

eHEALTH AND PEOPLE WITH SCHIZOPHRENIA SPECTRUM DISORDERS

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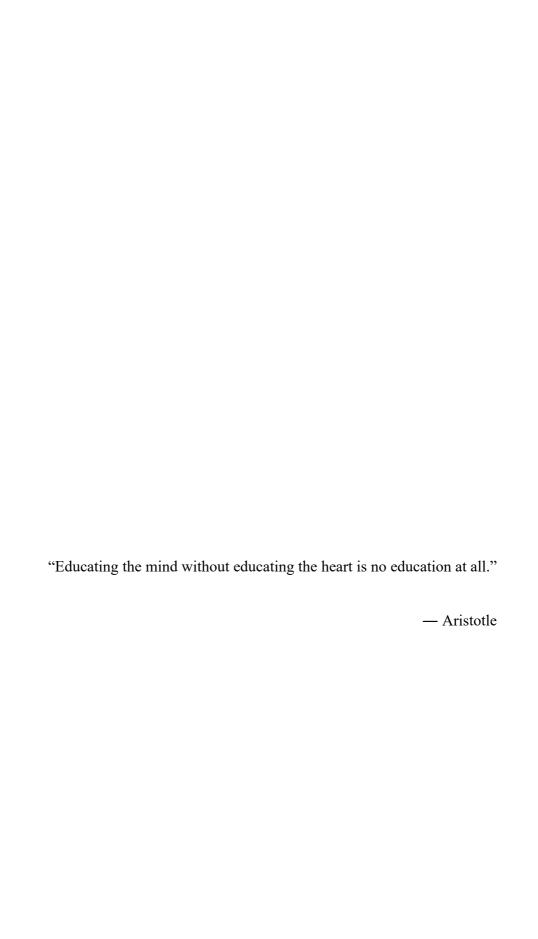
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4 Abstract

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ABSTRACT

eHealth is the transfer of health services and health care by information and communications technology. People with schizophrenia spectrum disorders (SSD) use the Internet for general and health-related reasons. Yet, it is unclear what kind of schizophrenia-related health information this population finds online. eHealth literacy is the ability of Internet users to find, understand, and apply the health information they acquire, to make appropriate health decisions. People with SSD exhibit cognitive deficits and consequently, their eHealth literacy can be affected. The goal of the study was to describe schizophrenia-related health information, to investigate eHealth use among adults with SSD in Finland and Greece, and to compare the country groups.

The methodology consisted of three principle procedures. First, a mixed methods study was conducted with descriptive, cross-sectional design, in order to describe and compare schizophrenia-related health information and videos found online when searched in Finnish and Greek language. Content analysis was performed. Data were analyzed with quantitative and descriptive statistics. Second, a survey study with a descriptive, cross-sectional design was conducted to describe and compare eHealth use among Finnish and Greek people with SSD. Data were collected by a structured questionnaire and analyzed with quantitative, descriptive statistics, partially, group comparisons were made with logistic regression techniques. Third, a systematic literature review and meta-analysis were performed to assess the potential effectiveness of social media interventions for people with SSD.

Our findings, first, showed that assessed online schizophrenia-related health information tended to be of low quality, with no significant differences between the two countries. Furthermore, schizophrenia-related videos tended to present mental illness in a negative, not medically-oriented way, again, without significant differences between the countries. Second, Internet use (FI: 87% vs. GR: 33%) and eHealth literacy (FI: mean 27.05 vs. GR: mean 23.15) of Finnish people with SSD was significantly higher (P<.0001) than their Greek counterparts. The interest component of attitudes toward computer/Internet was significantly higher (P=.006) among the Greek group (FI: mean 2.60 vs. GR: mean 3.16). Third, the systematic review and meta-analysis did not show superiority of social media mental health interventions compared to treatment as usual.

In conclusion, it is recommended that in the future, better quality mental health information and videos need to be made available in several languages and to be easily accessible through the most popular search engines and social media sites. eHealth literacy instruction and training is necessary so that people with SSD can find, understand, and apply the health information they retrieve online.

Keywords: Internet, social media, health information, quality, mental health, schizophrenia

Tiivistelmä 5

Christina Athanasopoulou

SÄHKÖISET TERVEYSPALVELUT SKITSOFRENIASPEKTRIN SAIRAUKSIEN HOIDOSSA

Hoitotieteen laitos, Lääketieteellinen tiedekunta, Turun yliopisto, Suomi Annales Universitatis Turkuensis, Turku, 2017

TIIVISTELMÄ

eHealth jotka -käsite tarkoittaa terveyspalveluja, välitetään informaatiokommunikaatioteknologian avulla. Skitsofreniaspektrin häiriöitä sairastavat henkilöt käyttävät Internetiä yleisiin ja terveyteen liittyviin tarkoituksiin. On kuitenkin epäselvää, minkälaista skitsofreniaan liittyvää terveystietoa he löytävät Internetistä. Sähköinen terveyslukutaito kuvaa Internetin käyttäjien kykyä löytää ja ymmärtää löytämäänsä terveystietoa sekä käyttää sitä tarkoituksenmukaisesti terveyteen liittyvissä päätöksissä. Koska henkilöillä, skitsofreniaspektrin häiriö, ilmenee usein kognitiivisia vajavaisuuksia, heidän terveyslukutaitonsa saattaa olla alentunut. Tämän tutkimuksen tarkoituksena oli kuvata skitsofreniaan liittyvää terveystietoa sähköisissä palveluissa, selvittää näiden terveyspalvelujen käyttöä aikuisten, skitsofreniaspektrin häiriöitä sairastavien henkilöiden keskuudessa sekä Suomessa että Kreikassa ja verrata maiden ryhmiä toisiinsa.

Aluksi toteutettiin tutkimus eri tutkimusmenetelmiä yhdistämällä (mixed methods) deskriptiivisellä, poikkileikkaavalla tutkimusotteella. Tarkoituksena oli kuvata ja verrata Internetistä suomeksi ja kreikaksi löytyvää terveystietoa ja videoita skitsofreniaa koskien. Aineisto analysoitiin sisällönanalyysin sekä kuvailevin tilastomenetelmin. Seuraavaksi suoritettiin kysely samalla tutkimusasetelmalla, jossa kuvattiin ja verrattiin sähköisten terveyspalvelujen käyttöä suomalaisten ja kreikkalaisten skitsofreniaspektrin häiriöitä sairastavien henkilöiden keskuudessa. Aineisto kerättiin strukturoidulla kyselylomakkeella ja analysoitiin kuvailevin tilastomenetelmin. Ryhmien väliset vertailut tehtiin logistisen regressioanalyysin avulla. Kolmanneksi tehtiin systemaattinen kirjallisuuskatsaus ja meta-analyysi, jossa arvioitiin sosiaalisen median vaikuttavuutta skitsofreniaspektrin häiriöitä sairastavien henkilöiden hoidossa.

Tulokset osoittivat, että skitsofreniaan liittyvää terveystieto oli yleisesti ottaen huonolaatuista molemmissa maissa; tutkittavien maiden välillä ei ollut tilastollisesti merkitseviä eroja. Skitsofreniaan liittyvät videot kuvasivat mielisairauksia negatiivisessa, ei-lääketieteellisessä valossa; tulokset eivät eronneet tilastollisesti maiden välillä. Suomalaisten skitsofreniaspektrin häiriöitä sairastavien henkilöiden Internetin käyttö (Suomi 87% vs. Kreikka 33%) ja sähköisen terveystiedon lukutaito (ka 27.05 vs. ka 23.15) oli korkeampi suomalaisilla kuin kreikkalaisilla potilailla; maiden väliset erot olivat tilastollisesti merkitsevät (P<.0001). Tietokoneisiin/Internetiin kohdistuvat asenteet olivat merkittävästi positiivisimmat kreikkalaisen keskuudessa (ka 2.60 vs. ka 3.16, P=.006). Systemaattinen kirjallisuuskatsaus ja meta-analyysi eivät osoittaneet sosiaalisen median olevan tehokkaampi kuin perinteiset hoitomenetelmät.

Tulevaisuudessa korkealaatuista mielenterveysinformaatiota ja videoita olisi oltava helposti löydettävissä eri kielillä suosituimpien hakukoneiden ja sosiaalisen median avulla. Potilaat tarvitsevat koulutusta sähköisten palvelujen medialukutaitoon.

Avainsanat: Internet, terveystieto, laatu, sosiaalinen media, mielenterveysongelmat, skitsofrenia

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ABBREVIATIONS

ANOVA Analysis of Variance

ATC/IQ Attitudes Toward Computer/Internet Questionnaire
CHITs Consumer Health Information Technologies

CI Confidence Interval

CINALH Cumulative Index for Nursing and Allied Health Literature

CONSORT Consolidated Standards of Reporting Trials

COREQ Consolidated criteria for Reporting Qualitative research

DALYs Disability-Adjusted Life-Years

eHEALS eHealth Literacy Scale

ETENE National Advisory Board on Social Welfare and Health Care Ethics

EU European Union

FIN Finnish GR Greek

HON Health On the Net

ICT Information and Communication Technology
LISTSERV Electronic mailing list server [Software]

MeSH Medical Subject Headings

MD Mean Difference

OECD Organisation for Economic Cooperation and Development

PC Personal Computer

PDF Portable Document Format

PRISMA Preferred Reporting Items for Systematic Reviews and Meta-analyses

QUOROM Quality of Reporting of Meta-analysis

RCT Randomised Controlled Trial
REVMAN Review Manager [Software]

SAS Statistical Analysis System [Software]

SD Standard Deviation

SSD Schizophrenia Spectrum Disorders

SPSS Statistical Package for Social Science [Software]
TIDieR Template for Intervention Description and Replication

URI Uniform Resource Identifiers
USA United States of America
WHO World Health Organization

LIST OF ORIGINAL PUBLICATIONS

This dissertation is based on the following publications referred by the Roman numerals I-IV:

- I Athanasopoulou C, Hätönen H, Suni S, Lionis C, Griffiths K.M, & Välimäki M. 2013. An analysis of online health information on schizophrenia or related conditions: a cross-sectional survey. BMC Medical Informatics and Decision Making 13:98.
- II Athanasopoulou C, Suni S, Hätönen H, Apostolakis I, Lionis C, Välimäki M. 2016. Attitudes towards schizophrenia on YouTube: A content analysis of Finnish and Greek videos. Informatics for Health and Social Care 41(3):307-24.
- III Athanasopoulou C, Välimäki M, Koutra A, Bertsias A, Löttyniemi E, Basta M, Vgontzas A, Lionis C. 2017. Internet use, eHealth literacy and attitudes toward computer/Internet among people with schizophrenia spectrum disorders: A cross-sectional study in two distant European regions. Submitted.
- IV Välimäki M, Athanasopoulou C, Lahti M, Adams CE. 2016. Effectiveness of social media interventions for people with schizophrenia: A systematic review and meta-analysis. Journal of Medical Informatics Research 18(4):e92.

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Introduction 11

1. INTRODUCTION

Mental and neurological disorders cause high burden, greater than all forms of cancer (Global Forum for Health Research, 2002). The World Health Organization (WHO), Harvard University and the World Bank have published various studies regarding the global burden of diseases (Murray and Lopez, 1996; Mathers et al., 2002). The findings of these studies reveal that mental illness in Europe is the disease group with the highest percentage of disability-adjusted life-years (DALYs), which is about 25% (Andlin-Sobocki et al., 2005). Among mental illnesses, specifically schizophrenia spectrum disorders (SSD) are among the most deliberating, accompanied with a wide range of symptoms such as, reality distortion, psychotic experiences (e.g. hallucinations and delusions), cognitive, social and functional impairments, and motivational deficits (Mamah & Barch, 2011). The debilitating nature of the disorder leads to lifelong treatment, with a large proportion of people, who get diagnosed, being admitted to a hospital inpatient unit on multiple occasions throughout their lifetime (Sarlon et al., 2012).

Notably, treatment is important not only to improve their daily life and quality of life, but also because the absence of treatment causes a huge personal and economic burden to the person diagnosed and his/her caregivers, but also to society (Chong et al., 2016). To date, more than half of people in the spectrum do not receive treatment (WHO, 2016a), and those who initially follow treatment, misuse or discontinue it (Bhanji et al., 2004; Lieberman et al., 2005). Not being treated adds more to the societal and economic cost of the disorder. Early interventions and public education could reduce psychiatric morbidity and burden of disease (Kalra et al., 2012). The development and implementation of improved interventions with the use of new scientific and technological advances, while taking into account the sociocultural and socioeconomic contexts, are two of the six priorities in Europe for policy action in the mental health sector (Wykes et al., 2015).

Sixteen years ago, the term 'eHealth' was coined by McLendon (2000), to describe the "delivery or enhancement of health services and information through the Internet and related technologies" (Mclendon, 2000, pp.22). Eysenbach (2001, pp.1) defined e-health as the 'intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, a commitment for networked and global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology'. The eHealth action plan 2012-2020 and the outcome of the mHealth Green paper opened the way to patient empowerment with the assistance of Information and Communication Technologies (ICT). "Patient empowerment is a process to help people gain control, which includes people taking the initiative, solving problems, and making decisions, and can be applied to different settings in health and social care, and self-management" (The Lancet, 2012, pp.1677). Applying ICT to human health is one of the main research goals for the 7th and 8th Framework of EU Programs and HORIZON 2020 (European Commission, 2016). EU and OECD surveys on the eHealth development and policy within EU

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countries have shown that Finland has regularly been one of the top countries. Finland is an eHealth forerunner, particularly in the field of digitalized health care information.

The focus on mental health through eHealth applications is important because to date, eHealth applications are more common for physical health care (Rotondi et al., 2015). Recent studies show that eHealth applications for physical care improve access, convenience, education, care quality, and care effectiveness (Bond et al., 2007; Brattberg, 2007; Muñoz et al., 2009). According to Rotondi and colleagues (2015), there is relatively less work creating applications for mental health treatments, however some progress has been made for disorders like depression and anxiety, panic/phobic disorders, and stress management. Despite this progress, severe mental illness (like schizophrenia spectrum disorders - SSD) has received little attention (Rotondi et al., 2015), nevertheless, there are some notable examples focused on SSD (Koivunen et al., 2007; Rotondi et al., 2010; Granholm et al., 2012; Kannisto et al., 2014; Schrank et al., 2014; van der Krieke et al., 2014).

Globally, healthcare systems are rapidly approaching a crisis point. This is due in part to the increase of the aging population and chronic diseases, the rise of healthcare costs increasing the share of the government expenditure, and the gradual decrease of healthcare professionals (Laxman et al., 2015). Currently, there is a clear gap between access to information and understanding this information (Alpay et al., 2009). When consumers search for health information online, they tend to begin the search with a search engine and consequently, we need to know what kind of information they access, if they understand it, and if they can distinguish between reliable and unreliable information. One way to approach this issue is to provide consumers with high quality health information which is easily understood and available in the first search engine results. By doing this, consumers will be empowered to better understand and manage their health and potentially to actively participate in treatment (Laxman et al., 2015). In fact, this requires a deep comprehension of the backgrounds, needs, and preferences of health information seekers, because their eHealth profile is evolving. Furthermore, health information seekers are gradually becoming more involved in their own healthcare, and more information technology experienced (Alpay et al., 2009).

The health phenomenon (Jack et al., 2010) examined in this study was eHealth and people with SSD. The study began with a qualitative approach (Phase I), specifically, content analysis for descriptive purposes, in order to portray the current situation concerning schizophrenia-related health information in websites (Paper I) and videos (Paper II). This part aimed to answer 'What is already available online related to schizophrenia?' (Papers I, II). In the second part of the study (Phase II), a quantitative approach using a survey research, provided a numeric description of use and patterns of computer/Internet among people with schizophrenia spectrum disorders (Paper III). It aimed to answer 'What is the eHealth use among people with SSD in Finland and in Greece?' and 'Do they use the Internet for general and health related purposes?' (Paper III). Last, a mixed methods systematic review was conducted to provide a synopsis of current literature as it related to the research question: 'Are social media interventions shown to be effective for people with schizophrenia spectrum disorders?' (Paper IV). This part of the study focused on interactivity (user-to-user contact) and social media (as broadly defined by Kaplan & Haenlein, 2010). Overall, the study results aimed to provide new insights about, first, the online health information (Paper I) and videos related to schizophrenia (Paper II), second, the Internet use of people with SSD (Paper

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III), and third, the current literature about the effectiveness of social media for this population (Paper IV).

Investigating the prevalence of Internet use among this population (Paper III) can: 1) support people's with SSD health-related Internet use in accordance with their specialized health information needs and preferences, while 2) for those people with SSD who are not Internet users, it is expected that we will acquire a better understanding of their attitudes towards computer/Internet and their preferred sources of health information, in order to support their preferable offline means of health information. The importance of this step of the study lies in acquiring a better understanding of what people with SSD need to have available online in order to empower them (Blair, 2004), support their health, and consequently have a better quality of life (WHO, 2009). The results of this dissertation generated knowledge for various stakeholders, such as users/patients, health professionals, IT experts, health care organizations, medical researchers, policy makers, system vendors, support staff, general public, mass media (Pagliari, 2005); in order to have an effective integration of eHealth applications adapted to each country's needs. More specifically, for users/patients their need (or not) of further training their eHealth literacy skills will be investigated, health professionals will know if their patients use the Internet for general and health-related purposes, and IT experts will get an insight from the evaluation of the quality of current websites offering mental health information. As IT experts are responsible only for the creation of the websites, not its' content, they have to be in close cooperation with health professionals every time they attempt to create (mental) health-related content.

eHealth was selected as the subject of this PhD study because eHealth interventions have shown potential and may have significant advantages over traditional forms of care (Ritterband & Palermo, 2009). The study began in year 2011 and data collection ended in 2015. This study was funded by the Finnish Doctoral Education Network in Nursing Science (University of Turku), the Faculty of Medicine Science (University of Turku), the University of Turku Graduate School – UTUGS, the Turku University Foundation, Academy of Finland, and the Operational Program Education and Lifelong Learning of the National Strategic Reference Framework (NSRF) 2007-2013 (2011-2-162; IKY, Greece).

2. REVIEW OF LITERATURE

This chapter provides a review of the literature on first, schizophrenia spectrum disorders, and second, eHealth. Specifically, the Finnish and Greek perspectives are being reported in order to draw conclusions in relation to our study samples, which are from these two distant European countries.

2.1 Schizophrenia spectrum disorders

2.1.1 Diagnosis, symptoms and living with schizophrenia spectrum disorders

Schizophrenia spectrum disorders (SSD) are amongst the most debilitating types of mental disorders (Ritsner, 2011). According to the 10th edition of the International Classification of Disorders (ICD-10) (WHO, 1992) the spectrum includes, schizophrenia, schizoaffective disorder, delusional disorder, schizotypal personality disorder, schizophreniform disorder, brief psychotic disorder, and psychosis associated with substance use or medical conditions (codes F20-F29). Schizophrenia alone has a 0.7 to 1% prevalence, with many people affected by it except those diagnosed, like the caregivers and immediate environment of these persons (Christodoulou & Franciosi, 2014). A study in Finland showed a similar prevalence of 0.87% (Perälä et al., 2007). Schizophrenia is a serious and chronic disease with a relapsing course (Tandon et al., 2009), and globally it is among the top ten causes of disease-related disability (Tandon et al., 2008).

The nature of SSD is complex and the cause is not explicitly known up until the present. So far, it is shown that a synthesis of genetic, environmental and psychosocial factors affect the onset of the disease. Genetic factors such as, family history of mental illness and parents' old age, as well as, environmental and psychosocial factors, such as, exposure to viruses and toxins in the first and second trimester of pregnancy, consumption of psychoactive drugs at a young age, stressful life events, acquired brain damage, low socioeconomic status, disturbed family environment, serious behavioural and emotional problems in childhood, and social dysfunction, contribute as risk factors for SSD (Institute of Medicine, 1994). In addition, several studies have reported that the season of birth, complications during birth, autoimmune diseases, ethnicity, urban residence, and cannabis use are also risk factors (Messias et al., 2007).

The onset of SSD typically occurs between late adolescence and early adulthood (Picchioni & Murray, 2007) and progresses slowly, starting with the person becoming socially withdrawn, having distorted perceptions and moving towards frequent delusions and hallucinations. Symptomatology of SSD generally consists of positive 'psychotic' symptoms, negative symptoms, and cognitive impairment. The positive 'psychotic' symptoms are hallucinations (most commonly auditory), delusions (strongly held unfounded beliefs), disorganized speech (incoherent speech), grossly disorganized or catatonic behavior (unusual behavior and psychomotor disturbances). Common negative symptoms include anhedonia (lack of pleasure), expressive deficits (including lack of emotional expression), alogia (reduced amount and content of speech), lack of motivation and

avolition (lack of interest in everyday activities) (Isohanni et al., 2001; Mueser & McGurk, 2004). Cognitive impairment in schizophrenia, for example, poor concentration and memory, decreased capability to plan and successfully engage in activities, lead to problems in attention, sensory perception, abstract thinking, problem-solving, ideation, sense of self, and reality distortion (Isohanni et al., 2001; Mueser & McGurk, 2004; Fischer and Carpenter, 2009; Tiffin & Welsh, 2013), which influence the person's social skills and performance in activities of daily living (Austin, 2005). A person must have a minimum of two of these symptoms for at least one month, and must show signs continuously for at least a six-month period for the diagnosis of schizophrenia to be confirmed. With increasing age, positive symptoms decrease and some amount of social and occupational functioning may be regained. However, the symptoms and course of disease vary and are patient specific.

Because of the serious impairments caused by the illness, people with the diagnosis face major difficulties in their everyday lives, especially those with cognitive deficits (Fett et al., 2011). Not only their mental health is tremendously affected (Bhanji et al., 2004), but they also have considerably shorter lifespan compared to the general population, because of physical health problems and unhealthy lifestyle choices (Connolly & Kelly, 2005; Correll et al., 2015). SSD produce a big impact on the person's functional capacity, which is difficult to restore (Viertiö, 2011). They tend to smoke, have unhealthy diets and abstain from exercise (Brown et al., 1999; McNamee et al., 2013). For someone diagnosed, every day can be a struggle for maintaining interest in daily life activities, such as, an interest in self-care, relationships, occupation, and social life. People with schizophrenia are 6-7 times more likely to be unemployed, often homeless, facing criminal justice issues, while 5-10% suicide (Christodoulou & Franciosi, 2014).

Despite the various serious symptoms of the illness, more than 50% of people affected, do not get treated (WHO, 2016a). Even those who initially follow treatment, misuse it, or stop at some point (Bhanji et al., 2004), while 30 to 50% are treatment-resistant. This adds more to the major cost of schizophrenia. Excluding its undeniably significant personal cost, schizophrenia creates high economical amount to the families and the society (Knapp et al., 2004). About 30% of its economic cost stems from the direct treatment, while the rest is absorbed by indirect costs, e.g. resistance to treatment, lost work time for those diagnosed and their caregivers, social services and criminal justice resources (Ran et al., 2010). In Finland, neuropsychiatric disorders contribute about 32.6% to the global burden of disease (WHO, 2011a), the percentage in Greece is about 26.8% (WHO, 2011b). In addition, mental health costs of the Finnish Ministry of Health are 3.86% of the whole health budget (WHO, 2011a), and mental health costs of the Greek Ministry of Health are 4.43% of the whole health budget (WHO, 2011b).

2.1.2 Healthcare delivery of schizophrenia spectrum disorders

Usually, for a mental health system to be effective, mental health services must ensure easy access, provide several points of entry for treatment and multiple specialists. Traditionally, mental health care systems consist of the private and public sector, and services like, outpatient and inpatient (Stuart, 2013). Optimally, the first treatment option is outpatient mental health services.

Nonetheless, if a person's psychiatric symptoms are severe, treatment in inpatient services of a psychiatric clinic may be needed (Mental Health Act 1116/1990).

Between Finland and Greece, the differences in mental health provision are clear. According to WHO (2014) in Finland there are 48.61 beds in general hospitals for mental health and 19.88 beds in mental health hospitals per 100,000 citizens. In Greece, although the general population is about double than in Finland (11,128,404 vs. 5,443,498), the beds in general hospitals are about six times less (7.44), and approximately 5 times less (4.94) in mental health hospitals per 100,000 citizens. Early involvement of patients and their families in mental health policy and law is fully implemented in Finland, while it is not in Greece (WHO, 2014). In year 2013, Finnish people with mental health problems received sickness benefit of a total of 3,5 million days lost from work (KELA, 2014). Respectively, this data is not available for Greece.

More specifically, Finnish municipal authorities are responsible for the implementation of mental health services. In addition, mental health services can be also provided by hospital districts, private service providers and third sector actors. In large cities, the structure of the mental health services is more resourceful with more service providers available. The usual treatment for mental health disorders is a combination of counselling and medication. In outpatient services people with more serious and long-term mental health conditions are treated. According to a person's place of residence and needs, outpatient services can offer supported living or rehabilitative activities (i.e. cooking, exercise, opportunities for socializing with others), enabling them to live as independently as possible. Inpatient services are for those patients whose symptoms are more severe and outpatient care is judged to be insufficient. In addition, and in contrast to outpatient services (mainly pharmacotherapy and psychotherapy), there are programs offering other forms of support (i.e. help with jobs and school), as well as family counselling. (Mieli, 2016)

The primary goal of the comprehensive treatment approaches is to relieve the wide range of symptoms, to enhance persons' general and psychosocial functioning, and improve their overall quality of life (Chien & Yip, 2013; Finnish Medical Society Duodecim & Psychiatric Association, 2008). Nowadays, there is a wealth of treatment approaches, such as with antipsychotic medication, psychotherapy, neuroprotective-based treatment, prevention and early intervention in at-risk states for developing psychosis, cognitive-behavior therapy (CBT), and other interventions improving social and vocational dysfunction in SSD (Ritsner, 2011).

Historically, there three periods of mental health services: 1) rise of the asylum, 2) decline of the asylum, 3) reform of mental health services (deinstitutionalisation, community-based and hospital based services) (Thornicroft & Tansella, 2004). In recent decades, this reform has changed the whole delivery of mental health services in many countries (Harjajärvi et al., 2006). In Finland, the deinstitutionalisation began later than in many Western countries (Honkonen et al., 1999, Rantanen et al., 2009). There has been a huge decrease of inpatient psychiatric beds, in the early 1980s there were about 20,000 beds (Rantanen et al., 2009) and in 2008 about 4,500 beds (National Institute for Health and Welfare, 2010). In addition between years 1981-1987, the National Schizophrenia Project (National Board of Health, 1988), targeted to decrease long-stay inpatient care, establish new community-based services, and improve patients' quality of life, which resulted in reducing

hospitalization rates. In addition, throughout the years the mental health staff's educational level has risen. Despite the fact that outpatient services are targeted as a primary mental health service (Finnish Medical Society Duodecim & Psychiatric Association, 2008; Ministry of Social Affairs and Health, 2009) inpatient services are still a critical element of psychiatric care. When treatment in outpatient services is not sufficient to manage a person's symptoms (Ministry of Social Affairs and Health, 2004; Pirkola & Sohlman, 2005), high-intensity care is provided by inpatient services, for example, for individuals who experience severe psychotic relapse (Thornicroft & Tansella, 2004) and behavioral disturbance or suicidal individuals. (Viertiö, 2011; Pitkänen, 2010).

Since 1983, in Greece and similarly in Finland, there has been a significant effort to decentralise mental health services and organize prevention-oriented services based on the EU recommendations. Until early 1980s, mental health care in Greece was based on 9 governmental and 40 private psychiatric hospitals. The staff number was not adequate and equipment was poor, while the treated patients were a mixture of mainly psychotic and intellectually disabled people. At that point, community mental health services were inexistent, those diagnosed with less severe mental disorders, children and the elderly could not receive almost any treatment. There was also lack of qualified staff in administrative and management positions (Madianos et al., 1999). In 1999, novel 10-year action programme was created entitled 'Psychargos' (http://www.psychargos.gov.gr/). 'Psychargos' programme aimed to provide a national mental health services reform. It emphasized on restructuring the previous mental health system, with a new focus on social inclusion and cohesion in the community. Further, new mental health units were established, e.g. mental health centres and mobile units, to serve citizens' needs and fight against social stigma. Hence, for the last 33 years, there has been a shift from institutionalization to more community-based settings for people with mental health problems. Despite that, much have been achieved through 'Psychargos' programme, a systematic review (Lionis et al., 2009) reported that the integration of mental health into primary care is an urgent issue in the health policy agenda (Argyriadou & Lionis, 2009).

Nonetheless, helping people to recover from mental health problems requires far more than the provision of services and treatments (Brimblecombe & Nolan, 2012). Leonard Kish (2012) is suggesting a new approach, patient engagement through technology, while he claims that: "patient engagement is the blockbuster drug of the 21st century".

2.1.3 Policy for schizophrenia spectrum disorders

In order to provide well-planned mental health care, its system and services must be instructed from specific policy and plan (WHO, 2009). A mental health policy consists of an official statement by a government or health authority that directs mental health. A mental health policy specifies the vision, principles, values, and objectives, and establishes a wide model for action to achieve that vision. For a policy to be effective, it should be accompanied by a more detailed action plan, which will be implemented in a systematic and well-coordinated way (WHO, 2009).

According to the Finnish Mental Health Act (1116/1990) people in need of mental health services should be supported and guided toward the improvement of their mental and overall health and wellbeing, train their ability to cope with stressful situations and achieve personal growth. On the other hand, mental health services should aim to prevent and cure mental health problems. Primarily, mental health care and services are organized on an outpatient basis, in a way that promotes patient engagement and voluntarily to seek for treatment. Social rehabilitation should be an integral part of the medical care of people diagnosed with a severe mental illness. Among municipalities' public health obligations is the implementation of mental health services (Finnish Health Care Act 1326/2010). Nonetheless, hospital districts offering specialized medical care are obligated to provide such care to all people who need it within their catchment area (Timlin, 2015).

According to the Greek Mental Health Act (2716/1999) state authorities are responsible for the organisation and implementation of mental health care services (Argyriadou & Lionis, 2009). Mental health services can be implemented by mental health outpatient and/or day treatment facilities, psychiatric clinics in general hospitals, community residential facilities, psychiatric hospitals, municipality mental health services, private service providers and third sector i.e. non-governmental organizations. Similarly to Finland, psychiatric services for severe and long-term mental health problems – such as SSD – are primarily implemented as outpatient care, where people do not stay overnight in the hospital, but they visit the clinic several times per week or month to get treatment (usually a combination of counselling and medication) (Fotiadis et al., 2015). Since 1999, a legal and policy framework named: 'Development and Modernisation of the Mental Health Services' explicitly states that the Greek State has the responsibility for the promotion of mental health and the prevention of mental disorders. The two general Acts that are expected to facilitate this kind of activities are: 'Act on Organization and operation of the Services for Public Health' and the 'White Paper on the Quality of Health Services and the National Health Information System'.

2.2 eHealth and schizophrenia spectrum disorders

2.2.1 eHealth in the field of schizophrenia or related conditions

eHealth will play a progressively critical role in forming healthcare systems in the 21st century. According to Gaddi & Capello (2014) the growing burden of chronic diseases (including their accompanying economic costs), make eHealth an excellent opportunity for providing, less costly, higher quality and more efficient health care. Accordingly, the World Health Organization (2005, pp. 109) defined eHealth as 'the cost-effective and secure use of information and communications technologies in support of health and health-related fields, including health-care services, health surveillance, health literature, and health education, knowledge and research'. A similar term, 'emental health', is defined as the use of telecommunication and information technologies to deliver mental health services at distance (Mucic, 2016). 'e-mental health' could be also used in this study, but the intention of using the more broad term - 'eHealth' - was to denote its application also outside the field of mental health. In other words, people with mental health problems have also general

health problems or physical health problems, thus the focus of the study was the overall health needs of people with SSD.

eHealth studies, specifically in the field of mental health, have shown the potential for improving the life of people with mental disorders (Kilbourne, 2012). A randomized controlled trial among persons with chronic depression, reported that participants exhibited less depressive symptoms, better physical functioning, and an enhanced quality of life when an Internet-delivered chronic care model was applied (Hunkeler et al, 2006). In the US, Deen and co-authors (Kilbourne, 2012) found substantial increases in individual and group telepsychotherapy encounters. In addition, eHealth could be of considerable importance in areas with limited resources, or geographical isolated patients; since the prevalence of mental health problems in rural areas is at least as high as in metropolitan areas (Campbell et al., 2006). Further, a potential benefit of eHealth applications could be the reduced costs, and the remote and efficient delivery of healthcare services. Adequate integration of eHealth support and applications have the potential to improve peoples' quality of life, such as promote safer, independent living and enhanced social inclusion (Hyppönen, 2007). People reporting to be in a "fair" or "poor" health are more likely to search for health information online as compared with people reporting "excellent" or "good" health condition (Stjernswärd & Östman, 2006). Health information is the basic element in guiding strategic health-related decisions and treatment choices, hence it is the most important resource in health care and health promotion (Kreps, 1988).

At an initial level, eHealth is intended to improve the quality of health care. eHealth services are intended for single individuals, for personalized health care. Particularly, main goal of eHealth is a flexible personalized approach based on tailored interventions. eHealth can be applied at any level of care, i.e. prevention, diagnosis, therapy, or follow-up (Gaddi & Capello, 2014). Thus, people with mental illness should not be excluded from eHealth services. However, even if eHealth is perfect in theory, in practice a serious barrier to its full development, is the awareness that sometimes innovations do not realistically fulfil the perceived needs of the user and from their capacity to use these technologies. Furthermore, eHealth applications should be adapted to the needs of users, in order to prevent the exclusion of some categories of people, and to prevent the consolidation of health inequalities (Gaddi & Capello, 2014). As a consequence, eHealth use of a population diagnosed with a highly deliberating disorder –as SSD– should be investigated in order to be applied effectively according to this population's needs and abilities.

According to the European Union's eHealth Action Plan 2012-2020 (COM, 2012), 'eHealth can benefit citizens, patients, health and care professionals but also health organisations and public authorities. eHealth —when applied effectively— delivers more personalised 'citizen-centric' healthcare, which is more targeted, effective and efficient and helps reduce errors, as well as the length of hospitalisation. It facilitates socio-economic inclusion and equality, quality of life and patient empowerment through greater transparency, access to services and information and the use of social media for health'.

Little research has been conducted to investigate the Internet and eHealth use and literacy among people with mental illness (Khazaal et al, 2008a; Gowen, 2013; Treisman et al., 2016). The

European Commission through its eHealth Action Plan 2012-2020, primarily targets to limit health inequalities and enhance health literacy (EPHA, 2011). At the same time, each European member state varies in computer skills, Internet access and frequency of use, and online health information seeking behavior. For example, 77% of Finnish people have basic computer skills, compared to 47% of Greeks (Eurostat, 2012). The majority of Finns (93%) aged 16-74 have used the Internet, while the percentage for their Greek counterparts is 59% (Eurostat, 2012). About 80% of Finnish people uses the Internet daily or almost every day and 6% have never used the Internet, while 47% of Greeks use the Internet daily or almost every day, and 36% have never used it (Eurostat, 2013). Furthermore, more than half of Finns (67%) searched for online health information, while almost half percentage of Greeks did the same (37%) (Eurostat, 2016a). Generally, almost a third of Internet users with a history of psychiatric disorder search the Internet for mental health information (Powell & Clarke, 2006).

2.2.2 Online health information on schizophrenia or related conditions

Between 2000 - 2016, the Internet grew about 918% (Internet World Stats, 2016), with a rising number of people searching for health and mental health information online. Almost three-quarters of American (Pew Research, 2015) and under a half (44%) of European Internet users (Eurostat, 2013) search for health information online. Online queries specifically for mental health information are approximately 33% (Fox & Jones, 2009). The anonymity that the Internet provides (Beaussart & Kaufman, 2013) makes it a popular source of mental health information (Schrank et al, 2010; Gowen, 2013; Powel & Clarke, 2006).

Interest in the quality of the health related information available online was first initiated in 1996 in United Kingdom (Bower, 1996) when a growing number of dubious health claims for products on the Internet (mainly advertisements) and British authorities claimed they were powerless to control. The next year in Canada, Davison (1997) raised concern about the quality of online health-related information concerning nutrition. They recommended that health professionals needed to take an active role in technology and establish strategies to address inconsistent dietary information, which could be found online. They also discussed elements to consider in webpage construction and evaluation, and provided a form to assist in their assessment. The same year in United States, Pealer and Dorman (1997) discussed elements to consider in webpage construction and evaluation, and provided a form to assist in their evaluation.

The focus on the mental health information available online was initiated in 2002 in Australia, when Griffiths & Christensen (2002) assessed the quality of online information about depression. The overall quality of online information on depression, social phobia (Khazaal et al., 2008b), and substance addictions (Khazaal, et al., 2008c) was reported to be low. A review of the quality of online mental health information reported that overall quality is low, but that information on affective disorders may be improving (Reavley & Jorn, 2011). However, Grohol and colleagues (2014) found that popular search engines tend to offer reliable results on mental health information, noting that readability of websites could be improved. Similarly, Landers (2013) reported that most common Internet resources about mental health are of reasonable quality. It is obvious that results

between studies are contradictive. It is important to note that, first, most studies evaluate the health information in the English language, and second, nothing has radically changed concerning the creation and dissemination of online health information.

A British study found that adults with mental health conditions, rank the Internet sixth in terms of accurate sources of information on mental health, and third among information sources used (Powell & Clarke, 2006). About one-fourth of those who search for health information online are aware about how to assess these information, another quarter report taking casual steps to assess the quality of online health information, and the remaining half relies on common sense when determining which health information to trust or not (Fox & Rainie, 2002). It appears that Internet users regularly seek for others' opinions and experiences related to health issues, since about half of adult online health information seekers read others' commentaries or experiences about health or medical issues on online news groups, websites, or blogs (Fox & Jones, 2009). The high prevalence of moderate or low quality of mental health information online, in combination with the limited skills of Internet users in evaluating the health information they find, adds to the urgently need for training users' eHealth literacy skills (the ability to use electronic health information resources when addressing a health problem) (Norman & Skinner, 2006). There could be numerous features affecting how someone is searching for health information online such as: sex, level of education, culture, Internet self-efficacy and eHealth literacy (Norman & Skinner, 2006; Peña-Purcell, 2008; Lemire et al., 2008; Rains, 2008; Tian & Robinson, 2009; Askola et al., 2010).

Importantly, the high prevalence of low-quality online mental health information is a challenge, especially for individuals with serious mental health conditions exhibiting low levels of eHealth literacy. More than half of adults with a psychiatric condition report that when they search online for mental health information, they only partially find what they need, or not find it at all (Khazaal, et al., 2008a). Even young individuals, who are found to be more familiarized with Internet use, report various barriers that block them from successfully accessing high-quality health information online. Two basic barriers where, first, feeling overwhelmed at the plethora of information, however, unable to trace the answers they were looking for, and second, they perceived that the information were not tailored to their needs. Additionally, privacy issues when accessing sensitive health information, was another important factor when searching for health information over the Internet. Last, frequently health information was text-heavy, which made its content difficult to understand among those with low literacy levels (Skinner et al., 2003).

It has been reported that if patients are provided with relevant health information in order to make informed choices and be aware of each treatment's risks and benefits (Vaitheeswaran et al., 2009), then, their improved comprehension generally increases adherence to treatment (Hulka et al., 1976), thus, reducing the illness' cost. It is clear that the provision of easily accessible, relevant, and trustworthy health information, provides patients' the option to be empowered (Schulz & Nakamoto, 2013), since they search online to cover their health information needs.

2.2.3 Online presentation of schizophrenia or related conditions

The negative portrayal of mental illness is a common and widespread phenomenon. Numerous studies have reported the negative depictions of mental disorders in traditional mass media like, television (Diefenbach, 1997, 2007; Wilson et al., 1999, 2000; Pirkis et al., 2005, 2006), newspapers (Duckworth et al., 2003; Chopra & Doody, 2007; Vahabzadeh et al., 2011; Magliano et al., 2011; Thornicroft et al., 2013), magazines (Wahl et al., 1995; Wahl, 2000), and films (Bischoff & Reiter 1999; Wahl et al., 2003). Owen (2012) evaluated more than 40 films related to mental illness and discovered that over 80% of the main characters diagnosed with schizophrenia, exhibited mostly violent and/or homicidal behaviors.

A more recent form of mass media is the Internet (Donovan & Herley, 2003). The Internet is also a very popular ICT medium, with global penetration 49.2% (73.9% in Europe) (Internet World Stats, 2016). Despite its popularity, only a few know about how mental health disorders are presented online. Recent literature reveals that the term 'schizophrenia' was used as a metaphor in one-third of articles retrieved from newspaper websites (Athanasopoulou & Välimäki, 2014), were the metaphoric use of 'schizophrenia', denoted mostly incoherence/contradiction/split, eccentricity/oddness, or dangerousness/aggressiveness. Similar studies on Twitter, reveal that Tweets use the term 'schizophrenia' mostly in a negative, medically inappropriate and sarcastic way in English (Joseph et al., 2015), and also in Greek language (Athanasopoulou & Sakellari, 2016).

Research on how mental disorders are presented online is essential, since negative depictions of schizophrenia and other mental disorders are promoted among Internet users. As a result, negative attitudes towards mental disorders might be created among those who access these negative depictions online. Consequently, having negative perceptions, or else 'stereotypes' about mental illness and agreement with these viewpoints, create negative reactions, or else 'prejudice' (Corrigan, 2004). These negative views may make people internalize viewpoints, which reflect devaluation and discrimination towards those afflicted with a mental illness (Corrigan et al., 2009), which is further related to mental illness stigma (Link, 1999). Further, mental illness stigma creates a major barrier to care since people with mental illness, in their attempt to avoid being labelled as 'mentally ill', thus stigmatized, tend to avoid treatment (Corrigan et al., 2014).

2.2.4 Use, attitudes and patterns related to computer/Internet, and eHealth literacy among people with schizophrenia spectrum disorders

A recent study showed that about 80% of people with psychiatric conditions use the Internet (Kalckreuth et al., 2014). Approximately 71% of them use the Internet specifically for mental health related reasons (Powell & Clarke, 2006; Kalk & Pothier, 2008; Kalckreuth et al., 2014). Several studies indicate that people with SSD tend to use the Internet as much as the average Internet user (Schrank et al, 2010; Kalckreuth et al., 2014; Miller et al., 2015). Among their online activities are, email exchange (Miller et al., 2015), Web 2.0 and social media engagement (Miller et al., 2015), interaction with peers (Scrank et al., 2010), health information-seeking and communication with professionals (Schrank et al., 2010; Miller et al., 2015; Kummervold et al., 2008).

A Swiss study (Khazaal et al., 2008a) reported that about 65% of adult psychiatric patients engaged in Internet activities such as search for, information related to their diagnosis (72.7%), possibilities of various treatment options (84.6%) and medication side effects (81.8%). A similar German study (Kalckreuth et al., 2014), found that approximately 48% of psychiatric patients who used the Internet, were also using social media websites, approximately 19% used social networks forums, 19% chats, and 12% blogs. In the same study, patients mostly searched for information on mental disorders (57.8%), information on medication (43.7%), mental health services (38.8%), used platforms with other patients (19.8%) and/or with mental health professionals (17.2%). Gowen (2013) reported that 60% of young adults with mental health challenges use the Internet several times a day, for 62.5% of them, home was the most common place for Internet access, followed by the library (12.5%), work (8.3%), other family member's house (8.3%), community centre (4.2%), or other location (4.2%). The vast majority of young adults (89%) searched for mental health information online. Some searched on a daily (15%) or weekly basis (11%), while over a half (63%) searched for mental health information online every few weeks or less frequently.

Information and communication technology (ICT) tools and specifically, consumer health information technologies (CHITs) can support health care management (Atkinson et al., 2009), yet patients not always accepted them (Or & Karsh, 2009). Reasons for that can be, low device usability, insufficient or lack of ICT and computer skills, and low self-efficacy (low confidence in the ability to use technology) (Mead et al., 2003; Or & Karsh, 2009). Major components of ICT acceptance are, interest and willingness to use ICT, satisfaction with the technology, efficient or effective use of the technology. Patients' non-acceptance of CHITs raises an important concern for health care organizations. Those who deny using CHITs will not benefit from them, which means a loss of return on investment for health care organizations (Or & Karsh, 2009). An important influence of peoples' perception and willingness to access health information is their attitude to computers and the Internet (Mead et al. 2003), thus, attitudes toward computer/Internet are important to investigate.

Little is known about the distribution and use of different kinds of ICT and eHealth tools among different populations or subgroups (Atkinson et al., 2009; Saranto et al., 2009), especially in the field of mental health. To date, it is unknown if Greek people with schizophrenia use the Internet, in which patterns and to what expend. On the other hand, in Finland there have been some recent studies on Finnish people with schizophrenia (Välimäki et al., 2008, 2012; Anttila et al., 2012). However, to our knowledge, Internet use patterns, eHealth literacy, and attitudes towards computer/Internet of people with SSD in these countries have not been investigated so far.

2.2.5 Effectiveness of social media interventions for people with schizophrenia spectrum disorders

People with mental disorders use social media and Web 2.0 applications. In addition, for people with serious mental illness, online interventions have been shown to have the potential to disseminate care and support the patient's participation in group interactions (Rotondi et al., 2013). The combination of online psychoeducation with various other online tools, including social media,

is becoming more popular, and online psychotherapy and videogames have been evaluated for their validity and efficacy characteristics (Parikh & Huniewicz, 2015)

Almost a third of Internet users spend their time specifically on social networking sites (Statista, 2016a). Globally, 2.34 billion people use social media websites (Statista, 2016b). Facebook (https://www.facebook.com/) is the most popular social networking site, with more than 1.7 billion active users (Statista, 2016c). By 2020, it is expected that more than 2.95 billion Internet users will use social networking sites (Statista, 2016b). Hence, since penetration of social media is so high, it is essential to understand the impact and potential usefulness of social media in health care (Grajales et al., 2014).

Studies on online interventions have explored online peer support (Eysenbach et al., 2004), online support groups for depression (Griffiths et al., 2009), online communication, social media and adolescent well-being (Best et al., 2014), social media of Asian immigrants' mental health needs (Leung & Li, 2015), online and social networking for the treatment of depression (Rise et al., 2014), social media and suicide prevention (Robinson et al., 2015) and effects of online intervention for depression in schizophrenia (Moritz et al., 2016).

The findings of the aforementioned studies seem promising, especially in the latest one where a significant decline of depressive symptoms was noted among those with schizophrenia. Authors suggest that online interventions could be a valuable tool in addressing patients' needs, further than the treatment of the core positive syndrome. Nonetheless, there is a concern about poor study designs, underpowered samples (Eysenbach et al., 2004; Griffiths et al., 2009; Rice et al., 2014), mixed findings (Bessell et al., 2002), or a lack of intervention studies (Robinson et al., 2015). It is clear, there is an essential need to evaluate the effects of innovative interventions through studies of high quality (Välimäki et al, 2014).

To date, the effects of social media interventions is a field not much investigated (Robinson et al., 2015), especially for people affected with a mental illness (Kaplan et al., 2011). Preliminary research on ICT and specifically social media has shown potential in treatment management of those with schizophrenia or related conditions. For instance, studies have reported improvement of psychotic and depressive symptoms, social skills, hospital admissions and medication adherence. However, studies are heterogeneous, at an early stage, and tend to be of poor quality, thus precise conclusions cannot be drawn (Alvarez-Jimenez, 2014). To our knowledge, there has been no systematic review and meta-analysis researching social media interventions for people with schizophrenia or similar disorders.

2.3 Summary of the literature review

As the overall goal of this study was to investigate eHealth use among people with schizophrenia spectrum disorders in Finland and Greece, the literature was reviewed in order to identify the concepts to be studied (Table 1) and to guide the study phases.

Table 1. Main concepts used in each paper of the study

Main concepts				
Paper I	Paper II	Paper III	Paper IV	
Online mental health information	Portrayals of mental illness	Computer/Internet use	Social media mental health interventions	
Quality indicators of websites	Attitudes towards mental illness	Attitudes toward computers/Internet	Effectiveness	
		eHealth literacy		

eHealth is a broad field, Pagliari and colleagues (2005) reviewed the literature and mapped eHealth. They identified four broad eHealth areas (Professional Clinical Informatics, Electronic Patient/Health Records, Consumer Health Informatics, and Healthcare Business Management) (Pagliari et al., 2005, Table 1). Based on this classification, this PhD study targets to contribute to the body of knowledge in three eHealth fields (Professional Clinical Informatics, Electronic Patient/Health Records, Consumer Health Informatics).

Paper I and Paper II, address the quality of online mental health information retrieved from websites. Thus, the results will contribute in the 'Consumer Health Informatics' area (specifically with issues concerning 'Information on the web' and 'Quality issues for health information on the net'), as it addresses the current mental health information retrieved from Web 2.0 (Google and YouTube). Focusing on the quality of health information and its' associated communication processes required by and for consumers, it can support consumers' health promotion, illness prevention, and the management of care for themselves, their family or friends (IMIA, 2016). Paper III, addresses computer/Internet use, eHealth literacy, and attitudes toward computer/Internet among people with SSD. Thus, the results will contribute in the 'Professional Clinical Informatics' area (specifically with issues concerning 'Educational aids', 'Electronic clinical communications tools', 'Primary care informatics'), 'Consumer Health Informatics' area (specifically with issues concerning 'Clinician-patient communication tools', 'Access and equity issues, and "virtual" health communities'), and 'Electronic Patient/Health Records' area (specifically with issues concerning patient access and control). Paper IV, addresses the potential effectiveness of social media interventions for people with SSD. Thus, the results will contribute in the 'Professional Clinical Informatics' area (specifically with issues concerning 'Educational aids', 'Telemedicine applications') and 'Consumer Health Informatics' area (specifically with issues concerning 'Clinician-patient communication tools' such as web-based messaging systems for consultation and disease monitoring, virtual health communities).

3. AIMS OF THE STUDY

The overall aim of the study was to acquire a deeper understanding of the experience and attitudes on eHealth use amongst people with schizophrenia spectrum disorders in two distant European countries, Finland and Greece. These two European countries were selected because they exhibit discrepancies in Internet availability and use, and citizens' ICT related behaviors (Eurostat, 2016a,b). It is important to investigate eHealth between these two countries, since a basic cornerstone of the European agenda is the right of freedom of movement across the EU (Eurofound, 2007), support of quality health services for citizens and intercountry collaboration (Reding, 2008). The study consisted of three phases, where each phase had one main objective. Each of the three main objectives consisted of research questions, nine research questions in total.

Main objectives and research questions of the study:

To describe and compare online schizophrenia-related health information and videos in Finnish and Greek language

- 1. What is the quality of online, schizophrenia-related health information in Finnish and Greek language?
- 2. How schizophrenia is presented online in Finnish and Greek language schizophrenia-related videos?
- 3. Are there any significant differences between the Finnish and Greek schizophrenia-related health information and videos?

Hypothesis: Finnish language schizophrenia-related health information and videos would be of better quality than Greek-language ones.

To describe and compare computer/Internet use, eHealth literacy, and attitudes toward computer/Internet among Finnish and Greek people with SSD

- 1. What is the prevalence of Internet use for general and for health-related purposes among people with SSD?
- 2. Which are the attitudes toward computer/Internet of those who are not computer/Internet users?
- 3. What is the eHealth literacy level of computer/Internet users with SSD?
- 4. Which are the Internet use patterns of current computer/Internet users?
- 5. Are there important differences regarding computer/Internet use between country groups?

Hypothesis: Finnish people with SSD would exhibit higher prevalence of computer/Internet use.

To retrieve research evidence related to the effectiveness of social media interventions for people with SSD

1. Which is the effectiveness of social media interventions for people with SSD according to previous studies?

Hypothesis: Social media interventions for people with SSD disorders indicate to be effective.

Studies behind each hypothesis for each paper of the study are presented in Figure 1 below.

Paper I & Paper II

Hypothesis: Finnish language schizophrenia-related health information and videos would be of better quality than Greek-language ones

- Studies and official statistics present Finland as a world leader in innovation and technology and more technology advanced than Greece (Eurostat, 2012; 2016), thus, it was expected that Finnish language schizophrenia-related health information and videos would provide better quality information than Greek-language ones.
- Finnish citizens do not have as stigmatizing beliefs and attitudes towards people with schizophrenia, as their Greek counterparts (Tzouvara et al., 2016; Wahlbeck & Aromaa, 2011; Economou et al., 2009). Finland and Greece represent two European extremes in people's beliefs about the degree of devaluation and discrimination towards people with mental disorders (Brohan et al., 2010) and about the integration of their primary care services (Lionis et al., 2009), thus, it was expected that Finnish language schizophrenia-related videos would provide more accurate, medically-focused schizophrenia-related information than the Greek-language ones.

Paper III

Hypothesis: Finnish people with SSD would exhibit higher prevalence of computer/Internet use

- Internet access and use are generally more prevalent in the Finnish than in Greek population (Eurostat, 2016a,b).
- Internet for health information has been somewhat less common in the south European countries (Kummervold & Wynn, 2012).

Paper IV

Hypothesis: Social media interventions for people with SSD indicate to be effective

- People with psychosis use forums and online chats, which could reduce the risk of isolation (Highton-Williamson et al., 2015).
- People with schizophrenia who are Internet users agree that social media improve their interaction/socialization and create interest in receiving text messages from their doctors (Miller et al., 2015).
- e-mental health interventions are at least as effective as standard mental health care (van der Krieke et al., 2014).

Figure 1. Studies behind every hypothesis of each paper of the study

4. METHODOLOGY

This chapter describes the procedures used to acquire empirical evidence in order to answer the research questions, to test hypotheses, and examine foreshadowed problems, following up on conjectures, and going forward from exploratory questions. The research design was a correlational design utilizing cross-sectional survey methodology and included a number of survey instruments. The purpose of the design was to measure and correlate the quality of Finnish and Greek language mental health-related websites and videos, to measure and correlate computer/Internet use of Finnish and Greek adults with SSD, as well as to identify, assess and synthesize the findings from previous studies related to the effectiveness of Web 2.0 interventions for people with SSD.

4.1 Theoretical and methodological orientation

This study aimed to examine online content and the population from two distant and different European countries would provide better understanding of the potential differences in, the online mental health information content, the use of computer/Internet for general and health-related purposes. This comprehension would provide support for future mental health reforms and general European acts. Since the study aimed to examine what is happening, portray the current situation, seek new insights and generate ideas for new research, a descriptive method was used (Robson, 2002). A pragmatic philosophical worldview (Creswell, 2009) guided the methodology design as mixed methods design, combining qualitative and quantitative approaches. Mixed method combining qualitative and quantitative approaches (Johnson et al., 2007) were applied, in order to acquire a comprehensive view of the topic.

In Paper I, the theory of interpretivism guided the study (Bryman, 2001), because the aim was to collect and interpret already published online mental health information (mental health-related websites) (Table 2). The goal of interpretivism is to understand, and its focus is on anything specific and unique (in this case webpages with specific content). Interpretivism considers culture to be a symbolic construction of shared meaning, and looks for what is unique in a culture and in a specific communication situation, observes and decodes patterns of thinking (meaning systems). Since the goal was to decode online mental health information in two different cultures (Finnish and Greek), this theory was found suitable for this part of the study. Qualitative research was selected because the aim was to explore and understand the current situation of the online mental health information in Finnish and Greek language (Creswell, 2009).

In Paper II, the theory of interpretivism guided the study (Bryman, 2001), because the aim was to collect and interpret already published online mental health information (mental health-related videos) (Table 2). The goal of interpretivism is to understand, and its focus is on anything specific and unique (in this case videos with specific content). Qualitative research was selected because the aim was to explore and understand the current situation of the online mental health videos in Finnish and Greek language (Creswell, 2009).

In Paper III, the Theory of Planned Behavior (TPB, Ajzen, 1985) was considered as a theoretical basis in this part of the study, and this is why concepts as 'attitudes' and 'efficacy' were investigated in this survey (Table 2). According to the TPB, human action is guided by three basic concepts: 1) behavioral beliefs and attitudes toward the behavior; 2) normative beliefs and subjective norm; and 3) control beliefs and perceived behavioral control. Finally, all these in combination lead to behavioral intention (Ajzen, 2006). Perceived behavioral control, originates from self-efficacy theory (Bandura, 1977). However, because we wanted to keep the survey as simple and short as possible (due to participants' cognitive limitations) this part of the study did intent to measure all TPB concepts because this would require a long questionnaire, which the pilot test showed that the participants were not willing to answer. The TPB was considered because, first, according to it, if individuals evaluate the suggested behavior as positive (attitude), and if they think their significant others want them to perform the behavior (subjective norm), this results in a higher intention (motivations) and they are more likely to do so; which in this study the attitudes towards computer/Internet were explored. Second, efficacy was also explored, as is the most important precondition for behavioral change, since it determines the initiation of coping behavior; which in this study it is efficacy towards computer/internet was explored. Quantitative research was selected because the aim was to examine the relationship among variables (Creswell, 2009).

In Paper IV, quantitative research was selected because the aim was to critically analyse results from previous individual research studies related to social media and SSD (Table 2). The purpose was to integrate the findings (Moody, 1990) derived from the conclusions on this specific topic.

	Table 2. Theory, memodology and design used in each paper					
	Paper	Theory	Methodology	Design		
	I	Interpretivism	Qualitative	Descriptive, cross-sectional,		
				unobtrusive, content analysis		
	II	Interpretivism	Qualitative	Descriptive, cross-sectional,		
				unobtrusive, content analysis		
	III	Theory of Planned Behavior	Quantitative	Non-experimental, cross-sectional		
				survey		
	IV	(Review of Theory)	Quantitative	Systematic review, meta-analysis		

Table 2. Theory, methodology and design used in each paper

4.2 Design of the study

In Paper I, descriptive, cross-sectional, unobtrusive study design was used. Deductive content analysis was selected because we used a coding tool with categories based on existing literature (Elo & Kyngäs, 2008). The data extraction instrument/coding tool was developed in previous similar studies. This design was selected because we aimed to quantify websites' content in terms of predetermined categories in a systematic and replicable manner (Pope et al., 2007). We aimed to capture what the average Finnish and Greek-speaking Internet user sees, when he/she searches for mental health information on the Web. This is why unobtrusive method (Webb et al., 1966) with descriptive cross-sectional design was used, in order to directly review the targeted data (webpages) without being affected by social desirability bias.

In Paper II, descriptive, cross-sectional, unobtrusive study design was used. Deductive content analysis was selected because we aimed to create a coding tool with categories based on existing theories (Elo & Kyngäs, 2008). The deductive content analysis measured frequencies by using a standard data extraction instrument. This design was selected because we aimed to quantify videos' content in terms of predetermined categories in a systematic and replicable manner (Pope et al., 2007). We aimed to capture what the average Finnish and Greek-speaking Internet user sees, when he/she searches for mental health videos on the Web. This is why unobtrusive method (Webb et al., 1966) with descriptive cross-sectional design was used, in order to directly review the targeted data (videos) without being affected by social desirability bias.

In Paper III, descriptive correlational study design was selected, because in this phase of the study the intention was not to change or manipulate participants' environment or treatment. A descriptive design approach was chosen, because it provides information about the naturally occurring behavior, attitudes or other characteristics of a particular group (Creswell, 2009). In addition, a correlational study design would demonstrate associations or relationships between the two study groups (Finnish and Greek). Thus, the descriptive correlational approach offers a more profound understanding of people's with mental illness views and experience on computer/Internet use and patterns (Lal & Adair, 2014).

In Paper IV, a systematic review with meta-analysis design (Egger et al., 2001, Glasziou et al., 2004) was selected. Systematic review is a systematic search and critical evaluation of all primary studies answering one specific question, while meta-analysis is the quantitative synthesis of all primary studies answering the same question using the same design. Thus, this approach was chosen because we wanted to find an answer on the effectiveness of Web 2.0 interventions for people with schizophrenia spectrum disorders, by exhaustively reviewing the literature and by following strict, detailed, methodological rules (Abalos et al., 2001). Systematic review and meta-analysis are applicable when combining single studies together to obtain up-to-date summaries of the effects of health care interventions (Egger et al., 2001). The use of meta-analysis helped to pool together the results of earlier literature impact evaluation (Rossi & Freeman, 1993).

4.3 Setting, population and sampling

In each study phase, the sample was selected by taking under consideration the cost and time constraints, and how error could be minimized (Sonenstein, 2012).

In Paper I, systematic search via Google Search was applied to identify the data (Table 3). The study population was websites retrieved online through a university PC. A non-probability, judgemental sampling was used (20 first search results of each Google search; 4 search terms in each language) to select the most probable sources of mental health information in Finnish and in Greek language. This sampling method was selected, as previous research has shown that it is unlikely for Internet users to go further than the first 20 Google Search results (Eysenbach &

Köhler, 2002). In total, 160 websites were reviewed for eligibility (N=160; FIN=80, GR=80), while in the end, 58 were included (FIN=24, GR=34).

In Paper II, systematic search via YouTube was applied to identify the data (Table 3). The study population was first-appearing videos retrieved online through a university PC. A non-probability, judgemental sampling was used (20 first search results of each YouTube search; 2 search terms in each language) to select the most probable videos presenting mental health information when someone would perform a simple YouTube search, assuming that Internet users would not go further than the first 20 results (Eysenbach & Köhler, 2002). In total, 80 videos were reviewed for eligibility (N=80; FIN=40, GR=40), while in the end, 52 were included (FIN=24, GR=28).

In Paper III, one catchment study area of psychiatric services was selected in each country (Table 3). The Finnish setting was outpatient services of two psychiatric clinics whose outpatient care serves about 170,000 citizens. In Finland, 128 patients (response rate 50%) were recruited. The Greek setting was outpatient (including the mobile unit) and inpatient services (excluding the acute inpatient care unit because of the severity of patients) of a University Hospital serving approximately 173,450 citizens (Population census, 2011) (Greece). Purposive sampling was used to maximize the likelihood of obtaining a broad range of views. The population consisted of adults with SSD. Hence, the target group consisted of people of different adult age ranges, sociodemographic backgrounds, and varying levels of computer/Internet use overall. In addition, this sampling method was considered useful because these participants hold the information needed to answer our research questions (Higginbottom, 2004; Gray, 2009). In total, 101 patients (response rate 76%) having contact with the outpatient and inpatient services of the Greek psychiatric clinic were recruited.

In Paper IV, a systematic literature review via ten electronic databases (PubMed, MEDLINE, Cochrane Database of Systematic Reviews, PsycInfo, CINAHL, JBI, Scopus, ISI Web of Science, SOCIndex, and Sociological abstracts) was applied to identify the data. The study population (subjects) were articles (N=3; 2 studies). Selective sampling based on inclusion criteria was used (Grove et al., 2013). All generated results from the searches were reviewed for eligibility (N=1044), while 3 articles were included (Table 3).

Table 3. Setting, population and sampling method used in every paper

Paper	Setting	Population	Sampling method
I	Online via www.google.fi and	Websites: N=58	Non-probability,
	www.google.gr, accessed from a university PC	FIN=24, GR=34	judgemental sampling
II	Online via www.youtube.com, accessed from	Videos: N=52	Non-probability,
	a university PC	FIN=24, GR=28	judgemental sampling
III	Psychiatric services in Turku (FIN) and psychiatric services in Heraklion (GR)	People with SSD: N=229 FIN =128, GR=101	Purposive sampling
IV	Online via ten electronic databases, accessed from a university PC	Articles: N=3 (2 studies)	Selective sampling

4.4 Instruments

In Paper I, an instrument developed in previous related studies was used (Griffiths & Christensen, 2000, 2002; Khazaal et al., 2008b) and was selected in order to evaluate the quality of websites and health information related to schizophrenia, accessible to everyone with an Internet connection. It was a coding tool assessing six quality indicators (Table 4) and consisting of 51 items (more about the coding tool in Paper I, Table 1). Coders pilot tested the coding tool and process, in order to ensure mutual understanding of data extraction and scoring.

In Paper II, an instrument was developed based on studies from Corrigan (2004), and Park and colleagues (2011) and it was created in order to evaluate the viewpoints on schizophrenia shown on videos accessible to everyone with an Internet connection. The focus of the content analysis was on both the manifest and the latent content of the videos (Graneheim & Lundman, 2004). It was a coding tool assessing three major indicators (Table 4) and consisting of 29 items (more about the coding tool in Paper II, Table 1). Coders pilot tested the coding tool and process, in order to ensure mutual understanding of data extraction and scoring.

In Paper III, an instrument was developed in a previous related study (Choi & DiNitto, 2013), and was selected because it was reliable and answered our research questions. It was a pen-and-paper, structured questionnaire, which consisted of three sections (Table 4) and a total of 30 to 36 items, depending on Internet use (never users answered 31 items, previous users 30, current users 36 items). The instrument was translated and culturally adapted from the source language (English) to the target languages (Finnish and Greek) based on the 'Minimal Translation Criteria' of the Mapi Research Institute (Acquadro et al., 2004). The translation took into account also the recommendations proposed by the original developers. Then the two translations were compared by a third person who can decide between any different proposals translation to produce an agreed translation (first reconciliation version). Then the agreed version was translated in the language of original questionnaire (backward translation), i.e. in English, a bilingual person (English native), without, however, knowing the original questionnaire. The final step of the translation process included an international harmonization meeting, comprised of two bilingual and bicultural persons (one Finnish who has lived in Finland and Greece, one Greek who has lived in Greece and Finland) to ensure that target versions truly were conceptually equivalent and maintain the content validity at a conceptual level across different cultures (Beaton et al., 2000). The version of questionnaire produced (backward translation) sent to the original authors for comments (authors' comments) and their comments were incorporated to give a second version of the questionnaire in Finnish/Greek (2nd reconciliation version).

The cultural adaptation of the questionnaire occurred with supplementing the questionnaire to 17 individuals (FIN=12; GR=5) having the same diagnosis as the target population (SSD). The pilot in Finland was made in a patient association in Turku, while in Greece in a patient guesthouse in Heraklion. Patients were informed about the purpose of the investigation by an accompanying letter from the researcher and the same document was signed in order to accept their participation in the research. They were all natives of target language in order to determine whether the translation is

accepted and understood by the way they are supposed to be and whether the language used is simple and convenient. The procedure followed is that proposed in the review process knowledge (cognitive debriefing process) (Medical Outcomes Trust, 1997). The interviewer sought if a person had difficulty understanding the questionnaire and each question to face interviews face. In case of a problem, the person was asked to propose something different (cognitive debriefing interview). Their suggestions were incorporated in the Finnish/Greek language. The questionnaires were previously coded in order to preserve the anonymity of the patients surveyed and the questionnaires did not bring any evidence (beyond gender and age).

Table 4. Instruments' components in every paper of the study

Paper Instrument components T 1) Type of website (Morel et al., 2008); 2) Characteristics (Griffiths & Christensen, 2000; 2002); 3) Accountability (Silberg et al., 1997; adapted by Griffiths & Christensen, 2000); 4) Interactivity (Abbott, 2000, adapted by Khazaal et al., 2008a); 5) Aesthetics (Abbot, 2000; adapted by Kisely et al., 2003); and 6) Content (based on Khazaal et al., 2008a). II 1) Basic information (Video category; Year of video upload; Number of views; Number of likes; Number of dislikes; Number of favorites; Viewers' top location; Viewers' gender; Viewers' age group; Number of comments) 2) Attitudes towards mental illness: a) Positive/neutral (Recovery; Real life goals; Empowerment; Objective; Other positive) b) Negative (Dangerousness; Unpredictability; Incompetence; Childlike; Blame; Contagion; Fear; Anger; Pity; Disgust; Other negative attitudes) 3) Video category: a) Positive/neutral, or b) Negative (according to how each video generally tended to present mental illness or those affected, based on the manifest (tangible, concrete content) and the latent (underlying meaning) content). 1) Basic Information (Demographics, Age of first contact with psychiatric services, Internet use Ш and reasons for non-use or discontinuation, Perceived importance of eight sources of health information, use of mobile phone, use of SMS). 2) a) Never Internet users filled: 'Attitudes Toward Computer/Internet' (Bear et al., 1995; adapted by Choi & DiNitto, 2013). b) Previous and Current Internet users filled: 3) eHealth Literacy Scale (eHEALS; Norman & Skinner, 2006; adapted by Choi & DiNitto, 2013). 3) Current Internet users filled: Internet use patterns part (Choi & DiNitto, 2013) (location of Internet access, existence of email address, frequency of Internet use, reasons of Internet use, difficulty in finding a website and searching for information, and physical restrictions which make Internet use difficult). IV 1) Basic characteristics (Methods; Participants; Intervention; Outcomes; Notes). 2) Characteristics of the studies (Country of origin; Purpose of the study; Setting of patient recruitment; Patient group; Inclusion criteria; Number of patients enrolled; Follow-up period; Number of drop-outs) 3) Social media interventions based on the TIDieR checklist (Hoffmann et al., 2014) (Brief name; Why (rationale or theory); What (materials, procedures); Who provided intervention; How; Where; When; How much; Tailoring; Modifications; How well planned; How well actual). 4) Outcomes and instruments used in each study were identified. 5) Reasons for exclusion of studies (Allocation, e.g. non-randomized; Participants, e.g.

6) The a) use of social media, and b) stress after social media use were also identified and

undergraduate students; Intervention, e.g. no social media)

described.

In Paper IV, an instrument for managing the data was based on the "Cochrane Handbook for Systematic Reviews of Interventions" (Higgins & Green, 2011). Assessment of eligibility of studies and extraction of data from study reports followed the Cochrane guideline (Higgins & Green, 2011). The coding tool included three points (Table 4). Then, outcomes and instruments used in each study were identified. Finally, reasons for exclusion of studies, use of social media, and stress after social media use were described.

4.5 Data collection

In Paper I, the Web search engine 'Google Search' was used on November 30th, 2011, to identify websites on schizophrenia or related conditions in the Finnish (http://www.google.fi/) and Greek (http://www.google.gr/) languages. Google Search is globally the most popular search engine (eBizMBA, 2016), thus the most likely to be used by someone searching for online health information. We aimed to generate a list of search results similar to a search produced by a Finnish or Greek adult with average medical, Internet, and computer expertise (Purcell et al., 2012), therefore, four simple search terms were used ('mental illness', 'mental disorder', 'schizophrenia', 'psychosis') in the Finnish and in Greek languages. The first 20 websites of each search (four searches each language) were examined for eligibility (N=160; FIN=80; GR=80), while the 20 direct links from each search were saved as PDF files. Additionally, screenshots of the direct webpages appearing from every of the eight searches were taken, and from each eligible website, five random webpages were saved. Inclusion criteria for websites were: 1) focused on health or mental health issues for adults in Finnish/Greek language; and 2) standard information websites, open web-based encyclopedias (e.g. 'wikipedia'), discussion forums, blogs or wikis. The latter was included since it has been reported that they are favoured online sources among people with schizophrenia (Schrank et al., 2010). Exclusion criteria for websites were: 1) not focused on health or mental health issues; 2) targeted educators or special schools' educators or described courses; 3) primarily involved advertisements or book promotion; 4) links leading to external files (e.g. .doc, .pdf, .ppt); 5) invalid addresses or malware; 6) incidental mental health articles or discussion in a non-health oriented forum or blog; 7) were not written in the Finnish or Greek languages; 8) or provided health information for a non-adult population (e.g. for children or adolescents, or parents of underage children). Coding was conducted by one rater for each language, where in an Excel file scored '1' to indicate a criterion was satisfied, and '0' when a criterion was absent.

In **Paper II**, the video-sharing website 'YouTube' was used on April 3rd, 2013, to identify videos describing schizophrenia or related conditions in the Finnish and Greek languages. The default search parameters were preserved, with selected language as English and not Finnish/Greek, since it only changes the interface without influencing the search (YouTube, 2013). Two search terms (schizophrenia, psychosis) were typed in the Finnish and Greek languages. Both terms reflect simple medical definitions of schizophrenia, requiring no medical expertise, and thus preferred among online health seekers (Zhang et al, 2012). The first 20 videos of each search (two for each language) were examined for eligibility (N=80; FIN=40; GR=40), since a typical Internet user is unlikely to click on more than the twenty first search results (Eysenbach & Köhler 2002;

Höchstötter & Lewandowski, 2009). After screening, 40% of Finnish (n=16) and 30% of Greek videos (n=12) were excluded. Included were all videos: 1) in Finnish/Greek language, or videos in another language including Finnish/Greek subtitles; and 2) those from which a connotation to schizophrenia/psychosis was present and a judgment on the attitudes of mental illness could be determined. Excluded were those videos which: 1) had already been analysed (duplicates); 2) were not in Finnish/Greek; 3) channels; 4) were unavailable or incomprehensible (their content could not be understood); or 5) incidental (no connotation to schizophrenia/psychosis or mental disorders in general). Coding was conducted by one rater for each language in an Excel file, where in an Excel file scored '1' to indicate a criterion was satisfied, and '0' when a criterion was absent. The content analysis focused on the videos' manifest and the latent content in order not only to identify the obvious attitudes towards schizophrenia presented in each video component, but also to identify potential underlying meanings within each video. After both raters had watched each video and read its accompanying title, they decided whether the video tended to present schizophrenia or those affected with the disorder in a positive/neutral or negative way and justified their judgements in an Excel table.

In Paper III, the Finnish data collection was made by psychiatric nurses, while a contact person was selected among them. The contact person was informed about the study goals and procedure and was the responsible of the information packages distribution to the nurses (information letter, two consent forms, structured printed questionnaire). An information session was held in June 2015, in which all nurses (N=20) who accepted to assist with the study participated. Health professionals were informed about the study goals, procedure, and expected results. Prior to data collection, all participants filled and signed the informed consent form. In Finland, participants were instructed to complete the instrument independently, using paper and pen. On average, it took approximately 10-30 minutes for a participant to complete the instrument. In Finland, data collection took place for 8 months (May-December 2015). In both country groups, eligible for inclusion were those: 1) 18 years old and above; 2) in contact with outpatient services from June – December 2015 (Finland), from September 6th - November 5th, 2015 (Greece); 3) diagnosed with schizophrenia spectrum disorder as a primary diagnosis (F20-29; ICD-10); 4) able to understand, speak and read Finnish/Greek language; 5) willing to participate in the survey based on their own free will (signed informed consent); 6) stable health status judged by the treating psychiatric nurse (Finland) or psychiatrist (Greece). Exclusion criteria were: 1) below the age of 18; 2) had other primary diagnosis than schizophrenia spectrum disorder (F20-29; ICD-10); 3) unable to understand, speak and/or read Finnish/Greek; 4) unwilling to participate and/or; 5) incapable to participate in the survey (due to their health status).

The Greek data collection was made by the PhD candidate (CA). CA informed the psychiatrists of the psychiatric clinic about the study goals and procedure, while she was the responsible of the information packages distribution in Greece (information letter, two consent forms, questionnaire). The responsible psychiatrists judged if screened participants were eligible to participate according to their health status. Prior to data collection, all participants filled and signed the informed consent form. Participants had the option to complete the questionnaire through a structured interview made by CA. On average, it took approximately 10-30 minutes for a participant to complete/answer the

questionnaire. The data collection took place for 2 months (September 6th – November 5th 2015). The same inclusion/exclusion criteria applied in the Greek study as well.

In Paper IV, all identified studies were exported to RefWorks (ProQuest LLC, 2016) and then duplicates were removed. The data collection extraction matrix, wherever possible, was based on the CONSORT-EHEALTH checklist (Eysenbach, 2011). Studies were included if they were: 1) Randomized control trials (RCT) evaluating the effectiveness of social media interventions for people with SSD, 2) in English-language, 3) published (or in press) prior to June 25th, 2015. For those included, basic characteristics, characteristics of the studies, and social media interventions were described. Outcomes and instruments used in each study were identified. Further, reasons for exclusion of studies were described. For narrative analysis, data of each included study were entered into the data extraction matrix; each study was treated as a separate case. Descriptive characteristics of the studies were categorized manually. Additionally the: 1) use of social media, and 2) stress after social media use, were also described.

4.6 Data analysis

In Paper I, the data was analyzed with descriptive statistics to describe individual characteristics of each quality indicator (see Paper I, Table 2). Accountability, interactivity, and aesthetics were computed by summing the value of each score of the item (yes=1; no=0). Correlations among accountability, interactivity and aesthetics were analyzed using Pearson's correlation coefficient (see Paper I, Table 3, Table 4 and Table 5). Differences between categorical variables was evaluated using Chi-Square tests or Fisher's Exact test if expected cell counts were <5. Differences in indicator scores between the Finnish and Greek websites were analysed using independent t-tests. Data was analysed using SPSS version 19.0 (IBM Corporation, 2011), while all statistical analyses and in all tests, an alpha of .05 was employed for identifying a statistically significant difference

In Paper II, the data was analyzed with descriptive statistics to describe individual characteristics of each variable (frequencies, median, quartile 1, quartile 3, range) (see Paper II, Table 2, Table 3, Table 4, and Table 5). Differences between Finnish and Greek data were compared with cross tabulation and Fisher's Exact tests, where P < .05 was taken to be statistically significant. Wilcoxon rank sum test was used to compare the numbers of views, likes, dislikes, favorites, and comments, between the Finnish and Greek videos. Data was analysed using SPSS version 19.0 (IBM Corporation, 2011).

In **Paper III**, the data was analyzed with descriptive statistics (counts, proportions, means, and standard deviations) and the demographic variables and individual survey questions were calculated (see Paper III, Table 1, Table 2, and Table 3). Group comparisons with multiple linear and logistic regression models (see Paper III, Table 4). All data was analyzed with the JMP Pro (2015) and SPSS Version 21.0 (IBM Corporation, 2011) for Windows. Analyses were considered statistically significant at the P <.05 alpha level (2-tailed).

In Paper IV, the data was analysed with quantitative methods using the Review Manager 5.3, a software used for preparing and maintaining Cochrane Reviews (Higgins & Green, 2011). First, the analysis explored the descriptive characteristics of the individual studies included (see Paper IV, Table 3, Table 4 and Table 5). Second, for continuous outcomes the mean difference (MD) between groups was estimated. When similar scales, such as symptom checklists, were used, it was presumed there was a small difference in measurement tools and combined the measurements. This decision was made to answer the overall question of whether there is evidence that social media can be an effective intervention among people with schizophrenia (Higgins & Green, 2011). In this approach, standard deviations (SD) were used together with the sample sizes to compute the weight given to each study. Random effect was used instead of fixed effect, because random effect allows the outcomes of studies to vary more than fixed effects. In other words, random effects can be seen to be a more natural way of explaining outcomes (Ades et al., 2005). Heterogeneity was checked by calculating I² – square statistic. Where the I² – square estimated was greater than, or equal to 50%, it was interpreted as indicating the presence of high levels of heterogeneity (Higgins & Green, 2011) (see Paper IV, Figure 2, Figure 3, Figure 4, Figure 5, and Figure 6). The Quality of the included studies was assessed based on the Cochrane Collaboration's tool for assessing risk of bias (Higgins & Green, 2011) (see Paper IV, Figure 7).

4.7 Ethical considerations

The doctoral study consisted of three phases, in which the basic principles of research ethics were followed (ETENE, 2001; Academy of Finland, 2003; Declaration of Helsinki, 2008). Ethical considerations started with the selection of research topic and continued until the publication of research findings (Burns & Grove, 2005). This study complied with the guidelines and recommendations of the National Advisory Board on Research Ethics (www.protsv.fi/tenk), while laws from the European (EUREC), Greek (Acts 2071/1992, 2472/1992, 2519/1997) and Finnish (Acts 488/1999, 523/1999, 295/2004,) legislation were followed. According to the Medical Research Act (488/1999, amended 295/2004) an independent ethics committee pre-evaluated and gave a favorable opinion before the study started. All data collected during this research process were handled and stored in an appropriate way (Act 831/1994, Personal Data Act 523/1999, Constitutional Act 731/1999).

In Paper I, permission to use the previously developed instruments for the websites' assessment was asked through email communication with the original authors. No ethics committee statement was needed for this paper because the study did not involve patients, but online information publicly available to everyone. Lately in nursing science, there is an increasing interest towards patient empowerment and involvement in treatment and health promotion. Since it is proven that people with serious mental disorders search for online health information which potentially affect their health-related decisions, health professionals have to be vigilant about the content of health information their patients access. Therefore, we wanted to promote the importance of access to accurate and trustworthy online health information, by assessing the characteristics of first appearing websites and detecting stigmatizing messages among first appearing online sources.

In Paper II, the Ethics committee of the University of Turku granted permission to collect and analyse the YouTube videos about schizophrenia (26/2014). Data (videos) were analysed and reported anonymously, so readers would not be able to identify the videos or the users who uploaded them on YouTube. Content analysis and other quantitative techniques which summarised insights across this population is considered of less ethical concern, than in-depth qualitative studies focused more on the individual (Hine, 2011).

In Paper III, permission to use the questionnaires was granted by the original authors via email communication. All (bio)ethical committees approved the study protocol, both from the central ethical committees (University of Turku and University of Heraklion) and from local ethical committees (e.g. hospitals) (Sermeus et al., 2011). The study was approved by the Ethical Committees of the participating Hospitals in Finland (157/1802/2014) and Greece (5162/20-4-2015), in accordance with the Helsinki Declaration. The ethical principles for medical research involving human subjects were followed (Declaration of Helsinki 2008). As people with mental disorders is a vulnerable group in health care (WHO, 2010), which means they could be incapable of protecting their own interests and have insufficient power, intelligence, education, resources, strength, or other needed attributes to protect their own interests. This is why their mental health status needed to be good enough to give informed consent, judged by the treating psychiatric nurse (Finland) or psychiatrist (Greece). The researcher did not underestimate participants' ability to make decisions and ensured the information she was giving were understandable (Royal College of Psychiatrists, 2001). Participants were informed both orally and with written material. Voluntary nature of participation was underlined, and that either participation or refusal do not have effect on their treatment (Medical Research Act 488/1999). Participants' autonomy was respected (CIOMS, 2002), and their privacy, dignity and integrity were protected (Royal College of Psychiatrists, 2001). The informed consent was asked carefully respecting participants': ability to consent (Kanerva et al., 1999), ability to understand, expect to know and understand/remember information (Dillon et al., 2005). Participants were told sufficient information regarding the study and their understanding was ensured (CIOMS, 2002) as well as their right to withdraw of the study without any reason. All of the permission and consent forms were stored in a locked closet to which only the researcher had a key. Data were coded, analysed and reported anonymously, and therefore coding numbers were used.

In Paper IV, no consent or permission was required or sought prior to conducting the literature review. However, all of the appropriate regulations and guidelines were adhered during the entire research process, from data collection to data analysis and reporting. General conventions on publication ethics and guidelines produced by various organizations were followed (ICMJE, 2014) as well as, the guidelines from the Cochrane handbook (Cochrane Collaboration, 2011). Contributors were properly acknowledged, potential conflicts of interest were declared, and the review did not contain plagiarized material (Wager & Wiffen, 2011).

5. **RESULTS**

This chapter contains published findings from Paper I, Paper II and Paper IV. While the data findings from Paper III have been submitted to a scientific journal and the manuscript is currently under review.

5.1 Characteristics of study participants (Papers I, II, III, IV)

In Paper I, 58 websites satisfied the inclusion criteria (FIN=24, GR=34). *Types* of websites were: commercial (n=18), personal pages developed by health professionals (n=7), university websites (n=1), non-profit organizations (n=7), governmental (n=2), open source (n=5) websites where anyone could modify the webpage content, or other sources (n=18), e.g. patient/professional associations. As for the websites' *Characteristics* most of them originated from Finland or Greece (FI=24, GR=31), while three were maintained by the European Commission. Other Language option was provided by about one third (34%, n=11) of the Finnish and Greek (29%, n=7) websites, mostly English and/or Swedish for Finnish websites and, English and/or French for Greek websites. Online services, such as video-conferencing or web counselling were available in a few of the Greek websites (n=2, 6%) and not at all in the Finnish websites. The Health On the Net certification (HON, 2011) was apparent in three Greek websites, and in none of the Finnish websites.

In Paper II, 52 videos satisfied the inclusion criteria (FIN=24, GR=28), with overall duration four hours and fifty-one minutes. The most common video category was *Music* (n=26, 50%), followed by *Education* (n=11, 21%). Most videos were uploaded in year 2011 (n=16, 31%), and the fewest in 2013 (as of April 3rd, n=6, 11%). Most viewers appeared to be male (n=21, 58%), between ages 45-65 (n=16, 44%). Viewers' ages for the Greek videos appeared to be higher than for the Finnish videos and statistically significant (P=.002). Video views ranged from 31 to 136128 (median 1518). On average videos had 4 'Likes', 0 Dislikes, while the median for Favorites was 2. In this part of the analysis, no statistically significant differences were found between the Finnish and Greek videos.

In Paper III, 389 people with the specific diagnosis (F20-29; ICD-10) were asked to participate (FI=256, GR=133). As a whole, 229 patients (response rate 59%) agreed to participate (FI=128, GR=101). Among them, 32% (n=73) had finished primary or middle school (FI=20, GR=53), and the vast majority of the sample was on disability pension (N=124, 54%, FI=91, GR=33). Most of them were single (n=141, 62%, FI=97, GR=44). Finally, a bit less than half, 48% lived alone (N=109, FI=87, GR=22), while the mean years since the illness' onset was at 27 years (SD=11.3).

In Paper IV, 1043 records were identified during the systematic review. After excluding duplicates, 727 records were screened, and finally 3 records (2 studies) fulfilled the inclusion criteria and were assessed. Both studies were conducted in the USA. Participants in these studies were recruited from outpatient facilities, websites and e-newslists. The Rotondi and colleagues study (2005, 2010) included people with schizophrenia or schizoaffective disorder (DSM-IV criteria; APA, 2013) (n=31), with a mean age of 37.5 years (SD=10.7). Most of the participants

were female (68%), and almost half Caucasian (48%). The other study by Kaplan and colleagues (2011), the participants were diagnosed with schizophrenia spectrum or affective disorder (n=300), their mean age was 47 years, one third were male (n=102), and 87% were white (n=260).

5.2 Online schizophrenia-related health information and videos (Papers I, II)

5.2.1 Quality of online schizophrenia-related health information in the Finnish and Greek languages (Paper I)

The *accountability* indicator was found poor with mean score 3.33 (SD 1.93) out of maximum 9 (Figure 2). The website ownership was specified in most of them (n=43, 74%), and over half (n=32, 55%) provided sources for their content. Eleven websites mentioned the authors' affiliations and the last date of modification. The total mean *interactivity* score was 1.79 (SD 0.87) out of maximum 5 (Figure 2). More specifically, five websites (9%) included evaluation questionnaires (e.g. enabling the user to provide feedback about the website or evaluate his/her health status). About three-quarters (n=43, 74%) of all websites provided the webmaster's e-mail address, while two-third (n=36, 62%) provided an intra-site search engine. The mean score for the *aesthetics* indicator was 2.6 (SD 0.62) out of maximum 4, which was higher to the maximum potential score than other indicators (Figure 2). Headings or subheadings appeared in all websites (n=58, 100%). Advertisements were not apparent in almost half of the sites (n=85, 49%). Hyperlinks to external sites existed in two-thirds of the sites (n=40, 69%), while four websites (7%) included diagrams in their content. Last, the *content* indicator, showed that Finnish webpages commonly provided information about diagnosis (n=17, 71%), while in Greek webpages information about treatment was the most common (32%).

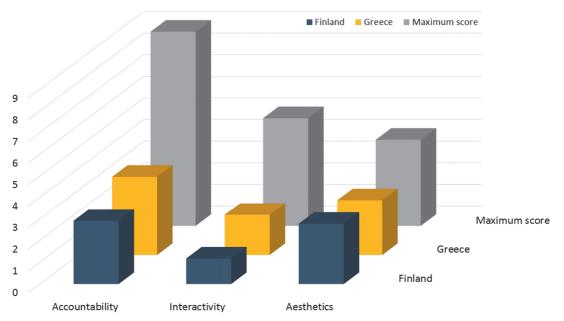


Figure 2. Mean scores of accountability, interactivity and aesthetics of Finnish and Greek websites

5.2.2 Presentation of online schizophrenia-related videos in the Finnish and Greek languages (Paper II)

The majority of the videos tended to be negative towards schizophrenia or those affected with the disorder (n=43, 83%). For example, negative videos were entitled 'schizophrenia' or 'psychosis' and used the term to denote obsessive love, sarcasm, unpredictability, lack of reality awareness. Negative videos were also found in the 'Education' category, where not all videos seemed to have an educational purpose. A few videos tended to present schizophrenia in a positive or neutral way (n=9, 17%). Out of the positive/neutral videos, most of them (n=7) showed health professionals sharing their expertise about mental disorders. For example, a video entitled 'What is schizophrenia' presented a doctor who was talking about the disorder. Another video which was a television documentary entitled 'Mental collapse', showed a person affected with the disorder talking about his experience. In addition, one animated video presented how symptoms of schizophrenia may affect a person's life and how the disorder progresses.

5.2.3 Differences between the Finnish and Greek online schizophrenia-related health information and videos (Papers I, II)

Regarding the Finnish and Greek websites presenting schizophrenia-related health information, when their *Characteristics* were compared, statistically significant differences were found in three factors: *Ownership by a health professional* (FIN=21% vs. GR=56%, P=.008); *Involvement of a health professional in the content development* (FIN=38% vs. GR=76%, P=.003); *Promotion of products or services* (FI=21% vs. GR=50%, P=.024). When *Accountability* of the Finnish and Greek websites was compared, only one statistically significant difference was found, *Authorship*, which was mentioned more often in the Greek than in the Finnish websites (FI=21% vs. GR=47%, P=.04). There were no statistically significant differences in the *Aesthetics* quality indicator for the Finnish and Greek websites. When the *Content* of the websites was compared, the only statistically significant difference between countries was the provided information about *diagnosis* (FI=71% vs. GR=18%, P<.001). Overall, proportionate to the potential range of scoring, the highest scoring quality indicator was *Aesthetics* of the websites (2.6 out of 4), followed by *Accountability* (3.33 out of 9) and *Interactivity* (1.79 out of 5) (Figure 2).

Regarding the Finnish and Greek online schizophrenia-related videos, after comparing the *attitudes* presented towards schizophrenia, no statistically significant difference was found. *Dangerousness* was the most diverse attitude, but not statistically significant (FIN=17% vs. GR=39%, P=.12). Dangerousness was apparent in the Finnish videos as: recounting of a violent situation (aural), hammer smashes egg and blood coming out (visual); while in the Greek videos as: broken screen (visual), stabbings (visual), screams (aural), dead bodies (visual), guns (visual), 'I am schizo, I hit from below' (aural/song lyrics), dragging someone by the feet (visual). In the Finnish videos the most prevalent attitude was neutral/objective views and dangerousness (Figure 3, left word cloud). In the Greek videos the most prevalent attitude was dangerousness, obsessive love, then neutral/objective, and that people with mental illness belong in a distorted world/irrational (Figure 3, right word cloud). When the general presentation of schizophrenia in the videos was compared,

both Finnish and Greek videos tended to be mostly negative (FIN=19, 79% vs. GR=24, 86%), with no statistically significant difference (P=.72). About a fifth of the Finnish videos (n=5, 21%) and less in the Greek videos (n=4, 14%) tended to present schizophrenia in a positive/neutral way.



Figure 3. Word clouds of most common attitudes towards schizophrenia presented in the videos (bigger word size denotes higher prevalence of the specific attitude)

5.3 Computer/Internet use, attitudes toward computer/Internet, and eHealth literacy among Finnish and Greek people with SSD (Paper III)

5.3.1 Prevalence of Internet use for general and health-related purposes among people with SSD (Paper III)

Among all participants, 32% were never Internet users (FI=14, 11% vs. GR=60, 59%), 5% were previous Internet users (FI=3, 2% vs. GR=8, 8%), and 63% were current Internet users (FI=111, 87% vs. GR=33, 33%). More than half of the Internet users in each country group (N=81, 56%, FI=61, 55%, GR=20, 61%) used the Internet for health-related purposes, such as, to search for health-related information, communicate with health professionals about health-related issues, and communicate with other users about health-related issues.

5.3.2 Attitudes toward computer/Internet among never computer/Internet users (Paper III)

Attitudes toward computer/Internet (ATC/IQ), specifically participants' self-rated efficacy and interest for computer/Internet were measured. Finnish participants, on average, reported a neutral level ('undecided') of efficacy with mean score 2.93 (SD=0.81) out of maximum 5 and mean score of interest 2.60 (SD=0.67) out of maximum 5. Greek participants' efficacy scored similarly to their Finnish counterparts at 3.06 (SD=0.86), however, their interest scored much higher at 3.16 (SD=0.50). What Finnish (Figure 4) and Greek participants (Figure 5) reported in each ATC/IQ item are shown below.

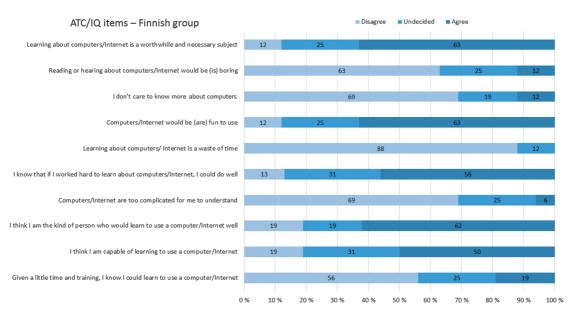


Figure 4. Finnish group's responses (%) for the Attitudes Toward Computer/Internet Questionnaire

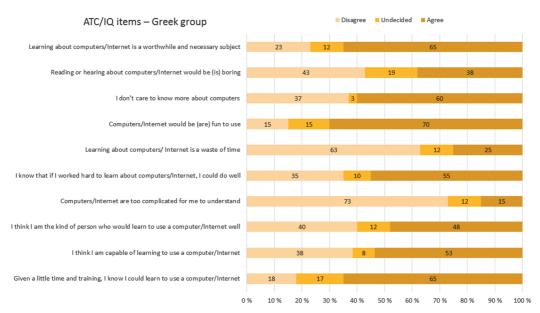


Figure 5. Greek group's responses (%) for the Attitudes Toward Computer/Internet Questionnaire

5.3.3 eHealth literacy among previous and current computer/Internet users (Paper III)

The mean score of the eHealth literacy (eHEALS) was 27.05 (SD=5.36) out of maximum 40 for the Finnish group. For the Greek group eHealth literacy scored at 23.15 (SD=7.23). What Finnish (Figure 6) and Greek participants (Figure 7) reported in each eHEALS item are shown below.

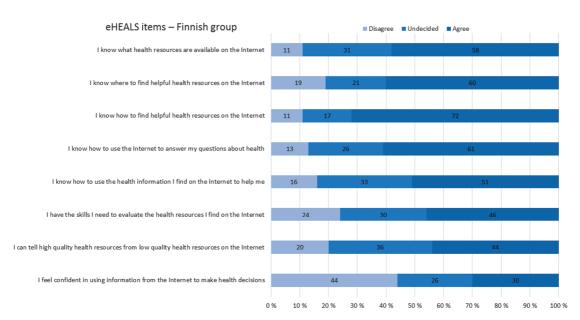


Figure 6. Finnish group's responses (%) for the eHealth literacy scale

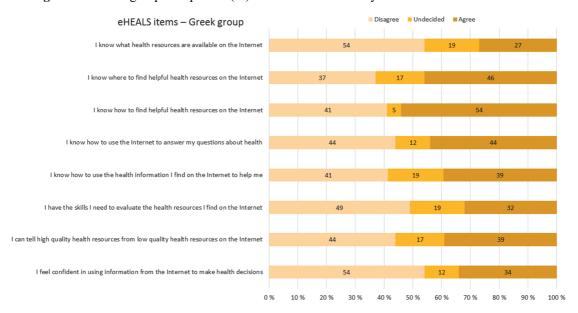


Figure 7. Greek group's responses (%) for the eHealth literacy scale

5.3.4 Internet use patterns among current computer/Internet users (Paper III)

Almost all of the Finnish Internet users had Internet connection at home (n=106; 95%), and had had an email address (n=104; 94%). Most of them they used the Internet at least once per day (n=85; 77%),

while sometimes found it easy to locate the website and the information they were looking for on the Internet (n=67; 60%). The top reasons of Internet use were: to do banking online/pay bills (n=101; 91%), search for information online (not health-related) (n=98; 88%), and send/receive email (n=91; 82%) (Figure 8). The most frequent reason which made Internet use harder for them, was difficulty in concentration for long periods of time (n=31, 28%). The majority of Greek Internet users had Internet connection at home (n=27; 82%), and a few accessed the Internet through their mobile phones or tablets (n=4), at work (n=1), Internet café (n=1), or a family/friends' house (n=1). Most of them had had an email address (n=29; 88%), where using the Internet at least once per day (n=23; 23%), and found it always easy finding the website and the information they were looking for on the Internet (n=12; 36%). The top reasons of Internet use were: research for information about topics of interest (not health-related) (n=30; 91%), watch videos (including YouTube) (n=30; 91), and use social networking websites and/or dating sites (n=25; 76%) (Figure 8). The most frequent reason which made Internet use harder for them, was difficulty in concentration for long periods of time (n=11, 33%).

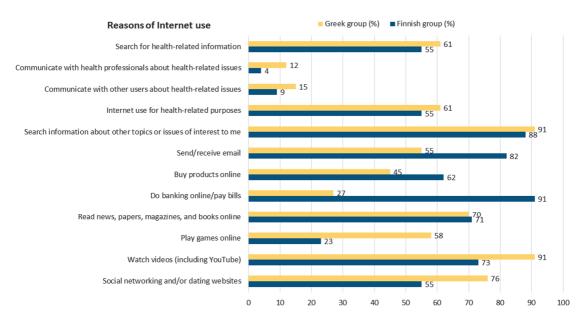


Figure 8. Reasons for Internet use (%) in the Finnish and Greek group

5.3.5 Differences regarding computer/Internet use between country groups (Paper III)

Internet use was found to be statistically different by country (P<.001), with a higher rate of use among the Finnish group. Regarding attitudes toward computer/Internet, Interest, was statistically significant different (P=.018), with the Greek sample reporting higher interest towards learning about computer/Internet. Efficacy (the other component of ATC/IQ) was not found significantly different. eHealth literacy was found to be statistically significant different between country groups, higher in the Finnish group. Among current Internet users, when comparing the Finnish with the Greek group, several statistically significant differences were found concerning: Internet at home

(P=.02) and use in other places (P=.02), frequency (P<.0001) and reasons of Internet use, and easiness to locate information and website (P<.0001).

As of the eHealth literacy (eHEALS) among previous and current Internet users, the Finnish group's eHEALS score was Mean=27.05 (SD=5.36) out of maximum of 40. Whereas, the Greek group's score was lower Mean=23.15 (SD=7.23), and statistically significantly different between countries (P<.0001). As of Internet use patterns among current Internet users, differences between country groups were found in: location of Internet access (P=.02), frequency of Internet use (P=.03), send/receive email (P=.001), do banking online/pay bills (P<.0001), play games online (P<.0001), watch videos (P=.03), use social networking/dating sites (P=.03).

5.4 Research evidence on the effectiveness of social media interventions for people with SSD (Paper IV)

People with SSD from both included studies appeared to be engaged in the social media interventions. Study participants were recruited from staff at in- and outpatient psychiatric care units and psychiatric rehabilitation centers (Rotondi et al., 2005, 2010) and from websites and enewslists targeting individuals with mental illnesses (Kaplan et al., 2011). The Rotondi and colleagues study (Rotondi et al., 2005, 2010) participants (N=31) were diagnosed with schizophrenia or schizoaffective disorder (DSM-IV criteria; APA, 2013). In the Rotondi et al. study, participants were randomized into: 1) a telehealth intervention group, or 2) the usual care group. This study aimed to evaluate the feasibility of a telehealth psychoeducation intervention for persons with schizophrenia and their family members. The main result of that study was that when compared with the control group, persons with schizophrenia in the telehealth intervention group had significantly less perceived stress and showed a trend toward greater perceived social support. However, there were no significant differences in outcome variables between the support persons in the telehealth and the control group.

In the Kaplan and colleagues study (Kaplan et al., 2011), participants (N=300) were diagnosed with schizophrenia spectrum or affective disorder. Participants were randomized into one of three groups: 1) experimental peer support LISTSERV (in which individuals communicated anonymously with one another using a group distribution email list, and participants were encouraged at study entrance to read and respond to email messages); 2) experimental peer support bulletin board (in which participants were given instructions on how to create a username and password and login to the bulletin board that was accessible only to them); or 3) a waitlist control condition. This study aimed to determine the impact of unmoderated, unstructured Internet peer support, similar to what is naturally occurring on the Internet, on the well-being of individuals with psychiatric disabilities. Interventions of the studies included interactivity and social media (peer-directed LISTSERV group, or Bulletin board group), as well as specific outcomes (Table 5). The main result of that study was that participation in an unmoderated, unstructured Internet LISTSERV or Bulletin board peer support group for individuals with psychiatric disabilities did not seem to enhance well-being.

The effectiveness of the social media interventions was investigated by a meta-analysis, performed to both studies (Rotondi et al., 2005, 2010; Kaplan et al., 2011). Comparisons for social support after six months from baseline showed some improvement in the treatment as usual group (P=.03, MD=0.22, 95% CI 0.02 to 0.42). When self-rated stress was compared six months from baseline, Rotondi et al. (2005) study reported some effects in the social media intervention group (P=.01, MD=-0.51, 95% CI -0.9 to -0.12). Regarding self-management, Kaplan and colleagues (2011) compared self-management between groups after 4 and 12 months from baseline. They found that the treatment as usual group was slightly more effective than the social media group (P=.00, MD=0.07, 95% CI 0.07 to 0.089).

Moreover, Kaplan and colleagues (2011) compared quality of life after 4 and 12 months from baseline and reported that participants in the social media group, had significantly higher QoL scores than participants in the control group (P=.00, MD=0.15, 95% CI 0.14 to 0.17). Generally, social media use was found to be less effective than treatment as usual. Nevertheless, there was not enough evidence to draw a definite conclusion. The methodological quality of the two studies varied. Incomplete details in reporting the sequence generation and allocation concealment decreases the methodological quality of both studies. Neither study was blinded, nor was an attempt made at blinding because of the nature of the intervention. Selective reporting may be possible as study protocols were not available.

Table 5. Outcomes of the included studies and potential improvement from social media interventions

Outcomes	Rotondi et al. study	Improvement	Kaplan et al. study	Improvement
Symptoms	Scale for the Assessment of Positive Symptoms	-	The Hopkins Symptom Checklist (HSCL)	-
Knowledge level	Knowledge About Schizophrenia Instrument	-	-	-
Recovery	-	-	The recovery assessment scale, RAS	-
Quality of life	-	-	The Quality of Life Interview (QoL)	Social media group, had significantly higher QoL scores than control group (P=.00, MD=0.15, 95% CI 0.14 to 0.17).
Empowerment	-	-	The Empowerment Scale	-
Social support	Perceived social support	Some improvement in the treatment as usual group (P=.03, MD=0.22, 95% CI 0.02 to 0.42)	The Medical Outcome Study (MOS)	-
Stress	Self-rated stress	Some effects in the social media intervention group (P=.01, MD=-0.51, 95% C1 -0.9 to -0.12)	-	-

5.5 Overview of study results

The main hypothesis of the study was that there would be major differences between the two countries (in favour of Finnish) since they are two European, but yet, diverse countries with Finland being more technologically advanced. The main results were in some cases unexpected since: 1) both Finnish and Greek language online schizophrenia-related health information, were found to be of low quality, without many major differences; 2) the presentation of schizophrenia in online Finnish and Greek language videos tended to be negative without important differences between the Finnish and Greek languages; 3) computer/Internet use among Finnish people with SSD was more prevalent than their Greek counterparts, while Finns scored higher also in eHealth literacy and lower in attitudes toward computer/Internet (interest); 4) to date, there is no clear evidence about the effectiveness of social media interventions for people with SSD.

Consequently, based on the study results we could summarize that:

- first-generated online mental health information, and first-generated online videos related to schizophrenia, provide inadequate health information, while many are unreliable, misleading, even stigmatizing. This alone, does not prove there are no high quality mental health information online, but brings to our attention that when mental health-related search terms are searched online, webpages with low quality come up, and related videos instead of informing about mental illness, tend to promote stigmatizing views about schizophrenia and psychosis.
- 2) people with SSD in two distant European countries exhibit different Internet use patterns, attitudes towards computer/Internet, and eHealth literacy levels. Never Internet users, exhibited moderate interest and efficacy towards computer/Internet (as measured in ATC/IQ), with the Greek group scoring a bit higher than the Finnish group, and significantly higher regarding interest. People did not use the Internet either because they believed they did not need it (majority of the Greek group) or due to cost (majority of Finnish group). Previous and current Internet users had moderate scores in eHealth literacy, which means that it is very likely they cannot find, access and evaluate online health information accurately. However, the Finnish group scored significantly higher in eHealth literacy than the Greek group. The majority of Internet users accessed the Internet from home, had an email address, used it at least once per day, and used it for Web 2.0 activities (i.e. watch videos, for social networking and/or dating websites). More than half of current Internet users, accessed the Internet for health-related purposes (i.e. research health-related information, communicate with health professionals about health-related issues, communicate with other users about health-related issues). Moreover, more than half search for online health information, most of them find it always or most of the times easy to locate the website they want, and the most prevalent problem hardening Internet use was their difficulty concentrating for long periods.
- 3) based on the two included RCT studies of the systematic review (as of June 2015), the use of social media interventions for people with SSD tended to be generally less effective than treatment as usual. Nevertheless, there was not enough evidence to draw a definite conclusion, since only two studies fulfilled the inclusion criteria, they were both from the

same country (USA), and their methodological quality varied. Consequently, clear evidence for the effectiveness of social media mental health interventions is still inconclusive.

In Figure 9 below, an overview of the main study results are visualized based on the research questions.

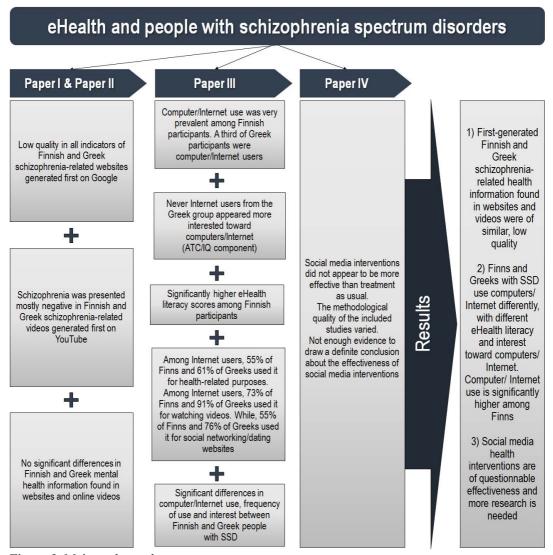


Figure 9. Main study results

6. DISCUSSION

In this chapter, study results will be given meaning by relating them to past research, and by reporting practice interpretations and opinions. *First*, the main results are discussed and explain how they answer the research questions, and how they fit in with the existing knowledge on the topic. *Second*, limitations and weaknesses are discussed in order to explain how they may affect the validity and reliability of the findings. *Third*, principal implications of the study are discussed, and the importance of how the results influence our knowledge and understanding of the problems being examined; and finally, recommendations for future research are provided.

6.1 Discussion of main results

6.1.1 Online schizophrenia-related health information in the Finnish and Greek languages

It was hypothesized that the mental health information retrieved from Finnish language websites would be of better quality when compared with Greek language websites. We expected Finnish language websites to score higher in each indicator, thus be of higher overall quality, based on the assumption that Finland is shown to be a world leader in innovation and technology and more technologically advanced than Greece (Eurostat, 2012, 2016). However, the top generated websites appearing from schizophrenia-related Google searches, scored low in all website quality indicators for both languages. Notably, it appears that Finnish and Greek Internet users who search for schizophrenia and related conditions online, access websites of similar, low, quality, lacking in good quality of mental health information.

Our findings showed that Finnish and Greek schizophrenia-related websites were inadequate on all assessed quality indicators. Similarly, a review of 23 studies investigating the quality of mental disorder information websites, reported similar results (Reavley & Jorm, 2011). Another study, assessing information about antipsychotic medication on UK schizophrenia websites was basic and incomplete (Akram et al., 2010). On the other hand, a more recent study assessing the quality of online information related to mental disorders (Grohol et al., 2014), found that popular search engines (Google and Bing) appear to offer generally reliable results, pointing to mostly good quality mental health websites. The same study, found readability of the websites should be improved, which is in line with our results. In our study, the Health on the Net certification logo (HONCode) was absent in the most websites. On the other hand, some researchers find certification logos to be of limited value because they have unreliable policing and taking follow-up action when notified of violations (Grohol, 2015). Therefore, it is risky to recommend relying on any certification code as a symbol that the website meets any type of minimal standards (Grohol, 2015).

Various studies confirm that whenever someone searches for (mental) health information online, he/she starts from a search engine, most likely Google Search. Clearly, the most popular search engines could facilitate the delivery of high quality health websites by adjusting the search

algorithm whenever a medical term is being searched. As a matter of fact, Google has recently announced that they are considering altering their search algorithm for health information (Verel, 2015). This will be a great improvement into empowering Internet users to find more easily reliable health information. Nevertheless, Google's country specific versions (other than in English language) could follow Google USA's example (Feufel & Stahl, 2012), where they partnered with the National Institute of Health to generate relevant health-related information in response to consumers' searches (Andrews, 2010). Nevertheless, judging from our findings it is important to stress that we do not imply that high quality mental health information, thus websites, are not already available online, but the issue here is how the average Internet user can easily access those high-quality information in a simple search since the top-generated results in the Finnish and Greek languages tend to be of average or low quality. Further, readability of websites is of great significance, since it is important that available health-related information is understandable and can be accessed without too much effort (Eriksson-Backa et al., 2012).

It is interesting to cite here a passage from 'e-Patient Dave' (deBronkart, 2015), a cancer patient and blogger who became an activist for healthcare transformation through participatory medicine and personal health data rights: "Listen, people: Googling does not mean I think I'm a doctor. It's a sign of being an engaged, empowered "e-patient." I partner with great doctors - I don't tell them what to do. And they welcome me doing it". "In 2014 the Belgian government got this spectacularly wrong: their insulting misinformed "Don't google it" commercials say at the end, "Don't google it. Check a reliable source." They're not mutually exclusive! "It's absolutely, demonstrably wrong for a doctor to think that doctors know everything that needs to be known and patients can't possibly know anything useful. To the contrary, not googling can bring death". "You can google and check a professional source. Googling is a sign of an engaged patient. The only reason a patient ever searches for information is because they're trying to learn more! To smack that down is to discourage engagement. In my speeches I often say, "If someone's trying something useful but they're not good at it, coach them, don't say 'Stop that.'". e-Patient Dave is an example of the great power Google has in informing, thus empowering, patients about their health. Hopefully in the future, Google's algorithm for health-related searches will be improved, as well as in other languages other than English. In this way, Internet users who seek for health information online, but speak another language other than English, could have easier and more simple access to high quality health related websites.

The above statements might seem to be strong, nonetheless, they describe a real situation adopted from the majority of health professionals. It is clear that the Internet should be recognized as a new medium for (mental) health information from all health professionals. A constantly increasing number of people will use the Internet to answer his/her (mental) health questions, thus, one of health professionals' duties is to support and coach their patients in exploring and taking advantage of new ways to be informed about their health, in order to manage their health, adopt healthier lifestyles, and given the chance to be empowered, to enhance the quality of their life. Although health professionals' acceptance of Google as a health information source was not the focus of the current study, this is a field for further investigation.

6.1.2 Online schizophrenia-related videos in the Finnish and Greek languages

It was hypothesized that the Finnish language videos would present mental illness in a more objective way when compared to the Greek language ones. We expected the Finnish language videos to present schizophrenia/psychosis in a neutral, medically-oriented way, based on the assumptions that Finns are shown to be more technologically experienced than Greeks, and second, more mental health literate, thus more likely to have produced and shared online mental health videos. However, the top generated videos appearing from schizophrenia-related YouTube searches, showed that schizophrenia was mainly presented with negative connotations in both languages. Notably, it appears that Finnish and Greek Internet users, who search for schizophrenia-related videos online, watch videos of similar, negative representations of mental illness.

Our findings showed that both Finnish and Greek language videos, appearing first on a schizophrenia-related search on 'YouTube', tended not to be educational or informative and to present schizophrenia negatively. In other words, viewers were exposed mostly to negative attitudes towards mental illness. How schizophrenia and psychosis are presented specifically in online videos has been a neglected field, since not many related studies could be found. Our findings are similar to those of other studies on mental disorders assessing the presentation of schizophrenia in traditional mass media, such as television and films (Gabband & Gabband, 1999; Wilson et al., 2000; Pirkis et al., 2005, 2006), or newspapers and magazines (Duckworth et al., 2003; Chopra & Doody, 2007; Magliano et al., 2011; Nawka et al., 2012; Thornicroft et al., 2013). Recent studies on the presentation of schizophrenia in online newspaper websites, report similar results such as, metaphoric use of schizophrenia predominately indicating incoherence/contradiction/split (Athanasopoulou & Välimäki, 2014). Further, in a popular online social networking service, Twitter, schizophrenia-related posts tend to be mostly negative, medically inappropriate and sarcastic (Athanasopoulou & Sakellari, 2016). Encouraging results were found in a study of schizophrenia-related Facebook groups, were the majority of the groups aimed to raise awareness and support those with schizophrenia, however negative connotations related to schizophrenia were not totally absent (Athanasopoulou & Sakellari, 2015).

Consequently, it is important to note that this part of our study does not imply that there is a definite absence of educational, informative, and medically-oriented videos presenting schizophrenia in a neutral or positive light. We did not retrieve all online videos, but only those which were generated in the top results. As stated in the previous part of our study, the issue here is how the average Internet user can easily access informative and educational videos in a simple search, since the top-generated results in the Finnish and Greek languages tend to be misleading and stigmatizing. Further, anti-stigma campaigns related to mental health are much needed in order to inform the public (who also happen to be Internet users) about the true dimensions of mental illness.

Finally, it is clear that the misinformation, misleading concepts, and negative attitudes towards mental illness are evident in online videos of the most popular video-sharing website. Misconceptions about mental illness, lead to stigma, which leads to discrimination, to loss of social opportunities and, ultimately, to poor quality of life. As poor mental health has substantial personal

and economic impacts, and stigmatizing attitudes exacerbate these impacts (McDaid, 2008), the need for anti-stigma campaigns is clear.

6.1.3 Computer and Internet use, attitudes toward computer/Internet and eHealth literacy among Finnish and Greek people with SSD

It was hypothesized that the majority of Finnish participants would be computer/Internet users and more eHealth literate, than their Greek counterparts. These assumptions were based on the fact that Internet access and use are generally more prevalent in the Finnish than in the Greek population. Indeed, the majority of the Finnish group was current Internet users and were using the Internet more frequently, in contrast to the Greek group. eHealth literacy score was slightly higher in the Finnish sample, while perceived efficacy and interest towards computer/Internet (components of ATC/IQ) were higher in the Greek sample, with interest being statistically significantly higher. Further, more than half of Internet users from both country groups, were using the Internet for health-related purposes, such as research health-related information, and/or communicate with health professionals and/or peers. Significant differences between groups were found regarding: important sources of health information, reasons for never using the Internet or discontinuing use, reasons for Internet use (among Internet users), location and frequency of Internet use, having an email address, and perceived easiness to locate a website.

Our findings showed that the majority of Finnish people with SSD use the Internet, while the majority of their Greek counterparts has never used it. Only 8% of the participants worked for pay, thus, this could explain why many of them responded that they had never used the Internet or stopped using it because of cost (9 out of 17 Finns, and 14 out of 68 Greeks). Surprisingly, cost was not the first reason for non-usage for the Greek population (as in Finns), but rather their notion of not needing the Internet. Furthermore, our study confirmed previous findings and provided some new evidence as well, regarding the effect of several socio-demographic factors on computer/Internet use. Earlier research had shown Internet for health information has been somewhat less common in the south European countries (Kummervold & Wynn, 2012), however, in our study the Internet users of both groups seemed to use the Internet for health information similarly. Moreover, for the Finnish group face-to-face contact with medical professionals, and then the Internet, were the top sources of health information. On the other hand, for the Greek participants face-to-face contact with medical professionals and pharmacies were perceived to be the most important sources of health information. Similarly, Askola and colleagues (2010) identified considerable variation in the importance placed on the Internet as a source of health information between Finnish and Japanese first-year university students, where for Finns, family and the Internet were found to be the most important sources of health information, whereas for the Japanese were family and TV/radio.

For the participants who never used the Internet, perceived efficacy towards computer/Internet (components of ATC/IQ) scored slightly higher in the Greek population, which means that Greeks perceived themselves to be more towards computer/Internet. However, the majority of the Greek sample did not use the Internet. This could be explained by their perception that they do not need it.

Other studies have also shown that people with SSD are willing and comfortable to use technology and eHealth services (van der Krieke et al., 2014, Forchuk et al., 2015).

Among previous and current Internet users, eHealth literacy was found to be slightly higher in the Finnish group. A recent study in Greece, identified that eHealth literacy decreases by 23% when the individual ages, while increases by 53% when he or she acquires higher level of education (Xesfingi & Vozikis, 2016). Since the level of education of the Greek participants was lower, and their mean age higher than their Finnish counterparts, this could explain in part the lower eHealth scores. This assumption is also supported by another study, aiming to measure health information literacy among Finnish seniors (measured in a way inspired by the eHEALS scale), found significant relationships between level of education and dimensions of health information literacy. In the same study, some categories of elderly people were found to be more vulnerable regarding obtaining and use of health information, such as those with lower levels of education, poor health, and not interested in and active at seeking information (Eriksson-Backa et al., 2012).

Among current Internet users, almost all Finns accessed the Internet from home, while the majority of Greeks from home, and close to about a fifth through other places, i.e. their mobile phones or tablets, from work, or Internet café. Generally, Finns tended to use the Internet more frequently than Greeks, which is in accordance with the general population where 80% of Finns use the Internet every day or almost every day, versus the 47% of Greeks.

6.1.4 Research evidence on the effectiveness of social media interventions for people with SSD

The two included studies in the review showed that social media use was found to be generally less effective than traditional treatment intervention. Nonetheless, due to the limited number of studies, there is not enough evidence to draw final conclusions. Participants of the study were active in therapy forums and on bulletin boards, exhibited high participation in peer support forums, while also other studies confirm that people with psychosis use forums and online chats, which could reduce the risk of isolation (Highton-Williamson et al., 2015). On the other hand, people who "highly participated" in social media use, were more distressed when compared to those in the "low participation" group. Additionally, those who reported positive experiences by social media forums use, felt more distressed than participants in the negative experience group. Kaplan and colleagues (2005) reported some clinicians' fears that patient participation in online peer support without professional moderation may foster anxiety. However, a recent study by Miller and colleagues (2015) reports that Internet users of this population agreed that social media improves their interaction/socialization, create interest in receiving text messages from their doctors, and disagreed that these technologies worsen their symptoms.

Social support, self-management, and quality of life ratings were better for the people with SSD in treatment as usual, than those in the social media interventions group. On the contrary, a recent systematic review showed that positive psychotic symptoms, hospital admissions, socialization, social connectedness, and medication adherence have the potential to improve via online and mobile-based interventions for people with psychosis (Alvarez-Jimenez et al., 2014). So, despite

that in the systematic review we run, it appeared that treatment as usual was more effective in many aspects than treatment via social media use, however, other systematic reviews reveal that online and mobile-based interventions have a positive impact (Alvarez-Jimenez et al., 2014). An additional systematic review by van der Krieke et al. (2014) supports the view that e-mental health interventions are at least as effective as standard mental health care.

A risk of social media use for persons with prodromal or newly diagnosed psychotic disorders, may be that they are vulnerable to cyberstalking (Dressing et al., 2011) and Internet delusions (Catalano et al., 1999). Delusions as a symptom of the specific diagnosis, can also interfere with the use of Webcams, sensors, and other devices (Bell, et al, 2005). Consequently, more research is needed to investigate how vulnerable is this population in using social media in general and to what degree their symptoms could be negatively affected and how this can be managed.

6.2 Reliability and validity

Validity and reliability are the most important criteria in evaluating the quality of a study. Reliability refers to the degree of consistency or dependability with which a measurement technique measures a concept under investigation. Validity refers to the degree to which the study results are accurate and well-founded, and whether the study instrument measures accurately what it is intended to measure.

In Paper I, unobtrusive, content analysis was performed, with an adapted coding tool which was used in previous studies (Griffiths & Christensen, 2000, 2002; Khazaal et al., 2008b, 2008c). The data was online, schizophrenia-related health information. In content analysis, reliability must be ensured because of the ambiguity of word meanings, categories' definitions (Weber, 1990). Three types of reliability are essential for content analysis: stability (data coding remains the same if analysed again over time), reproducibility (or else 'intercoder reliability', data coding produces the same results among the coders), and accuracy (data coding corresponds to a standard or norm) (Krippendorff, 1980). To strengthen reliability and to ensure that coders had the same understanding about the coding, the concepts and categories, a written research protocol was given to both of them prior to the analysis. Then, after carefully reading it, they run a 'pilot coding' to a similar, small sample (not the same data as in the main study). To ensure stability, data was coded twice by the same person in two different times, where not more than five scoring errors where found from each coder. Then, to ensure accuracy coders discussed the reasons of their coding, so both would have a common understanding about the data analysis protocol, as well as, reviewed together the data analysis of the previous similar study (Griffiths et al., 2002) which used the same instrument.

After the main analysis was performed, *reproducibility* (intercoder reliability) was ensured as follows. A random selection of one-fifth of the data was recoded. Then, the number of scoring errors (n=65) was divided by the number of coded cells (N=2538), which yield an error rate of 2.56%. Additionally, reproducibility was assessed also separately for the Finnish and Greek

analysis. The percent agreement was calculated by dividing the number of observations in which the raters agreed by the total observations (97%). In case of scoring disagreements, they were resolved through discussion between the two same-language coders. Content analysis percent agreement for the Finnish data was 80%, and for the Greek data 83% (Lombard et al., 2002). Semantic validity was ensured by having both coders discussing and listing in detail the list of words, meanings and connotations, which belonged in each coding category. This step was essential, as meanings and connotations can be perceived differently from each person (Weber, 1990). External validity (generalizability of findings) was not the goal in this part of the study, because the intention was to assess the 20 first-generated websites, on a specific time, under certain conditions (simple Google search in Finnish/Greek language). This was decided in order to acquire an insight on, what health information an average, Finnish or Greek-speaking, Internet user most likely see, when searching with schizophrenia-related search terms. Finally, since unobtrusive measures, thus the direct elicitation of the data was not affected by social desirability bias. In other words, the health information in this study possibly reflect the average Finnish/Greek-speaking Internet user's experiences.

In Paper II, unobtrusive, content analysis was performed, with a coding tool which was developed based in previous studies (Corrigan, 2004, Park et al., 2011). The data was online, schizophreniarelated videos. The coders who made the analysis were the same as in the previous paper (Paper I), which was a major advantage, as both coders were familiar and experienced with the procedure (Weber, 1990). This was a content analysis as in the previous paper, thus, reliability and validity were ensured in a similar way. To strengthen reliability and to verify that coders had the same understanding about the coding, the concepts and categories, a written research protocol was given to both of them prior to the analysis. The protocol included official schizophrenia guidelines (Kuipers et al, 2009; Chapter 2), to ensure a shared understanding of objective, medically-oriented beliefs about the disorder's symptoms and treatment. Then, after carefully reading it, they run a 'pilot coding' to a similar, small sample (not the same data as in the main study). To ensure stability, data was coded twice by the same person in two different times, where not more than four scoring errors where found from each coder. Then, to ensure accuracy coders discussed the reasons of their coding, so both would have a common understanding about the data analysis protocol. The Finnish data and scoring were presented to the Greek coder and vice-versa. Each of them kept a record of the exact time when a belief or attitude was identified in each video component (textual, visual, aural), so both coders could review them carefully.

Reproducibility (intercoder reliability) was examined by reanalysing half of the included data (n=12 for Finnish; n=14 for Greek language videos) and calculating a number recoded items (cells). Out of the possible cells (n=135), each coder made one mistake, which yielded an almost excellent agreement percent between the original and re-rated data (99.99%). For scoring disagreements, coders gave a rationale for each coding and they were resolved through discussion. Semantic validity was ensured by having both coders discussing and listing in detail the list of textual, aural, and visual meanings and connotations, which belonged in each coding category. This step was essential, as meanings and connotations can be perceived differently from each person (Weber, 1990). External validity (generalizability of findings) was not the goal in this part of the study, because the intention was to assess the 20 first-generated videos, on a specific time, under certain

conditions (simple YouTube search in Finnish/Greek language). This was decided in order to acquire an insight on, what videos an average, Finnish or Greek-speaking, Internet user most likely see, when searching with schizophrenia-related search terms. Finally, since unobtrusive measures were used, the direct elicitation of the data was not affected by social desirability bias. In other words, the health information in this study possibly reflect the average Finnish/Greek-speaking Internet user's experiences.

In Paper III, a cross-sectional survey was performed, with an adapted structured questionnaire from a previous study (Choi & DiNitto, 2013). The data derived from the answers of adults with SSD. The reliability and validity of the instrument and the survey were ensured as follows. Reliability is a fundamental way to reflect the amount of error apparent in any instrument (Streiner & Norman, 2003). Reliability was judged based on the instrument's degree of reliability when applied to this specific population under certain conditions. Internal consistency reliability (how well a test addresses different constructs and delivers reliable scores) of the items in each subscale (ATC/IQ, eHEALS) was calculated with the Cronbach α statistic. The internal consistency of the ATC/IQ subscale was found to be good/acceptable. In particular for the Efficacy subscale of ATC/IQ, Chronbach's α was .78 in the Finnish and α =.80 in the Greek sample. For the Interest subscale of ATC/IQ, Chronbach's α was .52 in the Finnish sample and α =.76 in the Greek sample. The internal consistency of the eHEALS subscale was good (Cronbach α =.86 in both Finnish and Greek sample), and comparable to reliability estimates reported in previous studies (Norman & Skinner, 2006; Choi & DiNitto, 2013). Face validity of the overall questionnaire (consisting of the above subscales) was generated from a number of sources, discussion with experts, and review of relevant literature (Rattray & Jones, 2007). Nonetheless, the same questionnaire (in English language) was used by Choi & DiNitto (2013).

Credibility, refers to confidence in the truth of the data, how well the data and data analysis process address the intended focus (Polit et al., 2001, Polit & Beck, 2010), was taken into consideration when sampling was conducted. The participants had personal experience of SSD diagnosis. In both countries, during patient recruitment a selection bias (Burns & Grove, 2005) could not be excluded. Patients who were not asked to participate or did not want to participate may have differed in some important way from the patients included in the study. Social desirability bias (tendency of participants to respond in a more socially desirable or acceptable way rather responding by reflecting their true thoughts or feelings) could not be excluded either (Hine, 2011). Researcher credibility is another aspect of credibility (Polit et al., 2001). In Greece, participants could select to be interviewed (instead of filling the questionnaire independently). Interviews were conducted and analysed by one researcher who was conscious that her involvement in the data collection might possibly affect her pre-understanding of the topic of interest, and thus tried to minimize the influence when analysing the data (Polit & Beck, 2010). Moreover, regarding credibility, the interview situation was kept unhurried and the interviewer helped the patients to describe their perceptions if further explanation was needed. Interviewing the patients more than once would perhaps have increased credibility (Tobin & Begley, 2004), however, this was not possible for practical reasons.

Dependability refers to the data stability over time and over conditions (Polit et al., 2001; Polit & Beck, 2010). Considering the symptomatology of SSD which can vary greatly from each person and in any given time period, dependability could not be ensured. Especially, for the Greek data collection, where the researcher was an integral component of the study process and thus the researcher's own actions inevitably impacted upon the study findings (Horsburg, 2003). However, the study is possible to be repeated producing similar results (Holloway & Wheeler, 2002). To enhance the dependability of the study the instrument used and its categories were discussed with the supervisor and a group of doctoral students (Graneheim & Lundman, 2004; Silverman, 2013).

Confirmability deals with the objectivity and neutrality of the data (Polit et al., 2001; Graneheim & Lundman, 2004; Polit & Beck, 2010). The data was not collected from the work environment of the researcher. Moreover, confirmability was increased by describing the analysis process in detail. In the categorization process, patients' original utterances and expressions were used as far as possible. Participants' recognition of the findings would be one aspect to improve confirmability (Graneheim & Lundman, 2004), but for practical reasons it was not possible.

Statistical conclusion validity concerns that relationship and differences drawn from statistical analysis are on accurate reflection of reality (Burns & Grove, 2005). In this study the sample size was quite large (N=229; FI=128, GR=101) and selection of statistical tests was confirmed by a statistician, which increased the statistical conclusion validity (Burns & Grove, 2005; Polit & Beck, 2010). A big study limitation was that sociodemographic characteristics between the two country groups were very different, however, multivariable analysis analyses adjusted by sociodemographics such as gender, age, level of education and duration of the disease, strengthened the study.

External validity, which concerns the degree to which the study results can be generalized to other samples or settings (Burns & Grove, 2005; Polit & Beck, 2010), was threatened because of the selection bias (who is included and who is not). More specifically, out of the 747 patients (FI=360, GR=387) who fulfilled the inclusion criteria, many were not asked to participate (FI=104, GR=254), while many Finnish eligible participants refused to participate (FI=118, GR=32). Performance bias (differences between conditions other than the ones of interest, e.g. running people in condition one in the morning and condition two in the afternoon) was also apparent considering the nature of the disorder, and situational specifics, such as: treatment conditions, time, location, lighting, noise, the presence of others or the investigator, timing, scope and extent of measurement. A main problem limiting the external validity of the findings was that participants were recruited from one organisation in each country, and in the Greek sample some participants were also from rural areas. However, a strength was that the data collection instrument does not require a lot of time to be filled and is transferrable to other groups or settings. On the other hand, detection bias (how the outcomes measures are coded and interpreted, blinding participant's condition) was controlled, since data were coded in a way in which the investigator could not identify the participants. (Steckler, & McLeroy, 2008).

Internal validity was threatened because the selected participants -chosen by the treating psychiatric nurse (Finland) or psychiatrist (Greece) and due to their psychiatric condition- may differ in some

important way from those not selected (Burns & Grove 2005). Moreover, the data was collected from patients in outpatient services and inpatient setting (Greece) at the end of their hospital period. Thus they were quite stable, even compared with outpatients. However, the characteristics of the sample may not be representative of all patients with SSD.

In Paper IV, a systematic review and meta-analysis were performed. The data was previous studies related to the effectiveness of social media interventions to people with SSD. The reliability and validity assessment was made as follows. First, the methodological quality of the included studies was assessed and, second, the validity of the review was evaluated. In the systematic review, the validity of the included studies was confirmed with the RevMan program (2008) risk of bias table. This table consisted of six questions: 1) Random sequence generation, 2) Allocation concealment, 3) Blinding, 4) Incomplete outcome data, 5) Selective reporting and, 6) Other. Potential answers to these questions were: 1) Low risk of bias, 2) Unclear risk of bias, or 3) High risk of bias. The risk of bias table is presented in more detail in Figure 6 in Paper IV (Higgins & Green, 2011.) Furthermore, the methodological quality of the included studies varied. Despite the fact that randomisation of the included studies was mentioned, no detailed description about the randomisation process was presented. This raised the question if the randomisation was done appropriately in all the studies, which could lower the validity of the results presented. Furthermore, a high risk of reporting bias was identified because of missing outcomes or non-availability of study protocols.

Second, regarding the validity of this systematic review; the detailed terms for each database and the searches were made by an information specialist at the University of Turku. Thus, the literature was searched with a systematic, structured approach, screening and reviewing studies. Data extraction was made with standardized forms guided by the Cochrane Handbook for Intervention Studies (Higgins & Green, 2011). Additionally, the search area was kept large enough to capture all possible studies in the scope of the inclusion criteria. Although all possible effort was made to find relevant literature, the findings of this review could be deemed by selective reporting missing some relevant study. Only two studies (three records) fulfilled the inclusion criteria. Using English language studies might have resulted in our results being biased toward Western countries. It is possible that analysis of studies produced in languages other than English could yield different findings. With both studies originating from the United States, it is unclear if the same findings would be reflected in other countries or cultures. Finally, to ensure that the reporting of the systematic review was done appropriately, the QUOROM statement checklist for reporting randomized controlled trials in systematic review was used, as well as, the PRISMA flow chart, to illustrate the search process (Moher et al., 2009).

6.3 Implications of the study

Fifty-five years ago, on May 31, 1961, Leonard Kleinrock reported his initial idea about the Internet in his dissertation entitled "Information Flow in Large Communication Nets". More than half a century later, when the Internet is well-established in our everyday life and continuously growing, the information provided through the Internet is freely available to anyone with a connection.

Health and mental health information provided online (through texts, images, infographics, videos, user-generated content, etc.) are growing day by day. Open to everyone, but the question here is how this information can be used in a safe and effective way in order to empower Internet users, especially those whose cognitive skills are affected by their diagnosis —as those with SSD. How this information can be easily accessed and understood from people with SSD in order to create autonomy and serve their needs? In an attempt to answer this question some implications are made below deriving from this study.

6.3.1 Implications for practice

Our study showed that online, top-generated, schizophrenia-related health information are of low quality, while schizophrenia-related videos promote stigmatizing depictions about SSD, both in the Finnish and in the Greek language. There is a need of high quality easily found mental health information, and informative, medically-oriented schizophrenia-related videos. We, health professionals, are frequent Internet users. Many of us, use social media and video-sharing platforms, and create user-generated content. Thus, health professionals who are more experienced Internet users could create and upload content which provides reliable information about schizophrenia and related conditions. A starting point is knowing the various quality indicators of a health-related website (e.g. accountability, interactivity, aesthetics, content, etc.) and trying to satisfy those indicators they produce health-related content and publish it online. Even sharing related information, like details about clinics or evidence-based new treatments, could have an impact. On the other hand, whenever unreliable or stigmatizing health information or videos are found online, they can be reported to the webmaster or flagged as inappropriate. This has the potential to gradually remove the inappropriate content from the Internet, and minimize the stigmatizing content related to mental illness.

eHealth literacy was found moderate and significantly lower among Greek participants. This means that patients are not good in finding and judging which (mental) health information is reliable and trustworthy. They are not trained on how to find high quality health information on the Internet, in order to apply them in their everyday health-related choices. This prevents them from being empowered and gaining more control over their diagnosis. Especially among the Finnish population, were almost all participants with SSD used the Internet. Health professionals can discuss the use of online health information and other resources with patients, as well as, discuss strategies for safe online navigation in order for the patients to gain maximum benefit.

Based on the assessed studies of the systematic review, social media mental health interventions did not seem to be more effective than treatment as usual. However, findings could not be conclusive, and do not imply that social media interventions cannot be effective in general. Especially when other types of social media can also be tested (not only peer support LISTSERV or Bulletin boards, and forums in a psychoeducation website) and in different countries (considering that both included studies were from USA). In addition, since there is a constantly increasing number of social media users, social media interventions will become more familiar to its users. Hence, as stated above, health professionals can explore the various social media currently available, familiarize themselves

with their functions and potential use in the field of health and well-being, and try to contribute to the creation and distribution of high quality mental health content online.

6.3.2 Implications for administration and ICT specialists

Our study showed that online, top-generated, schizophrenia-related health information are of low quality, both in the Finnish and in the Greek language. Accountability (information on who wrote the health-related content), interactivity (easiness of interaction with webmaster), and aesthetics (appearance) of websites were of low quality. ICT providers are not responsible about the content of websites, thus whenever they create health-related content, they must be in close cooperation with health care professionals and generate online content and websites which satisfy all quality criteria. Importantly, in order for people with SSD to understand the information they read online, professionals must be aware of the possible cognitive restrictions of those who would potentially read the health information. On the whole, the content should not only mention the creator of the information (accountability-name, affiliation, etc.), provide clear contact information (interactivity) and simple, well-structured website appearance (aesthetics); but also make the information easy to find, read and understand. This last implication is particularly important, considering in addition the low eHealth literacy of this population.

As a matter of fact, ministries and health organizations could realize the popularity of social media, and instead of blocking social media access to their employees (i.e. in hospitals), they could promote their use for the creation of mental health content online. Considering that some of the study participants used the Internet to communicate with health professionals, administrators could support the possible interactions in cases when users seek for further health information. Targeted and tailored interventions for relevant patient—consumer segments, and further suggests appropriate strategies for training the health illiterate part of the population. Formal guidelines about safe Internet navigation for (mental) health-related purposes have not yet been established. This initiative would be of great value, if also translated in various languages and adopted by professional organizations.

It is essential to note that a global approach is needed, meaning that Internet users come from around the globe, thus schizophrenia-related health information searches are not only in the English language. Search algorithms of the most popular websites (like Google and YouTube and their country specific versions) can be adapted to produce high quality (mental) health information. Easily found, reliable mental health information presented through text, images, infographics, and videos are the key for mental health empowerment. A possible solution could be through the cooperation of each country's Ministry of Health or other governmental organizations with the teams of highly accessed websites. The Ministry of Health could be responsible in producing, and updating high quality (mental) health information, while the most popular search engines and social networking websites, would ensure that those would be among the top results. In this way, first, reliable, up-to-date (mental) health content will be available online, and second, this content would be easily accessible since it would be among the top results.

6.3.3 Implications for education

Mental health professionals need to be educated and be aware on how their patients tend to search for (mental) health information online, how someone can judge which online (mental) health information and which quality criteria of a website offering (mental) health information, is reliable. By acquiring this knowledge, (mental) health professionals can show to their patients, who use the Internet, how to judge the reliability and trustworthiness of the information they find online. Being aware of a website's quality criteria, (mental) health professionals could potentially create reliable (mental) health-related online content, which satisfies these criteria and makes it a reliable source of (mental) health information. The study curriculum of (mental) health professionals could be updated, in order to offer various high level courses on eHealth education, not only meet minimum requirements. Additionally, continuing education eHealth programs could be organized by (mental) health organizations, since the field of eHealth is constantly evolving.

People with SSD need education and training in order to acquire the essential skills to find, read, and understand online (mental) health information. In other words, to improve their eHealth literacy at a sufficient level, in order to use the information they find online, in their everyday health-related choices, and thus, improve their well-being and empower them. Patient associations and/or outpatient services could offer these trainings, moderated by (mental) health professionals who are experts in ICT and user experience.

The general public needs to be educated about the harm of spreading false, inaccurate and negative depictions of mental disorders, to people with SSD. Not many people have ever met a person with SSD. However, the majority of the Finnish and Greek population uses the Internet. Online videos present stigmatizing attitudes about SSD. Thus, many people access those videos and potentially adopt negative stereotypes about mental disorders. Educating them about what mental disorders really are, how people with SSD feel, and how isolated they can become if they frequently face these stigmatizing views, there is a potential of positive impact. Starting from modifying the school curriculum in order to include mental illness awareness seminars among students, could be valuable. In addition, online campaigns targeting to raise awareness about mental illness could be of use.

Popular technology companies, such as Google Inc, need to be aware of the potential harm of promoting false and negative depictions about mental disorders in various languages, not only in English. Their webmasters should be able to provide assistance in any language whenever a content is flagged or reported as harmful.

To conclude, in order for eHealth to be effectively adopted from people with SSD in the future, various sectors and stakeholders need to cooperate (healthcare providers and organizations, ICT experts, administrators, educators, even the average Internet user) and a plethora of aspects to be considered. For example, being aware of critical website design elements/quality indicators, development of patient centered systems, user-led approach driven by the needs and preferences of people with SSD.

6.4 Suggestions for future research

Based on the study findings future research could:

- 1) Explore if, and to what extent online schizophrenia-related health information support (mental) health-related choices of people with SSD.
- 2) Systematically review the literature, identify related studies and create official guidelines about safe Internet navigation for (mental) health-related purposes in various languages. Then, train people with SSD to use these guidelines and test their effectiveness in practice.
- 3) Explore if, and to what extent: a) online negative portrayals/depictions of mental illness reinforce self-stigma among people with SSD, and b) promote public stigma towards mental illness for the average Internet user.
- 4) Measure the impact of eHealth trainings to people with SSD and focus if higher eHealth literacy improves their (mental) health-related choices.
- 5) Explore in depth the six core health literacies (traditional, Information, media, health, computer, and scientific literacy) of people with SSD.
- 6) Explore the effectiveness of mental health interventions through various social media, in RCT studies among people with SSD.

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7. CONCLUSION

The goal of the study was to describe online schizophrenia-related health information and videos, to investigate and compare eHealth use among adults with SSD in Finland and Greece, and to investigate the effectiveness of social media interventions for people with SSD. In a northern European country like Finland, the majority of the top-generated, easily retrieved online, schizophrenia-related health information is of low quality. The top-generated, easily retrieved, schizophrenia-related videos, present mostly false and negative depictions towards the illness over the Internet. The majority of Finnish people with SSD use the Internet, most of them on a daily basis. A bit more than half use social networking websites, more watch videos online, while more than half use the Internet for health-related purposes. Previous and current Internet users' eHealth literacy is moderate, with a room for improvement. Never Internet users' attitudes towards computer/Internet are average. Similarly, in a Southern European country like Greece, the majority of the top-generated, easily retrieved online schizophrenia-related health information are of low quality. The easily retrieved schizophrenia-related online videos, mostly present false and negative depictions towards the illness. In contrast with Finns, the majority of Greek people with SSD do not use the Internet. A third uses the Internet, mostly once per day. The majority of Greek Internet users access social networking websites and almost all watch online videos, while more than half use the Internet for health-related purposes. Previous and current Internet users' eHealth literacy is moderate, with a room for improvement. Never Internet users' attitudes towards computer/Internet are average. Consequently, since more than half of Internet users with SSD use the Internet for health-related purposes, easy access to high quality online mental health information in various languages is needed. The eHealth literacy skills of this population need to be improved. To date, the effectiveness of social media mental health interventions for people with SSD is unclear.

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