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Exploring the Impact of Open Dialogue Delivered on Digital Platforms:  
A Special Studies Project

By

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Exploring the Impact of Open Dialogue Delivered on Digital Platforms  
A Special Studies Project

By

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2015

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An abstract of  
A thesis submitted to the Faculty of the  
Rollins School of Public Health of Emory University  
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## **Abstract**

Exploring the Impact of Open Dialogue Delivered on Digital Platforms:  
By Lucy Dean Aranda

The world entered into a novel era of healthcare delivery on March 11, 2020 when the World Health Organization announced the Coronavirus Disease 2019 (COVID-19) as a pandemic. In response to the global emergency, social-distancing guidelines and travel restrictions were put in place around the world, greatly limiting people's access to essential health services as well as many other necessities in day-to-day life (Whaibeh, Mahmoud & Naal, 2020). Hospitals and other healthcare facilities found themselves in an urgent position of needing to rapidly transition the way they delivered their services to patients while adhering to social-distancing guidelines and travel restrictions to prevent risk of transition of the deadly virus. Telehealth has emerged as a primary solution to the limitations that the response to the global pandemic has placed on healthcare delivery and has allowed for the continuity of essential healthcare services. Grady Adult Outpatient Clinic (Grady AOP) located in Atlanta, GA is one example of many community health clinics in the United States and around the world that have transitioned services to digital platforms since March of 2020. The delivery of Open Dialogue, a treatment intervention for individuals experiencing psychosis, was moved from in-person clinic settings to digital platforms during this time. This Special Studies Project aims to better understand how Open Dialogue delivered on digital platforms impacted patient barriers and engagement with the program by developing data collection tools that can be used to explore this experience for clients, clinicians, and staff.

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## Chapter One: Introduction

### Background

Psychosis is a symptom found in many mental health conditions that causes strange or bizarre thinking, and unusual perceptions and behaviors. Conditions that have psychosis as a primary symptom are called schizophrenia spectrum disorders, however other disorders like bipolar disorder or major depressive disorder may include psychosis as a symptom as well, (Mental Health America, 2020). People with schizophrenia spectrum disorders may lose contact with reality and experience a range of extreme symptoms that usually include hallucinations and delusions (U.S. Department of Health and Human Services, 2017). Roughly 3.5% of the population will experience a schizophrenia spectrum disorder in their lifetime placing a substantial burden on affected individuals, their families and broader society. That burden includes both high rates of disability or lost productivity and increased mortality due to suicide and higher rates of chronic medical illness (Simon et al., 2017).

Grady Behavioral Health Adult Outpatient Clinic (Grady AOP) located in Atlanta, GA has a multidisciplinary behavioral health team comprising psychiatrists, psychologists, social workers, nurses and other experts who provide services for individuals living with psychosis and their families. This team, staffed by faculty members of Emory and Morehouse Schools of Medicine, is also involved in a variety of research programs that seek to improve the treatment and recovery of patients experiencing schizophrenia spectrum disorders. Among these programs is Open Dialogue (OD), an intervention that brings together the social and professional networks of the patient in network meetings where dialogue is used as the main form of therapy (Freeman et al., 2018). Open Dialogue is designed to treat first-episode psychosis however the program has been adapted at Grady AOP to serve any individual with schizophrenia spectrum disorder.

According to Bergström and colleagues (2018) the goal of OD is to “create a comprehensive, psychotherapeutically-oriented model of treatment within the psychiatric public health sector, to address the real and changing needs of first-contact schizophrenia patients, plus their families” (Bergström, 2018, p. 168-169).

The World Health Organization announced the Coronavirus Disease 2019 (COVID-19) as a pandemic on March 11, 2020. This news was followed by a prompt response from political decision makers and the Centers for Disease Control (CDC) who enacted social distancing guidelines to slow the spread of the deadly virus (Whaibeh, Mahmoud, & Naal 2020). Prior to March of 2020, Open Dialogue network meetings at Grady AOP were held in-person in a clinic setting. To adhere to social distancing guidelines and reduce the risk of COVID-19 transmission, network meetings have since been facilitated on digital platforms for the first time in its history at Grady AOP. This decision was made urgently to keep patients, health care providers and other hospital staff safe, however this urgency denied the Open Dialogue team time to investigate how the digital pivot might impact patients. The psychiatric services offered at Grady AOP largely serve a marginalized population in Atlanta, including people from racial and ethnic minorities as well as people of low socio-economic status. These populations already experience significant challenges and barriers to care, thus further warranting the need to investigate the impact that Open Dialogue delivered on digital platforms may have on how these individuals benefit from the program.

The delivery of health services through technology is not new, however it wasn't until the COVID-19 pandemic that telehealth implementation and use increased significantly. Policy changes since the pandemic have reduced barriers to telehealth access and have encouraged the use of telehealth as a way to deliver services to patients (Centers for Disease Control and



Prevention [CDC], 2020). Telehealth for psychiatric services has already proven to improve access and enhance quality of care in certain settings (Cowan et al., 2019). The diagnosis and assessment of mental health disorders, as well as the delivery of mental health treatments including cognitive-behavioral therapy using telehealth platforms has shown to be feasible, cost effective and accepted among a wide range of populations (Schaffer, Nakrani & Pirraglia, 2020). Now that the transition of Open Dialogue to digital platforms has been in effect for one year at Grady AOP, it's important to assess the impact this transition has had on patients to inform decisions of Open Dialogue delivery on telehealth platforms at Grady AOP and other community clinics in the United States in the future. This Special Study Project seeks to learn from the novel situation produced by the COVID-19 pandemic that has led to the delivery of Open Dialogue on digital platforms at Grady AOP. It will do this by creating data collection tools for Open Dialogue that can be used to gain insight into the impact that digital deliverance of the program has on barriers, including the needs and assets of patients.

## **Concept of Problem**

### ***Problem Statement***

The social distancing guidelines issued as a result of the COVID-19 pandemic produced extraordinary challenges in how mental health services are delivered. The transition from in-person services to services provided remotely via digital platforms was the best option to allow patients to continue to receive services that are critical to their health and wellbeing while adhering to social distancing guidelines. The transition of Open Dialogue delivery from in-person to exclusive delivery of the program on digital platforms has provided a unique opportunity to explore the implications that delivering Open Dialogue on digital platforms has on barriers to treatment amongst patients with schizophrenia spectrum disorders.

***Purpose Statement***

There is a need to evaluate the Open Dialogue efforts at Grady AOP since its transition to digital platforms. The purpose of this Special Study Project is to develop data collection tools for the Open Dialogue program that can be used to assess the impact of Open Dialogue on digital platforms, including patient experiences and barriers to treatment.

***Research Question***

What impact does Open Dialogue delivered on digital platforms have on patient barriers to treatment?

***Significance Statement***

Research generated from the data collection tools of this Special Study Project may be used to inform decisions on the future of Open Dialogue delivered on digital platforms at Grady AOP and at community clinics in the United States.

## Chapter Two: Literature Review

### Overview

The World Health Organization announced the Coronavirus Disease 2019 (COVID-19) as a pandemic on March 11, 2020. This news was followed by a prompt response from political decision makers and the Centers for Disease Control (CDC) who enacted social distancing guidelines in an effort to slow the spread of the deadly virus (Whaibeh, Mahmoud & Naal, 2020). According to the Centers for Disease Control (CDC, 2020), practicing social distancing means maintaining at least six feet of space between people who are not from the same household. Due to these social distancing guidelines, Grady Adult Outpatient Clinic (Grady AOP) in Atlanta, GA, as well as many other community behavioral health clinics in the United States found themselves in an unprecedented position of needing to rapidly transition the way they delivered psychiatric services to patients.

The Grady AOP clinic is a public healthcare facility that serves adults in the Atlanta area who are experiencing behavioral health issues. The clinic treats behavioral disorders including depression, psychosis, schizophrenia, bipolar disorder, anxiety and co-occurring substance use. Open Dialogue is a treatment intervention for individuals experiencing psychosis, offered at Grady AOP. This Special Studies Project explores the impact of Open Dialogue on patient barriers to treatment since the program has transitioned to digital platforms due to social-distancing guidelines brought on by COVID-19.

### Psychosis

#### *Symptoms, Signs, Diagnoses*

Psychosis is a term used to describe a combination of psychological symptoms that result in a loss of contact with reality (Calabrese & Khalili, 2020). It can present as a primary illness

such as in schizophrenia spectrum disorders, or as a symptom secondary to another mental health condition, a medical or neurological illness, or substance abuse (Althwanay et. al., 2020).

Roughly 1.5% to 3.5% of people meet diagnostic criteria for a psychotic disorder with an even larger percentage of people experiencing at least one psychotic symptom in their lifetime (Calabrese & Khalili, 2020). For purposes of this SSP, the term psychosis will be used to refer to schizophrenia spectrum disorders. This classification of disorders includes schizophrenia, schizoaffective disorder, delusional disorder, and brief psychotic disorder.

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria for schizophrenia spectrum disorders is the presence of at least two of the following five symptoms in a one-month period: delusions, hallucinations, disorganized thinking (speech), grossly disorganized or abnormal motor behavior (including catatonia) and negative symptoms. Table 1 outlines these five symptom areas, organized by their classification as either positive or negative (American Psychiatric Association, 2013). The presence of these symptoms must also significantly impact daily functioning in one or more of the following areas: interpersonal, academic, or occupational. Symptoms and their severity will vary among patients as well as within each disorder and stage of illness (Tandon & Carpenter, 2016).

**Table 1**

*Symptoms of Psychosis (American Psychiatric Association, 2013)*

<u>Positive Symptoms</u>
<b>Delusions</b> - false beliefs that are not responsive to conflicting evidence
<b>Hallucinations</b> - false sensations that occur without an external stimulus
<b>Disorganized Thinking (Speech)</b> - typically deduced from the individual's speech. The individual may switch from one topic to another. Answers to questions may be somewhat or completely unrelated
<b>Grossly Disorganized or Abnormal Motor Behavior</b> - may manifest in a variety of ways ranging from childlike "silliness" to unpredictable agitation
<b>Catatonic behavior</b> - decrease in reactivity to the environment. Examples include a complete lack of verbal and motor response; resistance to instructions; and/or maintaining a rigid, inappropriate or bizarre posture
<u>Negative Symptoms</u>
<b>Diminished emotional expression</b> - reductions in the expression of emotions in the face; reduced eye contact and reduced intonation of speech and movements of the hand; head and face that give an emotional emphasis to speech
<b>Avolition</b> - decrease in motivated self-initiated purposeful activities
<b>Alogia</b> - diminished speech output
<b>Anhedonia</b> - decreased ability to experience pleasure from positive stimuli
<b>Asociality</b> - marked lack of interest in social interactions

Psychosis can be extremely distressing to both individuals experiencing the disorder and their families (Calabrese & Khalili, 2020) and individuals with psychosis often experience greater rates of unemployment and homelessness as well as lower quality of life (Stepnicki, Kondej & Kaczor 2018).

The following section will discuss the etiology of psychosis as well as risk factors for developing the disease. This information serves to provide context for the population of Open Dialogue and will allow the reader to understand some of the common experiences that impact the onset and development of psychotic disorders. Some of the risk factors noted in this section are highly relevant to the population of interest (participants of Open Dialogue at a community clinic) including discriminated minority ethnic groups, urbanicity, and poverty.

### ***Etiology***

Approximately 50 in 100,000 people will experience an initial episode of psychosis each year and of this, roughly 15 people will develop schizophrenia (Calabrese & Khalili, 2020). Schizophrenia is associated with the poorest prognosis and outcomes of psychosis (Fusar-Poli, McGorry & Kane, 2017). Schizophrenia-spectrum disorders are most likely to develop in individuals aged 15 to 35 years old (Mueser et. al., 2015). The onset for males tends to happen during their teens to mid-20s, while for females, the onset tends to happen during their teens to late-20s. (Calabrese & Khalili, 2020).

The onset and prolongation of schizophrenia spectrum disorders is associated with a multitude of environmental and biological factors (see next section) interacting with genetic background (Longden & Read, 2016). Understanding the distinct role that genetics play in developing psychosis remains a challenge due to conflicting results linking genetic heritability with risk of developing psychosis. According to Loohuis and colleagues (2021), results from

twin studies have estimated a 30 to 50% linkage of heritability to risk of developing psychosis (Loohuis et al., 2021) whereas heritability is estimated at around 80% according to Bernardo and colleagues (2017). It is well understood, however, that risk of developing a psychotic disorder is subject to the interaction and exposure of certain environmental factors with genetic background, leading to alterations in the brain and neuroendocrine system (Bernardo et al., 2017).

### ***Factors that Increase Risk of Developing Psychosis***

Commonly identified environmental risk factors for psychosis are prenatal stress, paternal age, malnutrition, infections during pregnancy, perinatal hypoxia, childhood trauma, urbanicity, migration, poverty, minority ethnic groups and cannabis use (Bernardo et al., 2017). Additional risk factors for psychosis supported by meta-analytical level of evidence collected by Fusar-Poli, McGorry & Kane (2017) include parental psychosis and first and second-generation immigrant status.

According to a review of the literature conducted by Longden and Read (2016), “adverse events involving trauma, loss, stress, and disempowerment have a central etiological role in psychosis” (pp. 1). Although research is inconsistent linking specific traumatic life events to increased risk of psychosis, commonly reported traumatic life events amongst individuals with psychotic disorders include childhood sexual abuse, childhood physical abuse, childhood emotional abuse, childhood neglect, childhood bullying, life-threatening events and/or war exposure (Gibson, Alloy & Ellman, 2016).

Although it is understood that heritability plays a role in risk of developing psychosis, it remains unclear exactly how much these biological factors contribute to risk. Understanding risk factors that contribute to the onset and prolongation of psychosis is critical to better understanding and supporting individuals with psychosis as well as to developing preventative

efforts for individuals who are at clinical high risk. Open Dialogue at Grady AOP largely serves a marginalized population and many of the individuals of this program are likely to experience a number of interacting risk factors that influence treatment considerations.

### ***Course of Illness***

The onset of schizophrenia spectrum disorders may develop rapidly, or they may progress slowly (Bromley et al., 2015). According to Fusar-Poli, McGuire and Borgwards (2020), “the onset of schizophrenia is usually preceded by a prodromal phase characterized by functional decline and subtle prodromal symptoms” (pp. 1). The prodromal, (or prodrome) phase can last from several months to a year or more and during this time the individual may experience gradual changes in their thoughts, perceptions and behaviors as well as other non-specific symptoms that do not yet meet the diagnostic criteria for psychosis (Althwanay et. a., 2020). Characteristics of the prodromal phase may also include social withdrawal, poor self-care, poor sleep and/or appetite and experiences of depression and anxiety (Rae, Duncan & Krishnadas, 2020).

A first-episode of psychosis is the first time an individual experiences the onset of clearly defined symptoms that meet clinical criteria. Psychiatric treatment focuses on the reduction or elimination of symptoms in order to achieve the recovery phase, however some symptoms may never disappear completely (Mueser et. al., 2015). The recovery phase is when the individual begins to experience a reduction in symptom severity and its impact on daily life. The length of the various phases of psychosis vary from person to person and while some people will never experience another psychotic episode, others may relapse with repeated episodes (Bromley et al., 2015).

An individual is considered to have chronic psychosis following multiple relapses of



psychosis. Chronic psychosis should be treated with antipsychotics to maintain remission and prevent further relapses, even among stabilized patients. Short-term interruptions and dosage reductions of antipsychotic medicine may provoke a psychotic episode as well as call for increases in dosages (Tadokoro et al., 2011). Psychotherapy treatment should be used in addition to antipsychotic medications in the treatment of psychosis. Psychotherapy helps treat residual symptoms that are not impacted by antipsychotic medications. It also helps patients adhere better to their medications and it may encourage family support and involvement in the individual's treatment process (Patel et al., 2014).

It's important to note that not every person who experiences a prodromal phase of psychosis will go on to develop a full psychotic episode or schizophrenia spectrum disorder, and not every person with first-episode psychosis will develop chronic psychosis (Rae, Duncan & Krishnadas, 2020). Recovery is possible at every stage with psychosocial treatment and/or medication (Bromley et al., 2015).

### **Treatment for Psychosis**

Psychosis is treatable through the use of both antipsychotic medication, psychotherapy, and psychosocial interventions (Csillag et al., 2015.) Antipsychotic medications are mainly used to treat positive symptoms such as hallucinations and thought disorder (Stepnicki, Kondej & Kaczor, 2018). The sustained use of antipsychotic medication is critical for most individuals with psychosis in preventing relapse, and psychotherapy has been shown to discourage interruptions by educating these individuals and their families on the risks and effectiveness of treatment and providing strategies to understand and manage symptoms (Patel et al., 2014). The goal of antipsychotic medication and psychotherapy is to reduce and/or eliminate symptoms, prevent relapse, and increase quality of life (Patel et al., 2014).

A variety of psychosocial interventions exist for individuals with psychosis, some of which are designed to serve individuals during the early phases of the illness (Patel et al., 2014).

Table 2 includes a list of current psychosocial interventions.

**Table 2**

*Psychotherapy for Psychosis*

**Cognitive Behavioral Therapy**

Cognitive Behavioral therapy (CBT) is an evidence-based treatment recommended for schizophrenia spectrum disorders (Kopelovich et al., 2019). CBT focuses on cognitive restructuring and behavioral change by modifying an individual's interpretation of their experiences within the world (Soneson et al., 2019). A cognitive-behavioral approach to treating psychosis assumes that the way that an individual has interpreted certain life-experiences and events will impact the way they think and behave in the future. CBT aims to identify and modify unhelpful interpretations and thoughts around certain events to reduce negative symptoms and improve cognitive function (Mander & Kingdon 2015).

**Acceptance and Commitment Therapy**

Acceptance and Commitment Therapy (ACT) is typically offered as a treatment for psychosis in an individual session format (Cramer et al., 2016). ACT treats psychosis through a focus on six core principles: 1) acceptance, 2) contact with the present moment, 3) cognitive defusion, 4) self-as-context, 5) committed action and 6) values-based living (Wakefield, Roebuck & Boyden 2018). The goal of ACT is to promote psychological flexibility by focusing on the individuals' relationship with their feelings and thoughts. ACT works to reduce the negative day-to-day cognitive experiences that are associated with psychosis and improve social functioning and psychopathology (Reininghaus et al., 2019)

**Mindfulness-based Therapy**

Mindfulness-based therapy is typically offered in a group format and aims for participants to improve quality of life by promoting acceptance of their experiences and thoughts, both positive and negative, in the present moment (Cramer et al., 2016).

Mindfulness-based therapy typically treats psychosis through promoting daily meditation practices and experiential exercises (Louise et al., 2018). Exercises in mindfulness-based therapy may include sitting or walking meditation (Cramer et al., 2016). According to Louise and colleagues (2018) “mindfulness involves intentionally paying attention to present-moment experiences (including psychotic experiences)” (Louise et al., 2018, p. 57) in a non-judgmental way.

**Open Dialogue**

Open Dialogue is an integrative approach to treating psychosis that works to bring together and strengthen the social and professional networks of the person at the center of concern (Freeman et al., 2018). This Special Studies Project focuses on the efficacy of the Open Dialogue approach delivered on telehealth formats in a U.S. community clinic and as such, the following section will provide greater detail on the model and structure of the intervention as a treatment for individuals with psychosis.

***Open Dialogue***

The Open Dialogue (OD) approach was developed during the 1980s in Finland and has since been implemented in much of the rest of Scandinavia, various other countries in Europe including Germany, and in the United States (Razzaque & Wood, 2015). The intervention was developed to address psychosis through both preventative early intervention and integrative

treatment practices using seven treatment principles (Bergström et al., 2018). These seven treatment principles are outlined in Figure 1.

**Figure 1.**

*The Seven Treatment Principles of Open Dialogue Approach (Bergström et al., 2018)*

- 
- 1. Immediate help.** The first meeting will be arranged within 24 hours of the first contact; the aim is to integrate outpatient treatment as soon as possible with the patient's everyday life, and to prevent hospitalization if possible. In addition to this, a 24-hour crisis service will be set up.

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  - 2. A social network perspective.** Family members and other relevant members of the patient's social network will always be invited to the meeting, in order to mobilize support for the patient and the family. In addition to families, key members of the patient's social network can include other authorities, fellow workers, neighbors, or friends.

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  - 3. Flexibility and mobility.** The aim is to adapt the therapeutic response to the specific needs of each person, using the therapeutic methods that best suit each situation. The first meeting will often be organized at the patient's home.

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  - 4. Responsibility.** Whoever among the staff is first contacted will become responsible for organizing the first network treatment meeting, within which decisions will be made on the continuation of treatment and on the case-specific team responsible. The team will take charge of the entire treatment process.

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  - 5. Psychological continuity.** The team will be responsible for treatment for as long as necessary, in both the outpatient and the inpatient setting.

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  - 6. Tolerance of uncertainty.** In addressing psychotic crises, meetings will be arranged in as quick succession as possible, in order to generate an adequate sense of security for the joint process. It is imperative that decisions on treatment and premature conclusions should be avoided at the crisis phase; also that neuroleptic medication should not be introduced at the initial meeting, and should only be started if other efforts prove insufficient. In psychotic crises, efforts should be made to arrange meetings every day, at least for the first 10–12 days, in order to avoid premature conclusions and treatment decisions.

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  - 7. Dialogue.** The focus in the treatment should be on promoting an equal dialogue between the patient, his/her close networks, and treatment staff. The aim within the dialogue is primarily for patients and families to increase their sense of agency in their own lives, and secondarily, to induce change in the patient or in the family. A shared understanding of the situation can thus be constructed between the participants within an open dialogue. All issues should be discussed openly, in the presence of all persons.

The Open Dialogue approach is a network-based approach to care for young individuals experiencing psychosis. The intervention rapidly engages the individual in crisis (referred to as the person at the center of concern) and their family in regular network meetings either in the patient's home or in clinic settings (Gerken & Stoklosa 2017). All discussions and decisions around the clinical situation and treatment of the individual take place during the network meetings with everyone present (Gordon et al., 2016).

Open Dialogue acknowledges and addresses the feeling of powerlessness that individuals with mental illness often experience, especially in the context of mental health care settings, by working to deconstruct the hierarchy between patient and provider (Freeman et al., 2018). The intervention promotes dialogue between the person at the center of concern, their family or social network and several regularly attending clinicians where all voices and perspectives are considered equal (Razzaque & Wood, 2015). Network meetings are used to create a shared understanding of the individual's situation and to collaboratively develop a treatment plan using "dialogic practice". The term *dialogic practice* refers to the methods that Open Dialogue uses for communication during network meetings. It includes 12 key elements, listed below (Gerken & Stoklosa, 2017):

1. *Include two or more clinicians in a team meeting.* These can include psychiatrists, therapists, nurses, social workers, or a trainee such as a medical student (Gerken & Stoklosa, 2017).
2. *Include social supports.* Family members, friends or other people within the social network of the person at the center of concern (teachers, neighbors, etc.) are invited to participate in the treatment process (Gerken & Stoklosa, 2017).
3. *Use open-ended questions.* The person at the center of concern and their network should be doing the majority of the talking. Using open-ended questions ensures that the individual and their network lead the discussion (Gerken & Stoklosa, 2017).
4. *Use the clients own words.* Repeat the words of the individual and their network to promote a common language (Gerken & Stoklosa, 2017).

5. *Emphasize the present moment.* Use information on what is observed and shared during the meeting (Gerken & Stoklosa, 2017) rather than information on what has happened outside the network meeting (Olson, Seikkula & Ziedonis, 2014).
6. *Elicit multiple viewpoints.* All individuals should contribute to the conversation during the meeting and all perspectives are of equal value (Gerken & Stoklosa, 2017).
7. *Use a relational focus in the dialogue.* Use language that describes symptoms and behavior within a relational frame rather than using diagnostic labels. This is to encourage common understanding amongst all participants of the meeting and increased collaboration towards a solution (Gerken & Stoklosa, 2017).
8. *Responding to Problem Discourse or Behavior as Meaningful.* Listen for logic in each person's response and strive to see problem behavior as making sense in the given context (Olson, Seikkula & Ziedonis, 2014).
9. *Emphasizing the clients' own words and stories, not symptoms.* Emphasize the clients' experiences, thoughts and feelings that are shared through their own words rather than focusing only on their symptoms (Olson, Seikkula & Ziedonis, 2014).
10. *Discuss thoughts about the individual by having "reflecting talks" with other clinicians in the network meetings.* Allow time during the meeting to assess the individual and their network with the other clinicians. The individual and network will still be present, however the clinicians are advised not to look at them while talking to one another (Olson, Seikkula & Ziedonis, 2014). This will allow the individual and their network to hear the thoughts of the clinicians without feeling pressure to participate before the conversation is opened up again to everyone. (Gerken & Stoklosa, 2017).

11. *Be transparent.* All discussions and decisions take place in the presence of all participants and everyone's voice is equally heard. This includes but is not limited to discussion on hospitalization, medication and treatment alternatives (Olson, Seikkula & Ziedonis, 2014).
12. *Tolerate uncertainty.* Tolerating uncertainty is a key element of Dialogic Practice as well as one of the seven principles of Open Dialogue. It acknowledges and allows for uncertainty during network meetings and throughout the treatment process (Olson, Seikkula & Ziedonis, 2014). Tolerating uncertainty prioritizes taking time to finding better solutions as opposed to making decisions quickly (Gordon et al., 2016).

The Open Dialogue approach is still fairly new in the United States and as such, more research is needed to determine the efficacy of the program in the U.S. context as well as the impact of the numerous and diverse aspects of the intervention (Bergström et al., 2018).

Advocates of the Open Dialogue approach emphasize that the intervention may lead to a reduced need for mental health services, increased rates of employment and less reliance on benefits thereby leading to long-term cost savings (Pavlovic, Pavlovic & Donaldson, 2016). According to one feasibility study conducted to adapt and implement the Open Dialogue approach into a U.S. mental health agency, adaption of Open Dialogue appears feasible and participants from this study reported satisfaction with the openness and transparency of the approach. The study however identified various substantial barriers including costs associated with having at least two clinicians in network meetings and travel time for services implemented in client-home settings (Gordon et al., 2016). This is a critical finding as this Special Studies Project focuses on Open Dialogue delivered on digital platforms, which by nature eliminates the need for travel.

A review of quantitative and qualitative data from 23 studies on Open Dialogue outcomes conducted by Freeman and colleagues (2018) indicated that evidence supporting the efficacy of Open Dialogue is of low-quality and no strong conclusions can be drawn. Freeman and colleagues (2018) reported that “further studies are needed in a real-world setting to explore how and why OD works” (pp. 34) Preliminary studies of the Open Dialogue approach show promise for the treatment and care of individuals with psychosis and their families/social networks, however without controlled trials, the significance of the various elements of the Open Dialogue approach remains undetermined (Bergström et al., 2018). It is clear from the literature that more robust research is needed to determine the true effectiveness as well as feasibility of Open Dialogue within the United States. This Special Studies Project aims to create tools that can be used to assess the influence of digital delivery of the program on barriers to treatment. Results may contribute to the understanding of the feasibility and adaptability of the Open Dialogue approach on digital platforms as well as be used to inform future decisions on implementation options of the program in community clinics in the United States.

### **Barriers to Effective Treatment for Psychosis**

It is well understood that engagement with psychiatric services is imperative for improving outcomes among patients experiencing psychosis (Casey et al., 2016). Despite this, treatment engagement remains a major problem for individuals with schizophrenia spectrum disorders, largely due to the myriad of challenges that exist for patients as well as the contradictory information available on mental health services (Mueser et al., 2015). A significant percentage of patients with psychosis will eventually disengage from care, a problem that is even more pronounced among patients experiencing a first-episode of psychosis. (Casey et al., 2016).



Barriers to treatment seeking and adherence negatively influence rates of engagement with mental health services, contributing to poorer outcomes for people with psychosis (Marino et al., 2015). Extensive research exploring the barriers to treatment and recovery that exist among individuals with psychosis have identified numerous socio-demographic and clinical barriers to effective treatment engagement and adherence (Kim et al., 2019). Table 3 includes the most commonly identified barriers according to a review of existing literature.

**Table 3**

*Common Barriers to Treatment*

<p><b>Socio-Demographic</b></p> <ul style="list-style-type: none"> <li>• Stigma and discrimination (von Peter et al., 2019), particularly amongst racial and ethnic minorities (Marino et al., 2015)</li> <li>• Unemployment (Solmi, Mohammadi &amp; Perez, 2018) and Homelessness (Dixon, Holoshitz &amp; Nossel, 2016)</li> <li>• Comorbid substance abuse, alcohol, amphetamine, and cannabis use (Kim et al., 2019)</li> <li>• Lack of family support during treatment (Kim et al., 2019)</li> </ul>
<p><b>Clinical</b></p> <ul style="list-style-type: none"> <li>• Baseline clinical symptoms (Marino et al., 2015)</li> <li>• Baseline cognitive functioning (Marino et al., 2015)</li> </ul>

***Stigma and Discrimination***

Studies exploring the many barriers that individuals with psychosis experience in treatment utilization and engagement consistently identify stigma. Stigma may be perpetuated by ignorance or lack of correct knowledge on schizophrenia spectrum disorders, problems of attitude resulting in prejudice and/or problems of behavior resulting in discrimination.

Experiences of stigma, prejudice and discrimination may cause an individual with psychosis to delay or stop themselves from seeking treatment (Li et al., 2017).

According to Powell and colleagues (2020), “stigma can be conceptualized as labeling processes, within a power differential, that result in discrimination, stereotyping, separation, emotional reactions, and status loss” (p. 269). The feeling of stigma as well as powerlessness may at times be amplified in mental health settings that treat psychosis due to the hierarchal structure between patient and provider. This hierarchy can provoke a more passive role on behalf of the patient in their diagnosis and treatment plan while the provider plays the active role in the decisions made around the diagnoses and treatment of the individual. (Maanmieli & Maanmieli, 2019).

Evidence suggest that significant racial and ethnic disparities contribute to worsened treatment outcomes for individuals who identify as black or for individuals from other racial and ethnic minority groups (Oluwoye et al., 2018). According to Maura and De Mamani (2017), currently more than 100 million people in the United States identify as belonging to a racial or ethnic minority group and by 2044, it is estimated by the census that 50% of the U.S. population will fall under this category (Maura & De Mamani, 2017). These groups are more likely to lack insurance coverage and experience implicit bias as compared to their non-Hispanic white counterparts (Oluwoye et al., 2018). According to studies examining disparities and barriers within mental health settings, individuals from racial and ethnic minority groups are also less likely to seek and adhere to mental health treatment when compared to white individuals. When they do utilize and receive care, they often receive poorer quality of care and are less satisfied with mental health services (Maura and De Mamai, 2017). Differences in quality of treatment

may be influenced by stereotypes, prejudices and discrimination perpetuated by the provider and may lead to worse outcomes within the stigmatized groups (Gronholm et al., 2017).

### ***Unemployment and Homelessness***

Employment is essential in providing financial income. Unemployment may lead to financial insecurity and ultimately poverty, which can greatly reduce access to health services, especially in the context of insurance-based systems (Moreno et al., 2020). Individuals with schizophrenia spectrum disorders who are unemployed and/or lack financial resources might delay or stop seeking treatment. If treatment has begun, unemployment and/or lack of financial resources may contribute to increased risk of early termination of services (Li et al., 2017).

Unemployment may also contribute to increased risk of homelessness. Individuals with a schizophrenia spectrum disorder who are homeless face complex social service barriers and may face additional medical and mental health needs that can impact engagement and adherence to treatment. Additional medical needs often include high rates of substance use disorders and other medical priorities that may surpass need for mental health treatment (Dixon, Holoshitz & Nossel et al., 2016).

### ***Substance Abuse***

According to Dixon, Holoshitz & Nossel (2016), “comorbid substance abuse is one of the strongest factors associated with non-imitation and non-engagement in mental health treatment.”(pp 34). Substance abuse may contribute to increased rates of hospitalization, higher symptom severity, increased impairments in psychosocial functioning and increased risk of institutionalization in jails and other non-mental-health settings (Dixon, Holoshitz & Nossel et al., 2016).

### ***Family Support***

Although research is limited, studies suggest that families play a critical role in treatment initiation and engagement especially given that many patients may resist seeking help (Compton, 2005). Family involvement has been identified as a significant determinant of mental health service utilization and health outcome in numerous studies. Evidence suggests that lack of family involvement in treatment may contribute to increased rates of disengagement (Solmi, Mohammadi & Perez, 2018). Studies have also suggested that lack of family involvement may act as a more significant barrier to mental health service engagement amongst racial and ethnic minorities who are more likely than Whites to live with family members (Maura and De Mamani, 2017).

Family involvement in treatment can improve outcomes by educating family members on how to identify and address acute symptoms and prevent relapse (Kim et al., 2019). Without family support and involvement, individuals with psychosis are less likely to engage with treatment plans and early warning signs of relapse are more likely to go unrecognized or without proper response (Eassom et al., 2014).

### **Telehealth Interventions for Individuals with Psychosis**

Telehealth, also referred to as telemedicine, is the use of electronic communication to deliver medical information and improve a patient's health (Tuckson et al., 2018). Telemental health focuses on the assessment, diagnosis and treatment of mental illness (Kilty et al. 2013). A wide range of examples and evidence exist that support the effectiveness of telehealth in delivering mental health services through the use of videoconferencing, smartphone apps, text-messaging and e-mails (Santesteban-Echarri et al., 2018).

The COVID-19 global pandemic and the stay-at-home orders issued as a result produced unprecedented challenges to how mental health services are disseminated. Up until the global crisis, individuals living with psychosis typically engaged with in-person pharmacotherapy and/or behavioral health services to reduce symptoms, improve quality of life and increase community engagement (Lynch, Medalia, & Saperstein, 2020). Due to the social distancing measures enacted in early 2020, rapid changes to how services are provided to patients with psychosis were made, resulting in an increase in the use of telehealth services to ensure continuity of critical mental health care to these individuals.

Studies have already shown acceptability of telehealth services by patients with psychosis. One retrospective study found that the vast majority of participants with psychosis (90%) agreed to participate in telehealth services within ten days of service transition (Lynch, Medalia, & Saperstein, 2020). This study found that rates of attendance and missed appointments did not change when comparing services utilization of in-person and telehealth sessions. Studies conducted prior to COVID-19 found that individuals with psychosis were also willing to incorporate smartphone technology into treatment and revealed high compliance even when in-person services were still available (Kumar et al., 2018).

The use of digital platforms to deliver mental health services can also be a cost-effective solution to providing effective interventions for mental illness (Langarizadeh et al., 2017). Research has indicated that telemental health has the potential to address certain barriers among marginalized communities by reducing wait times for appointments, reducing travel time and reducing costs associated with travel (Cowan et al., 2019). Individuals with psychosis experience many complex cultural and systematic barriers to engaging with mental health care that include specific obstacles they may face just to attend a single follow-up appointment. A follow-up

appointment may take half a day after factoring in transportation time, waiting to be seen and coping with other factors. This process may need to be repeated weekly or bi-weekly which is not always feasible when the individual has other priorities such as caregiving and school and/or work schedules. Financial resources needed for transportation can exacerbate financial challenges that marginalized communities experience, especially when frequent follow-up appointments are necessary (Lal et al., 2020).

The rapid pivot to providing mental health services from in-person services as a result of COVID-19 did not allow time for the exploration into the complex factors that impact how a patient may receive their mental health services via digital platforms. Providing these services through digital platforms, however, was the best option available that allowed for the continuity of care while adhering to social distancing guidelines (Lynch, Medalia, & Saperstein, 2020). The situation that has resulted from COVID-19 offers a unique opportunity to investigate the acceptance of telehealth conversion amongst people with psychosis as well as establish the potential benefits for improving the quality of life in this population, the acceptability from the service user perspective, and the cost-effectiveness of its long-term use (Lawes-Wickwar et al., Oct-Dec 2020).

### **Open Dialogue at Adult Outpatient Clinic**

Prior to March, 2020 and the onset of the mandatory changes to health care deliverance brought on by COVID-19, Open Dialogue network meetings were held in person at Grady Adult Outpatient Clinic in Atlanta, GA. Due to social distancing guidelines that were put in place as safety measures during the global pandemic, Open Dialogue network meetings were transitioned rapidly from in-person to online platforms. These network meetings were and still are being delivered through websites like Zoom, where all attendees of the meeting are encouraged to

participate with the video and audio features on. This allows for the face-to-face interaction between the person at the center of concern, the members of their network and the health care providers.

Open Dialogue is still a relatively new program in the United States and although the intervention holds promise for the treatment of individuals with psychosis, more research is needed to support it as an evidence-based practice within the cultural context of community clinics in the United States. An exploration of Open Dialogue delivered on digital platforms and its impact treatment barriers is timely, especially when considering the future of Open Dialogue at Grady Behavioral Health Clinic and in community clinics across the United States even after social distancing guidelines are no longer in place.

This special studies project seeks to produce data collection tools that can be used to assess the effectiveness of Open Dialogue delivered on digital platforms to individuals with psychosis by identifying how digital delivery of the program impacts patient barriers to treatment. The tools of this special studies project are intended to be implemented at Grady Adult Outpatient Clinic however results may be useful in better understanding the general efficacy of Open Dialogue delivered on digital platforms for schizophrenia spectrum disorder patients at community clinics in the United States.

## **Conclusion**

Psychosis is characterized by abnormalities in one or more of the following five domains: delusions, hallucinations, disorganized thinking (speech), grossly disorganized or abnormal motor behavior (including catatonia), and negative symptoms. It significantly impacts daily life by causing individuals to lose touch with reality (American Psychiatric Association, 2013).

Barriers to treatment seeking and adherence negatively influence rates of engagement with mental health services, contributing to poorer outcomes for people with psychosis (Marino et al., 2015). When the World Health Organization declared COVID-19 as a global pandemic in March of 2020, (Whaibeh, Mahmoud & Naal, 2020) a rapid transition from delivering critical health services in-person was made to delivering these services remotely via digital platforms in an effort to adhere to social-distancing guidelines. This Special Studies Project aims to produce data collection tools to assess how Open Dialogue delivered via digital platforms influences barriers to treatment for individuals with psychosis at a community clinic in the United States. Due to a significant lack of research, the impact that delivering Open Dialogue on digital platforms has on patient barriers is unknown. Data generated from the data collection tools of this Special Studies Project may be used to better understand this impact as well as to inform future decisions on the deliverance of Open Dialogue in community settings.



## **Chapter Three: Methods**

### **Introduction**

This Special Studies Project (SSP) aims to explore the impact that Open Dialogue delivered on digital platforms has on patient barriers to treatment. The main objectives of this SSP are data collection tools that can be used to inform future decisions on the delivery of Open Dialogue on digital platforms in community clinics. The development of data collection tools through this SSP was in response to the lack of research on the topic and the identification of the current situation as an opportunity to explore ways to strengthen Open Dialogue efforts in United States community clinics. The data collection tools are informed by experience as a research assistant with the Open Dialogue team at Grady AOP, a review of existing literature on telehealth delivery of mental health services, and three surveys on relevant study topics.

### **Population and Sample**

Grady Health System is a public health system located in Atlanta, Georgia that primarily serves low-income and uninsured populations. The Grady Adult Outpatient Clinic (AOP) is Georgia's largest provider of behavioral health services, receiving over 45,000 outpatient visits and 1,200 in-patient admissions. The AOP treats individuals with behavioral health illnesses such as depression, schizophrenia, bipolar disorder, anxiety, psychosis, and co-occurring substance use (Grady Health System, 2020). Client services include individual therapy, group therapy, Assertive Community Treatment, and other psychosocial supports. Open Dialogue (OD) is one of the numerous therapy programs available at Grady AOP for individuals experiencing psychosis. A large make-up of the participants of the program are young, low-income African American adults and their families (Olson, 2019).

In order to best understand the impact of this recent transition, there are two target samples: 1) Clinicians and team members, and 2) clients.

### ***Clinicians and Staff of Open Dialogue at Grady AOP***

The overarching goal of collecting data using the tools developed from this SSP is to inform future decisions on the delivery of Open Dialogue at community clinics, so it is critical to gain insight into the perspectives and experiences of the individuals who lead the program.

Individuals in the target population include Grady AOP personnel who direct the administrative and research efforts of the Open Dialogue program as well as clinicians who facilitate network meetings.

The clinicians and team members of the Open Dialogue efforts at Grady AOP have experience delivering the program both in-clinic prior to COVID-19 and on digital platforms post COVID-19, and thus may offer insight into the impact that the program has had on patients at various stages of the digital transition. Clinicians may include psychiatrists, psychologists, social workers, medical residents, and nurses who make up the Grady Open Dialogue team and other team members may include research scientists, research assistants and people who lead the administrative efforts of Open Dialogue at the AOP.

This population is expected to offer a valuable perspective on the unique experiences of the population that the program serves and the ways in which certain socio-cultural factors impact patient engagement with treatment and barriers to care when services are delivered in-person and on digital platforms. Data collected may also be used to better understand the advantages and disadvantages of delivering Open Dialogue on digital platforms from both the provider and patient perspectives and will be valuable when making future decisions that strive to improve the impact of the program.

### ***Clients of Open Dialogue at Grady AOP***

The Open Dialogue program is offered to individuals experiencing psychosis and their families and/or social networks. The psychiatric services offered at Grady AOP largely serve a marginalized population in Atlanta, including people from racial and ethnic minorities as well as people of low socio-economic status. Patients' access to and engagement with treatment may be influenced by a number of socio-cultural, environmental, and psychological factors, and as such, the survey aims to better understand these individuals' experiences with and preference for Open Dialogue delivered in-person and on digital platforms.

### **Procedure**

Given the recent, unexpected pivot to telehealth, this Special Studies Project explores the impact of Open Dialogue delivered on digital platforms on patients' barriers to engaging with the program to inform future decisions about this service. A review of the literature was conducted to investigate existing treatments and programs for psychosis, including Open Dialogue, common barriers to treatment that are experienced by individuals with psychosis, and existing research on telehealth delivery of mental health services. The literature review was conducted by searching key words and phrases in academic databases and search engines including Pubmed, Google Scholar and PsychINFO. Key words and phrases that were used to populate relevant articles for this SSP include "psychosis", "treatment for psychosis", "Open Dialogue for psychosis", "barriers to treatment among individuals with psychosis" and "telemental health for individuals with psychosis". Articles were reviewed for pertinent information that provided relevant insight into the topics of psychosis, treatment for psychosis, Open Dialogue and telemental health.

A separate literature review was conducted to inform the development of the patient survey. This literature review was conducted by searching key phrases in search engines

including PubMed and Google Scholar. Key phrases used to generate the search included “survey study for telemental health in psychosis” and “survey study for patient satisfaction with telemental health” Inclusion criteria for articles reviewed include a focus on barriers to access and use of telehealth as well as the inclusion of a copy of the quantitative survey used in the study. Questions from surveys found in the articles were reviewed for their relevance to the research question of this SSP and questions deemed appropriate were modified and cited in the patient survey that was developed.

## **Instruments**

### ***Key Informant Interview with Open Dialogue Team at Grady AOP***

It was determined that the most appropriate tools to understand the effectiveness of OD using telehealth included qualitative and quantitative data collection tools that can be used to investigate the impact of Open Dialogue delivered on digital platforms. The qualitative component takes the form of a Key Informant Interview guide. A Key Informant Interview (KII) is an in-depth interview with individuals who have a key role in the project or problem. They are beneficial because they may contribute to a comprehensive understanding of the problem and/or population and can be used to inform important decisions. Implementation of the Key Informant Interview may take place in-person or online and aims to include at minimum four participants from the target population. Interviews may then be transcribed and coded to identify common themes in answers. These common themes may be useful in determining what questions to include in the survey as well as to inform the structure and organization of these questions.

KII questions were designed to gain insight into the experiences of the target population as clinicians and team leads of the Open Dialogue efforts at Grady AOP, as well as develop a better understanding of the population the Open Dialogue team serves.

### ***Patient Survey with Open Dialogue Clients at Grady AOP***

The goal of the survey is to generate data that can be used to inform decision of Open Dialogue delivery at Grady AOP and/or other community clinics in the United States. Questions included on the survey ask for information on demographics, patient access and use of technology and patient preferences for using technology in their mental health treatment. The survey may be adapted to include additional question topics to be determined from the key informant interviews. Inclusion criteria of the survey will be Open Dialogue clients who have received at least one network meeting on a digital platform. Exclusion criteria of the survey will be Open Dialogue clients who have not received at least one network meeting on a digital platform. Methods for distributing the patient survey is to be determined by the clinic but distribution may take place either in-person or online. Consequently, clinics interested in evaluating the impact of their Open Dialogue efforts delivered on digital platforms may adapt or modify this survey to fit their unique needs and the needs of the population they serve.

The questions included and structure of the Patient Survey was informed by other tools used by the Open Dialogue research team at Grady AOP as well as by three existing surveys on relevant study topics. These surveys were identified through search engines and academic databases using the keys phrase “survey study on technology in service delivery for individuals with psychosis”. The three surveys that were used to inform the development of the patient survey for this SSP include 1) a survey that was designed and implemented by Grady AOP assessing digital readiness and patient satisfaction among participants of an incentive program offered to patients with psychosis, 2) a screening questionnaire designed and implemented by Greer and colleagues (2019) on assessing access and confidence with internet-enabled technology among mental health service users, and 3) a survey developed and implemented by

Wong and colleagues (2020) on internet usage, internet frequency, and confidence in using technology amongst people with schizophrenia in South Australia.

## Chapter 4: Results

Review of the literature yielded information to assist in the development of two instruments that can be used to the research question. The instruments will each be described below. The full instruments can be reviewed in Appendices A and B.

### **Key Informant Interview Guide**

The key informant interview guide was informed by experience with the Open Dialogue research team at Grady AOP as well as by a review of existing literature on barriers and advantages of telehealth treatment among individuals with psychosis. The first section of the KII guide includes demographic questions and questions aimed to understand the participants' role and responsibilities on the Open Dialogue team. Key questions that follow ask the participant to provide information on their own experiences as well as perceived client experiences with Open Dialogue before and after the program's digital transition. The guide also includes questions aimed to understand the process and experience of transitioning the program to digital platforms. Questions focus on eliciting information on the specific challenges and advantages to delivering network meetings both in-person and on online and aim to gain a general understanding of the impact of the program before and after the digital transition. The KII guide concludes with an open-ended section where participants can provide any additional information or insight that might be useful, as well as to recommend specific questions that should be included in the survey.

Considerations on duration and focus of the interview were made based on the objective to elicit rich information while respecting participants' busy schedules. Consequently, the interview was designed to last roughly one hour and includes carefully thought-out questions that

are specific to the objective of the SSP. This was informed by previous experience with qualitative research collection and analysis. See Appendix A for a full copy of the KII Guide.

### **Patient Survey**

The patient survey was informed by experience with the Open Dialogue research team at Grady AOP as well as by three existing surveys on relevant study topics. The survey begins with demographic questions that cover age of participant, gender identity, racial identity, marital status, education level, living situation, employment status, diagnosis and length of time as an Open Dialogue client. Demographic questions may allow for a better understanding of the population that the Open Dialogue efforts at Grady AOP serve and may help identify correlations between socio-cultural factors and patient experiences with Open Dialogue on digital platforms. Following the demographic questions, participants are asked to indicate whether or not they have attended their network meetings online since March 2020. This question is followed by a question asking participants to identify the advantages of attending their Open Dialogue network meetings online, and a question asking participants to identify the challenges of attending their Open Dialogue network meetings online.

The survey then includes 11 questions asking participants to rate certain aspects of their experience with Open Dialogue network meetings online, using a Likert scale. Questions focus on participants' ability and comfort level attending their network meetings online as well as how well they perceive the program to be supporting them. This section also includes a question asking participants to respond on behalf of their social network and aims to better understand the degree to which their social network is able to attend their network meetings online. The final question on the survey asks participants to indicate their preference for attending Open Dialogue network meetings in the future, with answer options including preference for in-person meetings,



preference for online meetings, or preference for a combination of both in-person and online meetings.

Considerations that went into deciding the length, structure and makeup of the survey include a focus on creating a survey that could be taken in twenty minutes or less, structuring questions and answer choices so that they can be easily understood, and considering the quality and quantity of questions necessary to elicit information that can be used to understand patients' experiences with Open Dialogue on digital platforms. This was informed by previous experience with quantitative data collection and analysis. Please see Appendix B for a full copy of the survey.

## Chapter Five: Discussion

### Summary

The objective of This Special Studies Project (SSP) is data collection tools that can be used to better understand the transition of Open Dialogue at Grady AOP to digital platforms and the impact that this transition has had on clients of the program. Open Dialogue is an intervention for individuals experiencing a first-episode of psychosis, however the program has been adapted at Grady AOP to serve any individual with schizophrenia spectrum disorder. Schizophrenia spectrum disorders include conditions where there is the presence of at least two of the following five symptoms in a one-month period: delusions, hallucinations, disorganized thinking (speech), grossly disorganized or abnormal motor behavior (including catatonia) and negative symptoms (American Psychiatric Association, 2013). Treatment for schizophrenia spectrum disorders may include antipsychotic medication, psychotherapy and psychosocial interventions (Csillag et al., 2015). Open Dialogue is one of many psychosocial interventions that exist, and it's approach to treating psychosis includes bringing together and strengthening the social and professional networks of the individual at the center of concern (Freeman et al., 2018).

Open Dialogue was originally designed to be implemented in-person, however since March, 2020 and the onset of the mandatory changes to health care deliverance brought on by COVID-19, Open Dialogue network meetings at Grady AOP have been transitioned to delivery on online platforms. This Special Studies Project aims to better understand how Open Dialogue delivered on digital platforms has impacted patient barriers and engagement with the program by developing data collection tools that can be used to explore this experience for clients, clinicians, and staff. These data collection tools include a key informant interview (KII) guide to be

implemented with clinicians and staff of the Open Dialogue efforts at Grady AOP, and a patient survey to conduct with clients of Open Dialogue who have attended at least one network meeting on a digital platform.

### **Limitations**

An initial objective of this SSP was to implement the KII to collect data that could be used to inform the development of the patient survey. Due to unforeseeable challenges that have impacted the timeline of this thesis, the development of the patient survey took place prior to the *implementation* of the key informant interviews. Thus, the patient survey was developed based on a review of existing literature and published surveys of a similar nature. To address this limitation, the patient survey may serve as a template that can later be modified or adapted based on results from the key informant interviews.

Also due to time constraints, I was unable to pilot the survey or get initial feedback from the Open Dialogue team or Open Dialogue clients to make iterative changes. Thus, published surveys on relevant topics were used to inform the questions and structure of the survey. Future iterations should include piloted versions of the current KII and survey.

### **Future Directions and Recommendations**

#### ***Grady AOP***

Data collected from both the key informant interviews and the patient surveys can be used to help Grady AOP assess the impact of their Open Dialogue efforts when network meetings are delivered on digital platforms. Data may also be used to inform future decisions on the delivery of Open Dialogue at Grady AOP to improve the impact of the program by identifying and addressing barriers that clients and their families experience to attending and engaging with their network meetings.

It is recommended that the key informant interview be implemented first, with the two team leads of Open Dialogue and at least two additional staff members. Staff members may include individuals in research roles related to Open Dialogue as well as clinicians and healthcare providers who facilitate network meetings. Data collected from the key informant interviews should inform modifications to the patient survey in an effort to elicit information from clients that will be most useful in assessing the impact of Open Dialogue delivered on digital platforms at Grady AOP.

### ***Community Clinics in the United States***

Data collection tools of this Special Studies Project may also be used by other community clinics in the United States where Open Dialogue has been delivered both in-person and on digital platforms. The key informant interview guide and the patient survey may serve as templates which can be modified by the clinic based on their specific needs and the population they serve. Data collected from the tools may be used to explore the efficacy of adapting Open Dialogue to a U.S. context as well as contribute to the general knowledge of Open Dialogue as an evidence-based practice for treating psychosis. Further research on Open Dialogue in the United States may also encourage expansion of the program to additional clinics in the country.

### **Public Health Implications**

The Open Dialogue efforts in the United States began in the mid-to-late 2000s and adaptation of the program into the US context has focused on recognizing and addressing certain cultural trends. According to Olson (2019), these trends include 1) a mental health system that is “fragmented, overly medicalized, and often ineffective (pp 2)”; 2) increasing rates of psychiatric morbidity; 3) “theoretical and empirical challenges to biological psychiatry (pp 2)”; and 4) a growing embrace of a recovery movement that emphasizes the patients’ voice. Research that has

investigated the impact of Open Dialogue on individuals with psychosis has already produced promising results. According to a few small-scale pilot studies conducted with psychosis patients treated by Open Dialogue and psychosis patients treated with other programs, at 2 and 5 year follow up, participants of Open Dialogue had spent fewer days in the hospital, experienced a greater reduction in medication and had displayed significantly better outcomes when compared to participants who were treated with other programs. Among participants in the Open Dialogue group, 82% experienced a significant reduction or complete elimination of residual psychotic symptoms and 86% of participants had returned to full-time work and/or education (Razzaque & Wood, 2015).

The structure and guiding principles of the Open Dialogue approach may lend to the success of the program by mitigating certain barriers that are commonly experienced by individuals with psychosis. Stigma is one such barrier that the Open Dialogue approach may help to mitigate, in that the intervention heavily emphasizes autonomy of the individual as an active participant in their treatment plan. Open Dialogue prioritizes the use of common language and the individual's own words in network meeting discussions thereby leveling the hierarchy between patient and provider and promoting an equal status (Von Peter et al., 2019). *Tolerance of uncertainty* as a dialogic principle allows for greater flexibility when diagnosing and treating patients and may also help to address stigma by allowing the focus to be patient-centered rather than centered on a diagnosis or specific treatment plan. Studies have found that fear of stigma associated with mental illness may delay or prevent individuals from seeking out mental health services and adhering with treatment (Gronholm et al., 2017). The elements and structure of the Open Dialogue approach show promise for addressing stigma as a significant and commonly experienced barrier among those with psychosis and delivering network meetings on digital

platforms may further improve the experience of patients by allowing them to receive services from the privacy of their own homes. The tools of this special study project can be used to explore patient preference for receiving their mental health services on digital platforms and the patient survey may be later modified to include a focus on how stigma impacts preference for in-person or online network meetings.

The patient survey developed for this SSP was designed to be implemented with the clients of Open Dialogue at Grady AOP. A large make-up of the participants of the program are young, low-income African American adults and their families (Olson, 2019). The patient survey may be used to explore more general benefits of delivering mental health services on digital platforms, especially in regard to marginalized communities served by community clinics in the United States. Research has indicated that telemental health has the potential to address certain barriers among marginalized communities by reducing wait times for appointments, reducing travel time and reducing costs associated with travel (Cowan et al., 2019). Individuals with psychosis experience many complex cultural and systematic barriers to engaging with mental health care that include specific obstacles they may face just to attend a single follow-up appointment. A follow-up appointment may take half a day after factoring in transportation time and waiting to be seen. This process may need to be repeated weekly or bi-weekly which is not always feasible when the individual has other priorities such as school, work or childcare. Financial resources needed for transportation can exacerbate financial challenges that marginalized communities experience, especially when frequent follow-up appointments are necessary (Lal et al., 2020).

According to Freeman and colleagues, a review of 33 studies on the application of the OD approach in Scandinavia indicated that the intervention has been implemented in a variety of

ways, perhaps due to limited standardized descriptions. The review found that in some cases, selection and implementation of specific elements of Open Dialogue had been influenced by the priorities of those delivering the program (Freeman et al., 2018). Since Open Dialogue is still a relatively new approach to treating psychosis, especially within the United States context, research on the adaptability and feasibility is limited. The lack of available standardized descriptions of Open Dialogue implementation as well as the lack of research on the adaptability of the intervention into United States clinics leaves room to explore ways in which the intervention can be modified to fit the unique needs of the different populations that it currently serves. Investigating the impact of Open Dialogue delivered on digital platforms during a time when there are significant barriers to delivering network meetings in-person will be extremely useful in understanding how to improve the program in the future when it already has demonstrated promise as an innovative and impactful treatment approach for individuals experiencing psychosis. Given the potential advantages that delivering critical mental health services on digital platforms has on populations such as the one that Open Dialogue at Grady AOP serves, it's critical to investigate the experiences of participants with Open Dialogue since its digital transition in March, 2020. Further research on this topic will allow a better understanding of what direction the Open Dialogue approach should take in the future.

## **Conclusions**

Open Dialogue has already shown promise for greatly improving quality of life among individuals with psychosis, and as such it's important to continue research efforts to support Open Dialogue as an evidence-based program in the United States. The patient survey may be used by community clinics in the U.S. as is, or it can be modified based on results from key informant interviews to further explore how Open Dialogue delivered on digital platforms

impacts patient experience and engagement with the program. Results may be used to inform and improve the Open Dialogue efforts in community clinics in the United States. Ultimately, the goal of this special studies project is to promote exploration into different ways to deliver Open Dialogue to minimize barriers amongst marginalized populations and increase patient access to and engagement with the program.



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## Appendix A

Participant ID \_\_\_\_\_

### **Key Informant Interview Guide** **The Impact of Open Dialogue on Digital Platforms on Patient Barriers** Grady AOP

**Interview Date:** \_\_\_\_ / \_\_\_\_ / \_\_\_\_

**Start Time:** \_\_\_\_:\_\_\_\_ AM / PM

My name is (your name) and I am a Research Assistant for Grady Behavioral Health Adult Outpatient Clinic (Grady AOP). I'm conducting research on the Open Dialogue efforts at Grady AOP since the delivery of the program has transitioned to online platforms due to the COVID-19 pandemic. Information gathered from this interview will help to inform a survey for clients of Open Dialogue assessing the impact that the digital delivery of the program has on the patient barriers including their needs and assets. Research generated from this interview as well as from the patient surveys this interview will help to inform may be used to inform decisions on the future of Open Dialogue at Grady AOP as well as other community clinics in the United States.

The interview is expected to last an hour.

Your participation is completely voluntary, and you may decide at any point to end it. You are free to skip any question you want or ask to revisit a question later in the interview. Keep in mind that all of your responses will be kept confidential.

Given your fundamental role in the facilitation of the OD program at Grady AOP, the information and perspective you are willing to share today will be very valuable so I want to know if you would be okay with me recording our conversation. Before we get started, do you have any questions?

### **Warm up questions**

*I'd like to learn a little bit about you and your experience with Open Dialogue at Grady AOP.*

- 1. How long have you been part of the OD team?**
- 2. What made you interested in becoming part of the team?**
- 3. What are your role and responsibilities with the Open Dialogue program?**



## Appendix A

Participant ID \_\_\_\_\_

### Key Questions

*Thank you for sharing that. Now I would like to know more about the Open Dialogue clients at Grady AOP. The following questions will be aimed at gathering information on patient experiences with Open Dialogue **before** the transition to delivery on digital platforms.*

- 1. Can you tell me a little bit about the population that Open Dialogue serves?**
  - a. Follow up: What were the common barriers that patients experienced to engaging with treatment when Open Dialogue was facilitated in-clinic?**
  - b. Follow up: What were the common assets that increased patient engagement when Open Dialogue was facilitated in-clinic?**
- 2. What were the major challenges to implementing Open Dialogue while network meetings were still being held in-clinic?**
- 3. Is there anything else you would like to add?**

*Now I'm curious to learn more about what the process was like having to transition Open Dialogue to an online format due to COVID-19.*

- 1. Can you tell me about what it was like having to make the decision to move the Open Dialogue efforts on online platforms?**
  - a. Follow up: what was the process like of that digital transition?**
- 2. What were the challenges to adapting network meetings online?**
- 3. How did the participants of the program respond?**
  - a. Follow up: How did the families respond?**
- 4. Is there anything else you would like to add?**

*Now I'm going to ask some questions that are focused on patient experiences with Open Dialogue **after** the transition to delivery on digital platforms.*

- 4. What have been the challenges of facilitating network meetings online?**
  - a. Follow up: Have there been any advantages? If so, what are they?**
- 5. In your perspective, what have been the challenges that patients have experienced in receiving their network meetings online?**
  - a. Follow up: Have you perceived there to be any advantages? If so, what are they?**
- 6. What are some of the common elements of a patients' situation that act as assets for them in attending network meetings online?**
  - a. Follow up: How does digital readiness impact patient engagement with OD on digital platforms?**

## Appendix A

Participant ID \_\_\_\_\_

- b. Follow up: How does family involvement impact patient engagement with OD on digital platforms?*
- c. Follow up: What other aspects have increased patient engagement with Open Dialogue while network meetings have been held online?*

*Now I'm going to ask some questions comparing the patient and provider experiences of Open Dialogue before and after the digital transition.*

- 7. Can you talk about how patient follow-up rates to network meeting appointments have changed since the transition to delivery on digital platforms?*
- 8. Can you talk about how attendance and participation of family members in network meetings has changed since the transition to delivery on digital platforms?*

### Closing Questions

*Thank you so much for sharing with me some of your experiences with Open Dialogue and your perspectives on patient engagement with the program. We're almost done with the interview, so now I'd like to open up this space for you to share any other information that you think is relevant, as well ask for your input on the survey questions.*

- 1. Is there anything else that is important to know when developing a survey for the clients of Open Dialogue at Grady AOP?*
- 2. Are there any specific questions you think should be included in the survey to gather information on the impact that the digital transition of Open Dialogue has had on patients, particularly in regard to how the transition has impacted their needs and assets to engaging with treatment?*

*Thank you so much for your time and participation. I really appreciate your willingness to share with me your experience and perspective on this topic.*

## Appendix B

### *Open Dialogue Client Survey*

Date: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

Please tell us a little bit about yourself by answering the following questions.

1. Date of Birth: \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_
2. Gender Identity:
  - a) Male
  - b) Female
  - c) Transgender
  - d) Genderqueer/Gender non-conforming
  - e) Other gender identity: \_\_\_\_\_
3. Racial Identity:
  - a) American Indian or Alaska Native
  - b) Asian
  - c) Black or African American
  - d) Native Hawaiian or Other Pacific Islander
  - e) White
  - f) Hispanic or Latino
  - g) Other: \_\_\_\_\_
4. Marital Status:
  - a) Single, Never Married
  - b) Married or Living with a Partner
  - c) Separated
  - d) Divorced
  - e) Widowed
5. Highest Education Level Achieved:
  - a) Less than 7 years of school (Grades 1-6)
  - b) Junior High (Grades 7 or 8)
  - c) Some High School (Grades 9-11)
  - d) GED
  - e) High School Graduate (12)
  - f) Some College or Trade/Vocational School
  - g) College Graduate
  - h) Completed Graduate or Professional School
6. Who do you currently live with?
  - a) Alone

## Appendix B

- b) With Parent(s), Sibling(s), or Other Family Member(s)
  - c) With Boyfriend/Girlfriend
  - d) With Spouse/Partner
  - e) With Friend(s)
  - f) In Structured Living Arrangement
  - g) Homeless, or staying in a homeless shelter
  - h) Other: \_\_\_\_\_
7. What is your current employment status?
- a) Employed full-time
  - b) Employed part-time
  - c) Unemployed and currently looking for work
  - d) Unemployed and not currently looking for work
  - e) Student
  - f) Homemaker
  - g) Self-employed
8. What is your diagnosis? \_\_\_\_\_
9. How long have you been an Open Dialogue client?
- a) 0-6 months
  - b) 6-12 months
  - c) 1 year or more

(Questions 1-9 from Grady AOP TTI NICE Incentives Study)

### Access to Technology and Internet

1. Which of the following devices do you have access to? Circle all that apply.
- a) Computer
  - b) Cellphone (without internet access)
  - c) Smartphone (with internet access)
  - d) Tablet
  - e) None
- (Greet et al., 2019)
2. Do you have access to the internet?
- a) Yes
  - b) Sometimes
  - c) No
3. Do you have an email account?
- a) Yes
  - b) No

## Appendix B

### Online OD Network Meetings

1. Since the clinic closed in March 2020, did you start attending your mental health sessions online?
  - a) Yes
  - b) No
  
2. Which of the following are advantages in attending your Open Dialogue network meetings online? Please check all that apply.
  - a) Less time spent waiting for my appointments to start (Cowen et al., 2019)
  - b) Less time spent traveling to attend my appointments (Cowen et al., 2019)
  - c) Less costs spent on traveling to the clinic for my appointments (Cowen et al., 2019)
  - d) More time in my schedule on appointment days for other priorities such as school, work and caretaking (Lal et al., 2020)
  - e) My social network attends more of my network meetings when they are online
  - f) I enjoy the flexibility of attending my network meetings online
  - g) Other: \_\_\_\_\_
  
3. Which of the following are challenges in attending your Open Dialogue network meetings online? Please check all that apply.
  - a) Lack of access to devices (computer, smartphone, tablet)
  - b) Lack of access to internet
  - c) Cost of internet
  - d) Unsure how to use technology
  - e) Fear or discomfort with technology
  - f) Not wanting to receive services using technology
  - g) Disability (please specify): \_\_\_\_\_
  - h) Other: \_\_\_\_\_

(Wong et al., 2020)

## Appendix B

### Experience with OD Network Meetings Online

Please check one answer choice per question

	<b>Strongly Agree</b>	<b>Agree</b>	<b>I am Neutral</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	<b>Not Applicable</b>
1. I am comfortable communicating with my OD network face-to-face (Wong et al., 2020)						
2. I am comfortable communicating with my OD network online with video turned on (Wong et al., 2020)						
3. It is easy for me to attend network meetings online						
4. It is easy for my family members (or social network) to attend network meetings online						
5. I am more likely to attend my network meetings if they are offered online than if they are in-person						
6. I am able to communicate my needs online during my network meetings						
7. I feel comfortable attending my network meetings online						
8. I feel supported by my OD network when we meet online						

## Appendix B

9. I feel my condition is improving as a result of my online OD network meetings						
10. I enjoy the flexibility that having my network meetings online has on my time and schedule						
11. If offered in the future I would continue my OD network meetings online						

### Preference for Open Dialogue Network Meetings in the Future

Open Dialogue network meetings have been offered online due to social-distancing guidelines brought on by COVID-19. We would like to know your preference for how you would like to attend future Open Dialogue network meetings at Grady AOP.

1. What is your preference for how you attend OD network meetings?
  - a. I would prefer to have my network meetings in-person at the clinic
  - b. I would prefer to have my network meetings online
  - c. I would prefer to have a combination of in-person and online network meetings