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Formative evaluation: Developing measures for online family mental health recovery education

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ABSTRACT

Families facing mental health challenges have very limited access to ongoing support. A formative evaluation of *Families Healing Together* (FHT), a new online family mental health recovery program was conducted using five waves ($N = 108$) of data. Exploratory factor analysis of the measures identified as important to the program theory found strong reliability evidence ($\alpha = .77–.86$) for 6 constructs. A poor response rate (25%) did not allow for valid pre and postoutcome evaluation, however we did have enough information to assess the psychometric properties of the new measures. The new evaluation tool accounted for 34% of the variance in *Capacity to Support Family Member*, and nearly 50% of the variance in *Hopefulness toward Recovery*. New programs without existing measures require formative evaluation strategies that accurately describe program activities in order to develop outcome measures sensitive to novel aspects of program components. Most outcome measures are developed for individuals with mental health challenges not family members. These new measures may be beneficial to effectively evaluate programs that promote family recovery and wellness.

1. Introduction

The *Families Healing Together* (FHT) program was developed to address several deficiencies in the behavioral health system, including the prevalence of mental health challenges among children and adults and the negative effects of these problems on families, as well as workforce training shortages that have led to a lack of support for families in distress. *Families Health Together* capitalizes on the effectiveness of psychoeducation and family involvement in the recovery process, as well as new opportunities provided by the increasing use of Internet technology to provide expanded access to care. Here we describe both the problems and opportunities that *Families Healing Together* addresses, as well as the development of measures identified in the program theory helpful to evaluate this program and others like it.

In 2013, the Substance Abuse and Mental Health Services Administration (SAMHSA) using information from the National Survey on Drug Use and Health (NSDUH) reports one in five adults and 1 in 10 adolescents in the U.S. had "any mental illness" in the past year. Approximately 4% of adults had serious thoughts of suicide, and 0.6% made serious suicide attempt. In contrast, in recent years, definitions of positive mental health have been developed as a complementary construct to preventing mental illness. According to the World Health Organization, "Mental health is an integral part of health; indeed, there is no health without mental health" (World Health Organization [WHO], 2014). Furthermore, the WHO defines mental health as: "a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community." Common indicators of mental health are: (a) emotional well-being, for example, life satisfaction and peacefulness; (b) psychological well-being, for example, hopefulness and optimism; and (c) social well-being, such as social acceptance and sense of community (Centers for Disease Control [CDC], 2013).

This construct of "positive" mental health is similar to that of recovery in mental illness, which has become an increasing focus of the mental health system over the past several decades. During the late 1960s and early 1970s, the mental health field underwent a transformation with the implementation of deinstitutionalization and the birth of the recovery movement (Anthony, 1993), which includes initiatives driven by people with lived experience of the behavioral health system, such as the consumer/survivor/ex-patient

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movement (Jacobson & Curtis, 2000). This movement was driven by the failure of current mental health institutions to: (a) meet the desired goals of recovery and rehabilitation, (b) remove stigma from mental health illnesses, and (c) provide "adequate care for disadvantaged members of society" (Young & Ensing, 1999, p. 219). The concept of recovery includes self-determination and self-help for people with lived experience, and an emphasis on non-medical psychosocial approaches to well-being and community involvement (Ostrow & Adams, 2012).

Often, the journey of individuals with mental health challenges is not a solitary one. Approximately 40% of individuals who face mental health challenges live with their families, while 75% of them have frequent contact with their families. Furthermore, mental health challenges often co-occur with drug or alcohol problems (O'Grady & Skinner, 2012), as well as social problems such as disability and lack of supportive social networks beyond the family. Relatives of family members who face mental health challenges are often overburdened with financial stress, as well as health issues (Pitschel-Walz, Leucht, Bäuml, Kissling, & Engel, 2001). Family members of individuals who face mental health challenges are under considerable stress and are in need of psychosocial support. When first learning of their family member being diagnosed with a mental illness such as schizophrenia, many family members feel angry, anxious, and helpless (Spaniol, Zipple, & Lockwood, 1992). Assessments of these family members demonstrate high levels of anxiety and depression, and low levels of psychological well-being (Martens & Addington, 2001).

During the late 1980s and early 1990s, clinical professionals were not trained to provide support to family members (Spaniol et al., 1992). Therefore, there has been a continuing shortage in the workforce that can provide support for families. In recent years, the role of family in recovery is widely accepted as good clinical practice (Cohen et al., 2008). Several studies have shown that family involvement is important to the recovery process and related to the decrease the likelihood of relapse and readmission to mental health facilities as well as other positive outcomes (Cumhur, Aysen, Zeynep, & Martin, 2012; Glynn, Randolph, Garrick, & Lui, 2010; National Alliance on Mental Illness, 2013; National Institute of Mental Health, 2014; Randolph et al., 1994; Resnick, Rosenheck, & Lehman, 2006; Tarrier et al., 1988).

The importance of findings related to family involvement in the recovery process has led to the development of family psychoeducation practices with therapeutic goals to educate participants to enhance understanding and coping skills, and to improve communication and problem solving skills (Glynn, Cohen, Dixon, & Niv, 2007). Additionally, family psychoeducation has been explored in many different settings in order to establish evidence-based practice, procedures, and recommendations for treatment and education about mental health (Cohen et al., 2008).

In their exploration of the opportunities and obstacles in making family interventions more consistent with recovery principles, Glynn et al. (2007) maintained that, generally, the majority of family interventions reflect an older model of serious mental illness and do not incorporate the recovery principles. Glynn et al. called for the development of effective family interventions, which more closely integrate the principles of the recovery movement. At the level of the individual consumer and members of his or her family, effective treatment models include strategies for overcoming barriers to participation, such as stigma and a sense of hopelessness. Such strategies include: (a) offering to hold sessions in the home of the client or family member; (b) help family members understand that the intervention is designed to improve the lives of everyone in the family, not just the patient; (c) being flexible about scheduling family meetings, and (d) provide education during the engagement process to destigmatize mental illness and engender hope.

One of the settings in which psychoeducation has blossomed over recent years is in Internet based education and interventions. In the past decade, Internet based psychotherapy interventions have become more popular. As technology is an important part of everyday life in regard to employment, education, and entertainment, it also has provided opportunities in mental health care as well. The practice of online mental health services has been coined with different terms such as e-therapy, online therapy, Internet therapy, and cybertherapy. While Internet-based interventions have been opposed by some mental health professionals because of the lack of verbal communication (Barak, Hen, Boniel-Nissim, & Shapira, 2008), there are reasons to believe that anonymity, including visual anonymity (i.e., enabled by invisibility and the lack of eye-contact), is an advantage in terms of users' preference (Barak, Boniel-Nissim, & Suler, 2008). Additionally, Internet-based psychoeducation and/or therapy can be used to reach individuals who may not be reached by more traditional means (King, Spooner, & Reid, 2003). Online interventions also can offer a cost-effective method to increase access to support for persons who live in isolated geographic areas, including disenfranchised and racial/ethnic minority communities (Caldwell, Jorm, & Dear, 2004; Changrani et al., 2008). Another difficult-to-reach population is adolescents–a population who uses the Internet and prefers it for many activities – and prefer the anonymity the Internet provides (Gray, Klein, Noyce, Sesselberg, & Cantril, 2005; King et al., 2006). A simple online questionnaire, paired with the ability to communicate anonymously with a clinical therapist, has been demonstrated to significantly increase utilization rates by 300% in college students at risk for suicide (Haas et al., 2008). Overall, there has been consistent strong support for the value of online therapy to help to increase positive client outcomes (Robinson & Serfaty, 2008; Spek et al., 2007; Ybarra & Eaton, 2005). Consequently, there is a need for better understanding about how access of psychoeducation or therapy via technology, such as the Internet, would support the expansion of these services in the field while remaining focused on recovery and positive mental health. Unfortunately, little research has been conducted to study online interventions with caregivers or family members of an individual with a mental health challenge. Glynn et al. (2007) stated that "a cornerstone of the recovery movement is easy access to appropriate interventions" (p. 438), yet research focused on family support is sorely lacking in the literature. Likewise, there exists several scales focused on mental health recovery even for different age groups such as adolescents and adults. There are also mental health illness specific scales available such as psychosis, and depression, while there are different measures to assess hope and hopelessness. Researchers often use a combination of these scales for a single study (Haddock et al., 2011). Furthermore, Loukissa (1995) reviews scales developed in the 1980s and 1990s, however, the focus of these scales are on the burden placed on family members of individuals facing mental health challenges. Currently there are no available measures that are not only recovery oriented, but also from the perspective of the family member.

In an effort to ameliorate this gap, evaluators worked with *Families Healing Together* (FHT) staff to build the program's capacity toward tracking program outcomes. The FHT program is an 8 week course delivered online, which was designed to support families as they strive to help their loved ones cope with a mental health challenge.

FHT presents users with a curriculum intended to alter their perspective on their family and family members by educating them on the importance of story-telling, meaning-making, and alternative "illness narratives" to focus on strengths rather than weaknesses about people living with mental health challenges (Kleinman, 1988, pp. 185–186). Family members are often eager to tell their story, to describe "the saga of caring for the ill relative"