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Improving Mental Health Literacy: a Single-Subject Design Experiment Examining the Effects of Text Messaging on Adolescent Mental Health Literacy

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IMPROVING MENTAL HEALTH LITERACY: A SINGLE-SUBJECT DESIGN
EXPERIMENT EXAMINING THE EFFECTS OF TEXT MESSAGING ON
ADOLESCENT MENTAL HEALTH LITERACY

by

Emma Coffman

A Thesis Submitted in

Partial Fulfillment of the

Requirements for the Degree of

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August 2015

ABSTRACT
IMPROVING MENTAL HEALTH LITERACY: A SINGLE-SUBJECT DESIGN
EXPERIMENT EXAMINING THE EFFECTS OF TEXT MESSAGING ON
ADOLESCENT MENTAL HEALTH LITERACY

by

Emma Coffman

The University of Wisconsin-Milwaukee, 2015
Under the Supervision of Dr. Kris Barnekow

The purpose of the study is to determine the feasibility of delivering a text-based mental health literacy intervention for adolescent children who have family members with mental illness. The effectiveness of the text message intervention was measured using a single subject, multiple baseline study design. Each participant received three text messages per week for a total of 6 weeks, containing information regarding mental illness, managing crisis, resources, stigma, and assertiveness. The subjects were evaluated using qualitative and quantitative measures at multiple periods throughout the study.

Assessments utilized include: Schizophrenia Vignette quiz developed by Jorm et. al. (1997), Perceived Stress Scale-14(PSS-14) (Cohen et. al., 1983), 10-point Likert Scale to measure the quality of the relationship with their loved one, and the Weekly Check-In Script. All 3 participants reported decreased perceived stress, improved or no change in relationship quality, and changes in perceived causes of and treatment for mental illness.

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Improving mental health literacy: A single-subject design experiment examining the effects of text messaging on adolescent mental health literacy

Technology has become a large part of standard practice for many professions. Technology in occupational therapy specifically is used in all settings, including pediatrics, older adults, and upper extremity recovery. However, there is a gap in technology use in mental health services, especially in occupational therapy treatments. This practice area is lacking in evidence to support the innovative and wide ranging possibility of technology. There are few iOS and Android mobile applications, online psychoeducational programs and telehealth treatments for individuals with mental illness, and even fewer to support their families. This study aims to begin to fill that gap through creation of a new, text message intervention for adolescent children who have a family member that experiences psychosis due to a diagnosis of bipolar I or II, schizophrenia, or schizoaffective disorder.

The research problem: background

Mental Health Literacy

According to the U.S. Department of Health and Human Services, health literacy is defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (U.S.D.H.H.S, 2010). Mental health literacy is defined by Jorm et al (1997) as the “knowledge and beliefs about mental disorders which aid their recognition, management and prevention”. This term consists of three major components, which include: 1. Ability to recognize mental disorders and attitudes that contribute to this recognition 2. The knowledge of psychological distress risk factors as well as self-help

interventions 3. Knowledge of how to seek mental health information and the available professional resources (Jorm et al, 2012). Having high mental health literacy has been shown to decrease the stigma associated with mental illness, increase help-seeking behaviors and increased recognition of appropriate treatments (Kelly et al., 2007).

Unfortunately, the level of mental health literacy in the adolescent population is very low. Within the population of 426 adolescents, Melas et al (2013) found that 42.7% were able to accurately identify depression, while even fewer, 34.7%, accurately identified schizophrenia. When the disorders were incorrectly labeled, examples of alternative responses included bad lifestyle, lack of motivation, school problems, stress, social rejection, and loneliness. In other studies of this nature, similar results were found; about half recognized depression while roughly one quarter recognized psychosis (Kelly et al, 2007; Wright et al, 2006; Burns & Rapee, 2005). The lack of recognition of mental illness and the failure to recognize appropriate professional treatments are of primary concern to the mental health community and the researchers of this study, because it can lead to less help-seeking behaviors, increased negative stigma, and lower apathy for peers with mental illness. In order to address this issue, it is necessary to investigate what has been done in the past.

To improve mental health literacy, professionals have attempted various modes of communication to convey their messages. Across the globe, various programs exist to target mental health literacy in the adolescent population. A few of these include school based programs such as MindMatters-Understanding Mental Illness curriculum (Australia), Beyondblue Schools information sessions (Australia), The Science of Mental Illness curriculum (USA), and Mental Health Awareness in Action Program (USA).

Other initiatives include individual training programs such as SBIRT suicide prevention training (USA), Mental health first aid training (Australia) and Suicide Intervention Project (Australia) (Kelly et al, 2007). Another notable study examined the use of social networking site “Twitter” by health-related organizations to send health literacy messages to its’ followers, and found that the “tweets” were “retweeted” by up to 29 % of followers (Park et al, 2013). Due to the popularity of social media such as Facebook, Twitter or Instagram, this appears to be a slightly effective method to reach the population. However, the repercussions of low mental health literacy are too serious to have such a low level of engagement in conversations about mental illness.

Population

Children of parents with mental illness have unique needs. In a family setting, children often have various needs that are satisfied by their parent or caregiver, and familial role delineations are distributed according to those needs. However, when a child is cared for by a parent with mental illness, the child’s needs and role(s) can be different than what is typical. This population has been termed the “invisible dimension” in mental health (Farrell, 2001). Family therapy generally includes all members of the individual with mental illness’s family, but rarely does it address the needs of the children directly, which can be one of the parents largest support. Moreover, it is estimated that approximately 22% of children are living in households where at least one parent has a mental illness (Mayberry et al, 2005). Adolescence is a transition from childhood to adulthood and is difficult to manage under the best of circumstances. Adolescents who have a parent living with a mental illness have the added challenge of balancing this transition period while acting in many ways as a caretaker to their parent

and siblings (Children's Society, n.d.). Greater responsibility at home can lead to less time available to participate in age-appropriate activities such as play, friendships, and educational achievement. Parental mental illness often leads to increased stress for the child, as the home environment can at times be chaotic and even threatening (Jacobsen & Miller, 1998). Furthermore, a parent's mental illness may create challenges in forming meaningful relationships between parents and their children when they are young, and poor attachment bond between a child and parent has been shown to influence a child's emotional and cognitive development (Farrell, 2001). Multiple studies also explore concerns that adolescent children have in regards to their parent's mental illness. Various topics that were expressed include lack of understanding of their parent's mental illness, the need for a chance to ask questions, practical advice, support and understanding at school, someone to contact in a crisis, and the need for learning how to effectively communicate with their parent (Reupert, 2007; The Children's Society, 2014; COPMI, 2014). This demonstrates the critical need for an age-appropriate education and support program available to this population in the United States to improve current interventions and services.

Siblings of individuals with mental illness. When an adolescent has a sibling with mental illness in their family, it can lead to a variety of implications. When a sibling develops a serious illness of any kind, it can seriously impact the other siblings in the family. It can be extremely disruptive, regardless of the propensity of their bond (Lukens, Thorning & Lohrer, 2004). When the illness involves mental illness, specifically psychosis, the disruption can be very significant. In many situations, siblings become even become involved as caregivers. This can lead to emotional burden and feelings of

anger, shame, loss, guilt as well as negative implications on their personal health (Greenberg, Greenley & Benedict, 1994). In an exploratory study conducted by Lukens (2004), individuals reflected on living with a sibling who has mental illness throughout their lives. Common themes from the study were found to be sense of lack of support and loss of boundaries/role confusion. All of the needs identified in the literature points towards the need for a supportive, health literacy intervention.

Rationale and justification

Adolescents who have a family member with mental illness are a unique group that often go unnoticed in treatment of the illness (Farrell, 2001). Many of these adolescents become some level of carer to a parent with mental illness, especially during times when symptom levels are high. When their siblings have mental illness, they tend to experience significant stressors including stigmatization, lack of appropriate coping skills, and difficulties navigating the mental health system (Greenberg, Kim, & Greenley, 1997; Marsh, 1998). As a result, adolescents can experience high stress levels that can interfere with their daily life (Reupert, 2007). According to Saunders (2003), obtaining specific information regarding the family member's mental illness as well as learning methods for managing the family member's behavior helped them to better cope. Psychosis can negatively impact an adolescent family member's well being if there are not adequate supports in place. Since they are the future of our society, it is a wise investment to care for their well-being.

Significance of the study

Although other countries, namely Europe and Australia, have begun to support the population of adolescents who have a family member with a mental illness in this

way, there are currently few supports in the United States. Europe and Australia have set the standard of care, and this study intervention would be one of the first programs in the US for this population (COPMI, 2014; Children's Society, 2014).

Purpose of the Study

Specific Aims and Objectives

The purpose of the study is to determine the feasibility of delivering a text-based mental health literacy intervention for adolescent children who have immediate family members with mental illness. Specifically, the objectives of the study include: 1. Determining the feasibility of the eligibility criteria for recruitment purposes 2. Determining feasibility of obtaining the needed resources for the study 3. Determining the feasibility of research management of study data 4. Determining the clinical significance of the results of the intervention and 5. Determining the appropriateness of the outcome assessments for the intended outcome measures (i.e. reliability, validity, trustworthiness). The above objectives are guided by the typology criteria for feasibility studies given by Tickle-Degnen (2013), which include Process Assessment, Resource Assessment, Management Assessment and Scientific Assessment. A single-subject multiple baseline design will be used to address the feasibility of delivering and evaluating the mental health literacy intervention.

Research Question

How feasible is a text message intervention received three times per week, containing wellness tips and facts/tips about psychosis, to help adolescents who have a family member that experiences psychosis improve their mental health literacy, perceived stress, and relationship with their family member?

Literature Review

Psychosis affects daily functioning skills

Psychotic disorders are severe mental illnesses that cause a person to experience abnormal thinking and perceptions. Two main symptoms of psychosis are delusions (false beliefs such as someone is eavesdropping all telephone conversations) and hallucinations (false perceptions such as hearing voices that are not there) (DSM V, 2013). Schizophrenia/Schizoaffective disorder and Bipolar I & II typically involve psychosis. Other causes of psychosis include some personality disorders, severe depression, some drugs, brain tumors, stroke, and brain infections. When a person experiences psychosis it greatly affects their daily functioning skills, ultimately impacting their overall independence and safety. In times of high symptoms, a person with psychosis may rely on the support of their immediate family members to function. This can mean that adolescent children are enlisted to support an ill parent or sibling, leading to increased levels of stress and perceived burden. The mental illnesses that will be included in the population of this study are those where psychosis is the most prevalent: Schizophrenia, Schizoaffective Disorder, Bipolar I & II.

Schizophrenia and Schizoaffective disorders symptoms and prevalence.

Currently in the United States, about 2.4 million adults over the age of 18 are affected by schizophrenia or schizoaffective disorder. The etiology of this disorder lies in both environmental factors and genetics. Schizophrenia/Schizoaffective disorder generally first presents itself in men during their late teens and early twenties and in women during their late twenties or early thirties. Although the age of onset is slightly differed, schizophrenia affects men and women in equal proportions (NAMI, 2013).

Schizophrenia has a range of symptoms termed “positive” and “negative” based on their attributes. Positive symptoms include psychosis, catatonia, delusions, hallucinations, and disorganized thinking. Negative symptoms of schizophrenia include flat affect, and depressed mood, and may be difficult to recognize as part of the disorder. Individuals who have schizophrenia may also experience poor executive functioning and working memory (National Institute of Mental Health, 2012). Schizoaffective disorder is similar, but it combines the previously listed symptoms with mood disorder symptoms such as mania or depression (Mayo Clinic, 2014). The above symptoms can be treated with antipsychotic medications and psychosocial interventions. Although effective, these treatments are enhanced when the person’s whole family or support system is involved in the rehabilitation process. Tarrier explains that “Supportive and positive family environments have been shown to be protective factors that improve a patient’s ability to function, whereas family environments with high stress (i.e., those that are emotionally charged, critical, or over stimulating) increase the probability of relapse” (Tarrier, 1992). Since patients that are treated for schizophrenia within an inpatient setting are often released to their families, it is critical that their entire family is involved in their wellness process in order to promote a supportive environment. Family members that must be taken into account include spouses/significant others, siblings, parents, and children. All of these individuals have a unique role in the family dynamics in the home, and have a unique experience when supporting their loved one.

Bipolar I & II disorders symptoms and prevalence. Bipolar disorder, often called manic depression, is a brain disorder that impacts a person’s mood, energy, and ability to function independently (American Psychiatric Association, 2013). More than

half of all cases of bipolar disorder begin before the age of 25, but some individuals may not experience symptoms until later in life. In 2011, 4.4% of the population was diagnosed with bipolar disorder in the United States (NIH, 2012), with 82.9% of those cases classified as “severe”. This disorder can cause a person to have very dramatic mood swings from mania to depression stages, which can lead to periods of psychosis. During mania, a person may experience grandiose delusions, excessively risky behavior, less need for sleep, and sudden extreme irritability/rage. During periods of depression, a person may experience changes in appetite, thoughts of death or suicide, and loss of energy. The disorder is separated into two types: Bipolar I and Bipolar II. Bipolar I involves manic episodes, depressive, and mixed episodes, while bipolar II involves a pattern of depressive and hypomanic episodes without mixed episodes (APA, n.d.).

The effects of bipolar disorder induced psychosis can lead to damaged relationships, poor job and school performance, alcohol and other substance abuse and even suicide when left untreated (NIH, 2012). These disruptions in the lives of those with mental illness can diffuse into immediate family members and greatly impact the stress level and overall well-being of an adolescent sibling or child of a loved one who has bipolar disorder. The impact can be direct (i.e. destructive personal relationship with loved one) and indirect (i.e. perceived stress from strained family dynamics), and often is a combination of the two.

Current interventions for population.

Family psychoeducation. Family psychoeducation is a common treatment approach used when someone in the family suffers from a mental illness. Recent research shows that involving family in the treatment process helps the family unit become more

resilient when coping with the challenges of the mental illness (McFarlane, Dixon, Lukens & Lucksted, 2003). Family psychoeducation aims to help the relatives of a person who has a mental illness understand the illness and the individual as a whole, thus bringing about change in the family environment and reducing relapse (Sota, 2008). While the positive effects of this treatment have been reflected in the literature time and again, some family psychoeducation programs are shown to have participation rates as low as 14% (Rotondi, 2005). This shortcoming in participation rates exhibits the need for alternative and more convenient ways to administer family psychoeducation programs. Furthermore, it is common practice for family psychoeducation to occur in a clinic setting with multiple families gathering at once. This technique can be uncomfortable for some individuals due to the negative stigma associated with mental illness, especially for adolescents seeking mental health services. The intervention described in the present study could serve as the first step in the family psychoeducation process to help teens feel more comfortable in a face-to-face family psychoeducation group in the future. Using a less intimidating mode of communication like text messaging could improve their trust in mental health information and break down the barrier to increase help-seeking.

Current therapeutic use of technology in mental health. While the technology industry continues to grow and advance rapidly within general healthcare, technology is currently underutilized within the field of mental health. It is becoming increasingly common to see occupational therapists utilize tech tools such as iPads and smart phones within the pediatric and older adult populations. These devices have a wide array of uses such as communication aids or reminders to take one's medications. With new Android and iOS applications being developed daily, it is only a matter of time before technology

is fully accepted as an aid to treating individuals with a mental health diagnosis. It is well known that treatment for mental illness must be a collaborative approach to yield successful results, requiring a strong support system. For this reason it is vital to examine how technology can be utilized for all actors in the recovery process, not exclusively for the individual with the mental health diagnosis. Furthermore, with society becoming increasingly interconnected through different technological outlets such as cell phones and the internet, it is feasible to propose that these outlets be used to provide caregiver education and support. The use of technology in mental health is currently supported by the President's New Freedom Commission on Mental Health as goal number six which states "Technology Is Used to Access Mental Health Care and Information." This goal was developed in order to produce care that is safe, effective, efficient and client-centered. (NAMI, 2013).

mHealth technology interventions. One mHealth (mobile device health care) intervention in health care that has been very effective is Text4baby. Evans et al. (2012) evaluated the efficacy of this mobile phone technology used to support maternal and child health in a randomized pilot study. The researchers found it to be very promising, finding significant improvements in specific beliefs, such as alcohol consumption during pregnancy, targeted by the messages within the participants during follow-up interviews. Another program explored a mobile health technology intervention for inner city patients with poorly controlled diabetes and had very positive results as well. Researchers found that the TExT-MED program increased healthy behaviors, improved diabetes self-efficacy and medication adherence, and had excellent satisfaction scores from participants (Sanjay et al., 2012). A third mHealth intervention was conducted by

researchers interested in improving a cardiac rehabilitation program (Pfaeffli et al., 2012). Patients from a cardiac rehab program were recruited to participate in the study to determine whether or not they found the program to be useful, and to give feedback on the content of the text and video messages. Upon evaluation, researchers determined that 85% of patients found the program useful, with the main deterrent being the unfamiliarity with cell phone technology. Additional studies of mHealth interventions for aiding in the process of self-monitoring for weight loss showed continued success with the intervention. They found that, over a 6 month randomized weight loss trial, participants who used the mobile device technology had significantly lower BMI post-intervention than non-users (Turner-McGrievy et al., 2013). Finally, mHealth technologies are being utilized around the world, namely in Africa. The free mHealth campaign titled NightWatch has been used in Senegal, Tanzania, Cameroon, and Chad to help control Malaria outbreaks. The program involves an SMS text message sent each night to subscribers from partnering mobile partners that contain reminders to utilize malaria control tools, such as mosquito nets. The message reminders come from reputable and respected sources such as the Ministries of Health and celebrity spokespeople, and have been found to increase mosquito net use by 24% (Bowen, 2012). Although the number of studies is limited, the positive impact and feasibility of mHealth technology interventions is clear to see in the strong impacts made on the communities of implementation.

Telehealth interventions. Telehealth interventions are described by the National Alliance on Mental Illness (NAMI) (2013) as the use of electronic information and telecommunication technologies to provide long distance clinical care and health-related

education. NAMI also explains that this intervention is widely underused within the mental health population, a statement supported by many other research studies.

Telehealth interventions aimed specifically towards individuals who have schizophrenia have been found to reduce stress and increase social support at more significant rates than that of individuals involved in a usual care group (Rotondi, 2005). One study by Glynn et al also showed higher levels of satisfaction with telehealth interventions than with traditional methods. The primary reason for this, as expressed by participants, is that they are easy to access and don't require in-person confrontation; at times an intimidating aspect of treatment, due to the strong negative stigma attached to mental illness (Glynn, 2010). While telehealth interventions are well-perceived by participants and produce positive outcomes, we are faced with the challenge of assuring access to the interventions for individuals who don't have access to computers or other smart devices allowing them to go online. This is an important factor to address, as there is a strong relationship between socioeconomic status and mental health. According to NAMI, fewer than 15% of people diagnosed with schizophrenia are employed (NAMI, 2013). This puts these individuals and their children at a greater risk of having a low socioeconomic status and therefore they may have less access to technological resources such as computers and cell phones.

Children of parents with mental illness network- Australia. In 1999, the Minister for Health of the Australian Infant, Child, Adolescent and Family Mental Health Association (AICAFMHA) launched the Scoping Project on Children of Parents with a Mental Illness. As a result, the Commonwealth Government allocated enough funding for a three year national initiative meant to create guidelines and complementary resource

materials. One of these resources developed as a result was the Children of Parents with Mental Illness (COPMI) website. In 2007, after the initial three year funding, the COPMI program was extended for a second phase of funding from AICAFMHA. This program was also included under the Council of Australian Governments' New Early Intervention Services (NEIS) for Parents, Children and Young People measure, which supports mental health promotion and prevention. Australia's national secondary schools also supported a mental health initiative called "MindMatters" during this time frame, and began the expansion of the website to meet the needs of families, carers and workers who experience parental mental illness. The website's focus is to improve access to information for family members (including children) and professionals. In 2010, the website re-formatted their website to be more useable and with more recent information, separated into the categories "parents", "family and friends", "kids" and "teens/young adults". The organization has also published a supplement in the Medical Journal of Australia-Open Supplement titled "Parental Mental Illness is a Family Matter" in April 2012 (COPMI, 2014).

COPMI.net also has resources for professionals involved in the care of families living with mental illness. There are online eLearning courses that are free and accessible to anyone that is interested in taking them, and include "Keeping Families and Children in Mind", "Family Focus", and "Child Aware Supervision" courses. These courses are aimed at specific populations accordingly, such as mental health professionals and even the general public. The courses are developed by leading researchers, service providers in mental health, and a person who has the lived experience of parental mental illness (COPMI, 2014).

Under the section for “Teens/Young Adults”, there is access to YouTube videos, information fact sheets, tips for coping, how to help a parent, getting personal help, and real stories and advice from other teens. Australia also has two associated helplines that young adults who have a parent with a mental illness can call for support; Lifeline Australia and Kids Helpline. The information on the website is written in a manner that is easy to access for this age group, and provides many resources for them to access on their own time (COPMI, 2014). This resource is a strong platform and representation of what services for children of parents with mental illness in the United States could look like.

Young carers networks. Since adolescent children have been known to take on many caregiving responsibilities when a parent has a mental illness, it is important to have adequate social support for them. There are a variety of young carers networks around the world, outside of the United States. There are designated networks in Europe and Australia, each with their own support system, website, and group activities for members (COPMI, 2014; the Children’s Society, 2014; NNAAMI, 2001). It has become a trend in these countries that has been becoming more popular and reaching a wider audience as it grows. Unfortunately, this trend has not reached the United States. There is no set child carer network in the United States currently.

There are a few different websites that give young adults access to resources, but are very limited in the information they offer. Websites hosted in the United States that offer such information include American Academy of Child and Adolescent Psychiatry (aacap.org) and National Alliance on Mental Illness (nami.org). These websites are aimed at parents or adults who have children, in an effort to have them access the

information for their child. The information is not written in a health literate manner, and is not aimed at the adolescents themselves. Other sites that have information regarding parental mental illness include Mental Health America (nmha.org) and Psych Central (psychcentral.com), but their information is focused on family support rather than focusing on the unique needs of the adolescent child themselves due to the mental illness in their family. There is a hole in the availability of technological resources for adolescents who have a parent with a mental illness.

Methods

Study Design

The study is designed to be a feasibility study. Specifically, the following questions were asked: 1. Can we recruit appropriate participants? 2. How appropriate are the data collection procedures and outcome measures for the intended populations and purpose of the study? 3. Are study procedures and intervention suitable for and acceptable to participants? 4. What resources are needed to manage the intervention?

A feasibility study is designed to build a foundation for the intervention. A feasibility study is different from a pilot study in that they are “pieces of research done before a main study in order to answer the question ‘Can this study be done?’... used to estimate important parameters that are needed to design the main study” (Tickle-Degnen, 2013). A Pilot study varies in that it is a smaller version of an intervention to check whether the main study will work when implemented on a larger scale. Feasibility studies generally have smaller sample sizes and are not concerned with large sample sizes needed to power statistical null hypothesis testing. However, many feasibility studies yielding significant results will ultimately lead to significant larger scale studies.

Therefore, a single-subject multiple baseline study design was utilized to determine the appropriate parameters that are needed to conduct the study on a larger scale.

The effectiveness of the text message intervention was measured using a single subject, multiple baseline study design. This design helped to separate the factors of time and maturation from confounding upon the intended outcomes (Portney & Watkins, 2000). The subjects were evaluated using both qualitative and quantitative measures at multiple periods throughout the study. The qualitative measure used was the Vignette quiz (Jorm et al., 1997). The remaining instruments are quantitative, and include: the Perceived Stress Scale-14(PSS-14) (Cohen et al., 1983), 10-point Likert Scale to measure the quality of the relationship with their loved one, and the Weekly Check-In Script. The text messages were written by the researcher in partnership with others who have significant knowledge and experience working in the mental health profession. The topics are based on the needs of this population, as identified in the current literature. Outcome measures, methods of assessment and frequency of assessment are found in Table 1. Copies of the described assessments are also found in the Appendices.

Table 1 <i>Outcome measures and their associated assessments</i>		
Outcome Measure	Instrument	Frequency of Measurement
Adolescent's knowledge (health literacy level) of psychosis and its typical signs	Vignette Quizzes	<ul style="list-style-type: none"> • Baseline • Post-Intervention
Adolescent's Perceived Stress	Perceived Stress Scale (PSS)	<ul style="list-style-type: none"> • Baseline • Post-Intervention
Relationship with loved one	10-point Likert Scale	<ul style="list-style-type: none"> • Baseline • Post-Intervention
Relationship with loved one, subjective ratings of weekly text messages, change in behavior	Weekly Check-In Script	<ul style="list-style-type: none"> • 1x/week

[Link to Alt Text Description](#)

Participants

The participants in the study were selected based on a number of inclusion criteria. To participate, participants needed to be between the ages of 13-18 years, and have at least one close family member with diagnosed bipolar I or II, schizophrenia or schizoaffective disorder. It was not required that they reside with their family member currently. Participants were required to have a cell phone that is text message capable, and a phone plan that will last through the entire six weeks of the intervention. The participants were recruited using recruitment fliers hung at various locations around the UW-Milwaukee Campus and an ad placed on Craigslist.

Upon contact from an interested adolescent, the researcher conducted a brief initial eligibility questionnaire over the phone. The following questions were asked to ensure that the individual meet the eligibility criteria and to gather demographic information: 1. What is your age and grade level in school? 2. What is your gender? 3. What is your race/ethnicity? 4. What city do you live in? 5. Without telling me their

actual name, do you have an immediate family member who has a diagnosed mental illness? If so, which mental illness? 6. Without telling me their actual name, in what way are they related to you? 7. Do you live with this family member? 8. Do you personally have a diagnosed mental health condition? 9. Briefly (in 1-2 sentences), how would you describe your relationship with your loved one who has a mental illness? 10. Do you have access to a personal cell phone that is capable of receiving text messages? 11. Do you have access to a computer with a webcam?

If the participant met the criteria, they were asked to give the researchers their contact information in order to obtain informed consent to participate in the study.

Because the population being investigated is fairly small compared to the general population, the number of participants in the study was expected to be relatively small. Since feasibility studies do not require large sample sizes, the goal number of participants was 3 adolescents. This allowed for three separate baseline time frames to be used in the study design. UW-Milwaukee IRB approval was obtained and participants (and parents when under 18 years old) signed an informed consent document to participate in the study.

Materials

The main intervention materials included in this study was a cell phone that is text-message capable and a web-cam enabled computer to complete video calling. These were inclusion criteria to participate in the study, and thus was not a cost to the researchers. Paper, ink, envelopes and postage for the assessment materials are included into the budget.

The vignettes created by Jorm et al. (1997) have been developed to reveal the level of mental health literacy of the participants, specifically literacy of schizophrenia and depression. These vignettes are a well-respected tool to measure the level of health literacy surrounding mental illness, and the one being used in this study contains a story of an individual experiencing schizophrenia (see Appendix B). These vignettes and quizzes can be accessed for free, online. Cohen's Perceived Stress Scale (1983) can also be accessed for free online. Finally, the 10-Point Likert Scale to measure relationship quality and the Weekly Check-in Script were developed by the primary researcher, and are thus free. For a complete list of outcome measures and their associated measurement tool, see Table 1 in the Study Design section of this proposal.

Procedures

To begin the study, participants were recruited using flyers placed around the UWM campus with appropriate permission, as well as an online Craigslist ad. The flyer contained the basic inclusion criteria for participants, a statement offering compensation for participation, and the contact email of the primary researcher. A copy of the recruitment flyer can be found in Appendix F. The primary researcher is an Occupational Therapy Master's student, and is under the supervision of an experienced research faculty member at the University of Wisconsin, Milwaukee. Once interested participants and/or parents of participants contacted the researchers by phone, the primary researcher asked them the previously listed screening questions. If the participant met the criteria to participate in the study, and parent was willing to give consent for their child to participate, they were placed on a list of participants and contacted at the time of

initiation of the study. The recruitment period was 4 months, beginning in October 2014 and ending in January 2015.

When an individual was determined eligible for the study, a packet was mailed to their home, including: pre-addressed and stamped envelope to return necessary documents to researcher, Informed Consent document, Pre-assessments (3), and a local mental health resource handout. Once each participant received the packet, they called the primary researcher to set up a time to complete the IRB Informed Consent paperwork as well as the Pre-assessments via video call using GoToMeeting. The researcher emailed a unique link to an encrypted video call generated by GoToMeeting.com to each participant immediately prior to each scheduled meeting to initiate the video call. Initially, the participants under 18 years old spoke to the researcher with their parents to complete the IRB Informed Consent document. The participant 18 years old did not require a parent/guardian present to complete the consent process. After signing the informed consent document, the researcher asked that the parents left the room while the adolescent completed the assessments.

Once the parents separated from their children into a different space, the primary researcher read aloud the schizophrenia vignette created by Jorm et al. (1997). Next, the participant completed the pre-intervention vignette fact quiz, Perceived Stress Scale-14 (PSS-14), and the Relationship with loved one 10-point Likert Scale. The researcher instructed the participants to place completed assessments into the pre-addressed envelope and place it in the mail the following morning. These assessments were scored by the primary researcher, and recorded in an Excel Spreadsheet. All of the electronic

data in this study was kept in a password protected computer database, and all of the paper copies of assessments kept in a key-locked file cabinet.

The participants received three text messages per week for a total of 6 weeks, containing information on the topics found in Table 2. The text messages were sent out on Mondays, Wednesdays and Fridays at approximately the same time of day. Each week, the researcher contacted each participant for a brief, weekly check-in. During this check in, participants were asked questions regarding their subjective ratings of the text messages, if they had changed any behaviors as a result of the messages, as well as a subjective rating of their relationship.

After completion of the 6 weeks of intervention, the primary researcher contacted all participants and set up a time to meet via video calling to complete the post-intervention vignette quizzes, Perceived Stress Scale, and Relationship with Loved One 10-point Likert Scale. The post-assessments were scored by the primary researcher and stored in a key-locked file cabinet, and the electronic spreadsheet of the results will be stored on a password protected computer. Figure 1 shows a flow-chart of the sequence of events for the entire study.

Table 2 <i>Weekly schedule of text message themes</i>	
Week of Intervention	Weekly theme of text messages (3x/week)
1	Understanding Mental Illness and Psychosis. Definitions and causes.
2	Typical treatments of mental illness
3	What's my role? Assertiveness and Boundaries
4	Understanding Stigma
5	Managing crisis
6	Resources and Navigating the System

[Link to Alt Text Description](#)

Figure 1: Timeline

	Sep	Oct	Nov	Dec	Jan	2-Feb	9-Feb	16-Feb	23-Feb	2-Mar	9-Mar	16-Mar	23-Mar	6-Apr	Jul	Aug
Preparation of Materials																
Participant Recruitment																
Written Assessments						Pre-intervention Assessment						Post-Intervention Assessment	Post-Intervention Assessment	Post-Intervention Assessment		
Text Message Intervention																
Data Analysis & Writing Report																
Distribute Results																

[Link to Alt Text Description](#)

Data

As previously mentioned, the results of the pre-intervention and post-intervention assessments were recorded in a Microsoft Excel spreadsheet with a pseudo name for each participant. A complete list of participants' correct names and contact information was stored separately from the data, to uphold confidentiality. To obtain the quantitative data, the primary researcher used the results from the Perceived Stress Scale-14 (Cohen et. al., 1983), Relationship with Loved One Likert Scale and Weekly Check-in to conduct visual analysis. The Vignette quiz responses were read and themes identified by the researcher.

Administrative Support

Budget

Due to the nature of this study, and free resources utilized, the costs needed to conduct it were minimal. All assessment tools used are free- the Perceived Stress Scale (PSS), Vignette quizzes are found online and have no cost to use, and the 10-point Likert Scale and the Behavior Survey are developed by the primary researcher and are thus free. A small sum of money was needed to account for printing costs including ink and paper, as well postage for mailing the assessment so/from participants. The estimated cost of these expenses is \$30. To administer the text message intervention, researchers used Google Voice online software. This is a free, online resource that allows a person to send text messages from the secure website. Using Google Voice eliminated privacy issues with participants having access to the researcher's cell phone number, and eliminated the major anticipated cost of the study. In total, the estimated cost of expenses related to the research study is \$30. Since the cost of the intervention is very low, participants were reimbursed for their time through a \$40 VISA gift card, with a total cost for all

participants of \$120. The total expense amount for the study was \$150.00. A UWM College of Health Sciences Graduate Student Research Grant was awarded to the Student Principle Investigator for the amount of \$202.00. These funds were used to cover all study expenditures.

Lastly, while the researchers involved in this study, including both graduate students and staff, were not reimbursed for their time, this study required a considerable time commitment. While one's time commitment will vary depending on what phase the study is in, it is estimated that the primary researcher spent 10-15 hours per week working on tasks related to the study, with a larger time commitment during the data analysis and report writing phase.

Resources and Environment

Given that this research involves an mHealth intervention, a physical meeting place for the participants was not needed. Data analysis done by the primary researcher took place in room 135 of Enderis Hall, which offers ample space and access to computers and other office supplies. Furthermore, ninth floor offices occupied by supporting faculty were utilized for any contributions they have to the research process.

Personnel

As previously stated, this research was conducted by an Occupational Therapy Master's Student at the University of Wisconsin- Milwaukee with support from research faculty within the Occupational Therapy department. The primary researcher was responsible for organizing the study, collecting participants, administering the intervention, gathering data, and performing a data analysis. The advising faculty members contributed to these tasks by acting as both a support system and pool of

resources. The team of faculty involved in this study has many years of professional and research experience in all fields related to the research topic including work with adults, pediatrics/adolescents, and the mental health population.

Results

Recruitment

Participants were recruited using flyers placed in various locations at UWM, and Craigslist Ads over a period of 4 months. A total of 4 participants were recruited for the study, with one dropping out prior to completing the pre-intervention assessments. Screening data for this dropout is included in Table 3, but is not included in the data analysis. A total of 2 females and 1 male adolescent agreed to participate in the study by signing the IRB Informed Consent document.

Demographics

Participants that participated in this study resided in various locations throughout Wisconsin (see Table 3 for demographics). Ages ranged from 14 to 18 years old, but race/ethnicity of participants was universally Caucasian. The adolescents' relation to a loved one who had a mental illness varied, but the majority were mothers and fathers. There was also an array of relationship dynamics among participants and their loved one. One participant described her relationship with her mother as a "normal mother-daughter relationship", while another described his with his father by saying "There was a long period of time when I didn't want to be around him because of his episodes and have just recently been in contact again". Diagnoses were predominantly Bipolar Disorder. Participant 1 was unique in that she had two immediate family members who had a Bipolar diagnosis (step-father and mother). Her responses to assessments focused on her

relationship with her mother, as she felt that relationship was strained the most between the two.

Table 3
Participant demographics

	P1	P2	P3	P4 (dropout)
Age	17y	14y	18y	14y
Gender	F	F	M	F
Race/ethnicity	Caucasian	Caucasian	Caucasian	Caucasian
Name of Loved One's Mental Illness	Bipolar Disorder (Unknown type)	Bipolar Disorder (Unknown type)	Bipolar Disorder, Type II	Schizophrenia
Family member relation	Step-Father & Mother	Mother	Father	Aunt
Describe your relationship with them	"We don't get along very well"	"Normal mother-daughter relationship, we socialize together"	"There was a long period of time when I didn't want to be around him because of his episodes and have just recently been in contact again"	"She forgets a lot of things but does a lot for me"
Do they Reside with you?	Yes	Yes	No	No

[Link to Alt Text Descriptions](#)

Statistical Outcomes

Perceived Stress Scale-14. Each participant completed the Perceived Stress Scale (Cohen et. al., 1983) prior to and following the 6-week intervention. The researcher read instructions aloud via GoToMeeting video call and instructed participant to complete form. There was a significant decrease in perceived stress level among all 3 participants following the intervention. A visual analysis of pre-post scores revealed a change in

level among the group as a whole, demonstrating a change in stress (see Figures 2, 3 and 4). The smallest decrease in stress was found to be 5 points lower (P1), while the greatest decrease was 9 points lower (P2, P3). Scores are interpreted via comparison to normative data and correlating perceived stress level (see Table 4). All 3 participants scored in the “Much higher than average” level prior to receiving the intervention. Following the intervention, 2 participants reported scores in the “slightly higher than average” category, and 1 participant in the “average” level. All participants demonstrated significant decreases in perceived stress following the 6-week intervention.

Table 4
Scoring and interpretation of Perceived Stress Scale-14

Total Score	Perceived Stress Level
0-7	Much lower than average
08-011	Slightly lower than average
012-15	Average
16-20	Slightly higher than average
21+	Much higher than average

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Figure 2: Perceived Stress Scale-14 Score: Participant 1

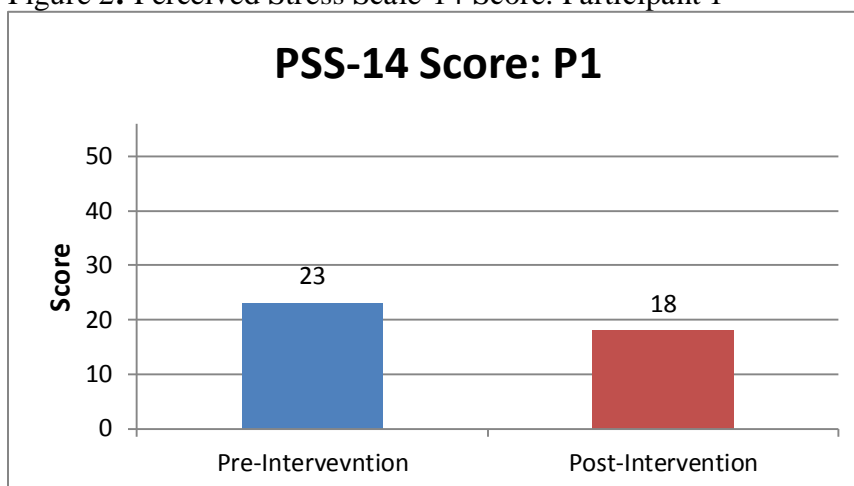
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Figure 3: Perceived Stress Scale-14 (PSS-14) Score: Participant 2

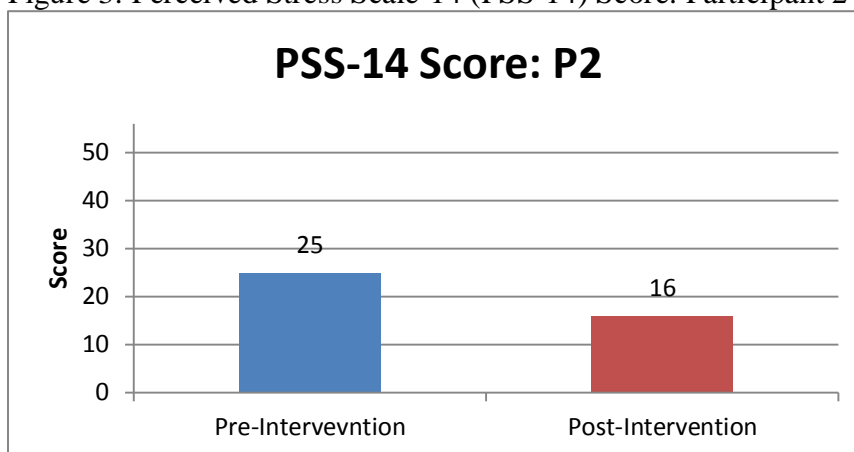
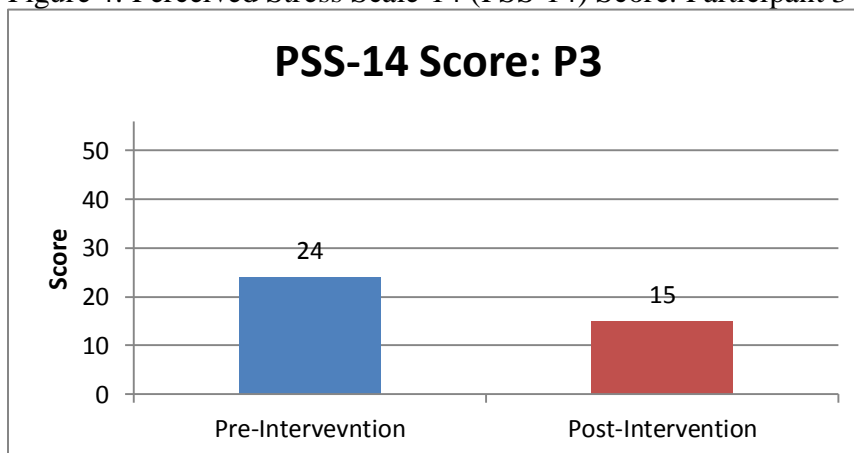
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Figure 4: Perceived Stress Scale-14 (PSS-14) Score: Participant 3

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Vignette Assessment. Prior to receiving the intervention, the researcher administered the Vignette assessment (Jorm et al., 1997) via video call. After reading the short vignette, participants answered questions regarding what they felt was wrong with John, how he could best be helped, perceived effects of various interventions (helpful, harmful, or neither) and perceived causes of the character's problems (very likely, likely, not likely). The Vignette assessment (Jorm et al., 1997) was administered a second time following the intervention, and pre-post scores were compared.

When responding to the two open-ended questions prior to receiving the intervention, participants appeared to have a broad understanding of the character's diagnoses and how he could be helped. These answers became more specific and concrete after receiving the intervention (see Table 5). Participant 1 initially responded by saying that John had schizophrenia, and could best be helped by talking to someone who could help him cope. Upon completion of intervention, her diagnosis of John did not change but her interpretation of what would help John became more concrete: medication and see his doctor. This was consistent with P2, who felt both pre- and post-intervention that John was depressed and had anxiety, but her response to the second prompt became more specific. She initially responded by saying John should seek a medical professional and his family should be supportive, but following intervention, changed her response to "see a licensed psychologist". P3's responses were slightly different for the two prompts when comparing pre- and post- intervention. Pre-intervention, he felt that John possibly had schizophrenia, then post-intervention changed his response to depression. P3 initially responded to prompt number two by saying John

should talk with a therapist or with his family, then later broadened his response to additional coping strategies such as stress management or getting new hobbies.

Participants demonstrated a few changes in response to perceived causes of John's problems (see Figures 8 and 9). The most notable of these was a unanimous increase from "Likely" to "Very likely" that his difficulties were caused by childhood problems. This is significant because the adolescents may feel that their own childhood stress could eventually lead to a serious mental illness.

Participants responded very similarly to which interventions they perceived to be "helpful" when comparing pre- and post- answers. Participants universally (n=3) viewed the following as "helpful" both pre- and post- intervention: relaxation/stress management, becoming more physically active, help from close friends and family, psychologist, telephone counseling service, counselor, pharmacist, and psychiatrist. An increased number of participants perceived the following interventions as "helpful" after the intervention, when compared to pre-intervention: reading about people with similar problems and how they dealt with them (n=3) and herbal medicines (n=2). A decreased number of participants felt the following interventions would be "helpful" following the intervention: clergy (n=1), having an occasional drink to relax (n=0), going on a special diet (n=0), and sleeping pills (n=1). Participants had varying responses to which interventions they perceived as "harmful" when comparing pre- and post- responses as well. Fewer participants felt that the following interventions would be "harmful" following the intervention: going on a special diet (n=1), undergoing ECT (n=2), being admitted to psychiatric ward of hospital (n=0), hypnosis (n=0), antibiotics (n=0), antidepressants (n=0), antibiotics (n=0), and pain relievers (n=1). There was no change

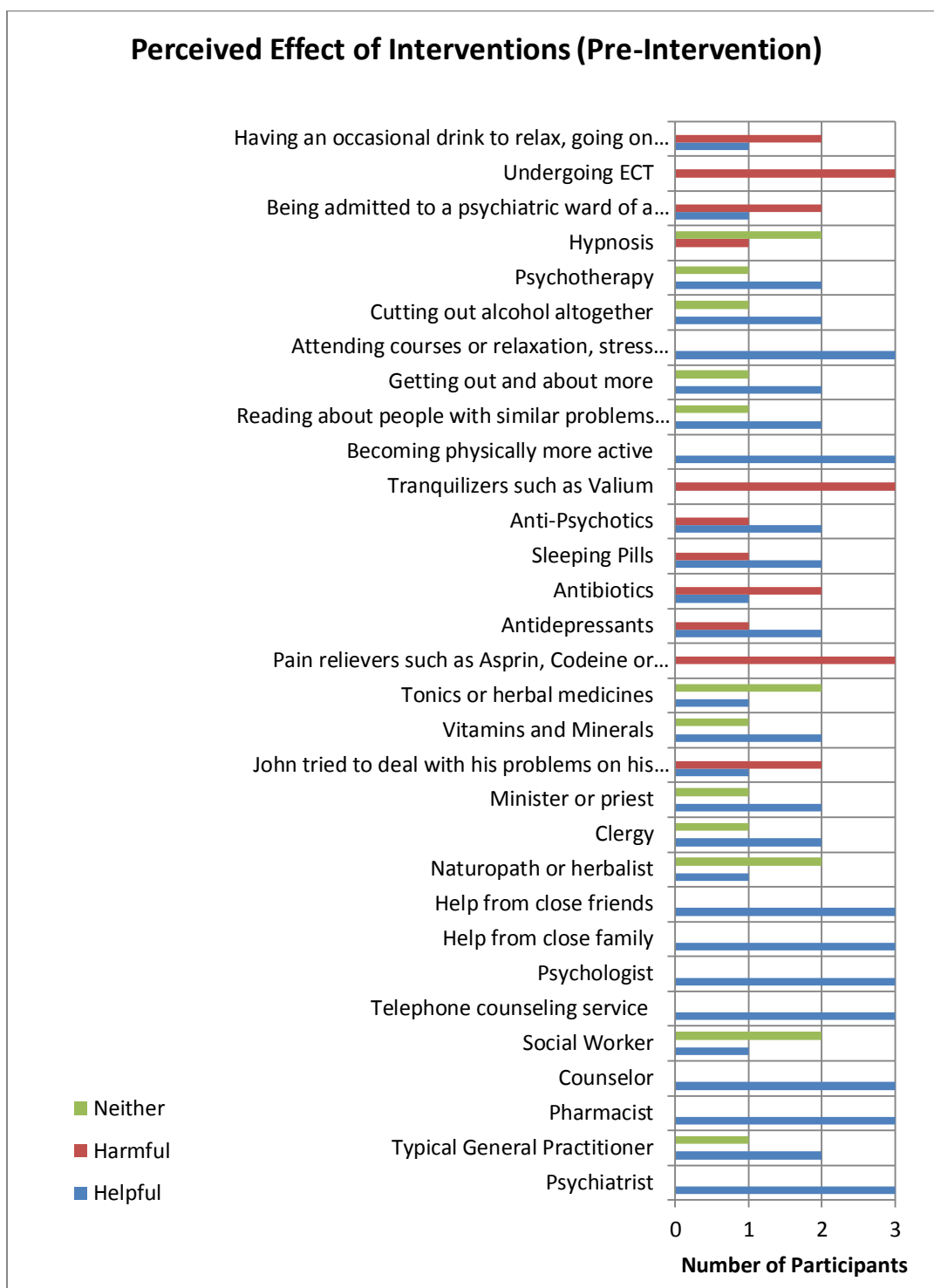
in perception of the following interventions being “harmful”: tranquilizers (n=3), John tried to deal with his problems on his own (n=2), anti-psychotics (n=1), and sleeping pills (n=1) (see Figures 6 and 7).

Table 5:
Vignette Qualitative Subjective Responses

Vignette Question	Participant Number	Pre-Intervention Response	Post-Intervention Response
“What would you say, if anything, is wrong with John?”	P1	“schizophrenic”	“has a mental illness”
	P2	“depressed” “Has anxiety”	“has lots of anxiety”
	P3	“Has a mental illness, possibly schizophrenia”	“depressed and another mental illness”
“How could John best be helped?”	P1	“talk to someone who can help him cope”	“medication “ “see his doctor”
	P2	“be seen by medical professional” “his parents should be supportive”	“therapy” “see a licensed psychologist”
	P3	“go to a therapist to talk about problems” “talk with his family”	“get new hobbies to keep himself busy” “stress management to calm him down”

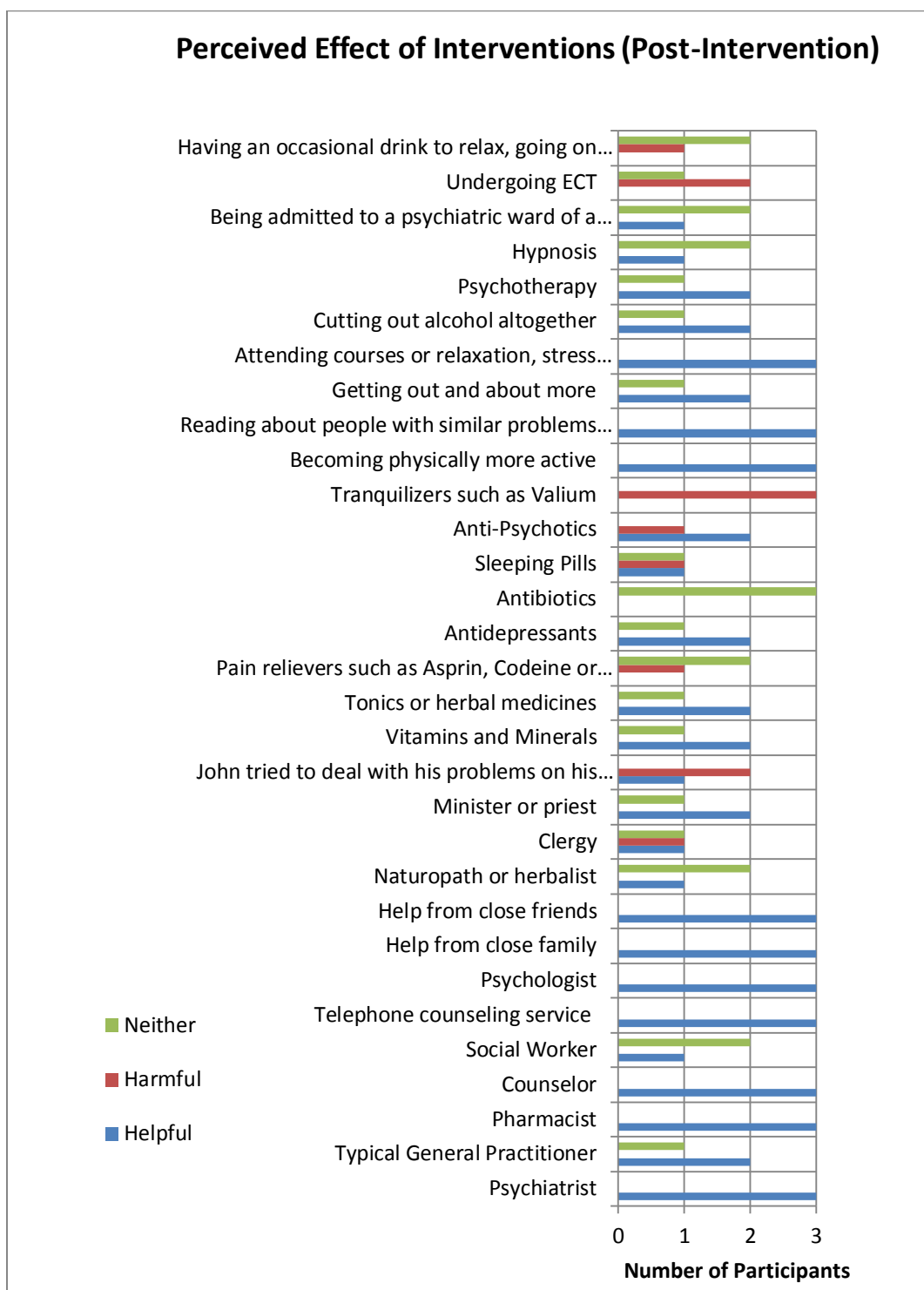
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Figure 5: Perceived effect of various interventions (pre-intervention)



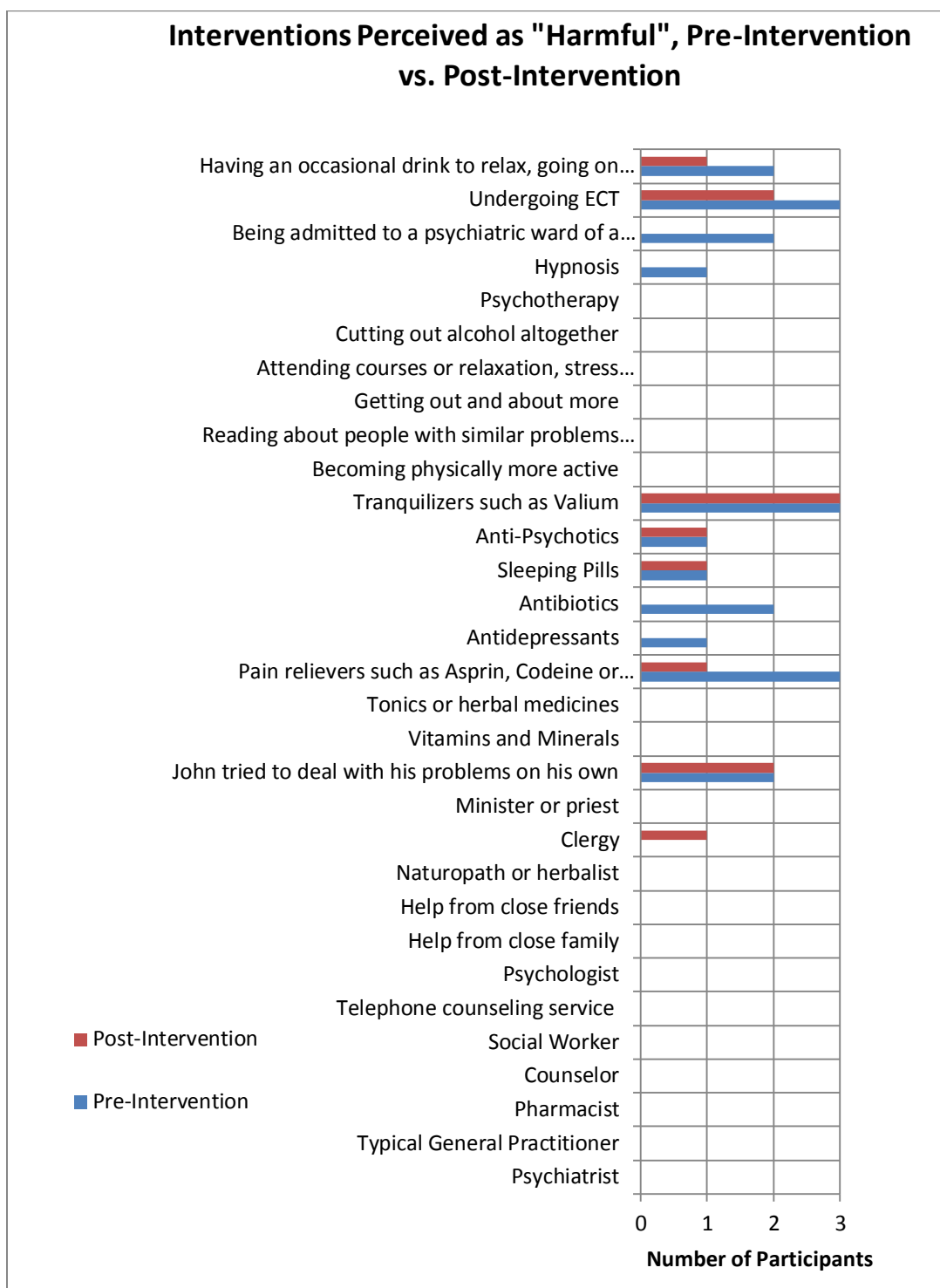
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Figure 6: Perceived Effect of Interventions (Post-intervention)

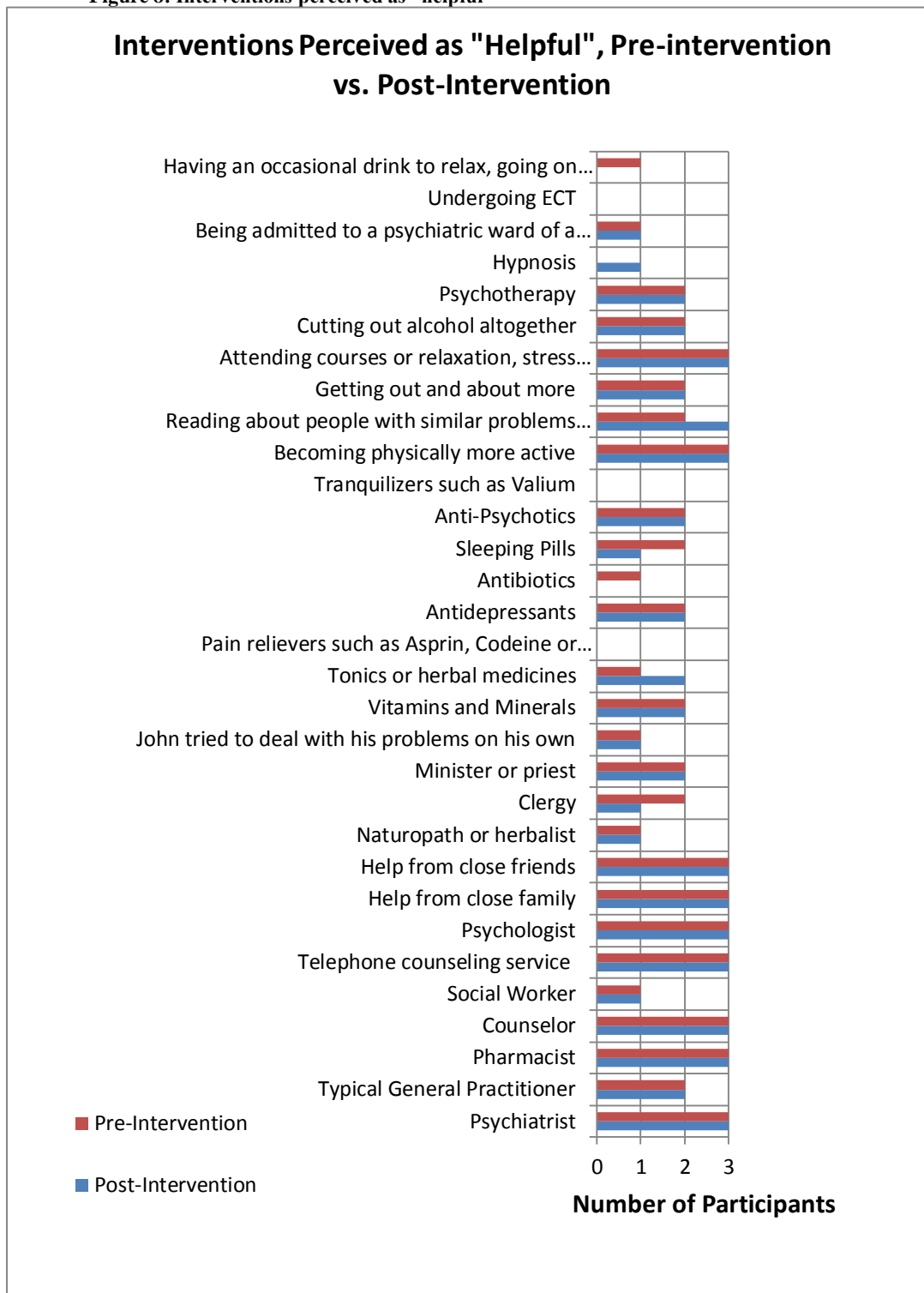


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Figure 7: Interventions perceived as “harmful”

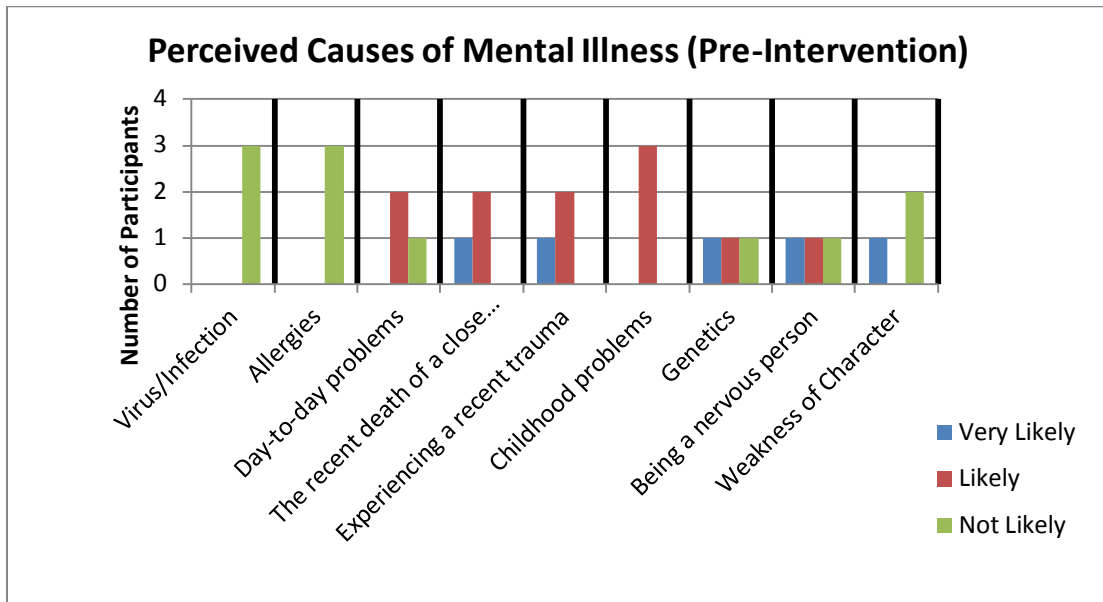


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Figure 8: Interventions perceived as “helpful”

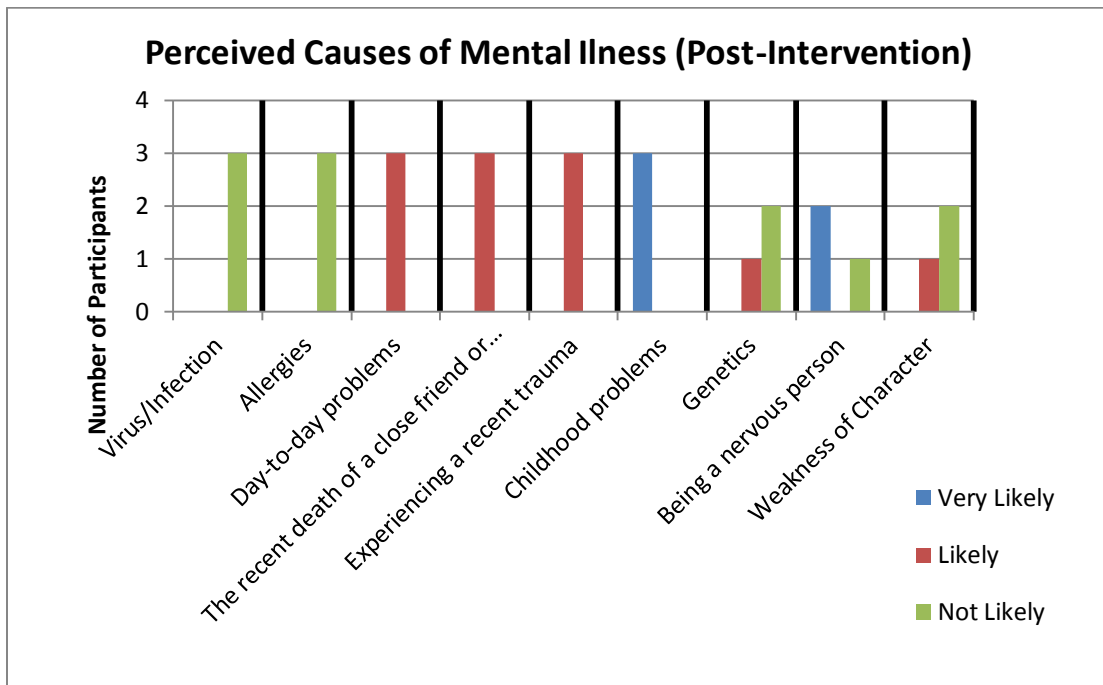
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Figure 9: Perceived causes of mental illness (pre-intervention)



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Figure 10: Perceived causes of mental illness (post-intervention)



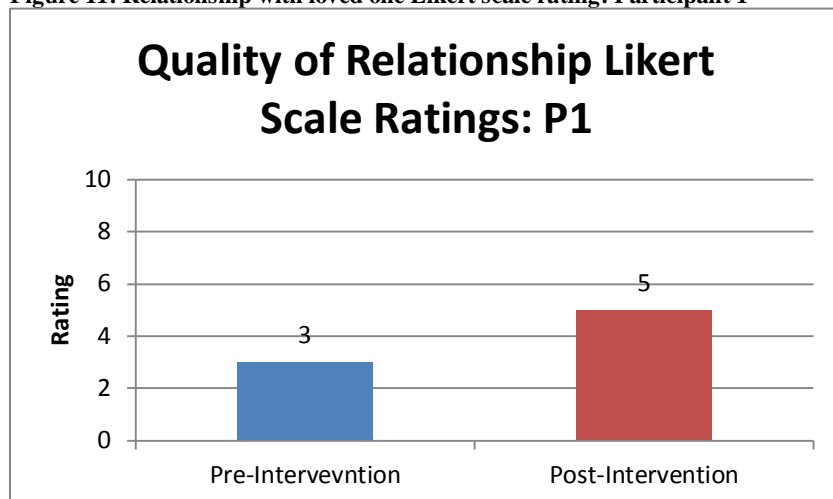
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Weekly Check-in

Each week, the researcher contacted each participant via phone call to gather data. Participants were asked the following check-in questions: “How would you rate the quality of your relationship?” (Likert Scale), “How interesting do you feel the week’s messages were?” (Likert Scale), “How useful do you feel the week’s messages were?” (Likert Scale), and “Did you change anything as a result of something you learned from the messages?” (open-ended question). These brief calls lasted about 5 minutes per participant each week. At times, the phone call took place up to 3 days following the week’s messages, secondary to difficulty contacting the participants. The researcher called on the weekday and time that was requested by each participant, but often needed to make additional call attempts to connect with them. The highest number of call attempts to a participant was 4 times.

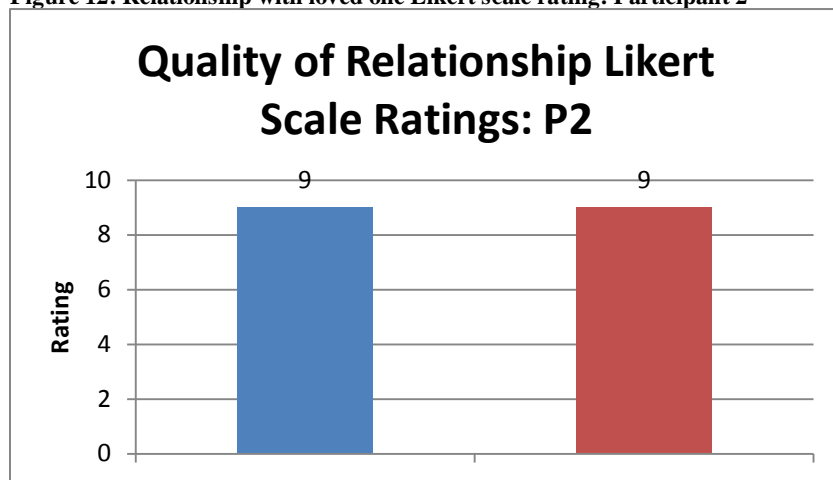
Quality of Relationship Likert Scale. Participants reported widely varying scores to represent the quality of the relationship with their loved one. The 10-point Likert Scale was given to participants prior to intervention, once per week during the intervention, and once following the intervention. A score of “0” indicated a very poor relationship, and “10” indicated very high quality relationship. 2 Participants reported increased quality of relationship following the intervention (P1=increase of 2 points, P3=increase of 1 point), and the remaining participant reported no change in quality. Throughout the 6-week intervention, all 3 participants reported changes in their relationship quality. Figures 10-13 provide visualization of the results.

Figure 11: Relationship with loved one Likert scale rating: Participant 1



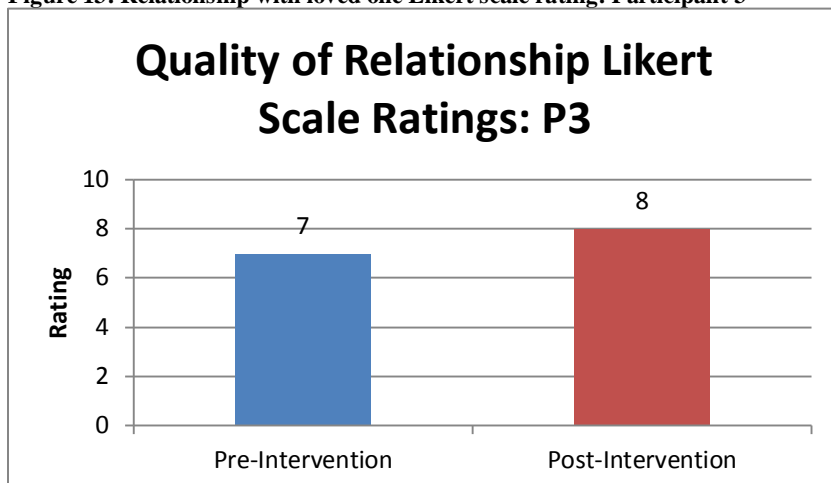
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Figure 12: Relationship with loved one Likert scale rating: Participant 2



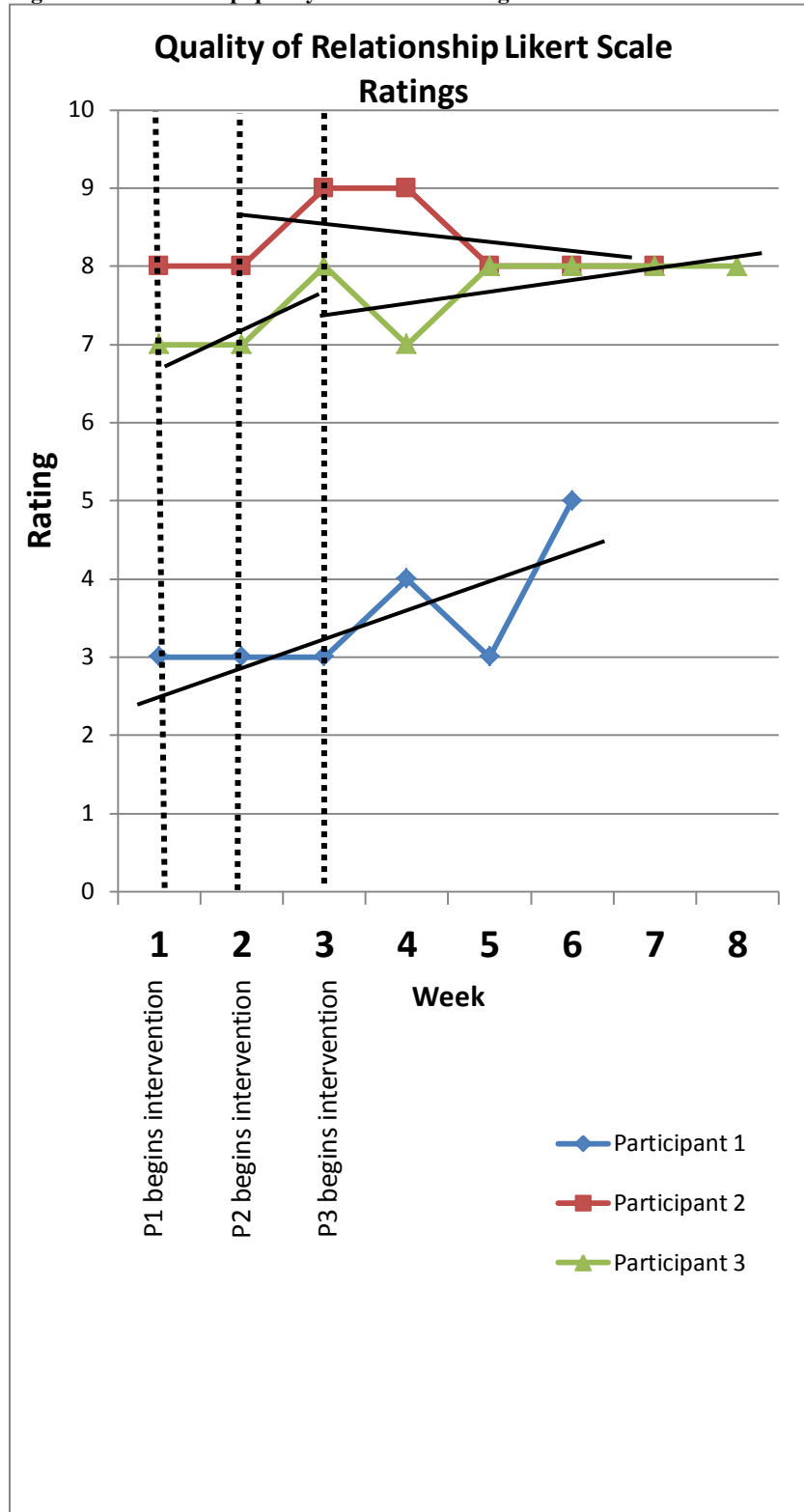
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Figure 13: Relationship with loved one Likert scale rating: Participant 3



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Figure 14: Relationship quality Likert Scale ratings

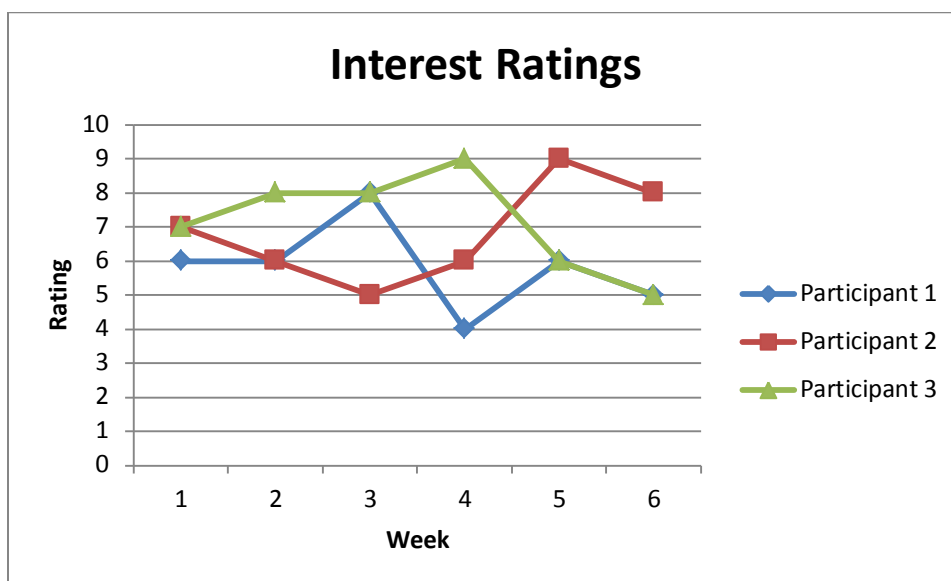


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Text message ratings. Interest ratings varied from week to week and among the participants (see Figure 14). The highest average rating was week 5: managing crisis (7.5/10). The highest consistency among weekly ratings among participants was week 1: Understanding Mental Illness, definitions and causes (1 point difference between highest and lowest ratings). The highest variability in responses was found in week 4: Understanding stigma (5 point difference among highest and lowest ratings). These findings were consistent among the usefulness ratings among participants (highest variability found in week 4, highest consistency found in week 1). The usefulness ratings were consistently higher than the interest ratings each week, indicating that although participants did not find messages highly engaging, they agreed that the information was useful (see Figure 15).

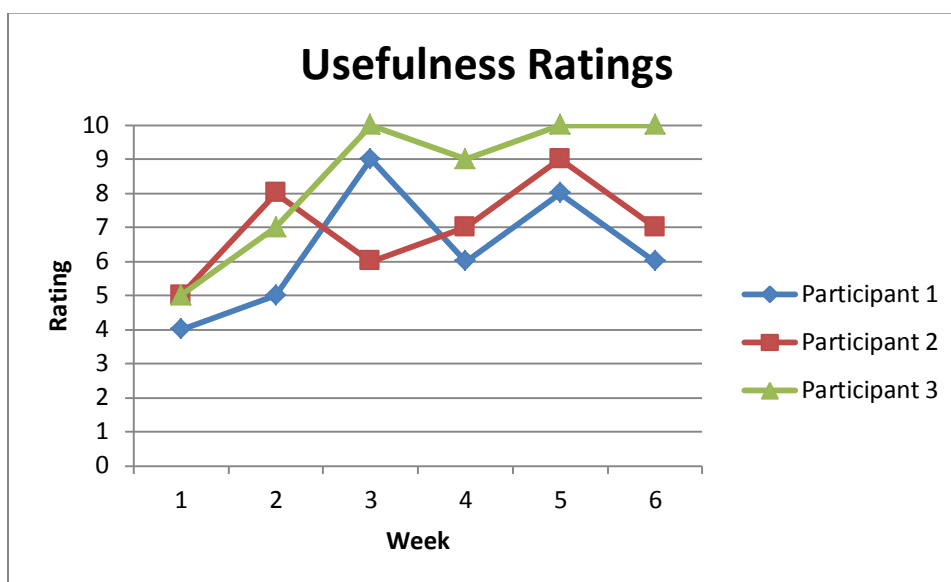
As each week surrounds a unique topic under the umbrella of mental health literacy, it would not be appropriate to group all 6 week ratings into one total average interest and usefulness rating. Since each participant has a different background and health literacy level upon initiation of the intervention, it could account for the widely varying interest and usefulness ratings each week among the participants. It may be more useful to create a “library” of text message topics for participants to choose from, based on their interest and needs. This individually tailored approach would likely keep the participants more engaged, improve the usefulness, and create an overall more therapeutic intervention for teens.

Figure 15: Interest level of text messages Likert Scale ratings



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Figure 16: Usefulness of text messages Likert Scale ratings



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Change in behavior. Each week, participants reported any change in behavior resulting from weekly messages (see Table 6). P1 changed behaviors 4/6 weeks, P2 changed 2/6 weeks, and P3 changed 3/6 weeks. It is significant to note that the highest

pre-intervention relationship rating was P2, who changed behaviors the fewest amount of weeks during the study. Conversely, P1 changed behaviors the most amount of weeks, and had the lowest initial relationship rating. This may indicate that since P2's relationship quality was already generally high, she had already known the information given in the intervention and not required many changes to improve her relationship. P1 may have had a lower relationship quality because she had not been previously exposed to the intervention's information. A change in behavior during the week was moderately correlated with an increase in quality of relationship.

Table 6:

Participant's responses to question "Did you change any behaviors this week as a result of something you learned in the text messages? If so, what?"

Week	P1	P2	P3	Anecdotal Evidence
1	No	No	No	-
2	No	Yes	Yes	"It put me in a more positive mood, cheered my mood up", "take better care of myself", "yes, a lot nicer after understanding more about her illness"
3	Yes	No	Yes	"yes, I've been more open and friendly with people who have disabilities specifically", "understand them better"
4	Yes	No	Yes	"yes about holding stigma, I've been nicer to peers with disabilities, less judgmental", "continued to take better care of myself"
5	Yes	Yes	No	"Take better care of myself", "when something happens, I stop and think before acting because sometimes what I say hurts my mom's feelings"
6	Yes	No	No	"I'm taking better care of myself"

[Link to Alt Text Description](#)

Feasibility of Study for Future Intervention

Process Assessment

Recruitment. Recruitment for a study of this nature requires an electronic or online recruitment. Since the mHealth nature of the study allows participants to be recruited from virtually anywhere in the world, it makes the most sense to recruit using a similar means. When recruiting for this study, there was a much higher success rate when using Craigslist.com ads than hard copy flyers placed in public places. When targeting the younger generation, it is critical to use their generally preferred and accepted means of communication-the internet and cell phones. It is recommended that future studies looking to recruit large sample sizes use an internet or other electronic-based recruitment method.

Appropriateness of intervention and data collection methods. Providing an intervention via text messages appeared to be a useful method of information transfer. With texting becoming the main stream means of communication for adolescents, it only makes sense that an intervention of the sort would be well received by participants. As a researcher, it would be more efficient and time-saving to enlist the services of an automated text messaging service. This would decrease the risk of error when typing individual messages each week, especially if the study involves a large sample size.

When conducting the pre- and post- assessments, it was sufficient and efficient for the primary researcher to use video calling for the small sample size. However, it may be necessary to recruit study assistants to complete portions of the video calls in order to decrease the burden on the primary researcher. Introducing multiple administrators would require training in order to standardize assessment administration to maintain reliability of results. Mailing participants' assessments and requesting return of completed assessments using pre-stamped/addressed envelopes worked very well and

participant compliance was 100%. Although it comes with a price, it appeared to be a very successful means of data collection for this study.

However, attempting to collect data from participants weekly via phone call was a challenge. Although the researcher asked participants' preferences of day of the week and time to check-in upon initiation of the study, schedule conflicts arose frequently. As a result, weekly check-ins occurred within 1-3 days following the week's text messages (Saturday-Monday), rather than the day immediately following the messages (Saturdays). Instead of phone calls, it would be useful to utilize a different method of data collection, such as a text message or email. Doing so would likely improve the frequency of responses in the intended time frame, improving the validity of the information collected.

Resources Assessment

Material resources required to complete this study were very minimal. However, the researchers involved contributed a significant amount of time to conduct the intervention and to analyze the results. Future research should utilize the suggestions stated previously to reduce the amount of time required and to increase the efficiency of the study procedures. Although the amount of time required was manageable for the small sample size, it would not be feasible if the sample was larger without altering the study procedures.

Scientific Assessment

Level of Safety. Throughout the study, participant privacy was upheld. The privacy of each participant was maintained by never attaching their name or identifiable information to their telephone number or assessments/data. This allowed each of the participants to remain completely confidential and protected during and after the

intervention. As an extra level of safety, participant phone numbers were never saved to the GoogleVoice account used to contact participants each week. Following the intervention, the phone number was disconnected and account closed. This was a very manageable task, and should be continued in further studies to protect participants. Although no participants contacted the researcher for support in a time of crisis, this is a realistic concern for future studies that researchers should be prepared for. If this occurs, it would be necessary to inform the participant once again that it is not legally permissible for the researcher to intervene. Researchers should refer patients to the “Helpful Resources” handout given upon initiation of the study, unless they are in immediate danger. In which case, they should be instructed to hang up and dial 9-1-1.

Trustworthiness and usefulness of outcome measures. In future studies, it is recommended to utilize the Perceived Stress Scale-14 (PSS-14) (Cohen et al., 1983), a text message weekly check-in and brief interviews to collect anecdotal evidence. The Vignette’s developed by Jorm et al. were a useful tool to gather high volumes of data relating to perception of causes and treatments for mental illness. However, the feasibility of younger participants completing such a lengthy assessment was found to be lower than initially presumed. Assessment exhaustion may have occurred and the responses to the questionnaire may not be valid, given the number of items on this assessment. Finally, it is not meant to be analyzed apart from visual analysis. If studies wish to explore to effectiveness of an intervention, they would not be able to “score” the Vignettes, as there is no correct or incorrect response. It would be more useful to gather qualitative data from an interview at various stages of the intervention. This is where the strongest evidence was found in the present study. As previously discussed, a text-based

check-in may be more useful than a phone call to gather Likert Scale ratings in a timely manner. The data gathered from the check-ins were very valuable to understand how the participants were receiving the intervention, and should be continued in future studies. The open-ended nature of the interview check-ins allowed participants to respond candidly to the intervention, rather than a quantitative assessment, giving the data higher validity.

Intervention as a useful tool. After exploring the feasibility of a text message-based mental health literacy intervention for adolescents, it was determined that it is a feasible and valuable tool that meets this population's needs. Upon assessment of the feasibility of various aspects of study, including recruitment, data collection, participant safety, intervention approach, and outcome measures, numerous positive qualities were identified and were discussed in previous sections of this analysis. It appears that this type of intervention is cost effective, efficient, and population-centered. This intervention should be considered for future studies on a larger-scale, in order to deeper explore its' effectiveness for the adolescent population.

Review of objectives. After review of the study's specific aims, it was determined that all aspects were addressed and discussed above. These objectives include: 1. Determining the feasibility of the eligibility criteria for recruitment purposes 2. Determining feasibility of obtaining the needed resources for the study 3. Determining the feasibility of research management of study data 4. Determining the clinical significance of the results of the intervention and 5. Determining the appropriateness of the outcome assessments for the intended outcome measures (i.e. reliability, validity, trustworthiness).

Discussion and Conclusions

Clinical significance of outcomes

It is significant to note that all participants demonstrated a significant decrease in perceived stress following the intervention. They also unanimously responded that John's issues were "very likely" due to childhood problems; an aspect that may be highlighting their own experiences handling difficult situations with their loved one who has a mental illness. As identified in the literature, adolescents who have a family member who is living with a serious mental illness can have the following implications: increased emotional stress, difficulty focusing on schoolwork, possible loss of boundaries/role confusion, and increased responsibility when taking on a caregiver role (Jacobsen & Miller, 1998; Reupert, 2007). When a parent-child relationship is strained, as some of the participants in this study identified, it is likely that they are experiencing some, or all, of the above stress-inducing factors. The intervention described in this study could serve as a preventative and protective measure to lessen this stress burden for teens on a large scale, as it appeared to in this study. This could lead to a healthier and mental health literate adolescent community. Ultimately, this could translate to an overall healthier society, healthier communities and decreased healthcare costs.

Comparison of results with work of others

As far as this author is aware, this study is the first of its kind to explore the feasibility of an adolescent mental health-focused mHealth intervention. As a study investigating the feasibility of methods, the effectiveness of the intervention is not of primary concern. Thus, it is inaccurate to compare the results of this study to other mHealth effectiveness studies.

Limitations and Strengths

There are a few potential limitations surrounding this study. The first limitation was recruitment of participants. It was somewhat difficult to recruit a large number of adolescents that were willing to participate in the program. This may have occurred for a few reasons. First, it could have been due to a parent's reluctance to give consent to their child if they are in a high-symptom state. Also, teens may hold a strong stigma against mental illness, and could be reluctant to participate in a study where they feel their family's "problems" are brought out into the open. Next, the inclusion criteria of requiring access to a cell phone may have limited the types and number of participants in the study. Since adults with mental illness often come from lower socioeconomic status and may not have access to cell phones, it might mean that this population is more difficult to access with this inclusion criterion. It also may slightly bias the results, as it might not be a true representative sample of the population. Next, all participants self-identified as "Caucasian". This may be due to small sample size, but could also indicate that the intervention or recruitment methods were not applicable to a range of cultures. Finally, it should be noted that the subjects participated in the study with some type of personal investment. These may include a desire for learning the information or for the monetary compensation for participating.

However, the study has various strengths. Although all were Caucasian, the participants displayed a range of relationship qualities, ages, and genders which improves the validity of the results. Next, the study's feasibility design provides suggestions to refine future study methods and increase the effectiveness of the intervention. These contributions are significant to the growing body of research surrounding mental health

literacy and technology. This study is one of the first studies investigating the effects of a technology intervention to improve mental health literacy, and it could show how effective this type of intervention could be. It could facilitate the United States to begin to strive for a higher standard of care for this population that is currently demonstrated in countries around the world, like Europe and Australia.

Suggestions for further study

There are many directions for possible further research based on the study's findings. It would be worthwhile to explore the effects of this intervention on a larger scale with a much larger sample size. As previously discussed, expanding the intervention to different areas of the country and/or globe would better show the usefulness of this type of intervention. This would require researching additional local resources for participants to utilize in their home communities. Future researchers could provide electronic resources that could guide participants to organizations or mental health providers unique to their geographic location. Second, it would be meaningful to develop alternate, standardized assessments to measure mental health literacy. This would strengthen the results of studies investigating the effectiveness of the intervention. Next, the development of a text message "Library" of various categories to choose from could improve the usefulness of the intervention and broaden the audience. Additionally, a psychometrically sound assessment for mental health literacy should be developed to measure this construct in a more valid and reliable way. Finally, a focus group of adolescents to better understand their impressions of the intervention would be a very valuable tool to improve its efficacy.

Equivalent Text Descriptions: Figures

Figure 1:

This figure depicts the process of study events over time. Each event (listed on left side) is noted by a blue box according to when it occurs.

Figure 2:

This bar graph shows a decrease in PSS-14 score when comparing pre-intervention (blue column) and post-intervention (red column) for Participant 1. Participant 1 demonstrated decrease in perceived stress following the intervention.

Figure 3:

This bar graph shows a decrease in PSS-14 score when comparing pre-intervention (blue column) and post-intervention (red column) for Participant 2. Participant 2 demonstrated decrease in perceived stress following the intervention.

Figure 4:

This bar graph shows a decrease in PSS-14 score when comparing pre-intervention (blue column) and post-intervention (red column) for Participant 3. Participant 3 demonstrated decrease in perceived stress following the intervention.

Figure 5:

This bar chart shows the number of participants that thought the given intervention (listed on left side) was either helpful, harmful, or neither before receiving the intervention. Participants varied in their responses but felt that most interventions would be helpful for a mental illness.

Figure 6:

This bar chart shows the number of participants that thought the given intervention (listed on left side) was either helpful, harmful, or neither for a mental illness, after receiving the intervention. Participants demonstrated more unanimity in responses following the intervention.

Figure 7:

This bar chart shows the number of participants that felt a given intervention (listed on left side) would be harmful for a mental illness. Pre-intervention responses are in blue and post-intervention responses are in red. The participants overall felt that more interventions were harmful following the intervention when compared to pre-intervention responses.

Figure 8:

This bar chart shows the number of participants that felt a given intervention (listed on left side) would be helpful for a mental illness. Pre-intervention responses are in red and post-intervention responses are in blue. The participants overall felt that the same interventions were helpful both pre and post intervention.

Figure 9:

This bar chart depicts the number of participants that felt a given factor (listed below graph) caused a mental illness, prior to receiving the intervention. The likelihood of each factor causing mental illness is depicted through colors: “very likely” in blue, “likely” in red, and “not likely” in green. Participants had both unanimous and varied perceptions of likelihood of each factor to cause a mental illness.

Figure 10:

This bar chart depicts the number of participants that felt a given factor (listed below graph) caused a mental illness, after receiving the intervention. The likelihood of each factor to cause a mental illness is depicted through colors: “very likely” in blue, “likely” in red, and “not likely” in green. Participants had more unanimous perceptions of the likelihood of each factor to cause a mental illness, compared to pre-intervention responses.

Figure 11:

This bar chart shows the pre-intervention and post-intervention 10-point Quality of Relationship Likert Scale ratings for participant 1. Pre-intervention score is shown by a solid blue bar and post-intervention score is shown by a solid red bar. Participant 1 reported a 2-point increase of relationship quality following the intervention.

Figure 12:

This bar chart shows the pre-intervention and post-intervention 10-point Quality of Relationship Likert Scale ratings for participant 2. Pre-intervention score is shown by a solid blue bar and post-intervention score is shown by a solid red bar. Participant 2 reported no change of relationship quality following the intervention.

Figure 13:

This bar graph shows the pre-intervention and post-intervention 10-point Quality of Relationship Likert Scale ratings for participant 3. Pre-intervention score is shown by a solid blue bar and post-intervention score is shown by a solid red bar. Participant 3 reported a 1-point increase of relationship quality following the intervention.

Figure 14:

This line graph shows the quality of relationship Likert scale ratings for all 3 participants over the entire 8 weeks of baseline and intervention for the study. Each participant is represented by data points connected by lines, and an individual trend line showing the trend of data points over time. Participant 1 is shown with a blue line, and reported an overall increase in relationship quality over the course of the intervention, shown by a positively sloped trend line across the data points. Participant 2 is shown with a red line, and reported no change overall in relationship quality from baseline to post-intervention. A trend line beginning at week two, when the participant began the intervention, has a negative slope towards the final data point. Participant 3 is shown with a green line and reported an overall increase in relationship quality from baseline to post-intervention. A trend line during baseline period of weeks 1-3 is positively sloped, and a second trend line during the intervention period shows a positive slope.

Figure 15:

This figure depicts how interesting the participants found each week of text messages to be, based on a 10-point Likert Scale. Participant 1 is shown with a blue line, Participant 2 is shown with a red line, and participant 3 is shown with a green line. The ratings varied between participants and week to week. The highest average rating was week 1: Understanding Mental Illness, and the lowest was week 6: Resources and Navigating the System.

Figure 16:

This figure depicts how useful the participants found each week of text messages to be, based on a 10-point Likert Scale. Participant 1 is shown with a blue line, Participant 2 is shown with a red line, and participant 3 is shown with a green line. The

ratings each week demonstrated similar trends across participants and weeks. The highest average rating was week 5: Managing Crisis, and lowest was week 1: Understanding Mental Illness.

Appendix A:

This image shows the Perceived Stress Scale-14 used as a pre-intervention and post-intervention assessment. Directions instruct participants to note how often in the past month they have experienced all of the 14 items on the list. Options for response include “never”, “almost never”, “sometimes”, “fairly often”, and “very often”.

Appendix F:

This image shows the recruitment flyer used to recruit participants for the study. The title of the intervention, eligibility criteria, participation expectations, statement offering compensation and contact information of the researcher are included on the form.

Appendix G:

This image shows the “Helpful Resources” handout given to participants upon initiation of the study. It lists mental health resources that participants could utilize if needed. Categories of resource options include “for Wisconsin residents”, “for Milwaukee County Residents”, “for UWM students”, “for All college students”, and “for All teens”.

Equivalent Text Descriptions: Tables

Table 1:

Outcomes to be evaluated during the study and their associated assessments.

Table 2:

A list of weekly text message themes for the study intervention.

Table 3:

Table depicting the demographics of study participants.

Table 4:

A table showing how to interpret the Perceived Stress Scale-14, based on normative data.

Table 5:

Participant responses to the open-ended questions on the Vignette Quiz.

Table 6:

Participant's responses to the weekly check-in question "Did you change any behaviors this week as a result of something you learned in the text messages? If so, what?"

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Appendix A: Perceived Stress Scale (PSS)-14

PSS-14

INSTRUCTIONS:

The questions in this scale ask you about your feelings and thoughts during THE LAST MONTH. In each case, you will be asked to indicate your response by placing an "X" over the circle representing HOW OFTEN you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

	Never 0	Almost Never 1	Sometimes 2	Fairly Often 3	Very Often 4
1. In the last month, how often have you been upset because of something that happened unexpectedly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. In the last month, how often have you felt that you were unable to control the important things in your life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. In the last month, how often have you felt nervous and "stressed"?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. In the last month, how often have you dealt successfully with day to day problems and annoyances?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. In the last month, how often have you felt confident about your ability to handle your personal problems?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. In the last month, how often have you felt that things were going your way?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. In the last month, how often have you found that you could not cope with all the things that you had to do?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. In the last month, how often have you been able to control irritations in your life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. In the last month, how often have you felt that you were on top of things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

PSS-14

	Never	Almost Never	Sometimes	Fairly Often	Very Often
	0	1	2	3	4
11. In the last month, how often have you been angered because of things that happened that were outside of your control?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. In the last month, how often have you found yourself thinking about things that you have to accomplish?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. In the last month, how often have you been able to control the way you spend your time?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

[Link to Alt Text Description](#)

Appendix B: Vignette and Quiz

Vignette:

John is 24 and lives at home with his parents. He has had a few temporary jobs since finishing school but is now unemployed. Over the last six months he has stopped seeing his friends and has begun locking himself in his bedroom and refusing to eat with the family or to have a bath. His parents also hear him walking about his bedroom at night while they are in bed. Even though they know he is alone, they have heard him shouting and arguing as if someone else is there. When they try to encourage him to do more things, he whispers that he won't leave home because he is being spied upon by the neighbour. They realize he is not taking drugs because he never sees anyone or goes anywhere.

Please answer the following questions:**1. What would you say, if anything, is wrong with John?**

2. How do you think John could best be helped?

3. Rate the likely helpfulness of these interventions as “helpful”, “harmful”, “neither”. Place an X in the appropriate box below:

Intervention	“Helpful”	“Harmful”	“Neither”
Psychiatrist			
Typical General Practitioner or family doctor			
Pharmacist			
Counselor			
Social Worker			
Telephone counseling service such as Lifeline			
Psychiatrist			
Psychologist			
Help from close family			
Help from close friends			
Naturopath or herbalist			
Clergy			
Minister or priest			
John tried to deal with his problems on his own			
Vitamins and minerals			
Tonics or herbal medicines			

Pain relievers such as Asprin, Codeine or Panadol			
Antidepressants			
Antibiotics			
Sleeping Pills			
Anti-Psychotics			
Tranquilizers such as Valium			
Becoming physically more active such as playing more sports			
Reading about people with similar problems and how they have dealt with them			
Getting out and about more			
Attending courses or relaxation, stress management, meditation or yoga			
Cutting out alcohol altogether			
Psychotherapy			
Hypnosis			
Being admitted to a psychiatric ward of a hospital			
Undergoing Electro-convulsive therapy (ECT)			

Having an occasional drink to relax; going on a special diet or avoiding certain foods			
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4. Rate the likelihood of the following as causes for the disorder described in the vignette as: 'very likely' 'likely,' or 'not likely'. Place an X in the appropriate box below:

Cause	Very Likely	Likely	Not Likely
Virus or infection			
Allergies			
Day-to-day problems			
The recent death of a close friend or relative			
Experiencing a recent trauma			
Childhood problems			
Genetics			
Being a nervous person			
Weakness of character			

Appendix C: 10-Point Likert Scale

On a scale of 1 to 10, how would you describe the quality of your relationship with your loved one who has a mental illness? Please circle your answer below.

Extremely
Low Quality

Extremely
High Quality

1 2 3 4 5 6 7 8 9 10

Appendix D: Weekly Check-in Script

Hello ____ (name) _____,

This is Emma Coffman from the research study you are participating in. I am calling to talk about this week's text messages you received. Do you have a few minutes to talk?

1. On a scale of 1-10, with 1 being completely not useful and 10 being extremely useful, how would you rate the usefulness of this week's messages?

2. On a Scale of 1-10, with 1 being completely boring and 10 being extremely interesting, how would you rate this week's messages? _____
3. Did you change any of your daily activities as a result of something you learned from this week's messages? If so, what did you change?

4. How would you rate the quality of your relationship with your loved one who has a mental illness on a scale of 1-10?

Thanks ____ (name) _____! Have a great weekend.

Appendix E: Text Message Content

Text Message Content

Week 1: Understanding Mental Illness and Psychosis. Definitions and causes

- A. There are good qualities in the person you love. That person isn't just a mental illness, however the symptoms of mental illness sometimes interfere with those good qualities. A mental illness is never a person's "fault". A mental illness is a medical condition that disrupts a person's thinking, feeling, mood, ability to relate to others and daily functioning. The specific cause is unknown, but it could be genetic or stress from the environment. It is similar to a bolt of lightning that could hit anyone at any time.
- B. Learn to separate the symptoms from the person. Psychosis may be a symptom of schizophrenia and bipolar disorders. That's when a person has thoughts or sensations that most other people don't have and/or ideas that they are being followed, or that they are on a superstar level such as the president or God. This includes hallucinations- seeing or hearing things that are not there.
- C. A common myth about mental illness is that individuals who experience it are violent and dangerous. This is not the case. In fact, those who experience psychosis are often the victims of violence themselves.

Week 2: Typical treatments of mental illness

- A. Successful treatment of mental illness involves a team of specialists, including psychologists, psychiatrists, medical doctors, social workers, and occupational therapists, but also friends and family. The best treatment involves talk therapy, medication, and the loved one feeling a sense of purpose in everyday life such as having a job or getting involved in healthy enjoyable activities. Family education is known to be a very important part of successful treatment.
- B. Some medications that people take for mental illness have some tough side effects. Some of these include weight gain, trouble going to the bathroom, blurred vision, dry mouth, muscle spasms, and feeling sleepy. It is important for your loved one to communicate with their doctor how they feel about medications and if they need to check out other options.
- C. Just because you have a family member who has a mental illness does not mean that you will also develop one. Although some mental illnesses run in families, there are ways to keep yourself healthy. Do not fear it-mental illnesses aren't contagious!

Week 3: What's my role? Assertiveness and Boundaries

- A. Remember that you are a young adult-your job is to be a teenager. You love your family member, but you can't save them or cure them. You can love them

unconditionally and also respect yourself even in challenging times. Sometimes plans get cancelled or your loved one is “sick”. It is okay to have your own feelings of disappointment, frustration, anger or sadness. Assertive communication respects both you and your loved one. Some ways to be assertive are saying “I feel disappointed when (my plans get cancelled or interrupted). I would like__”

- B. Don’t forget to take care of yourself! Do things you like to do. Join a group at school like drama club, music, or art. Try a new sport, eat healthy foods, get plenty of rest, play video games. Try exercising for 30 minutes per day, writing in a journal, or listening to relaxing music, talking about your stress with a friend, teachers or other family members.
- C. Did you know you don’t need to have a specific mental illness to seek your own mental health treatment? It can be very helpful for family members to seek their own mental health treatment. Many teenagers have found talking to a professional about their experiences to be very helpful and stress relieving. Your school nurse, counselor, occupational therapist, teacher or doctor can point you in the right direction. Think of it as a tune up for your mind-just as you would for your bike or car!

Week 4: Understanding stigma

- A. Is it hard to talk to others about mental illness? Are you afraid of their reaction? Would it be easier to say “I love someone with a broken leg” than “I love someone with mental illness”? This is an example of what stigma is- some things are more socially “acceptable” than others but don’t give up! We can fight stigma!
- B. When stigma exists in society, there can be harmful effects like bullying, harassment, extreme isolation, and can cause people to not seek help. When we fight stigma, we can fight these negative things. You have the power to change it!
- C. How to reduce stigma: Talk about it! When we don’t talk about the stigma of mental illness, we allow it to continue. Other ways to fight stigma are to speak out when friends or peers make negative comments about mental illness, don’t stand on the sidelines when bullying occurs in your presence, and to join an advocacy group such as NAMI or start your own group at school.

Week 5: Managing crisis

- A. One way to be prepared include talking to your loved one while they are well . Creating a wellness plan with your family and the loved one with mental illness can help alleviate stress and anxiety in case things start to break down. As a group, list things that help the person stay well and triggers that cause stress. They can help create an action plan. (visit www.copelandcenter.com for info

about the Wellness Action Recovery Plan (W.R.A.P)). Store it in a safe place so it is ready if needed.

- B. Mental illness can be like a roller coaster. Sometimes things are smooth, other times scary. Always keep yourself safe and listen to your instincts. If your loved one is acting very different and could accidentally hurt themselves or others- seek help. Let them know you are worried about them and let others know you're worried. If the situation is an emergency and you or your family member is in immediate physical danger, call 911. Some places have Crisis Intervention Training certified police officers-ask for these officers.
- C. Communicating in crisis can be difficult. Try these tips: keep your voice calm, use short sentences, don't argue or shout, express support or concern, avoid eye contact, and offer options instead of trying to take control of the situation. It may also help to announce your actions before actually doing them and giving them physical and emotional space.

Week 6: Resources

- A. Do you know where to go to learn more about mental illness? Try checking out the resources that your school counselor or nurse has for you to explore about mental illness.
- B. There is a variety of free mental health information and support resources right in your own back yard. Here are just a few for you to check out! NAMI: Family to Family course (www.nami.org), Mental Health America: Wisconsin (www.mhawisconsin.org), Veteran's Administration (www.mentalhealth.va.gov), and Man Therapy (www.mantherapy.org).
- C. There are also many worldwide mental health information and support resources that you can access for free online. Here are a few for you to check out! Children of Parents with Mental Illness (copmi.net.au), Mind Check (www.mindcheck.ca), OneinFive (oneinfive.ca).

Appendix F: Recruitment Flyer

Improving mental health literacy in adolescents through text messages

[illegible]

[Link to Alt Text Description](#)

Appendix G: Helpful Resources Handout

Helpful Resources

If you experience any type of troubling emotional or mental symptoms at any point in the study, please feel free to use these resources:

For Wisconsin Residents:

Mental Health America of Wisconsin
<http://www.mhawisconsin.org/>
 (414) 276-3122 or (866) 948-6483
 Phone is staffed 9 a.m. – 3 p.m.
info@mhawisconsin.org

For Milwaukee County Residents:

The Psychiatric Crisis Line
 (414) 257-7222
 Available 24/7
<http://county.milwaukee.gov/BehavioralHealthDiv7762/CrisisServices.htm>

The Access Clinic
 (414) 257-7665
 Open Mon. through Fri., 8 a.m.-4 p.m.
 New patients should arrive by 2p.m.
 and are seen in order of arrival
<http://county.milwaukee.gov/BehavioralHealthDiv7762/CrisisServices.htm>

WRAPAROUND Milwaukee
 (414) 257-7611
<http://county.milwaukee.gov/WraparoundMilwaukee.htm>

WRAPAROUND Mobile Urgent Treatment Team (MUTT)
 (414) 257-7621
<http://wraparoundmke.com/programs/mutt/>
 “Crisis Intervention 24/7 to families enrolled in the Wraparound Milwaukee Program and to any family in Milwaukee County with a child who is having a mental health crisis when behavior of the child threatens his or her removal from home, school, etc.”

For UWM Students:

Norris Health Center
 3351 N Downer Ave
 Milwaukee, WI 53211
 For appointments, call: (414) 229-4716
<http://www4.uwm.edu/norris/mentalhealth/>

For all college students:

ULifeline – Online resource for college mental health
 1-800-273-TALK (8255)
 Available 24/7
www.ulifeline.org

For all teens:

Crisis Text Line- Support for teens (CTL)
 Text “LISTEN” to 741-741
 Available 24/7
<http://www.crisistextline.org/>
 “Text about anything that is on your mind, and a live, trained specialist receives the text and responds quickly. Provides effective, secure counseling and referrals. CTL partners with existing organization that are experienced and highly trained in teen crisis.”

[Link to Alt Text Description](#)

Appendix H: IRB Protocol Form

IRBManager Protocol Form

NOTE: If you are unsure if your study requires IRB approval, please review the UWM IRB Determination Form.

Instructions: Each Section must be completed unless directed otherwise. Incomplete forms will delay the IRB review process and may be returned to you. Enter your information in the **colored boxes** or place an **“X”** in front of the appropriate response(s). If the question does not apply, write **“N/A.”**

SECTION A: Title

**A1. Full
Study Title:**

Improving mental health literacy: A single-subject design experiment examining the effects of text messaging on adolescent mental health literacy

SECTION B: Study Duration

B1. What is the expected start date? *Data collection, screening, recruitment, enrollment, or consenting activities may not begin until IRB approval has been granted. Format: 07/05/2011*

11/01/14

B2. What is the expected end date? *Expected end date should take into account data analysis, queries, and paper write-up. Format: 07/05/2014*

08/15/14

SECTION C: Summary

C1. Write a brief descriptive summary of this study in Layman Terms (non-technical language):

This study is aimed at improving adolescents, who have a mentally ill family member, understanding of mental illness through text messages. The content of the message will focus on a theme each week. The themes include: 1) understanding mental illness and psychosis, 2) typical treatments of mental illness, 3) What's my role? Assertiveness and Boundaries, 4) Understanding stigma, 5) Managing crisis, and 6) Resources. The six week intervention will involve three text-messages sent to participants per week, followed by a weekly telephone call check-in. The investigators would like to see if this type of intervention helps increase adolescents knowledge of mental illness, changes any health-promoting behaviors in their daily life, improves the relationship with their loved one and decreases their perceived stress.

C2. Describe the purpose/objective and the significance of the research:

The purpose of the study is to determine the feasibility of delivering a text-based mental health literacy intervention for adolescent children who have immediate family members with mental illness. Specifically, the objectives of the study include: 1. Determining the feasibility of the eligibility criteria for recruitment purposes 2. Determining feasibility of obtaining the needed resources for the study 3. Determining the feasibility of research management of study data 4. Determining the clinical significance of the results of the intervention and 5. Determining the appropriateness of the outcome assessments for the intended outcome measures (i.e. reliability, validity, trustworthiness). A single-subject multiple baseline design will be used to address the feasibility of delivering and evaluating the mental health literacy intervention.

Although other countries, namely Europe and Australia, have begun to support the population of adolescents who have a family member with a mental illness in this way, there are currently few supports in the United States. Europe and Australia have set the standard of care, and this study intervention would be one of the first programs in the US for this population.

C3. Cite the most relevant literature pertaining to the proposed research:

Jorm, A.F., Korten, A.E., Jacomb, P.A., et al. (1997). Mental Health Literacy: a survey of the public's ability to recognise mental disorders and their beliefs about the effectiveness of treatment. *Medical Journal of Australia*, 166, 182-186.

Jorm, A.F. (2012). Mental Health Literacy: empowering the community to take action for better mental health. *American Psychology*, 67, 231-243.

Kelly, C. M., Jorm, A. F., & Wright, A. (2007). Improving Mental Health Literacy as a strategy to facilitate early intervention for Mental Disorders. *Medical Journal of Australia*, 187(7), 26-30.

Tickle-Degnen, L. (2013). Nuts and bolts of conducting Feasibility Studies. *American Journal of Occupational Therapy*, 67(2), 171-176.

Farrell, G. A., Handley, C., Farrell, G. A., Josephs, A., Hanke, A., & Hazelton, M. (2001). The Tasmanian children's project: The needs of children with a parent/carer with a mental illness. *Australian & New Zealand Journal of Mental Health Nursing*, 10(4), 221-228. doi: 10.1046/j.1440-0979.2001.00214.x

Burns, J. R., & Rapee, R. M. (2005). Adolescent mental health literacy: young people's knowledge of depression and help seeking. *Journal of Adolescence*, 29, 225-239. Retrieved July 10, 2014, from the ScienceDirect database.

SECTION D: Subject Population

Section Notes...

- D1. If this study involves analysis of de-identified data only (i.e., no human subject interaction), IRB submission/review may not be necessary. **Please review the [UWM IRB Determination Form](#) for more details.**

D1. Identify any population(s) that you will be <u>specifically targeting</u> for the study. Check all that apply: (Place an “X” in the column next to the name of the special population.)			
<input type="checkbox"/>	Existing Dataset(s)	<input type="checkbox"/>	Institutionalized/ Nursing home residents recruited in the nursing home
<input type="checkbox"/>	UWM Students of PI or study staff	<input type="checkbox"/>	Diagnosable Psychological Disorder/Psychiatrically impaired
<input type="checkbox"/>	UWM Students (but not of PI or study staff)	<input type="checkbox"/>	Decisionally/Cognitively Impaired
<input type="checkbox"/>	Non-UWM students to be recruited in their educational setting, i.e. in class or at school	<input type="checkbox"/>	Economically/Educationally Disadvantaged
<input type="checkbox"/>	UWM Staff or Faculty	<input type="checkbox"/>	Prisoners
<input type="checkbox"/>	Pregnant Women/Neonates	<input type="checkbox"/>	International Subjects (residing outside of the US)
<input type="checkbox"/>	Minors under 18 and ARE NOT wards of the State	<input type="checkbox"/>	Non-English Speaking
<input type="checkbox"/>	Minors under 18 and ARE wards of the State	<input type="checkbox"/>	Terminally ill
<input type="checkbox"/>	Other (Please identify):		

D2. Describe the subject group and enter the total number to be enrolled for each group. For example: teachers-50, students-200, parents-25, student control-30, student experimental-30, medical charts-500, dataset of 1500, etc. Then enter the total number of subjects below. Be sure to account for expected drop outs. For example, if you need 100 subjects to complete the entire study, but you expect 5 people will enroll but “drop out” of the study, please enter 105 (not 100).

Describe subject group:	Number:
Adolescents (13-18 years old)	10
TOTAL # OF SUBJECTS:	10
TOTAL # OF SUBJECTS (If UWM is a collaborating site for a multi institutional project):	

D3. For each subject group, list any major inclusion and exclusion criteria (e.g., age, gender, health status/condition, ethnicity, location, English speaking, etc.) and state the justification for the inclusion and exclusion criteria:

-13-18 years old (adolescent age)
 -at least one immediate family member with diagnosed Bipolar I or II, schizophrenia or schizoaffective disorder
 -do not need to reside with their family member currently
 -must have a cell phone that is text message capable, and a phone plan that will last through the entire six weeks of the intervention
 -residing in Southeastern Wisconsin area in order to complete assessments in person
 -English speaking to communicate with S.P.I and P.I. and to complete assessments written in English
 -must not have a diagnosed mental health condition themselves in order to reduce the number of variables that could cause skewed results
 -Participants must have access to a computer with video calling capabilities (i.e. has microphone and webcam). Participants will be screened for this inclusion criteria during the telephone screening script, and be informed of this on the informed consent document.

SECTION E: Study Activities: Recruitment, Informed Consent, and Data Collection

Section Notes...

- Reminder, all recruitment materials, consent forms, data collection instruments, etc. should be attached for IRB review.
- The IRB welcomes the use of flowcharts and tables in the consent form for complex/ multiple study activities.

In the table below, chronologically describe all study activities where human subjects are involved.

- In **column A**, give the activity a short name. Please note that Recruitment, Screening, and consenting will be activities for almost all studies. Other activities may include: Obtaining Dataset, Records Review, Interview, Online Survey, Lab Visit 1, 4 Week Follow-Up, Debriefing, etc.
- In **column B**, describe who will be conducting the study activity and his/her training and/or qualifications to complete the activity. You may use a title (i.e. Research Assistant) rather than a specific name, but training/qualifications must still be described.
- In **column C**, describe in greater detail the activities (recruitment, screening, consent, surveys, audiotaped interviews, tasks, etc.) research participants will be engaged in. Address **where**, **how long**, and **when** each activity takes place.
- In **column D**, describe any possible risks (e.g., physical, psychological, social, economic, legal, etc.) the subject may **reasonably** encounter. Describe the **safeguards** that will be put into place to minimize possible risks (e.g., interviews are in a private location, data is anonymous, assigning pseudonyms, where data is stored, coded data, etc.) and what happens if the participant gets hurt or upset (e.g., referred to Norris Health Center, PI will stop the interview and assess, given referral, etc.).

Name:	A. Activity	B. Person(s) Conducting Activity	C. Activity Description (Please describe any forms used):	D. Activity Risks and Safeguards:
Recruitment		S.P.I (OT Master's student)	Flyers placed at Norris Health Center and at NAMI Greater Milwaukee office until three participants have been found to meet eligibility criteria. Flyers will be distributed electronically as well. This will take place as soon as IRB approval has been reached.	-no known risks
Screening		S.P.I (OT Master's student)	A Screening Questionnaire will be used to perform screening process. Questions will be asked over the phone to determine eligibility, and will take approximately 5-10 minutes to complete.	-privacy and confidentiality is minimal risk -phone conversation will be made in a closed office to ensure privacy. Screening and demographic information obtained will be stored in a locked cabinet in a locked office (Enderis Hall, room 996).
Obtaining Consent		S.P.I (OT Master's student)	Consent for participants under 18 years old will be obtained using the Consent Template for Parent and Child. Parental/Guardian consent will be given after reviewing and signing this form, and Minor Assent will be obtained on the same form.	-subjects may not understand aspects of the consent form --the S.P.I will be available via video call to explain or clarify any parts that are unclear or that

		<p>Participants that are 18 years old will sign the Adult Consent form. This will take place over GoToMeeting video calling with the SPI and each individual participant (and parent if under 18 years old) on their own computer, individually. The SPI will view the participant (and parent if applicable) sign the informed consent over the video call. Participants will be asked to mail these back to the SPI in the same envelope as the pre-assessments. Immediately after this occurs, the SPI will begin administering the pre-assessments. This should take about 15-20 minutes to review and sign.</p>	<p>subjects would like further explanation of.</p> <p>-[3] If parent is the family member with a mental illness, there is a slight risk of privacy for the parent. However, the child will not be asked to give any identifying criteria of their parent outside of their relation to the child and their diagnosis, so the parent's name and contact information will not be collected for data purposes. The consent forms will be kept separate from the screening data containing the information about which family member in the child's family has a mental illness, and what their diagnosis is, in a locked cabinet and office.</p> <p>- If parent is the family member with a mental illness and symptoms are high, there is a slight risk of the child feeling pressured to participate in the study. However, it is assumed that if the parent has custody of their child, they are competent to give consent to their child's participation in the study. Also, the child independently has the option to decline signing the informed assent, which would protect them if they did not wish to participate in the study.</p> <p>-Security, privacy, and confidentiality of GoToMeeting video calling are a minimal risk</p> <p>-To minimize security risk of video calling, researchers chose GoToMeeting software that has built-in security measures including: SSL-encrypted website, End-to-end 128-bit AES encryption, automatic inactivity time-out, strong passwords, and a safety oriented user interface. Users must receive a uniquely generated URL by GoToMeeting website, emailed to each participant before their video call, from the SPI, in order to access the call. The</p>
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			<p>software is continuously monitored by GoToMeeting computer programmers for viruses and malware to reduce this possibility for participants and SPI.</p> <p>-The website also primarily uses cookies to provide secure access on your personal account.</p> <p>-Privacy and confidentiality will be upheld by the SPI conducting video calls from a closed office and using headphones to reduce opportunities for outsiders to hear conversation between SPI and participant.</p> <p>-Participants will not need to download any software to participate in the meeting, they will only need to open their browser using the URL given to them by the SPI. This will minimize security risks as well.</p> <p>-Video calls will not be recorded. The risk of this occurring is minimized by the choice of video calling software: GoToMeeting free version, which does not have a recording feature built in to the call.</p>
List all other study activities in the following rows			
Pre-intervention assessments	Research Assistant (OT student)	<p>Assessments will be completed by all subjects immediately after consent is obtained from subjects, prior to the intervention. This will take place over GoToMeeting Video calling with the SPI and each participant using their own computer, in an independent video call, immediately following the signing of the informed consent document. The assessments to be given and their estimated time to complete include: Vignette Quizzes (20 minutes), Perceived Stress Scale (10 minutes), and a 10-point Likert Scale (2-3 minutes). After completion, participants will be asked to mail back assessments</p>	<p>-privacy and confidentiality is minimal risk</p> <p>-The subject data from the assessments will be coded using pseudo names, with actual participant information stored separately from the data in a locked office in a locked computer. After converting the data from the paper copies to an Xcel spreadsheet to analyze, it will be stored on a password protected computer (Enderis Hall, room 996).</p>

		using the business reply envelope provided.	<p>-Security, privacy, and confidentiality of GoToMeeting video calling are a minimal risk</p> <p>-To minimize security risk of video calling, researchers chose GoToMeeting software that has built-in security measures including: SSL-encrypted website, End-to-end 128-bit AES encryption, automatic inactivity time-out, strong passwords, and a safety oriented user interface. Users must receive a uniquely generated URL by GoToMeeting website, emailed to each participant before their video call, from the SPI, in order to access the call. The software is continuously monitored by GoToMeeting computer programmers for viruses and malware to reduce this possibility for participants and SPI.</p> <p>-The website also primarily uses cookies to provide secure access on your personal account.</p> <p>-Privacy and confidentiality will be upheld by the SPI conducting video calls from a closed office and using headphones to reduce opportunities for outsiders to hear conversation between SPI and participant.</p> <p>-Participants will not need to download any software to participate in the meeting, they will only need to open their browser using the URL given to them by the SPI. This will minimize security risks as well.</p> <p>-Video calls will not be recorded. The risk of this occurring is minimized by the choice of video calling software: GoToMeeting free version, which does not have a recording feature built in to the call.</p>
Sending text messages	S.P.I (OT Master's student)	Text messages will be sent three times per week using the Google Voice online system. No	<p>-privacy and confidentiality is minimal risk</p> <p>-Privacy of personal phone numbers is</p>

		<p>intervention (text messages) will be delivered until the signed informed consent documents have been returned to the SPI. The messages will be sent out on Mondays, Wednesdays and Fridays for the entire six weeks of the intervention. Text message content has been determined prior to initiation of the study. The computer used to deliver the text messages will be located in Enderis Hall, room 996, and is password protected.</p>	<p>minor risk</p> <ul style="list-style-type: none"> - When using the GoogleVoice online text messaging service, confidentiality will be maintained by using a new, unique login username and password created by the S.P.I., and after sending the text messages the S.P.I. will log out of the account immediately. The username and password will be stored in a locked cabinet in a locked office, along with the participants personal phone numbers (Enderis Hall, room 996). Each time the S.P.I. sends text messages, they will delete all numbers and text messages from the cell phone to ensure privacy. After completion of the study and post-assessments, the subject's personal phone numbers will be deleted from the "contacts" on the Google Voice account permanently. -Psychological distress after reading text messages containing messages about sensitive topics is a minimal risk. To safeguard the participants' well-being, the S.P.I and P.I. will refer subjects to appropriate professional mental health resources if needed, and give them a handout with a list of such resources.
Weekly phone call check-ins	S.P.I (OT Master's student)	A weekly phone call check-in will be done each week on Fridays for the entire 6 week intervention. The S.P.I. will ask questions about	<p>-privacy during phone conversations is a minimal risk</p> <p>-Privacy of personal phone numbers is</p>

		<p>how the subject felt about the week's text messages, and if they changed any behaviors as a result of the messages. The conversation will take about 5-10 minutes each time.</p>	<p>minor risk</p> <p>-Phone calls made in a closed office to ensure privacy, using the same designated Google number used to send text messages, from a cell phone used study purposes only. The Google number will be deleted after the study is completed so that participants are unable to contact the researcher using it. The cell phone and Check-in information obtained will be stored in a locked cabinet in a locked office (Enderis Hall, room 996). Each time the S.P.I. completes the weekly phone calls, they will delete all numbers from the cell phone to ensure privacy. After completion of the study and post-assessments, the subject's personal phone numbers will be deleted from the "contacts" on the Google Voice account permanently.</p>
<p>Post-intervention assessments</p>	<p>Research Assistant (OT student)</p>	<p>Assessments will be mailed to participants and completed by all subjects one week after completion of the 6 week intervention. This will take place over GoToMeeting Video calling with the SPI and each participant using their own computer, in an independent video call. The assessments to be given and their estimated time to complete include: Vignette Quizzes (20 minutes), Perceived Stress Scale (10 minutes), and a 10-point Likert Scale (2-3 minutes). After completion, participants will be asked to mail back assessments using the business reply envelope provided.</p>	<p>-privacy and confidentiality is minimal risk</p> <p>-The subject data from the assessments will be coded using pseudo names, with actual participant information stored separately from the data in a locked office in a locked computer. After converting the data from the paper copies to an eXcel spreadsheet to analyze, it will be stored on a password protected computer (Enderis Hall, room 996).</p> <p>-Security, privacy, and confidentiality of GoToMeeting video calling are a minimal risk</p> <p>-To minimize security risk of video calling, researchers chose GoToMeeting software that has built-in security measures including: SSL-encrypted website, End-to-end 128-bit AES encryption, automatic inactivity time-out, strong passwords, and</p>

			<p>a safety oriented user interface. Users must receive a uniquely generated URL by GoToMeeting website, emailed to each participant before their video call, from the SPI, in order to access the call. The software is continuously monitored by GoToMeeting computer programmers for viruses and malware to reduce this possibility for participants and SPI.</p> <ul style="list-style-type: none"> -The website also primarily uses cookies to provide secure access on your personal account. -Privacy and confidentiality will be upheld by the SPI conducting video calls from a closed office and using headphones to reduce opportunities for outsiders to hear conversation between SPI and participant. -Participants will not need to download any software to participate in the meeting, they will only need to open their browser using the URL given to them by the SPI. This will minimize security risks as well. -Video calls will not be recorded. The risk of this occurring is minimized by the choice of video calling software: GoToMeeting free version, which does not have a recording feature built in to the call.

E2. Explain how the data will be analyzed or studied (i.e. quantitatively or qualitatively) and how the data will be reported (i.e. aggregated, anonymously, pseudonyms for participants, etc.):

The data will be analyzed quantitatively and qualitatively using pseudonyms for participants. It will be analyzed using computer software such as SPSS and qualitative coding software.

SECTION F: Data Security and Confidentiality

Section Notes...

- Please read the [IRB Guidance Document on Data Confidentiality](#) for more details and recommendations about data security and confidentiality.

F1. Explain how study data/responses will be stored in relation to any identifying information (name, birthdate, address, IP address, etc.)? Check all that apply.

☐ **Identifiable** - Identifiers are collected and stored with study data.

☒ **Coded** - Identifiers are collected and stored separately from study data, but a key exists to link data to identifiable information.

☐ **De-identified** - Identifiers are collected and stored separately from study data without the possibility of linking to data.

☐ **Anonymous** - No identifying information is collected.

If more than one method is used, explain which method is used for which data.

F2. Will any recordings (audio/video/photos) be done as part of the study?

☐ Yes

☒ No [SKIP THIS SECTION]

If yes, explain what activities will be recorded and what recording method(s) will be used. Will the recordings be used in publications or presentations?

F3. In the table below, describe the data storage and security measures in place to prevent a breach of confidentiality.

In **column A**, clarify the type of data. Examples may include screening data, paper questionnaires, online survey responses, EMG data, audio recordings, interview transcripts, subject contact information, key linking Study ID to subject identifiers, etc.

In **column B**, describe the storage location. Examples may include an office in Enderis 750, file cabinet in ENG 270, a laptop computer, desktop computer in GAR 420, Qualtrics servers, etc.

In **column C**, describe the security measures in place for each storage location to protect against a breach of confidentiality. Examples may include a locked office, encrypted devices, coded data, non-networked computer with password protection, etc.

In **column D**, clarify who will have access to the data.

In **column E**, explain when or if data will be discarded.

A. Type of Data	B. Storage Location	C. Security Measures	D. Who will have access	E. Estimated date of disposal
<u>Subject screening and demographic information</u>	<u>Paper copies kept in cabinet in Enderis 996, electronic versions on desktop computer in Enderis 135.</u>	<u>Locked office with locked cabinet. Desktop computer is password protected and in a locked office. All screening and demographic information will be coded using pseudo names, with actual names and associated pseudo names stored separately from the data.</u>	<u>S.P.I and P.I.</u>	<u>5 years from initiation of study</u>
<u>Pre- and Post-Assessment results</u>	<u>Paper copies kept in cabinet in Enderis 996, electronic versions on desktop computer in Enderis 135</u>	<u>Locked office with locked cabinet. Desktop computer is password protected and in a locked office. All assessments will be coded using pseudo names, with actual names and associated pseudo names stored separately from the data.</u>	<u>S.P.I and P.I., Research Assistant</u>	<u>5 years from initiation of study</u>
<u>Weekly check-in information</u>	<u>Paper copies kept in cabinet in Enderis 996,</u>	<u>Locked office with locked cabinet. Desktop computer is password protected</u>	<u>S.P.I and P.I.</u>	<u>5 years from initiation of study</u>

<u>(questionnaire)</u>	<u>electronic versions on desktop computer in Enderis 135</u>	<u>and in a locked office. All check in information will be coded using pseudo names, with actual names and associated pseudo names stored separately from the data</u>		
Subject contact information (phone number, email address, residential address)	<p>Paper copies kept in cabinet in Enderis 996, electronic list versions on computer in Enderis 135.</p> <p>Subject phone numbers will be stored as “contacts” within Google Voice account created by the S.P.I.</p>	<p>Locked office with locked cabinet. Desktop computer is password protected and in a locked office.</p> <p>After completion of study, the contacts will be deleted from the Google Voice account, and the entire account deleted.</p> <p>All contact information (paper and electronic versions) will be coded using pseudo names for each participant.</p> <p>The cell phone and Check-in information obtained will be stored in a locked cabinet in a locked office (Enderis Hall, room 996). Electronic versions will be stored on a password protected, desktop computer in a locked office. Each time the S.P.I. completes the weekly phone calls, they will delete all numbers from the cell phone to ensure privacy.</p>	<u>S.P.I and P.I.</u>	<p><u>5 years from initiation of study</u></p> <p><u>Upon completion of the study, the contacts on the Google Voice account will be deleted immediately.</u></p>

F5. Will data be retained for uses beyond this study? If so, please explain and notify participants in the consent form.

Data will be retained for five years after the study is completed.

SECTION G: Benefits and Risk/Benefit Analysis

Section Notes...

- Do not include Incentives/ Compensations in this section.

G1. Describe any benefits to the individual participants. If there are no anticipated benefits to the subject directly, state so. Describe potential benefits to society (i.e., further knowledge to the area of study) or a specific group of individuals (i.e., teachers, foster children).

By participating in this study, subjects will receive the direct benefit of useful receiving information about mental illness and possibly benefit from increasing health literacy levels. Participants could potentially gain a deeper understanding of how to cope and even thrive in a relationship with a loved one who has a mental illness. This study is the first of its kind in the United States, and would mirror others similar to it in countries such as Europe and Australia. It would increase the growing literature base for this area of study, specifically for an under recognized population: adolescents.

G2. Risks to research participants should be justified by the anticipated benefits to the participants or society. Provide your assessment of how the anticipated risks to participants and steps taken to minimize these risks (as described in Section E), balance against anticipated benefits to the individual or to society.

Social risks

- There is a minimal risk that subjects will experience some type of social discomfort between themselves and their loved one who has a mental illness during the intervention. There is a slight risk that the intervention could create an awkward situation within their relationship.
- There is also a minimal privacy risk if the subject is overheard speaking on the phone with the S.P.I. during weekly check-ins, or if their text messages being received are viewed by others. This risk will be minimized by the S.P.I. conducting phone calls alone from a closed, locked office.
- To minimize the minimal security and privacy risk of video calling, researchers chose GoToMeeting software that has built-in security measures including: SSL-encrypted website, End-to-end 128-bit AES encryption, automatic inactivity time-out, strong passwords, and a safety oriented user interface. Users must receive a uniquely generated URL by GoToMeeting website, emailed to each participant before their video call, from the SPI, in order to access the call. The software is continuously monitored by GoToMeeting computer programmers for viruses and malware to reduce this possibility for participants and SPI. Privacy and confidentiality will be upheld by the SPI conducting video calls from a

closed office and using headphones to reduce opportunities for outsiders to hear conversation between SPI and participant. The benefits of using video calling outweigh the risks.

Psychological risks

- There is a minimal risk that subjects will experience psychological discomfort, agitation or distress if the topics presented in the text message intervention bring up sensitive issues.

To minimize the possibility of these risks from occurring, the P.I. and S.P.I. will have certain safeguards in place. If participants indicate that they are experiencing either negative social or psychological effects, they will be given appropriate professional resources to address their issues. Local mental health resources will be given to subjects and their caregiver/guardian. Subjects will be reminded that participation in the study is voluntary and that they can withdraw at any time. Overall, the risks are very minimal, and the benefits greatly outweigh the risks.

SECTION H: Subject Incentives/ Compensations

Section Notes...

- H2 & H3. The IRB recognizes the potential for undue influence and coercion when extra credit is offered. The UWM IRB, as also recommended by OHRP and APA Code of Ethics, agrees when extra credit is offered or required, prospective subjects should be given the choice of an equitable alternative. In instances where the researcher does not know whether extra credit will be accepted and its worth, such information should be conveyed to the subject in the recruitment materials and the consent form. For example, "The awarding of extra credit and its amount is dependent upon your instructor. Please contact your instructor before participating if you have any questions. If extra credit is awarded and you choose to not participate, the instructor will offer an equitable alternative."
- H4. If you intend to submit to the Travel Management Office or Accounts Payable for reimbursement purposes make sure you understand the UWM "Payments to Research Subjects" Procedure 2.4.6 and what each level of payment confidentiality means ([click here for additional information](#)).

H1. Does this study involve incentives or compensation to the subjects? For example cash, class extra credit, gift cards, or items.

☒ Yes

☐ No [SKIP THIS SECTION]

H2. Explain what (a) the item is, (b) the amount or approximate value of the item, and (c) when it will be given. For extra credit, state the number of credit hours and/or points. (e.g., \$5 after completing each survey, subject will receive [item] even if they do not complete the procedure, extra credit will be award at the end of the semester):

Each participant will receive a 40\$ gift card for participation in the full 6 week intervention. It will be given after the study is completed.

H3. If extra credit is offered as compensation/incentive, please describe the alternative activity (which can be another research study or class assignment) which will be offered. The alternative activity (either class assignment or another research study) should be similar in the amount of time involved to complete and worth the same extra credit.

N/A

H4. If cash or gift cards, select the appropriate confidentiality level for payments (see section notes):

☐ **Level 1** indicates that confidentiality of the subjects is not a serious issue, e.g., providing a social security number or other identifying information for payment would not pose a serious risk to subjects.

- Choosing a Level 1 requires the researcher to collect and maintain a record of the following: The payee's name, address, and social security number, the amount paid, and signature indicating receipt of payment (for cash or gift cards).
- When Level 1 is selected, a formal notice is not issued by the IRB and the Account Payable assumes Level 1.
- Level 1 payment information will be retained in the extramural account folder at UWM/Research Services and attached to the voucher in Accounts Payable. These are public documents, potentially open to public review.

☒ **Level 2** indicates that confidentiality is an issue, but is not paramount to the study, e.g., the participant will be involved in a study researching sensitive, yet not illegal issues.

- Choosing a Level 2 requires the researcher to maintain a record of the following: The payee's name, address, and social security number, the amount paid, and signature indicating receipt of payment (for cash or gift cards).
- When Level 2 is selected, a formal notice will be issued by the IRB.
- Level 2 payment information, including the names, are attached to the PIR and become part of the voucher in Accounts Payable. The records retained by Accounts Payable are not considered public record.

☐ **Level 3** indicates that confidentiality of the subjects must be guaranteed. In this category, identifying information such as a social security number would put a subject at increased risk.

- Choosing a Level 3 requires the researcher to maintain a record of the following: research subject's name and corresponding coded identification. This will be the only record of payee names, and it will stay in the control of the PI.
- Payments are made to the research subjects by either personal check or cash. Gift cards are considered cash.
- If a cash payment is made, the PI must obtain signed receipts.
- If the total payment to an individual subject is over \$600 per calendar year, Level 3 cannot be selected.

If Confidentiality Level 2 or 3 is selected, please provide justification.

The participants will be involved in a study researching sensitive, yet not illegal issues.

SECTION I: Deception/ Incomplete Disclosure (INSERT “NA” IF NOT APPLICABLE)

Section Notes...

- If you cannot adequately state the true purpose of the study to the subject in the informed consent, deception/ incomplete disclosure is involved.

II. Describe (a) what information will be withheld from the subject (b) why such deception/ incomplete disclosure is necessary, and (c) when the subjects will be debriefed about the deception/ incomplete disclosure.

NA

IMPORTANT – Make sure all sections are complete and attach this document to your IRBManager web submission in the Attachment Page (Y1).