

Chapter 12

An Analysis of Privacy Language in the Scholarly Literature on Mental Health Apps

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ABSTRACT

This chapter charts the language of privacy in published scholarship on mental health apps. What definition of privacy is assumed? What meanings of privacy are deployed in the research about mental health apps? Using a qualitative thematic approach, this analysis shows that privacy language can be understood as occurring in three phases: Phase 1: Discourse of Technological Possibility; Phase 2: Discourse of Privacy Challenges and Threats; and Phase 3: Discourse of Advocacy. The authors discuss each of these phases and propose a more critical discourse of privacy by identifying the issues inherent in understanding privacy as security.

INTRODUCTION

Since the founding of Apple's App Store in 2008, apps for iOS and Android phones have become a burgeoning industry. Comprising the largest and fastest-growing segment of digital therapeutics, there are over 325,000 health apps with an annual growth rate of 25% (Wykes & Schueller, 2019). In this chapter, we focus exclusively on apps designed for mental health to illuminate the privacy issues at stake. Globally, nearly 30% of the population will experience a mental health condition in their lifetime, and in the U.S., an estimated forty-five million adults live with mental illness (Henson, Wisniewski, Hollis, Deshavan, & Torous, 2019). As a key area of the apps economy, there are over 10,000 mental health apps available for use in psychiatry, psychology, counseling, mental health services, and self-care (Torous et al., 2018).

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Mental health apps leverage the immediacy and accessibility of mobile devices using cognitive behavior therapy (CBT) tools, games, meditation, relaxation, mood and symptom tracking, hypnosis, crisis management strategies, real-time on-demand talk with licensed therapists and even chatbots to cope with a range of conditions including mild to acute stress and anxiety, suicide prevention, sobriety assessment, addiction, bipolar disorder, obsessive-compulsive disorder, and schizophrenia (Huguet et al., 2016; Radovic et al., 2016; Stawarz, Preist, Tallon, Wiles, & Coyle, 2018). While curated app libraries exist, most consumers select mental health apps through their own searches (Larsen et al., 2019).

Estimates about the number of users are difficult to pin down. Figures based on the total combined Apple App Store (iOS) and Google Play (Android) global downloads provide some perspective. Mental health apps, *Headspace* (mindfulness) and *Calm* (for sleep and anxiety), top the list of global downloads with 26 million and 25 million downloads, respectively. Active users, on both a daily and monthly basis, comprise a fraction of these figures. *Headspace* has about 1 million active users monthly and 231,000 active users daily. Similarly, *Calm* has about 1 million active users monthly and 237,000 active users daily (Carlo, Ghomi, Renn, & Areán, 2019). Given that there are over 10,000 mental health apps, the numbers of persons engaged with these apps are significant.

Initially, popular discourse referred to mental health apps as the “pocket therapist” (Trudeau, 2010), describing the early work of Margaret Morris’s team at Intel Digital Health Group that created the app, *Mobile Therapy* to track moods, energy, sleep, and diet by users moving a red dot on their phone screen (Morris et al., 2010). While it once would have been science fiction to describe a society in which people carry devices for regulating moods and curbing anxiety, today, these are ubiquitous in work and everyday life. College students use apps like *Headspace*, *Anxiety Coach*, or *Optimism*, among thousands of other apps including those designed by students to help with stress or interrupt negative thought patterns. First Responders use *CrewCare* for social support and stress management. Baristas at over 30,000 Starbucks globally, have free subscriptions to *Headspace* in their benefits package, and insurance companies, such as *Cigna*, offer *Happify Health* to covered employees.

The booming mental health app market has also led to blogs and news sites that rank the popularity of apps annually. In 2019, the website *PSYCOM* lists the app *notOK* as the most widely used app for adolescent suicide prevention. It features a digital panic button that generates a text message, “Hey, I’m not OK! Please call, text, or come find me,” from the user’s GPS location and sent to up to five contacts.

Also noted are CBT apps that use a range of strategies from games, to mood-charting, to instant message alerts, to peer or therapist chats including *What’s Up* (habit tracking), *MindShift* (tools for fear, panic, and phobias), and *Mood Kit* (anxiety and mood improvement activities). The 2020 list at *Psychiatry Advisor* highlights *Code Blue* for adolescent bullying in which supportive people are alerted to contact the user quickly, and *Breathe2Relax* for stress management. Also featured are *PTSD Coach* designed by and for military personnel, *Lantern*, that links a user to a CBT coach, *Optimism* for mood tracking, and *Talkspace* for anytime chats with a licensed therapist.

Used in conjunction with, as well as independent of mental health professionals, (Buitenweg, Bongers, van de Mheen, van Oers, & van Nieuwenhuizen, 2019; Wykes & Schueller, 2019), mental health apps raise critical questions regarding privacy (Powell, Singh, & Torous, 2018; Sleight, 2018). While personal data sharing is part of the business model and operating architecture for most apps (Parker, Halter, Karliychuk, & Grundy, 2019; Torous et al., 2018), information about health is considered private particularly the sensitive and often socially stigmatized information related to mental wellness (Larsen et al., 2019; Lipschitz et al., 2019). Personal mental health information, if shared inappropriately, can threaten employment, social and political opportunities, personal relationships, and contribute to social isolation and

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