instagram (see Table 13).

On Twitter, advocacy was predicted more frequently in English content (40%) than in Korean content (22%), but the effect size was negligible (Φ = 0.09). Counter-advocacy was also predicted more frequently in English content (65%) than Korean content (60%), but the effect size was negligible (Φ = 0.02). The fact that the percent of content that was detected as both advocacy and counter-advocacy for English Twitter posts is greater than 100% tends to indicate that the models perform more poorly on Twitter. This would not be surprising given the tweet character limit that strips away necessary context for the machine learning algorithms to make determinations. Training algorithms on only Twitter data could improve predictions.

On Facebook, advocacy was predicted more frequently in Korean content (16%) than in English content (11%), and the effect size was negligible (Φ = 0.08). Counter-advocacy was detected more frequently in English content (27%) than in Korean content (26%), and the effect size was negligible (Φ = 0.01). As expected, advocacy and counter-advocacy were not as common on Facebook for either language as on Instagram or Twitter. Many Facebook posts were about news that had no direct relevance to schizophrenia and thus had many responses unrelated

to mental health or schizophrenia (e.g., President Donald Trump insinuating that a spy infiltrated his 2016 presidential campaign, to which one user responded that the President must be schizophrenic among other unrelated replies; see Chapter 5).

Comparison between SMPs.

For English posts, advocacy was predicted most frequently on Twitter (40%) than Instagram (32%) and Facebook (11%), and the effect size was small (V = 0.12). Counter-advocacy was predicted more frequently on Twitter (65%) than on Facebook (27%) and Instagram (6%), and the effect size was large (V = 0.59).

For Korean posts, advocacy was predicted most frequently on Twitter (22%) than Instagram (19%) and Facebook (16%), and the effect size was negligible (V = 0.06). Counter-advocacy was also predicted most frequently on Twitter (60%) than Instagram (30%) and Facebook (26%), and the effect size was medium (V = 0.32).

Language-wise, the effect sizes were insignificant or small for most variables, understandably as English posts and comments outnumbered Korean posts and comments.

Advocacy and Counter Advocacy Comments on Advocacy and Counter Advocacy Posts

Table 14 lists the mean number of comments on advocacy and counter-advocacy SMP posts with at least one comment. There were very few Korean counter-advocacy posts with at least one comment on both Instagram and Twitter.

On Instagram, there was an average of 0.64 advocacy comments on English advocacy posts; the box plot in Figure 3 does however indicate that at least half the posts do not have any advocacy or counter-advocacy comment, indicating that English Instagram posts with advocacy content do not necessarily trigger advocacy

reactions. As seen in Chapter 5, the reactions elicited are probably of light support, like an emoji. English counter-advocacy posts saw comparably more advocacy comments than English advocacy posts with their counter advocacy content. While the distributions of counter advocacy comments appear highly skewed (Figure 3 and Figure 4), this could indicate that Instagram is a positive SMP where users may advocate for mental health on counter-advocacy posts. Korean advocacy posts on Instagram saw more advocacy comments on average than English advocacy posts, and the difference was significant (Table 15). The findings on Instagram advocacy and counter-advocacy conversations should however be mitigated by the fact that Instagram users can reply to their own posts and could include further advocacy content, thus not necessarily meaning a rich advocacy conversation is taking place.

There were fewer Twitter advocacy and counter advocacy posts with at least one reply. According to Figure 4, the median for counter-advocacy comments on Twitter counter-advocacy posts is 1; these posts could be exchanges of incivilities where the initial recipient may be compelled to return the favor.

Table 14. Mean and standard deviation of the number of comments on advocacy and counter-advocacy SMP posts with at least one comment. *p<.05; **p<.01; ***p<.001

	Mean (STD)				F (df)	η2
Variable	en - in	en - tw	ko - in	ko - tw		
Comments on advocacy posts						
n	968	93	46	68		
Advocacy	0.64 (0.89)	0.28 (0.47)	3.24 (3.96)	0.81 (0.74)	20.253 (3, 1171)***	0.052
Counter advocacy	0.39 (0.79)	0.44 (0.60)	0.24 (0.64)	0.26 (0.48)	2.859 (3, 1171)*	0.007
Comments on counter advocacy posts						
n	1,373	406	4	8		
Advocacy	0.57 (0.86)	0.38 (0.65)	2.00 (1.83)	0.88 (0.83)	7.703 (3, 1787)***	0.013
Counter advocacy	0.76 (1.62)	0.75 (0.74)	0.00 (0.00)	0.12 (0.35)	14.682 (3, 1787)***	0.025

Table 15. Pairwise comparisons: Number of comments with Advocacy/counter advocacy on advocacy SMP posts with at least one comment (* The mean difference is significant at the .05 level).

I	J	Mean Group Rank Difference (I-J)	Sig.	Lower Bound	Upper Bound	Mean Group Rank Difference (I-J)	Sig.	Lower Bound	Upper Bound
		Advocacy				Counter advocacy			
en - in	en - tw	131.0*	0.000	43.9	131.0	-39.2	0.718	-117.9	-39.2
en - in	ko - in	-271.3*	0.000	-392.5	-271.3	90.9	0.161	-18.5	90.9
en - in	ko - tw	-102.6*	0.043	-203.3	-102.6	45.3	0.718	-45.7	45.3
en - tw	ko - in	-402.4*	0.000	-547.1	-402.4	130.1	0.052	-0.6	130.1
en - tw	ko - tw	-233.7*	0.000	-361.8	-233.7	84.5	0.286	-31.2	84.5
ko - in	ko - tw	168.7*	0.022	15.5	168.7	-45.6	0.946	-184.0	-45.6

Table 16. Pairwise comparisons: Number of comments with Advocacy/counter advocacy on counter-advocacy SMP posts with at least one comment (* The mean difference is significant at the .05 level).

I	J	Mean Group Rank Difference (I-J)	Sig.	Lower Bound	Upper Bound	Mean Group Rank Difference (I-J)	Sig.	Lower Bound	Upper Bound
		Advocacy				Counter advocacy			
en - in	en - tw	103.3*	0.000	36.6	103.3	-159.4*	0.000	-228.1	-159.4
en - in	ko - in	-438.8	0.269	-1030.1	-438.8	378.0	0.478	-231.6	378.0
en - in	ko - tw	-216.8	0.681	-635.5	-216.8	278.6	0.430	-153.0	278.6
en - tw	ko - in	-542.1	0.094	-1135.5	-542.1	537.3	0.119	-74.3	537.3
en - tw	ko - tw	-320.1	0.245	-741.7	-320.1	438.0*	0.047	3.4	438.0
ko - in	ko - tw	222.0	0.962	-501.2	222.0	-99.4	1.000	-844.8	-99.4

A Dunn & Sidak posthoc test (Table 15) suggests significant differences in the mean group rank of advocacy comment count on advocacy posts for all English/Korean and Instagram/Twitter pairs. No significant difference was detected for counter-advocacy.

A Dunn & Sidak posthoc test (Table 16) suggests significant differences in the mean group rank of advocacy comment count on counter-advocacy posts between English Instagram and English Twitter content. A different Dunn & Sidak posthoc suggests significant differences in the mean group rank of counter advocacy comment count on counter-advocacy posts between English Instagram and English Twitter content, and between English Twitter and Korean Twitter content.

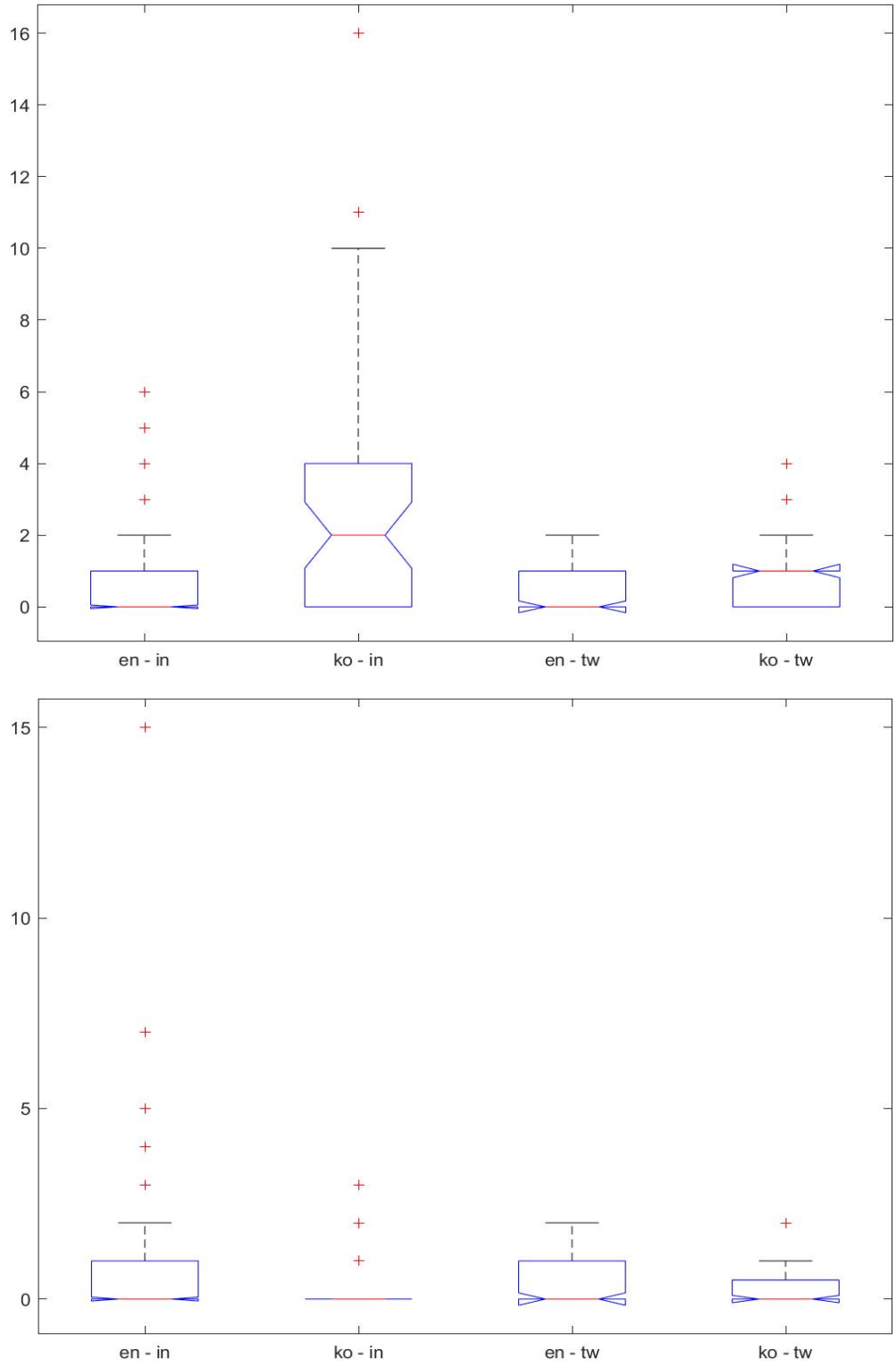

Figure 3. Top: advocacy comment counts for advocacy posts with at least one comment. Bottom: counter advocacy comment counts for advocacy posts with at least one comment.

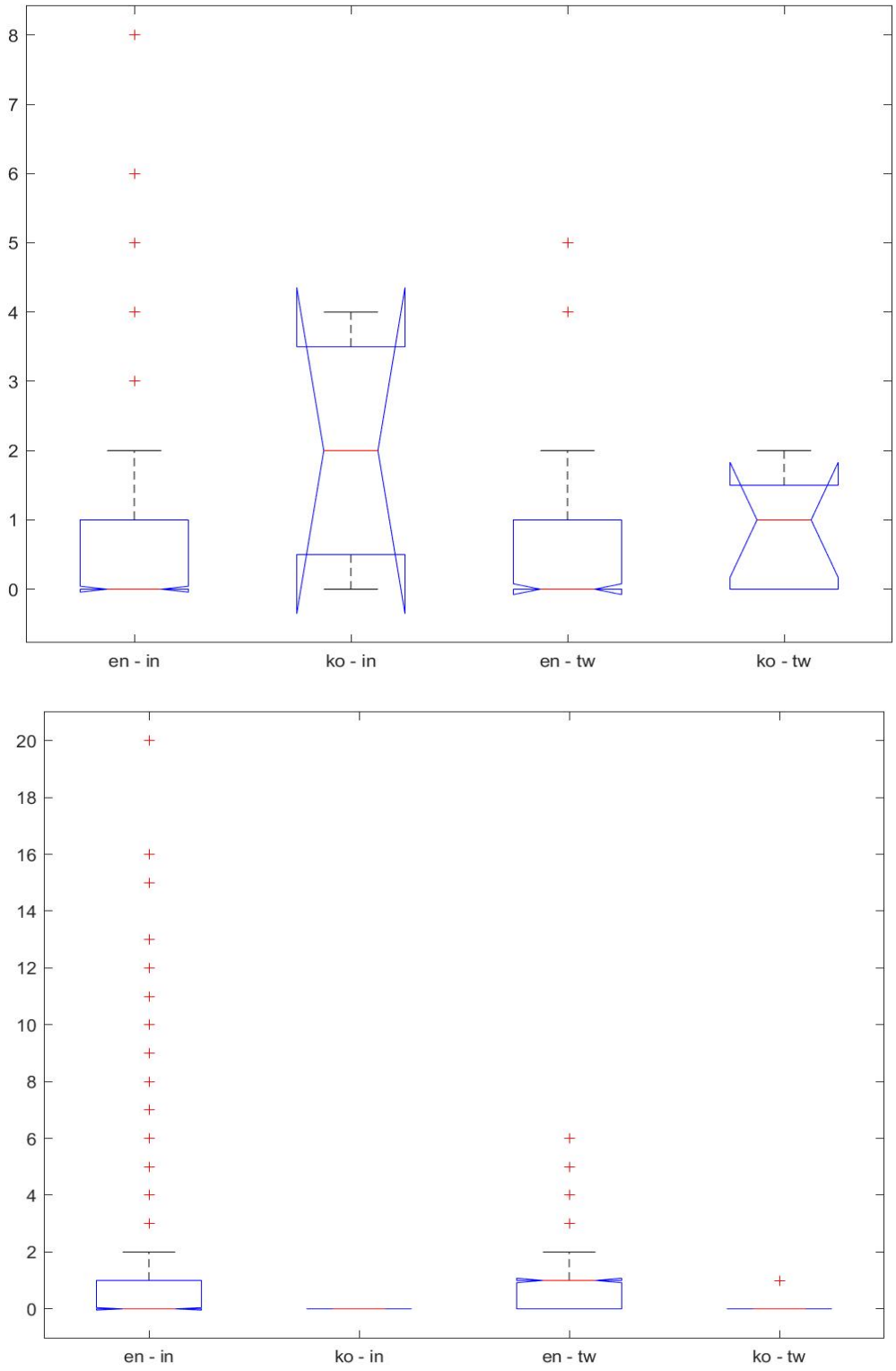

Figure 4. Top: advocacy comment counts for counter advocacy posts with at least one comment. Bottom: counter advocacy comment counts for counter advocacy posts with at least one comment.

Discussion

The results of this quantitative analysis of advocacy and counter-advocacy online show that detecting advocacy and counter-advocacy is feasible with caveats, that advocacy and counter-advocacy as defined for this study are present throughout the dataset for both English and Korean and confirm some of the assumptions about the comparative volume of advocacy and counter-advocacy content between English and Korean languages on SMPs.

Implications for Online Schizophrenia Advocacy

Although the differences between languages were for the most part insignificant (mostly because of unbalanced sample sizes), the results do suggest that mental health advocacy is a lot more present in SMP content in English than in Korean. When considering all SMPs, 46% of English posts were predicted to be any kind of advocacy (with a classifier that had 88% accuracy on its training dataset), whereas only 22.95% of Korean posts were predicted as such (with a classifier that also had 88% accuracy on its training dataset); at the same time, 60% of Korean posts were predicted to contain any type of counter-advocacy, versus 50% for English posts. Twitter seems to be driving counter-advocacy up for both English and Korean SMP content, confirming early judgment made in the qualitative analysis given the insults using schizophrenia-related terms seen in both languages. These could be explained by different demographics using each SMP. For example, a 2016 study showed that UK Twitter use was influenced by age and income, Facebook use by age and gender, and Instagram use by Internet skills and self-efficacy (Blank & Lutz, 2016); in the US the Pew Research Center showed that different demographic

groups have different adoption rates of Facebook, Twitter, and Instagram (Pew Research Center, 2021b).

These differences indicate the commonality of certain behaviors for specific language-SMP pairs, for example, Korean Instagram users repeatedly using jeongshinbunyeol (정신분열) as a joke for self-derision, while Korean Twitter users may use more insults (predicted at 60% of Twitter posts but only 5.6% of Instagram posts, with 0.81 accuracy but F1 score of 0.39). Language may thus not be the only "cultural" marker that impacts the model for online mental health advocacy; SMP platforms need to be factored in as their usage can vary drastically. They for example attract different types of user demographics (e.g.,Blank & Lutz, 2016), and they encourage a different type of dialogue (e.g., short verbal bursts on Twitter versus thoughtful image uploads on Instagram) possibly because of the different emotions they foster (Pittman & Reich, 2016; Waterloo et al., 2018).

Relevance of the Findings for Practice

As many of the comparisons were widely underpowered given the great divergence in sample sizes, most notably between English and Korean posts, most of the computed effect sizes were deemed negligible (albeit significant differences). In percent terms, the differences between some of the observed constructs were nonetheless striking. For example, the prediction of advocacy and counter-advocacy in respectively 61% and 9% of English Instagram posts versus 33% and 62% in Korean Instagram posts had negligible effect sizes.

Despite the lack of large effect size, the percentages are telling for any practitioner allocating resources to boost online schizophrenia advocacy. These results also tell the practitioner what campaigns fighting against mental health

counter advocacy should focus on when it comes to schizophrenia. For example, this analysis highlighted that the use of schizophrenia-related words as a joke or as an insult was prevalent in both languages. Campaigns aiming to fight the stigma of schizophrenia may start by addressing the incorrect use of the word “schizophrenia” on the Internet by English and Korean speakers. Even simple campaigns can have beneficial effects on stigmatization, as pointed out by studies in highly stigmatized areas, such as the use of the word “gay” by heterosexuals to mock one another (Burn, 2000) and even some mental health-related words in some communities (Arthur et al., 2010). These campaigns must nonetheless be well designed to avoid perpetrating unintended stigma (Holland, 2012).

Beyond campaigns, the imbalance of counter-advocacy content versus advocacy content on some SMPs such as Twitter can be remediated by having mental health supporters and organizations increase the number of interactions they have with other users on these SMPs. These interactions can take several forms, such as leaving comments of support on posts by other advocates (that are more involved than a simple emoji) or posting more frequently about various facets of mental health and specific diagnoses so that this generated content can be re-shared by other users. SMP-specific features to improve reach can also be taken advantage of, like political social media campaigns have done in the past (Bossetta, 2018). These actions must be carefully crafted and continuously monitored to look out for and inhibit the generation of new counter advocacy content. Such counter advocacy could happen if lambda users increasingly post about advocacy topics, as they risk looking unauthentic to their friends or followers (Wilson & Cohen, 2019). Mental health organizations could also see counter advocates advancing negative

points in the comments section of their posts; continuous monitoring of comments would help address these replies by reporting them if improper or correcting the counter-advocate if, for example, a word is used incorrectly.

Understanding the Implications of Machine Learning Predictions for Future Analyses. While classifiers with accuracy and F1-scores over 0.8 could be found for several variables, these classifiers are bound to this specific dataset and should not be used to predict advocacy and counter-advocacy in random SMP content outside this dataset. The classifiers were built with the specific intent of predicting advocacy and counter advocacy content within the dataset. Some of the classifiers were trained on very small sample sizes and could therefore have high false discovery rates despite good F1 scores; classifiers meeting such criteria must thus be cautiously considered if used in further analyses.

The automated process for finding the classifiers intrinsically considered the specifications of the dataset. For example, the classifiers using word embedding representations were likely aware that Korean posts associated with the “Schizo Chronicles” online game (as seen in Chapter 5) did not count as counter-advocacy. Such posts are however unlikely to be found in contemporary online posts as the game has been discontinued since 2018; any contemporary mention of the game with an actual message about schizophrenia—a good example would be an advocate for people with schizophrenia retrospectively decrying the use of the term “Schizo” in the name of the game—could be misclassified as having neither advocacy content nor counter-advocacy content.

As explained in this chapter, cultures as manifested in SMP content may be more than a matter of language but also take into account the specificities of each

SMP that draw in different users and online behaviors (Pew Research Center, 2021b). These different behaviors, paired with the various limitations that each platform has on posted content (for example, former character limit on Twitter), suggest that separate classifiers may need to be trained on each language-social media pair in order to improve performance on validation metrics. While more costly coding-wise, doing so would also generate validation metrics for each language-social media pair and thus make subsequent analyses more interpretable and limit bias occurring when SMPs are over- or under-represented in the dataset (eg., Twitter having many more posts than Facebook comments in this dataset, mitigated in this study by an undersampling of Twitter posts during coding).

Limitations. The classifiers were trained separately for each language but were not trained separately for each social media. Doing so would have required coding significantly more posts for each language and was not possible because of limited resources.

Despite outcome variables being coded with values ranging from 0-3, the outcome variables were mapped to 0-1 binary values to be used for classification; future work shall explore other models that can take advantage of the higher granularity, such as regression or multi-class classification machine learning algorithms.

The validation dataset used was derived from the coded posts (30% of the coded posts used for validation); as such, its sampling is not necessarily representative of the entire dataset. Validation measures may reflect some of this bias. Future iterations on this work should have a sample selected randomly to be

set aside for validation before introducing bias in the selection of the training samples.

The values predicted by the best model for each variable were assumed to have no error embedded in them to simplify comparison between domains, a flawed assumption given no model reached an MMC of 1. In the future, an error statistic or confidence intervals for the predictions should be calculated to not overstate findings derived from predictions.

Instagram images were not taken advantage of for improving classification results. As pointed out in chapter 5, some Instagram posts contain text in their pictures and could thus have fewer words in their caption to determine advocacy or counter advocacy outcomes.

As spam and bot messages were not filtered out, the number of positive predictions for some variables may have been inflated.

CHAPTER SEVEN. DISCUSSION

In this section I propose a revision of Chapter 3's online mental health advocacy model, implications for HCI and mental health advocacy, and perspectives on future work.

Revision of the Online Mental Health Advocacy Model

Based on the results from Chapters 5 and 6, the model for online mental health advocacy proposed in Chapter 3 can be further refined by adding social media and language as inherent components of the model, as depicted in Figure 5.

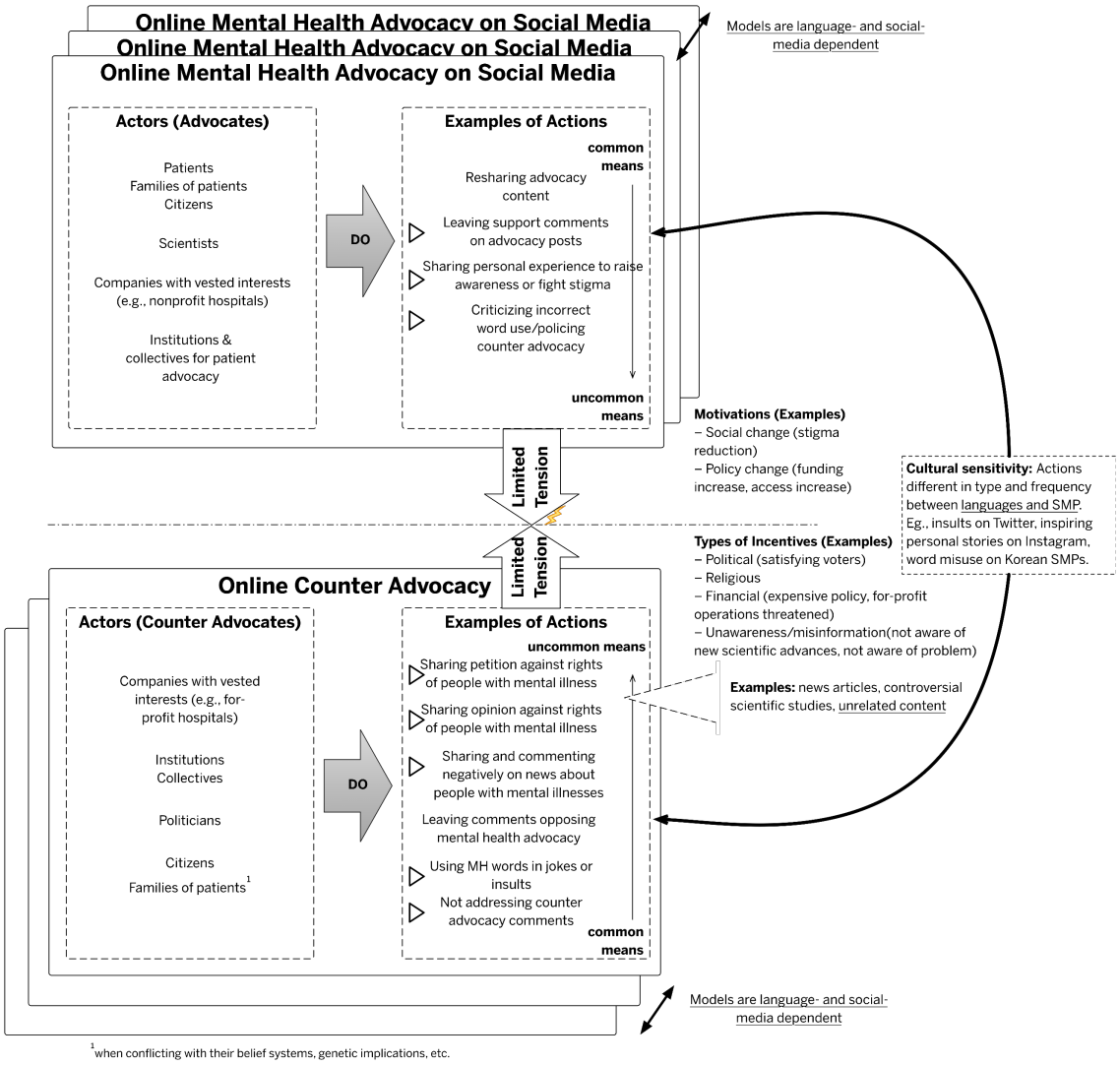

Figure 5. Revised online mental health advocacy model. Right-pointing triangles and underlined text highlight the changes brought to the model based on Chapters 5 and 6.

Besides the redefinition of the actions being performed by advocates and counter advocates, SMPs were added as a component of the cultural sensitivity interacting with advocacy and counter advocacy, alongside languages. Indeed, some SMPs or combinations of SMPs and languages seen in Chapters 5 and 6 were unique in the characteristics they exhibited. For example, Twitter posts were

unique by the constraints imposed by the platform (text limited to a specific length) that likely restricted the nature of the content being shared. Lengthy posts about personal experiences with MH were thus unlikely to happen on Twitter (in line with findings from prior research; Bisafar et al., 2016) and more likely to happen on Instagram, while insults were frequent on Twitter in both English and Korean, potentially reinforcing the development of a culture proper to Twitter.

Another example of cultural sensitivity beyond languages can be found in the difference between English and Korean Instagram posts. English posts featured personal stories and positive messages about MH, while Korean Instagram posts did not have such posts and were instead frequently misusing schizophrenia-related words. Such use could however not be attributed to being posted by Korean speakers, as Korean Facebook users generally showed no such misuse (and comparatively displayed more vehement feelings towards people with schizophrenia).

Some constructs of the model were not frequently observed and therefore may or may not be impacted by cultural sensitivity. There is not enough data to assess the impact of cultural sensitivity on interactions between advocates and counter advocates as only few interactions were observed during the qualitative analysis. The nature of users on the different SMPs, while outside the scope of this dissertation, could also likely be influenced by the cultural sensitivity aspect of the model; future research could establish such relation.

Impact for Human-Computer Interaction Research

As explained in Chapter 2, advocacy, activism, and social movements are constructs that have been studied extensively since the 1920s (Staggenborg, 2011).

However, the advent of the Internet has brought a new perspective to the study of collective behavior and advocacy. It has enabled diverse people in various geographical locations to synchronously and asynchronously collaborate to achieve a common goal of fostering social and policy change (Laverack, 2013b). While some researchers argue that the Internet complements advocacy and collective action in general (especially circa. the 2000s, before the phenomenal rise of social media), since the 2010s social science researchers have tended to agree that online advocacy and activism contribute significantly to offline collective action; the Internet is even sometimes its starting point (e.g., Occupy Wall Street; Tan et al., 2013). Online advocacy also exists as an independent construct, as some advocacy and activism exist solely online. Consequently, studying these online phenomena directly contribute to human-computer interaction as a discipline, as one of the prime mission of HCI is the study of how computers transform society and human interactions.

Health advocacy concepts have been used in HCI, notably in the design and evaluation of health and wellness technologies. For example, Parker et al. (2012) describe a tool, community mosaic, that fosters health advocacy within African-American communities with lower socioeconomic status through culturally-sensitive user-generated content. In a separate piece Parker (2013) also advocates for using “an activist approach” in HCI studies, specifically in the design of technologies bringing up positive change for specific populations (e.g., minorities). The aforementioned studies, as well as other studies such as Bisafar et al. (2016) investigating how the youth utilizes SMPs for health advocacy (as an example rather than a construct), have focused the health advocacy lens on community

dynamics at a micro-scale, i.e., looking at individuals or communities and the advocacy actions they can take and thus often foregoing the consideration of all tenants of health advocacy such as opponents. This approach is in line with broader calls within HCI for "social justice-oriented interaction design" (Dombrowski et al., 2016) and appears complementary to the macro lens of this dissertation, with broad comparisons between communities (e.g., English vs. Korean ones, Facebook vs. Twitter) that allow easier consideration of all tenants of health advocacy.

Implications for Bilingual Research on Social Media

This research emphasized the differences between Korean and English mental health advocacy content on Instagram, Facebook, and Twitter. While existing HCI research has analyzed mental health discourse on social media platforms (De Choudhury et al., 2017), and research in other domains has explored differences between countries or languages (Bruns et al., 2013; Krendl & Pescosolido, 2020), there has been a lack of research about health advocacy looked at across languages. Furthermore, research that has been conducted across several countries or languages has mostly underreported methodological challenges. As the world grows more open and communities increasingly interact with each other, the need for multilingual research will grow. In fact, there has been a steady increase in the number of non-native English speakers in the US in the last 30 years (Rumbaut & Massey, 2013). A deep analysis of those communities' social media content is undoubtedly paramount, but not comparing it with another culture's content or mainstream content shared within the same geographical area limits the conclusions to be drawn; it also prevents any comparison between these subcommunities and the main community. There have also been limited

recommendations on how to conduct multilingual HCI studies. Based on my dissertation research, I devised a list of steps to follow to conduct multilingual HCI research and listed some of the challenges that I encountered with suggestions for mitigation.

Framework for Bilingual Research on SMPs. I propose a methodology for analyzing content about a specific topic in several languages. The methodology starts with a pilot, followed by data collection based on the pilot's results, and ends with a qualitative study followed by a quantitative study. The methodology's steps are summarized in Table 17 and detailed subsequently.

Table 17. Overview of steps for bilingual research on SMPs.

1. Identify the concept to be studied and related keywords. Objective: understanding the domain. Methods: literature and vocabulary review. Deliverables: keywords for initial data retrieval.
2. Settling on SMPs and data collection methods. Objective: choosing popular SMPs in either or both languages; understanding the technical or legal characteristics proper to the chosen SPMs that could impact data collection methods. Methods: marketing data analysis, survey of data collection methods. Deliverables: set of relevant SMPs and associated data collection methods that will be used for data retrieval.
3. Pilot study. Objective: obtaining additional keywords for data pull and checking the fitness of the data collection methods. Methods: data collection methods identified in step 2., qualitative or frequency analysis to identify additional keywords. Deliverables: final set of keywords for data pull.
4. Data pull. Objective: capturing the final study dataset. Methods: data collection methods identified in step 2. Deliverables: final study dataset.
5. Data processing and analysis. Objective: processing final study dataset and readying it for qualitative and/or quantitative data analysis. Methods: computer scripting, appropriate qualitative/quantitative methods. Deliverables: study results.

1. Identify the concept to be studied and related keywords. An understanding of the domain to be studied should be first acquired by doing a

literature review, optimally in both languages. This literature review will help devise a list of seed keywords that will be used to generate other keywords with the pilot study. This initial review should be accompanied by a dictionary or encyclopedia search of each of the keywords to determine if the keywords would have meanings that would conflict with the concept to study. For example, the term "pear" in English mostly refers solely to the fruit, whereas the direct translation into French ("poire") designates the fruit but is also a common slang term to refer to somebody's face.

2. Settling on SMPs and data collection methods. The selection of SMPs is primordial and must always be contemporary to the analysis being conducted as SMPs' popularity continuously evolves (e.g., see Auxier & Anderson, 2021). SMPs popular in the countries where the languages are predominantly spoken are optimal candidates; other good candidates are SMPs enjoying worldwide popularity. One way to ensure the pervasiveness of the SMPs in consideration is to look at social media statistics in the countries where the languages are predominantly spoken; for example for this study I used the Pew Research Center, a US "nonpartisan fact tank" (Pew Research Center, 2021a), and the Korea Information Society Development Institute, an institute supported by the South Korean government (KISDI; Korea Information Society Development Institute, 2021). Beyond SMP usage considerations, researchers may be confronted to practical barriers to data collection proper to the chosen SPMs. Application programming interfaces (APIs) of SMPs tend to have different query limits, content limitations, and restrictions (for example, on Twitter; Bruns et al., 2013). The policy of some SMPs may prescribe the direct use of their APIs and therefore require the

research team to code against the APIs, while data from other SMPs may be accessed via third-party platforms such as Netlytic (Gruzd et al., 2017); some SMPs may also lack APIs or third-party access and may need to be crawled manually by writing computer scripts (Ferrara et al., 2014). Regardless of the data collection method chosen, the programming skills of the research team thus become paramount to successful research in this space.

3. Pilot Study. The pilot study is intended to understand what terms are used to talk about the concept studied and generate the keywords (search terms) to be used for data collection; this can be done qualitatively or by looking at the most frequent search terms or hashtags in the fetched content. The pilot study also needs to investigate if the domain yields sufficient results in both languages through a rapid review of the posts that were fetched. Ultimately, the pilot study brings confidence that the subject can be treated in both languages. If quantitative analyses are desired to compare the two languages, the pilot can serve as a way to measure how distant the two languages are in terms of volume of posted content. The pilot study can also validate that the data collection methods being used will work when scaled for the final data pull.

Once the pilot study is completed, a final list of keywords to be used for content crawling can be established by reviewing the most frequent terms and hashtags present. This list needs to be established through manual review of commonly occurring hashtags. Initial search terms may be removed at this step if they are deemed too broad for the analysis. Each should be nonetheless carefully considered. In this dissertation for example, the Korean term 스키조 (“schizo”) was kept as it referred in some cases to schizophrenia and in others to a videogame. If

doing so, a second pilot may be conducted, especially in cases where the first pilot had too many results returned, making the analysis of hashtags and terms difficult.

4. Data pull. The final data pull can be started after completion of the pilot and based on the list of search terms devised. It is recommended to concurrent fetch both datasets at the same time and as contiguously as possible in order to limit biases introduced by punctual events, such as weeklong events (e.g., mental health awareness week) or news headlines including one of the search terms. The number of posts collected during the pilot may be a good indicator of how long the collection needs to be, but the addition of hashtags and search terms because of the pilot may invalidate that. If possible, continually controlling the number of posts obtained day after day may be a better strategy.

5. Data processing and analysis. Once the data analysis is conducted, the data needs to be processed and saved. Recommended tools are MATLAB and Python for simplicity, but databases such as MongoDB may reveal more appropriate to store large quantities of data and accelerate data processing. Saving and processing documents coming from different platforms requires an important effort and should not be neglected. Code and routines need to be written to process the data from the crawlers (put that in the pilot stage), and data needs to be saved in a format that is interchangeable across language and social media without sacrificing particularities associated with each language as much as possible. The challenges associated with such processing include, for Twitter, how to deal with retweets, how to associate replies with tweets; for Instagram, how to deal with information such as type of filter used that have no reciprocity in the other social media. See for example (Bruns et al., 2013) for a methodology example for Twitter posts. Not every

field has to be kept, but it is essential to consider each field's potential usefulness for future analysis, especially if machine learning or data mining methods may be considered. Based on my dissertation work, I suggest that the storage of social media posts needs to be normalized as much as possible by, for example, storing posts, replies (comments), and replies of replies in separate data structures to facilitate subsequent analyses.

Posts may have to be processed differently based on the SMPs being studied. Fields provided by SMPs' APIs or third-party services will vary between SMPs and, in some cases, may not consistently be present (e.g., some third-party services may be unable to provide Instagram comments). In such cases, additional fields may need to be captured separately through additional API calls or custom crawlers coded for the study, using programming languages such as MATLAB, Python or JavaScript. In this dissertation, I executed the latter approach for Facebook posts: the original posts only had the text typed by the authors but did not have the preview text that typically figures with a shared link. A crawler was thus built with MATLAB using the function *webread* and custom code to process the function's output.

Challenges and Lessons Learned.

The crawlers used for data collection need to be verified constantly and the outputs need to be checked for quality periodically, ideally every day. During data collection for this research project, the crawlers stopped crawling once because of human error, but the daily control put in place helped avoid a more prolonged interruption of study data. It may be wise to have two researchers collect the same data simultaneously on different machines if collecting critical data or data for

timeseries analysis. In some cases, collecting the same dataset with multiple machines may also allow the obtention of fuller datasets as restrictions imposed by different platforms may limit the content displayed or personalize the content to the user. Crawlers and social media APIs used need to be reviewed periodically as changes and updates may impact data collection during data collection; for example, fields returned by APIs may change names, or the volume of data or type of access required may change during data collection (Clairns & Shetty, 2020).

Systematicity of the methods

The methods used for parsing and processing posts also need to be equal or as similar as possible throughout the project. I used MATLAB 2021a, a platform providing native processing for English, Korean, Japanese, and German, making the processing and comparison as consistent as possible between English and Korean. Even in the search for trained texts. I also searched for word embeddings that had English and Korean versions that were trained on similar datasets; the embeddings on the FastText website are good candidates as there are embeddings for 157 languages trained on broad datasets, namely Wikipedia and pages in the Common Crawl project (Grave et al., 2018). While the quality of Wikipedia versions varies by language (Lewoniewski et al., 2017) and the approach can be biased (e.g., if there are fewer articles about schizophrenia on the Korean web than on the English web), the similar approach nonetheless contributes to the systematicity of the research.

The qualitative analysis may be based on an existing framework or may be developed with grounded theory. In the latter case, code reciprocity between the two languages must be ensured by analyzing posts in the two languages constantly rather than doing one language and then the other. If a grounded theory approach

is used, one must make sure that the posts are continuously coded for both languages, as the content of posts in one language may inform codes that could be used in the other language. For example, if a pattern obviously appears in one language, the coder needs to ensure that the pattern never exists in the second language or that the same pattern does not appear in more subdued forms in the second language. This constant comparison, akin to constant comparing when coding against an existing framework, ensures that there is no gap in the codes for either of the languages. It also helps identify specificities proper to content in either language.

The differences between cultures need to be analyzed during study planning and prior to starting data collection. In the case of a comparison between Korean and English posts, the comparison of Eastern and Western societies may inform differences in the type of content being shared online.

For example, in many cases, when looking at online social media posts on specific platforms, the English language can be used as a proxy for the US and UK, although English content is delicate to analyze because pinpointing the origin of a post to a specific geographical location is difficult. In the research, several posts could be tied back to English countries where English is recognized as an official language, often because of former colonial associations (e.g., Singapore). While these posts were anecdotally few in the English dataset of this study, they may have a larger representation in other datasets depending on the topic studied.

The assumption that English content represents Western culture is therefore not exact but may be acceptable depending on the domain studied and the volume of these posts originating from countries other than the UK and the US. English is

also sometimes the de-facto language spoken by people from other countries to share content on the web. Notable examples anecdotally seen during the qualitative analysis of English posts in this study were off-topic music-related and tattoo-related posts posted by South American and German-speaking people; while the association between the post and the origin of the speaker was not always obvious, the comments often revealed the real origin of the poster as they responded to comments in their native tongue. In other cases, the native tongue of the poster was oftentimes anecdotally revealed by triangulation of several posts in English with comments in languages other than English; while these findings were not used for the analysis, content posted by people who live in different cultures than the one intended to be studied may reveal problematic. For example, in the case of Singaporean posts about mental health done in English, the mental health content being shared may reveal to be more in line with an Eastern conception of what mental health is rather than a Western conception. While this difference may be perceived in qualitative analyses, the datasets used to train machine learning algorithms need to be mindful of these subtle differences, e.g., by having a field indicating the location of the author, especially if the outputs are used to dictate decision making. An additional filtering step could also be performed prior to analysis to detect and remove speech from non-native speakers, a feat achievable with the correct methods (Goldin et al., 2018).

Researchers need to be also aware of cultural differences within countries (Taras et al., 2016), possibly even within speakers of the same language, that tend to manifest even online (Sheldon et al., 2020; Sheldon et al., 2017). For example, the output of an algorithm analyzing mental health content could interpret that the

"English" posts have less advocacy than they actually have because some Eastern content was included.

Implications for Technology Design for Mental Health Organizations

The findings from this dissertation can be used to design technologies that mental health organizations could use. Based on the results of this dissertation, I generated recommendations for features that could be combined and integrated into technologies that mental health organizations could use to better harness SMPs (Sas et al., 2014). The recommendations are listed in Table 18, accompanied by the reasoning behind them and how they could be used by mental health organizations to perform their mission.

Table 18. Recommendations for technology features for mental health organizations

Advocacy post detector Description: A feature that continuously scans SMPs for posts with advocacy content. The technology could single out posts with higher like or comment counts, or posts by influential people. Reason: As shown in Chapter 5 and Chapter 6, the number of advocacy posts on a given SMP can be low. Potential benefits: Mental health organizations could identify advocacy posts and leave comments to direct followers of the posting account—who could be potential activists—to their own page or share about current initiatives that could potentially interest followers. Such detector would avoid organizations with limited resources combing through large numbers of posts, which would be valuable if the number of advocacy posts on a given SMP is usually low.
Counter-advocacy post detector Description: same as *Advocacy post detector* but for counter-advocacy. Reason: As seen in Chapter 5 and Chapter 6, the number of counter-advocacy posts on a given SMP can be low. Potential benefits: Such detector could help mental health organizations identify counter-advocacy content to potentially correct word misuse in the comments, work with post authors on how to frame content differently to present mental health in a better light (e.g., Korean news content posted on Facebook as seen in Chapter 5), or identify what SMPs or subsets of SMP posts (e.g., posts in Korean, posts in English) have more counter-advocacy to target their resources and message to address the counter-advocacy actions (e.g., word misuse, lack of understanding or awareness).

Advocacy/counter-advocacy action classifier

Description: A feature that classifies the advocacy/counter-advocacy actions performed by SMP users.

Reason: The nature and prevalence of actions vary based on culture and SMP (Chapters 5 and 6). Counter-advocacy actions may have different levels of urgency attached to them (e.g., using a word inappropriately vs. sharing calls to vote for a law repelling rights for people with mental illnesses).

Potential benefits: Mental health organizations could prioritize their resources based on the type of actions that are prevalent at a given time, on a given SMP, or for a given demographics (e.g., Korean immigrants vs. Mexican immigrants). Based on the type of advocacy actions performed by SMP users, mental health organizations could choose to help advocates by providing them with resources to perform advocacy better (e.g., by creating logos and filters that could be used to unify the message of advocates). When paired with other features, a counter-advocacy classifier could help mental health organizations identify specific posts with strong counter-advocacy content (e.g., calls for harming a person with a mental illness who caused harm to a third party, as seen on Korean Facebook comments) to take action (e.g., reporting the person).

Tension Detector

Description: A feature that detects SMP posts where advocacy and counter-advocacy conflict in comments.

Reason: Although seen only occasionally in the posts analyzed in Chapters 5 and 6, other MH issues could have higher levels of tension displayed in comments.

Potential benefits: knowing what MH-related content triggers tension between SMP users would help mental health organizations create or tailor campaigns addressing these tensions. For example, SMP users arguing in posts over funding mental health services for immigrant populations could, if detected, lead mental health organizations to create social media campaigns educating people on the benefits of funding such services. Mental health organizations could also interact directly with commenters and provide facts *in situ* in the comments section of posts.

Advocacy/counter-advocacy barometer

Description: A feature that continuously scans SMPs and estimates how much advocacy/counter-advocacy content is being posted at a given time. Such a barometer could also track specific advocacy issues, such as funding for new mental health facilities.

Reason: General public opinion about mental health topics is bound to change as stigma and understanding evolve, or news stories about mental health topics emerge. While longitudinal analyses were not performed, the reactions to news articles explained in Chapter 5 are demonstrative of how SMP users can negatively react to current events and potentially affect other users.

Potential benefits: Such a feature would allow mental health organizations to promptly react to rapidly shifting opinions, especially when current events elicit negative reactions from SMP users. Over a longer timeframe, it would also allow organizations to assess if opinions are shifting in favor or against advocacy issues. If using a standardized scale, barometers could be compared between each other; for example, a barometer tracking schizophrenia advocacy on Facebook and another tracking advocacy on Instagram, or a barometer tracking opinion surrounding the construction of a new mental health facility in a neighborhood among white US American users vs. first-generation immigrants. With such technology, organizations would be able to tailor their message based on culture and social media to elicit the wanted reactions from SMP users.

Impact for Social Sciences

The study of online mental health activism contributes to the understanding of how health advocacy is performed on the Internet, an area of online advocacy that has been little covered by scholars despite calls to do so (Laverack, 2013b; Zoller, 2005). The findings of this study can benefit online platforms that are dedicated to change., such as Change.org, as well as creating new platforms that have featured based on the findings of the study.

The revised online mental health advocacy framework explains that the relationships between online actors are mostly superficial. As revealed by the study, SMP users posting about schizophrenia online advocate for schizophrenia in weak ways; for example, few are posting and participating in active calls for action as seen for other social movements, such as Black Lives Matter (Asad & Dantec, 2015; Brown et al., 2017; Cornet et al., 2017). This lack of engagement can also be explained by the relative absence of organizations posting meaningful content about schizophrenia; indeed, absent were the organizations supporting schizophrenia in the real world.

Unlike Black Lives Matter or other movements with a strong online presence, online schizophrenia advocacy showed no strong online traction during the study period, despite initiatives like mental health awareness month. Agencies advocating for mental health have an essential role to play in generating traction and could organize new events to rally people behind their cause. An excellent example in recent years was the ice bucket challenge backed by the ALS foundation. The challenge had no other purpose than raising money for ALS and bringing awareness to what ALS was; and while many people partook in the challenge

without understanding or caring to know what ALS was (Pressgrove et al., 2018), many got to know about ALS through this challenge and some, especially celebrities, made monetary contributions to the cause (Ward & Edmondson, 2015). While they do not have to imitate the ice bucket challenge, mental health advocacy agencies could come up with strong, well crafted and visible punctual actions that would cement schizophrenia into people's minds and push for change.

For Korea, events or campaigns related to schizophrenia would have to be especially tailored to the Korean audience. The demonstrated negative opinion of people on schizophrenia-related subjects, the lack of advocates that could relay the message and the low volumes brought by keywords related to schizophrenia are all red flags that need to be overcome. The stigma and misconceptions surrounding schizophrenia in Korea are also already strong (Lee et al., 2014), and complicated by sensationalistic news topics like murders committed by people with schizophrenia, that raising awareness or money through disguised means like the ice bucket challenge could backfire (Ward & Edmondson, 2015). Even Korean people wanting to support people with schizophrenia by advocating for them more may refrain from doing so because the word and illness have such stigma attached to them that they may want to avoid any association with it.

While interactions between advocates and counter-advocates were not frequently seen in this dissertation, the potential for more conflicts emerging from more prominent advocates should not be ignored. Previous research has shown interactions between counter advocates and advocates in the context of grassroot mobilization on SMPs, such as governments infiltrating movement pages to corner advocates, governments generating fake tweets, and trolls (Felt et al., 2018), or in

the context of vaccination, with organizations promoting vaccinations having to counter online misinformation (Steffens et al., 2019).

Implications for mental health advocacy

Mental health organizations wanting to harness the power of social media need to first study what dialogue is happening on social media regarding the issue at hand. As pointed out by several SMP users, severe mental illnesses often do not get the attention they deserve, especially compared to mild forms of depression or other milder diagnoses; some important diagnoses have also been banalized or are progressively losing the attached stigma, like bipolar disorder (Wong et al., 2017). Getting the support of people who are already sharing about these more severe mental illnesses like schizophrenia could help.

When considering the model of health activism that Zoller put forward in 2005 and schizophrenia health advocacy, it appears that some parts of advocacy are not present on SMPs. Some tenants that are present in English content are also absent in Korean content. Instead, the counter advocacy argument is well represented, but rather than people affronting each other, people post negative content about schizophrenia and stand uncorrected; in Korean posts, this phenomenon is even more glaring as post authors and commenters get a reaffirmation of this counter advocacy by responses from other users.

Among Korean content, calls for taking away the rights of people with schizophrenia were numerous. Direct calls to politicians to act on the rights of people with schizophrenia were few and far between, emphasizing that the most activist positions in the online mental health advocacy model are scarce. This

contrasts once again to other, more engaged movements like racial movements in the US or the fight against the defunding of Planned Parenthood.

Petitions or calls for political action were little relayed in the analyzed posts. This can either mean that people sharing advocacy content about schizophrenia are so outnumbered by other content that they have no voice; it could also mean that there is simply no such action happening at scale on social media. Overall, there was thus no strong schizophrenia advocacy online, and thus the online mental health advocacy model does not support strong advocacy. This is in line with some other online movements, but in contrast with movements with more engaged advocates, like Black Lives Matter which may benefit from the sheer number of activists compared to schizophrenia advocacy. Racial justice is also often brought to the forefront because of a continuous flow of events bringing the movement to the spotlight.

Regarding counter advocacy, strong forms of counter advocacy were in contrast found online, especially in South Korean posts. The vehemence of certain posters against people with schizophrenia was noticeable and appeared in several posts. People calling for the death or internment of people with schizophrenia were frequent in Korean posts. Also, lighter forms of counter advocacy like the ones mentioned in the previous paragraphs were very frequent in both languages.

Thus, the new model for online mental health advocacy proposed is heavily skewed toward counter advocacy and lighter forms of advocacy. Future work may look at whether this skewness is specific to online schizophrenia advocacy or is reflective of a wider mental health pattern. Illnesses with milder symptoms may have more vocal advocacy groups, but that may not necessarily translate to more

engagement. At the same time, the use of depression or bipolar disorder as an insult may be less frequent if the dialogue surrounding these issues is more mature online.

Implications for Digital Advocacy by Health Advocacy Agencies

This section provides a few practical implications that advocacy agencies can use to improve their digital advocacy strategy.

This dissertation showed that English Instagram boasted a positive community when sharing about schizophrenia topics. Agencies can tap into the emotions and feelings of these users by creating campaigns around personal stories as they seem to elicit positive reactions. Agencies also need to expand the reach of their posts by adding hashtags broader than the issue at hand (e.g., "#mentalhealth" for a schizophrenia-related post) to foster additional interactions. This must be done with the understanding that people with these less severe mental illnesses may be offended; organizations thus have to tread carefully to unite people and not diminish the importance of other diagnoses. Calls to action should be added into the posts to redirect users to reshare posts, sign petitions, or other advocacy actions with varying levels of engagement (Seelig et al., 2019).

In comparison, Korean SMP and English Twitter users generally exhibited a lack of awareness of what schizophrenia is as a mental illness diagnosis, epitomized by inappropriate word choices to talk about themselves or insult other users. As mentioned earlier in this chapter, advocacy agencies can create campaigns like the ice bucket challenge to raise money for and shed light to issues they advocate. Advocacy agencies should also create campaigns to sensitize SMP users to the common misuse of MH-related terms, ask users to refrain from using them and correct such use in the posts of users they interact with. Efforts such as the "Stop

the Stigma" campaign by Hartford Healthcare (2016) should be considered and tailored to the lingua employed by SMP users.

When considering South Korea, and regardless of specific SMPs, a lack of awareness as well as stigma surrounding schizophrenia is pervasive throughout Korean society, as this dissertation—in Instagram and Twitter posts as well as news stories shared by Facebook pages—and other research have evidenced (Park & Jeon, 2016). As such, advocacy agencies should aim to create campaigns that are as pervasive; campaigns could be multi-platform (e.g., concurrently shown on TV, Internet, and radio), following trends in commercial advertising (Kenneth, 2018); this would prove all the more beneficial as Korean SMP users have been shown to advocate for issues by reusing content from other media more than creating their own content (Yang & Stohl, 2020). Other tactics borrowed from commercial advertising could also be adapted to reach a broader audience; akin to how companies use product placement in traditional media, agencies could partner with social media influencers and influential accounts (Liu et al., 2015) to raise awareness about mental health issues among followers, or be integrated in popular South Korean content such as television series. Proven advocacy advertising strategies from other countries may however need to be adapted for South Korean audiences and thus need to be carefully considered (Lee et al., 2011).

Broad recommendations for social media use by nonprofits reported by Milde and Yawson (2017) that would also apply to mental health advocacy agencies include creating guidelines for SMP use, managing SMP accounts internally to be consistent with the mission of the nonprofit, and doing cost-benefit analyses for new projects or campaigns,

Limitations

Only two languages, English and Korean, were used for answering this dissertation's research questions and augmenting the model for online mental health advocacy that was described in Chapter 3. The model would benefit from being tested against SMP content in additional Western and Eastern languages which, like Korean, have most Internet users located in a specific country, such as Italy or Japan, to verify if the model can be generalized to the East/West divide or if it is rather country- or language-specific. Besides languages, the online mental health advocacy model proposed in this dissertation would also gain in being tested against other SMPs that are gaining in popularity, such as Snapchat or Tik Tok, two SMPs that have become popular among young people (Auxier & Anderson, 2021). Snapchat and TikTok would be interesting because they are different from the SMPs studied and because they are almost exclusively video- and picture-driven (Serrano et al., 2020; Xu et al., 2016). As such, different forms of advocacy and counter-advocacy are likely to be uncovered, warranting extending the model to be more inclusive of different forms of online communication. Country-centric SMPs could also provide interesting insights while not being comparable one-to-one with SMPs in other countries.

I conducted the qualitative and quantitative analyses of this dissertation on my own with limited external input. There was notably no interrater reliability score computed for the coding performed in Chapter 6 (quantitative study); such coding would preferably be computed, using for example a subset of the posts coded by another researcher before publication in a peer-reviewed journal. The lack of inter-rater reliability for the qualitative arm of this dissertation (Chapter 5)

is less damageable given the ethnographic qualities of the research and the discussable suitability of inter-rater reliability calculation when using grounded theory methods (McDonald et al., 2019). The outcome of the qualitative study was also not generating codes to be used for any quantitative analysis but instead augmenting the model of online mental health advocacy with findings from the grounded theory approach used; an inter-rater reliability score would have been appropriate had that not been the case (McDonald et al., 2019).

Future work

The work described in this dissertation can be extended in several meaningful ways.

As mentioned earlier in this section, the link between the nature of users and the cultural sensitivity aspect of the model was outside the scope of this dissertation and thus not established. Future research could investigate whether specific SMPs, languages, or combinations of both lead to specific traits among advocates and counter advocates present online.

Regarding HCI, future research can investigate how to formalize this macro analysis of health advocacy on SMPs to use in the more common microlevel design studies in social justice HCI. In an HCI design context, the methods and type of findings that this dissertation exemplifies would be most useful in the formative research phase of a user-centered design process; as such, researchers could build upon this framework for multicultural studies and tailor it more to design so that the proper artifacts required for design are generated through the process.

In the context of multilingual HCI design studies, future work would investigate how to adapt the methods used in this dissertation to generate the

artifacts necessary for design. For example, researchers seeking to adapt an existing health advocacy tool designed for Americans to recent immigrants to the United States would need to understand what phenomena to look for in SMPs in order to derive design implications. Such a study may for example place less emphasis on counter advocacy but instead investigate how conversations that new immigrants have differs from conversations Americans have on social media platforms. This process of selecting the suitable constructs for the SMP analysis is not defined nor explored in this dissertation and would need additional work and validation.

In the context of social work and advocacy agencies, this dissertation proposes implications for mental health advocacy agencies. Agencies can tailor their message to populations and SMPs by investigating social media traces using methods similar to this dissertation's. While the process of investigating social media traces has been demonstrated in this dissertation, the implications that were generated would benefit from validation by subsequent research.

Cross-cultural research will increasingly be needed as individual countries further become pluricultural. Future work could expand the bilingual framework from SMP research proposed previously and adapt it to the study of cultures rather than languages and check its fitness when applied to more than two cultures at the same time. Additionally, akin to how resources like the Ethnologue (Simons, 2021) map specificities of languages around the world, repertories of traits pertaining to specific combinations of SMPs, languages, and health advocacy topics could be erected. Such resources would be valuable to health advocacy organizations as they

would avoid costly investigations of SMP content that require skills that such organizations may not have.

CHAPTER EIGHT. CONCLUSION

This dissertation draws from both the mental health and HCI fields to advance research in these fields and create more opportunities for collaboration between both. Through the analysis of social media, the work supports existing research that explains the differences between the perception of mental illness in Eastern Asian countries and Western countries.

An immediate future project will be the comparison of the posts about self-harm between US and South Korean users. Results will likely direct towards the redaction of culture-sensitive recommendations for the various social media platforms studied (for example, Instagram displays a warning to US users searching for self-harm-related posts but does not do so when the query is in Korean). Further studies should be conducted to verify if the hypotheses hold for other mental health diagnoses, such as bipolar disorder. More generally, subsequent studies will be needed to assess whether the proposed model for online health advocacy and activism holds true for other health domains, such as geriatrics.

The limited scope of this study prevents studying the consequences of using specific devices to redact posts and comments about health activism and advocacy for online social media. While Instagram is a mobile-first platform, Facebook and Twitter are not focused on only mobile phones. Posting from mobile devices could be significantly different from posting on other devices as the type of device used can impact thoughts and behaviors (e.g.; Lambert & Miller, 2015).

This research is relevant as the results uncovered by this investigation can potentially apply to other health activism domains, such as the fight against sexually transmitted diseases.

APPENDICES

Appendix A. Comparison of the United States and South Korea

People from different disciplines have long differentiated between Western societies (US, Europe) and Asian countries. Anthropologists have identified the characteristics of both groups explaining the divide by referring to the two groups as individualistic societies and collectivistic societies, respectively (Hall, 1989). Most notably, Edward Hall theorized in great detail the divergences between high-context culture (which Korea belongs to) and low-context cultures (e.g., US) (Hall, 1989); this has been subsequently tested in the specific case of the US, Korea, and China (Kim et al., 1998).

Appendix B. Comparison of South Korea and the US for SMP use

Specific studies have compared the differences in the use of SMPs by South Korea and the United States. Differences exist in the motivations for using online SMPs (Cyworld, Facebook) (Kim et al., 2011), deception used in the profile of SMPs vs. face-to-face discussion (Lewis & George, 2008). Researchers have attributed these differences to several causes, the main of which being the difference in the "prototype cultures" (Korea being a collectivistic society vs. the US being an individualistic society), which in turn informs the difference in communication styles, namely high context vs. low context (Kim et al., 2011).

Based on reports published by the Pew Center (Pew Research Center, 2016) and the Korean Information Society Development Institute (Korea Information Society Development Institute, 2016), the most popular social networks could be identified for both countries. As far as the US, 79% of people surveyed reported using Facebook, 32% Instagram, 31% Pinterest, and 29% LinkedIn (Pew Research Center, 2016). The social media the most used in Korea in 2015 were KakaoStory (46%), Facebook (30%), Twitter (11%), Naver Band (7.2%), Kakao Group (1.9%), and Instagram (1.9%) (Korea Information Society Development Institute, 2016).

Appendix C. Comparison of the Korean and US healthcare system

The Korean healthcare system has been profoundly overhauled as the Korean economy has grown from an underdeveloped country to a major East Asian powerhouse, with its Human Development Index comparable to the US one (respectively 89.1 and 91.4, The Economist, 2015). As South Korea emerged from extreme poverty following the Korean war, the Korean government was left with the task of creating a healthcare system from scratch, as most resources had been destroyed during the war (Kim & Lee, 2010). Past Korean governments were able to create a functional healthcare system from a blank state, inspired by other sovereign states. Over the years, as resources increased, the Korean government was able to provide multiple additional provisions to cater to the yet untouched parts of healthcare, such as the Welfare of the Aged Act (Government of the Republic of Korea, 2013), first enacted in 1981, or the Public Health and Medical Services Act of 2000 (Government of the Republic of Korea, 2014). In parallel, a national health insurance system (NHIS) was first introduced in 1977 (National Health Insurance Service, n.d.). While, in its beginnings, not all citizens were covered and several insurance companies were participating in the scheme, everything was eventually merged in 2000 to create a universal single-payer system run for the most part by the national government (National Health Insurance Service, n.d.). NHIS manages the medical payments made by citizens, the claims filled, the payments to healthcare services, etc. with reduced inefficiencies because of the single-payer model (Kwon, 2003), notably the US system with multiple intertwined payers which can quickly become a headache for citizens and healthcare facilities alike, as well as a general model for inefficiency.

When it comes to the mental health care of both countries, Korea lags the US by several years in moving from hospital-based mental healthcare delivery to community-based delivery (Roh et al., 2016). While the funding allocated to mental health has been increasing in Korea over the years, it remains deficient at 2.6% of the total spending (Roh et al., 2016). In comparison, the US spends 6.1% (2005 figure) of its total healthcare spending on mental health.

Appendix D. Data points for each SMP

Facebook

- Title of the post
- Description
- Image
- Number of “reactions” (likes and other sentiments)
- Number of comments
- Number of shares
- Comments
    - Message

As per IRB protocol, the identity of people responding to these posts and message content is kept confidential and confined to the research investigator.

Twitter

- Title
- Description
- Link
- Number of likes
- Number of reshares
- Number of comments
- Comments

Instagram

- Posts
    - User ID (enciphered for privacy)

- link to the post
- comments
    - User ID (enciphered for privacy)
    - Message
    - Number of people tagged per comment.
- number of likes
- number of comments

Appendix E. Qualitative Analysis Codebook

Post in foreign language
Specifically about schizophrenia in a mental health context
Explicit Self-disclosure of a diagnosis of schizophrenia (of poster), no hashtag
(AC) Promoting MH awareness (general)
(AC) Promoting facts, tips, and education
(AC) Relating MH journey
(AC) Sharing resources
(AC) Promoting therapy/treatment option/method
(AC) Promoting organization
(AC) Providing support to SNS community
(AC) Pushing for change in attitude
(AC) Positive messages and art
(AC) Abstract art
(AC) Real life advocacy actions
(AC) Developing argument for ending stigma (not just #)
(AC) Calling for more supporters/support online
(AC) Calling for more supporters/support offline
(AC) Advocate/positive opinion of meds
(AC) Promoting Research trial
(AC) Discussing problems patients face
(CA) Use schizophrenia-related term to joke about oneself or others
(CA) Wrong use of schizophrenia-related term
(CA) shedding strange light on schizophrenia
(CA) Insulting person
(CA) Mocking people with schizophrenia
(CA) Sharing negative fact about schizophrenia/Using wrong example
(CA) Attributing diagnostic of schizophrenia to crime, pb
(CA) Should deprive schizophrenia people from their rights
Hallucinations
Promotion of products with positive MH meaning
Promotion of CBD products
Promotion of other products
(CA) Saying “schizophrenia” is used as an excuse (e.g., for commuting sentence)
Including racial theme
Including religious theme
Including cultural reference
Include political theme
Including news item (discussion of news item)
Including report on research
Including crime theme
Including marijuana/CBD theme
Including name of product/song w/ schizophrenia relation
Alternative cultures/music
Service dog
Suicidal thought content/sadness/eating/self harm
YouTube/SNS automated message
Spam/Bot
Comments
Support for MH content (we need to talk more, etc.

Self-promotion
Weak support of poster (smiley, “yass”, etc.)
Support/encouragement to author for mental health post
Weak arguing against MH content (thumb down, joke on content)
Posting “I’m depressed” on positive MH message
Sharing personal story
Comments to friends (familiar tone)
Argue with poster
Advocacy against CA
Back-and-forth argument in comments
Perpetuating CA in CA post
Arguing (CA) on positive AC content
Disjointed support and backlash or AC & CA
Author supporting other replier in comments
Other replier supporting AC replier

Appendix F. News Sources

Posts and two-level comments from different Facebook news pages will be collected as follow:

Source Name	Language	Notes
ABC News	ENG	Main network news.
AP News	ENG	US news agency.
BBC News	ENG	Non-American news source.
BCC Lifestyle & Health	ENG	BBC feed specialized in health and lifestyle news.
CBN News	ENG	Christian-affiliated news network.
CBS News	ENG	Main network news.
CNN	ENG	Cable network news, world focus.
CNN Health	ENG	CNN feed specialized in health and lifestyle news.
Fox News	ENG	Traditionally conservative-learning news network.
HuffPost	ENG	Internet-only news source.
NBC News	ENG	Main network news.
NBC News Health	ENG	NBC feed specialized in health and lifestyle news.
New York Times	ENG	US Newspaper.
NPR	ENG	Public network.
Wall Street Journal	ENG	US Newspaper.
KBS 뉴스	KOR	Public broadcasting network.
SBS 뉴스	KOR	Main broadcasting network (equivalent to ABC news).
노컷뉴스	KOR	Christian-affiliated news network (CBS Network).
스브스뉴스	KOR	Focused on social issues.
연합뉴스	KOR	Korean news agency.
위키트리	KOR	Internet-only news source.
인사이트	KOR	Internet-only news source.
조선일보	KOR	Traditionally conservative-leaning newspaper.
채널A뉴스	KOR	Newspaper-affiliated cable channel.
한겨레	KOR	Traditionally liberal-leaning newspaper.

Appendix G. Search Keywords

- Schizophrenia
- Schizophrenic
- 조현병 [johyeonbyeong] / 조현증 [johyeonjeung] (schizophrenia, since 2010)
- 조현병환자 [johyeonbyeonghwanja] patient with schizophrenia
- 정신분열 [jeongshinbunyeol] (schizophrenic)
- 정신분열병 [jeongshinbunyeolbyeong] / 정신분열증 [jeongshinbunyeoljeung].

Appendix H. Glossary

Hashtag: keyword or term used to share or promote content about a specific subject or theme on social media platforms.

Appendix I. Quantitative Study – All variables and best classifiers

Table 19. Predicted variables and accuracy/F1 scores (ntrain=size of validation dataset, nval=size of validation dataset, AC = advocacy, CA = counter-advocacy).

Outcome Variable	LNG	Model	Training Sample Size	Validation Sample Size	Accuracy	F1 Score	MCC
(AC) Advocating against odd word use	en	Ensemble, using Word2Vec, Own Training, 50 dimensions	34	293	0.72	0.13	0.19182
(AC) Advocating for a change in attitudes	en	SVM with Chi-Square Feature Selection, using Word2Vec with addl Metadata, Own Training, 50 dimensions	118	293	0.91	0.61	0.58977
(AC) Advocating for a change in attitudes	ko	SVM with Chi-Square Feature Selection, using Word2Vec, Own Training, 50 dimensions	42	147	0.96	0.57	0.55674
(AC) Advocating for more mental health resources	en	SVM, using Word2Vec, Own Training, 25 dimensions	22	293	0.98	0.44	0.43869
(AC) Advocating for MH policy change	en	SVM, using Word2Vec, Own Training, 25 dimensions	28	293	0.90	0.22	0.29181
(AC) Any advocacy	en	Ensemble, using Word2Vec with addl Metadata, Own Training, 50 dimensions	588	293	0.88	0.87	0.7645
(AC) Any advocacy	ko	Ensemble with Chi-Square Feature Selection, using Word2Vec, Own Training, 100 dimensions	148	147	0.88	0.75	0.67507
(AC) Raising mental health awareness	en	SVM, using Word2Vec, Own Training, 100 dimensions	400	293	0.94	0.90	0.85253

(AC) Raising mental health awareness	ko	Ensemble, using Word2Vec, Own Training, 100 dimensions	98	147	0.86	0.63	0.5928
(AC) Raising awareness on issues patients face	en	SVM with Chi-Square Feature Selection, using Word2Vec, Own Training, 100 dimensions	174	293	0.81	0.54	0.49956
(AC) Raising awareness on issues patients face	ko	SVM with Chi-Square Feature Selection, using Word2Vec, Own Training, 50 dimensions	52	147	0.82	0.38	0.38123
(AC) Raising awareness of treatment options	en	SVM with Chi-Square Feature Selection, using Word2Vec, Own Training, 50 dimensions	92	293	0.92	0.54	0.51606
(AC) Raising awareness of treatment options	ko	Ensemble, using Word2Vec, Own Training, 25 dimensions	46	147	0.86	0.47	0.51514
(AC) Supporting people with mental health issues	en	Ensemble with Chi-Square Feature Selection, using Word2Vec, Own Training, 100 dimensions	212	293	0.84	0.61	0.5414
(AC) Supporting people with mental health issues	ko	Ensemble with Chi-Square Feature Selection, using Word2Vec, Own Training, 100 dimensions	48	147	0.77	0.35	0.39716
(CA) Any counter-advocacy	en	SVM with Chi-Square Feature Selection, using Word2Vec with addl Metadata, Own Training, 50 dimensions	216	293	0.90	0.73	0.68008
(CA) Any counter-advocacy	ko	Ensemble, using Word2Vec with addl Metadata, Own Training, 50 dimensions	234	147	0.80	0.74	0.59882
(CA) Arguing against the rights of people with mental illness	ko	KNN, using Word2Vec, Own Training, 50 dimensions	26	147	0.86	0.28	0.32326
(CA) Calling for a negative action towards an individual	ko	SVM, using Word2Vec, Own Training, 25 dimensions	20	147	0.64	0.10	0.184

(CA) Negative opinion of people with schizophrenia	ko	SVM, using Word2Vec, Own Training, 50 dimensions	48	147	0.80	0.38	0.42497
(CA) Diagnosing schizophrenia as a problem	en	Ensemble with Chi-Square Feature Selection, using Word2Vec, Own Training, 100 dimensions	20	293	0.63	0.05	0.1293
(CA) Using odd meaning of “schizophrenia”-related word	en	SVM, using Word2Vec with addl Metadata, Own Training, 50 dimensions	76	293	0.88	0.42	0.44703
(CA) Using odd meaning of “schizophrenia”-related word	ko	Ensemble, using Word2Vec with addl Metadata, Own Training, 50 dimensions	112	147	0.90	0.76	0.71799
(CA) Using schizophrenia as an insult	en	Ensemble, using Word2Vec, Own Training, 50 dimensions	78	293	0.88	0.44	0.46798
(CA) Using schizophrenia as an insult	ko	Ensemble, using Word2Vec with addl Metadata, Own Training, 50 dimensions	48	147	0.81	0.39	0.44033
(CA) Using schizophrenia as a joke	en	SVM, using Word2Vec, Own Training, 50 dimensions	74	293	0.95	0.62	0.62201
(CA) Using schizophrenia as a joke	ko	Ensemble, using Word2Vec with addl Metadata, Own Training, 50 dimensions	126	147	0.93	0.84	0.80728
(CA) Using schizophrenia in a negative example	en	SVM with Chi-Square Feature Selection, using Word2Vec, Own Training, 100 dimensions	30	293	0.83	0.19	0.29745
(CA) Using schizophrenia term in a political context	en	SVM with Chi-Square Feature Selection, using Word2Vec, Own Training, 100 dimensions	54	293	0.96	0.59	0.58471
News article about schizophrenia or person with schizophrenia	en	KNN, using Word2Vec, Own Training, 50 dimensions	84	293	0.98	0.86	0.84847

News article about schizophrenia or person with schizophrenia	ko	SVM, using Word2Vec, Own Training, 25 dimensions	70	147	0.97	0.84	0.82473
Band or product with schizophrenia relation	en	SVM, using Word2Vec, Own Training, 50 dimensions	32	293	1.00	1.00	1
Band or product with schizophrenia relation	ko	Ensemble, using Word2Vec with addl Metadata, Own Training, 50 dimensions	48	147	0.99	0.94	0.93941
Counterculture using the word schizophrenia	en	KNN, using Word2Vec, Own Training, 100 dimensions	66	293	1.00	0.97	0.96436
Promotion of for-profit product or service to help with schizophrenia	en	SVM, using Word2Vec, Own Training, 100 dimensions	58	293	1.00	0.96	0.95573
Promotion of for-profit product or service to help with schizophrenia	ko	SVM, using Word2Vec, Own Training, 50 dimensions	26	147	0.96	0.62	0.6598
Content is about mental health	en	Ensemble with Chi-Square Feature Selection, using Word2Vec with addl Metadata, Own Training, 50 dimensions	670	293	0.92	0.92	0.83695
Content is about mental health	ko	Ensemble, using Word2Vec, Own Training, 100 dimensions	272	147	0.88	0.86	0.76218
Post focusing on schizophrenia	en	Ensemble with Chi-Square Feature Selection, using Word2Vec with addl Metadata, Own Training, 50 dimensions	506	293	0.97	0.97	0.92763
Post focusing on schizophrenia	ko	SVM, using Word2Vec with addl Metadata, Own Training, 50 dimensions	250	147	0.95	0.96	0.88139
Post tone is negative	en	Ensemble, using Word2Vec, Own Training, 25 dimensions	346	293	0.84	0.73	0.64461

Post tone is negative	ko	CHI2FeatureSelectionKNN, using Word2Vec, Own Training, 25 dimensions	282	147	0.78	0.75	0.56199
Post tone is neutral	en	Ensemble, using Word2Vec with addl Metadata, Own Training, 50 dimensions	588	293	0.81	0.83	0.62715
Post tone is neutral	ko	SVM, using Word2Vec with addl Metadata, Own Training, 50 dimensions	314	147	0.71	0.71	0.44567
Post tone is positive	en	Ensemble with Chi-Square Feature Selection, using Word2Vec with addl Metadata, Own Training, 50 dimensions	670	293	0.90	0.90	0.80894
Post tone is positive	ko	Ensemble, using Word2Vec, Own Training, 100 dimensions	248	147	0.79	0.74	0.57549
Replier argues	en	SVM, using Word2Vec, Own Training, 25 dimensions	46	293	0.75	0.20	0.28556
Replier argues	ko	SVM with Chi-Square Feature Selection, using Word2Vec, Own Training, 100 dimensions	24	147	0.48	0.09	0.15097
Replier argues with post author	en	Ensemble, using Word2Vec with addl Metadata, Own Training, 50 dimensions	38	293	0.83	0.25	0.34091
Replier self-promotes	en	SVM, using Word2Vec, Own Training, 25 dimensions	20	293	0.88	0.15	0.22091
Replier self-promotes	ko	KNN, using Word2Vec, Own Training, 25 dimensions	36	147	0.93	0.55	0.5578
Replier supports	en	Ensemble, using Word2Vec with addl Metadata, Own Training, 50 dimensions	256	293	0.96	0.90	0.87783

Replier supports	ko	Ensemble, using Word2Vec with addl Metadata, Own Training, 50 dimensions	96	147	0.88	0.69	0.6633
Replier supports other replier	en	Ensemble, using Word2Vec with addl Metadata, Own Training, 50 dimensions	60	293	0.96	0.63	0.63046
Replier supports other replier	ko	KNN, using Word2Vec, Own Training, 25 dimensions	20	147	0.59	0.12	0.18785
Replier supports post author	en	SVM, using Word2Vec with addl Metadata, Own Training, 50 dimensions	202	293	0.90	0.75	0.71576
Replier supports post author	ko	Ensemble, using Word2Vec with addl Metadata, Own Training, 50 dimensions	74	147	0.86	0.59	0.59193
Sharing about personal situation	en	Ensemble, using Word2Vec, Own Training, 100 dimensions	96	293	0.82	0.40	0.41963
Sharing about personal situation	ko	SVM, using Word2Vec with addl Metadata, Own Training, 50 dimensions	104	147	0.82	0.59	0.53669
Using schizophrenia for advertising	en	SVM, using Word2Vec with addl Metadata, Own Training, 50 dimensions	56	293	1.00	1.00	1

Appendix J. Quantitative Study – Kruskal Wallis Tables

Kruskal-Wallis, posts with advocacy and their comments

Variable	en - in	en - tw	ko - in	ko - tw	F (df)	η2
n	968	93	46	68		
Content is about mental health	1.08 (1.22)	1.42 (0.95)	5.96 (6.70)	0.51 (0.63)	34.323 (3, 1171)***	0.088
Post focusing on schizophrenia	0.18 (0.50)	0.15 (0.42)	0.65 (1.06)	0.41 (0.76)	11.498 (3, 1171)***	0.029
Post tone is positive	0.02 (0.22)	0.08 (0.27)	1.59 (1.61)	0.01 (0.12)	212.436 (3, 1171)***	0.542
(AC) Advocating for a change in attitudes	0.14 (0.67)	0.37 (0.60)	0.93 (1.47)	0.69 (1.01)	50.050 (3, 1171)***	0.128
(CA) Any counter-advocacy	0.39 (0.79)	0.44 (0.60)	0.24 (0.64)	0.26 (0.48)	2.859 (3, 1171)*	0.007
(AC) Any advocacy	0.64 (0.89)	0.28 (0.47)	3.24 (3.96)	0.81 (0.74)	20.253 (3, 1171)***	0.052
Post tone is neutral	0.86 (1.10)	1.02 (0.69)	1.89 (2.66)	0.57 (0.83)	8.199 (3, 1171)***	0.021
Replier supports	0.33 (0.72)	0.31 (0.59)	0.98 (1.09)	0.49 (0.76)	10.155 (3, 1171)***	0.026
Replier supports other replier	0.30 (0.65)	1.26 (0.87)	0.07 (0.33)	0.10 (0.35)	67.316 (3, 1171)***	0.172
(CA) Using odd meaning of “schizophrenia”-related word	1.85 (2.02)	1.14 (0.73)	0.83 (0.93)	0.54 (0.85)	27.134 (3, 1171)***	0.069
Replier supports post author	0.06 (0.28)	1.03 (0.96)	1.15 (1.07)	1.10 (1.12)	163.354 (3, 1171)***	0.417
Post tone is negative	0.61 (0.83)	0.39 (0.55)	0.61 (0.54)	0.65 (0.99)	2.374 (3, 1171)	0.006
Replier argues	0.01 (0.12)	0.23 (0.57)	5.76 (6.54)	0.21 (0.41)	213.848 (3, 1171)***	0.546
Replier self-promotes	0.01 (0.10)	0.01 (0.10)	1.20 (1.28)	0.41 (0.76)	178.148 (3, 1171)***	0.455
(AC) Raising awareness of treatment options	0.09 (0.29)	0.00 (0.00)	0.59 (0.88)	1.41 (1.04)	106.858 (3, 1171)***	0.273
(CA) Using schizophrenia as an insult	1.09 (0.62)	1.15 (1.01)	0.78 (0.87)	0.44 (0.78)	44.812 (3, 1171)***	0.114
News article about schizophrenia or person with schizophrenia	1.04 (0.29)	2.13 (0.91)	0.43 (0.58)	0.00 (0.00)	240.826 (3, 1171)***	0.615

(CA) Using schizophrenia as a joke	1.26 (1.43)	1.06 (0.87)	1.35 (1.23)	0.53 (0.68)	8.233 (3, 1171)***	0.021
Band or product with schizophrenia relation	1.18 (0.96)	1.23 (0.95)	1.13 (1.05)	0.15 (0.40)	41.343 (3, 1171)***	0.106
(AC) Supporting people with mental health issues	2.83 (2.75)	0.53 (0.80)	0.76 (0.87)	0.01 (0.12)	111.924 (3, 1171)***	0.286
(AC) Raising awareness on issues patients face	1.53 (1.77)	1.35 (0.88)	0.91 (0.69)	1.74 (0.97)	7.805 (3, 1171)***	0.020
Sharing about personal situation	1.08 (1.81)	1.00 (0.81)	1.39 (2.07)	0.76 (0.93)	3.019 (3, 1171)*	0.008
(AC) Raising mental health awareness	0.48 (1.05)	0.49 (0.60)	4.74 (5.28)	1.00 (0.98)	46.176 (3, 1171)***	0.118
Promotion of for-profit product or service to help with schizophrenia	0.02 (0.14)	0.01 (0.10)	4.85 (4.72)	0.31 (0.55)	233.942 (3, 1171)***	0.597

Appendix K. Quantitative Study – Chi2 Tables

All social media, Posts only, by language

Outcome Variable	chi2	p	Odds Ratio	Odds Ratio Confidence Interval	Phi Coefficient	Counts (EN, All, posts)	Counts (KO, All, posts)	% (EN, All, posts)	% (KO, All, posts)
lsb123_ac_advocates_attitude_change_mental_health	151.57	0.00	1.62	[1.5; 1.75]	0.03	17,117	741	0.16	0.1
lsb123_ac_aggregate	1,425.18	0.00	2.86	[2.7; 3.02]	0.11	49,233	1,620	0.46	0.22
lsb123_ac_raise_awareness_mental_health_awareness	549.44	0.00	1.96	[1.85; 2.08]	0.06	38,567	1,573	0.36	0.22
lsb123_ac_raise_awareness_mental_health_issues	423.91	0.00	0.55	[0.52; 0.58]	-0.07	37,371	1,618	0.34	0.22
lsb123_ac_raise_awareness_mental_health_treatment_options	379.07	0.00	2.14	[1.97; 2.31]	0.05	5,974	793	0.05	0.11
lsb123_ac_supporting_people_with_mental_health_issues	18.71	0.00	0.88	[0.83; 0.93]	-0.02	24,749	1,791	0.23	0.25
lsb123_ca_aggregate	263.34	0.00	0.66	[0.63; 0.7]	-0.05	53,994	4,265	0.5	0.6
lsb123_ca_using_odd_meaning_schizophrenia	0.00	0.96	1.00	[0.95; 1.05]	0.00	46,690	3,078	0.43	0.43
lsb123_ca_using_schizophrenia_as_insult	1,724.47	0.00	2.7	[2.58; 2.84]	0.12	32,947	3,857	0.3	0.54
lsb123_ca_using_schizophrenia_as_joke	2,524.02	0.00	3.75	[3.55; 3.96]	0.14	10,799	2,092	0.1	0.29
lsb123_na_news_about_schizo	63.06	0.00	1.38	[1.27; 1.5]	0.02	7,887	702	0.07	0.09
lsb123_name_of_band_or_product_with_schizo_rel	2,989.09	0.00	6.36	[5.9; 6.86]	0.16	2,867	1,053	0.02	0.14
lsb123_other_promoting_for_profit_product_service_help_schizo	951.35	0.00	7.3	[6.29; 8.46]	0.09	571	266	0.00	0.03

lsb123_post_about_mental_health	886.15	0.00	2.09	[1.99; 2.2]	0.08	59,822	2,661	0.55	0.37
lsb123_post_focusing_on_schizophrenia	239.22	0.00	1.91	[1.76; 2.08]	0.04	101,387	6,382	0.94	0.9
lsb123_post_tone_is_negative	95.54	0.00	0.78	[0.74; 0.82]	-0.03	57,314	4,203	0.53	0.59
lsb123_post_tone_is_neutral	56.71	0.00	1.2	[1.14; 1.26]	0.02	54,450	3,265	0.5	0.46
lsb123_post_tone_is_positive	80.62	0.00	1.3	[1.22; 1.37]	0.02	29,339	1,589	0.27	0.22
lsb123_replier_argues	466.48	0.00	0.58	[0.55; 0.61]	-0.07	48,695	4,146	0.45	0.58
lsb123_replier_self_promotes	197.99	0.00	3.16	[2.66; 3.74]	0.04	6,435	140	0.06	0.01
lsb123_replier_supports	NaN.00	NaN.00	NaN.00	[NaN.00; NaN.00]	NaN.00	0	0	0.00	0.00
lsb123_replier_supports_other_replier	15,937.22	0.00	0.04	[0.04; 0.05]	-0.38	2,589	2,413	0.02	0.34
lsb123_replier_supports_post_author	56.68	0.00	Inf.00	[NaN.00; Inf.00]	0.02	853	0	0.00	0.00
lsb123_sharing_about_personal_situation	664.45	0.00	0.41	[0.38; 0.44]	-0.08	29,813	974	0.27	0.13

All social media, All posts, by language

Outcome Variable	chi2	p	Odds Ratio	Odds Ratio Confidence Interval	Phi Coefficient	Counts (EN, All, posts)	Counts (KO, All, posts)	% (EN, All, posts)	% (KO, All, posts)
lsb123_ac_advocates_attitude_change_mental_health	89.59	0.00	1.37	[1.28; 1.46]	0.02	19,110	1,041	0.12	0.09
lsb123_ac_aggregate	1,149.16	0.00	2.22	[2.12; 2.33]	0.08	55,699	2,255	0.36	0.2
lsb123_ac_raise_awareness_mental_health_awareness	588.75	0.00	1.82	[1.73; 1.91]	0.05	44,833	2,042	0.29	0.18
lsb123_ac_raise_awareness_mental_health_issues	567.77	0.00	0.55	[0.53; 0.58]	-0.06	46,242	2,154	0.3	0.19
lsb123_ac_raise_awareness_mental_health_treatment_options	556.71	0.00	2.12	[1.99; 2.26]	0.05	8,303	1,199	0.05	0.1
lsb123_ac_supporting_people_with_mental_health_issues	23.93	0.00	0.88	[0.84; 0.93]	-0.02	29,719	2,356	0.19	0.21
lsb123_ca_aggregate	365.57	0.00	0.68	[0.66; 0.71]	-0.05	58,433	5,232	0.38	0.47
lsb123_ca_using_odd_meaning_schizophrenia	64.56	0.00	1.19	[1.14; 1.24]	0.01	49,488	3,163	0.32	0.28
lsb123_ca_using_schizophrenia_as_insult	979.87	0.00	1.87	[1.8; 1.95]	0.07	38,668	4,289	0.25	0.38
lsb123_ca_using_schizophrenia_as_joke	1,320.2	0.00	2.44	[2.32; 2.56]	0.08	14,318	2,224	0.09	0.2
lsb123_na_news_about_schizo	73.78	0.00	1.39	[1.28; 1.49]	0.02	8,097	796	0.05	0.07
lsb123_name_of_band_or_product_with_schizo_rel	2,925.82	0.00	5.75	[5.35; 6.17]	0.13	2,997	1,139	0.01	0.1
lsb123_other_promoting_for_profit_product_service_help_schizo	1,114.19	0.00	7.07	[6.19; 8.08]	0.08	661	329	0.00	0.02

lsb123_post_about_mental_health	341.52	0.00	1.46	[1.4; 1.52]	0.04	66,559	3,807	0.43	0.34
lsb123_post_focusing_on_schizophrenia	377.09	0.00	1.47	[1.42; 1.53]	0.04	106,679	6,719	0.69	0.6
lsb123_post_tone_is_negative	1,281.21	0.00	0.48	[0.46; 0.5]	-0.09	70,848	7,061	0.46	0.63
lsb123_post_tone_is_neutral	397.03	0.00	1.51	[1.45; 1.58]	0.04	63,648	3,526	0.41	0.31
lsb123_post_tone_is_positive	1,017.4	0.00	2.00	[1.91; 2.08]	0.07	64,542	2,948	0.42	0.26
lsb123_replier_argues	1,440.89	0.00	0.47	[0.45; 0.49]	-0.1	62,222	6,531	0.4	0.58
lsb123_replier_self_promotes	927.35	0.00	4.35	[3.92; 4.82]	0.07	20,645	382	0.13	0.03
lsb123_replier_supports	59.81	0.00	1.2	[1.14; 1.26]	0.01	37,772	2,364	0.24	0.21
lsb123_replier_supports_other_replier	7,658.79	0.00	0.18	[0.17; 0.19]	-0.22	16,342	4,341	0.1	0.39
lsb123_replier_supports_post_author	0.03	0.85	0.99	[0.95; 1.04]	-0.01	34,902	2,527	0.22	0.22
lsb123_sharing_about_personal_situation	1,496.04	0.00	0.3	[0.29; 0.32]	-0.1	41,204	1,131	0.26	0.1

Posts only, English

Outcome Variable	chi2	p	Cramer V	CramerV Ci	Counts (FB, posts)	Counts (IN, posts)	Counts (TW, posts)	% (FB, posts)	% (IN, posts)	% (TW, posts)
lsb123_ac_advocates_against_odd_meaning_mental_health_words	5,610.41	0.00	0.22	[0.22; 0.23]	47	5,226	34,297	0.41	0.18	0.43
lsb123_ac_advocates_attitude_change_mental_health	5,136.21	0.00	0.21	[0.21; 0.22]	1	8,299	8,817	0.00	0.29	0.11
lsb123_ac_advocates_more_resources_for_mental_health	177.38	0.00	0.04	[0.03; 0.04]	6	703	3,344	0.05	0.02	0.04
lsb123_ac_advocates_positive_mental_health_policy_rights_change	397.45	0.00	0.06	[0.05; 0.06]	20	3,310	13,150	0.17	0.11	0.16
lsb123_ac_aggregate	3,634.38	0.00	0.18	[0.17; 0.19]	24	17,308	31,901	0.21	0.61	0.4
lsb123_ac_raise_awareness_mental_health_awareness	4,243.96	0.00	0.19	[0.19; 0.2]	17	14,676	23,874	0.15	0.52	0.3
lsb123_ac_raise_awareness_mental_health_issues	27.22	0.00	0.01	[0.01; 0.02]	40	10,216	27,115	0.35	0.36	0.34
lsb123_ac_raise_awareness_mental_health_treatment_options	858.85	0.00	0.08	[0.08; 0.09]	2	2,545	3,427	0.01	0.09	0.04
lsb123_ac_supporting_people_with_mental_health_issues	9,160.07	0.00	0.29	[0.28; 0.29]	11	12,345	12,393	0.09	0.43	0.15
lsb123_ca_aggregate	26,594.11	0.00	0.49	[0.49; 0.5]	48	2,496	51,450	0.42	0.08	0.65
lsb123_ca_schizo_diagnosizing_as_problem	6,921.93	0.00	0.25	[0.24; 0.26]	56	6,497	40,649	0.5	0.23	0.51
lsb123_ca_using_odd_meaning_schizophrenia	28,076.61	0.00	0.51	[0.5; 0.51]	52	340	46,298	0.46	0.01	0.58
lsb123_ca_using_schizophrenia_as_insult	15,904.03	0.00	0.38	[0.37; 0.39]	31	302	32,614	0.27	0.01	0.41
lsb123_ca_using_schizophrenia_as_joke	1,932.31	0.00	0.13	[0.12; 0.14]	6	943	9,850	0.05	0.03	0.12

lsb123_ca_using_schizophrenia_negative_example	3,066.61	0.00	0.16	[0.16; 0.17]	38	3,640	23,251	0.33	0.12	0.29
lsb123_ca_using_schizophrenia_political_context	3,999.86	0.00	0.19	[0.18; 0.19]	27	68	10,441	0.24	0.00	0.13
lsb123_na_news_about_schizo	2,357.05	0.00	0.14	[0.14; 0.15]	6	253	7,628	0.05	0.00	0.09
lsb123_name_of_band_or_product_with_schizo_rel	722.1	0.00	0.08	[0.07; 0.08]	0	133	2,734	0.00	0.00	0.03
lsb123_other_counterculture_schizophrenia	11,594.84	0.00	0.32	[0.32; 0.33]	0	4,138	88	0.00	0.14	0.00
lsb123_other_promoting_for_profit_product_service_help_schizo	266.49	0.00	0.04	[0.04; 0.05]	0	322	249	0.00	0.01	0.00
lsb123_post_about_mental_health	5,214.06	0.00	0.22	[0.21; 0.22]	28	20,934	38,860	0.25	0.74	0.49
lsb123_post_focusing_on_schizophrenia	9,782.23	0.00	0.3	[0.29; 0.3]	7	23,902	77,478	0.06	0.84	0.98
lsb123_post_tone_is_negative	11,364.82	0.00	0.32	[0.31; 0.33]	85	7,458	49,771	0.75	0.26	0.63
lsb123_post_tone_is_neutral	660.88	0.00	0.07	[0.07; 0.08]	91	12,561	41,798	0.81	0.44	0.53
lsb123_post_tone_is_positive	25,158.72	0.00	0.48	[0.47; 0.49]	2	17,937	11,400	0.01	0.63	0.14
lsb123_replier_argues	18,919.6	0.00	0.42	[0.41; 0.42]	85	2,976	45,634	0.75	0.1	0.58
lsb123_replier_argues_with_post_author	2.35	0.3	0.00	[NaN; 0.01]	0	335	874	0.00	0.01	0.01
lsb123_replier_self_promotes	1,666.94	0.00	0.12	[0.11; 0.13]	8	3,096	3,331	0.07	0.1	0.04
lsb123_replier_supports	NaN	NaN	NaN	[NaN; NaN]	0	0	0	0.00	0.00	0.00
lsb123_replier_supports_other_replier	132.94	0.00	0.03	[0.02; 0.04]	0	431	2,158	0.00	0.01	0.02
lsb123_replier_supports_post_author	801.95	0.00	0.08	[0.08; 0.09]	0	588	265	0.00	0.02	0.00
lsb123_sharing_about_personal_situation	1,859.89	0.00	0.13	[0.12; 0.13]	19	5,086	24,708	0.16	0.18	0.31
lsb123_using_schizophrenia_words_for_advertising	32.59	0.00	0.01	[0.01; 0.02]	0	34	256	0.00	0.00	0.00

Posts only, Korean

Outcome Variable	chi2	p	Cramer V	CramerV Ci	Counts (FB, posts)	Counts (IN, posts)	Counts (TW, posts)	% (FB, posts)	% (IN, posts)	% (TW, posts)
lsb123_ac_advocates_attitude_change_mental_health	22.37	0.00	0.05	[0.03; 0.08]	3	29	709	0.03	0.05	0.11
lsb123_ac_aggregate	43.00	0.00	0.07	[0.05; 0.1]	9	184	1,427	0.1	0.33	0.22
lsb123_ac_raise_awareness_mental_health_awareness	28.67	0.00	0.06	[0.04; 0.08]	17	173	1,383	0.2	0.31	0.21
lsb123_ac_raise_awareness_mental_health_issues	30.59	0.00	0.06	[0.04; 0.08]	15	178	1,425	0.17	0.32	0.22
lsb123_ac_raise_awareness_mental_health_treatment_options	186.54	0.00	0.16	[0.13; 0.18]	6	159	628	0.07	0.28	0.09
lsb123_ac_supporting_people_with_mental_health_issues	3.75	0.15	0.02	[NaN; 0.04]	29	139	1,623	0.34	0.25	0.25
lsb123_ca_aggregate	61.63	0.00	0.09	[0.07; 0.11]	16	345	3,904	0.19	0.62	0.6
lsb123_ca_argues_against_rights_policy_mental_health	101.37	0.00	0.11	[0.09; 0.14]	25	16	1,258	0.29	0.02	0.19
lsb123_ca_call_negative_action_toward_individual	219.28	0.00	0.17	[0.15; 0.19]	73	64	1,901	0.86	0.11	0.29
lsb123_ca_negative_opinion_of_people_with_schizo	214.21	0.00	0.17	[0.15; 0.19]	66	57	2,233	0.78	0.1	0.34
lsb123_ca_using_odd_meaning_schizophrenia	182.59	0.00	0.16	[0.13; 0.18]	0	364	2,714	0.00	0.66	0.42
lsb123_ca_using_schizophrenia_as_insult	693.93	0.00	0.31	[0.29; 0.33]	1	31	3,825	0.01	0.05	0.59
lsb123_ca_using_schizophrenia_as_joke	334.86	0.00	0.21	[0.19; 0.24]	1	344	1,747	0.01	0.62	0.27
lsb123_na_news_about_schizo	236.78	0.00	0.18	[0.16; 0.2]	46	6	650	0.54	0.01	0.1
lsb123_name_of_band_or_product_with_schizo_rel	102.72	0.00	0.12	[0.09; 0.14]	0	8	1,045	0.00	0.01	0.16

lsb123_other_promoting_for_profit_product_service_help_schizo	920.39	0.00	0.36	[0.33; 0.38]	1	151	114	0.01	0.27	0.01
lsb123_post_about_mental_health	48.89	0.00	0.08	[0.06; 0.1]	62	191	2,408	0.73	0.34	0.37
lsb123_post_focusing_on_schizophrenia	427.84	0.00	0.24	[0.22; 0.26]	21	486	5,875	0.25	0.88	0.91
lsb123_post_tone_is_negative	57.49	0.00	0.09	[0.06; 0.11]	66	253	3,884	0.78	0.45	0.6
lsb123_post_tone_is_neutral	55.86	0.00	0.08	[0.06; 0.11]	60	319	2,886	0.71	0.57	0.44
lsb123_post_tone_is_positive	646.36	0.00	0.3	[0.27; 0.32]	10	363	1,216	0.11	0.65	0.18
lsb123_replier_argues	226.8	0.00	0.17	[0.15; 0.2]	43	158	3,945	0.51	0.28	0.61
lsb123_replier_self_promotes	341.83	0.00	0.22	[0.19; 0.24]	0	69	71	0.00	0.12	0.01
lsb123_replier_supports	NaN	NaN	NaN	[NaN; NaN]	0	0	0	0.00	0.00	0.00
lsb123_replier_supports_other_replier	15.89	0.00	0.04	[0.02; 0.07]	12	200	2,201	0.14	0.36	0.34
lsb123_replier_supports_post_author	NaN	NaN	NaN.00	[NaN.00; NaN.00]	0	0	0	0.00	0.00	0.00
lsb123_sharing_about_personal_situation	2,180.97	0.00	0.55	[0.53; 0.57]	3	439	532	0.03	0.79	0.08

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PROFESSIONAL EXPERIENCE

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AFFILIATIONS

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HONORS AND AWARDS

Year	Award
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PUBLICATIONS

PAPERS PUBLISHED

Pater, J. A. Phelan, C., **Cornet, V. P.**, Ahmed, R., Colletta, S., Hess, E., … Toscos, Tammy. (2021). User-centered Design of a Mobile App to Support Peer Recovery in a Clinical Setting. *Proceedings of the ACM on Human-Computer Interaction*, 5(CSCW1), 1-31.

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BOOK CHAPTERS

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ABSTRACTS

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