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Modifying Psychotherapy When Working with an Adult Diagnosed with a Co-Occurring Intellectual Disability and Mental Disorder

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Modifying Psychotherapy When Working with an Adult Diagnosed with a
Co-Occurring Intellectual Disability and Mental Disorder

By

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MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work
Saint Catherine University and the University of Saint Thomas
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in Partial fulfillment of the Requirements for the Degree of Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at Saint Catherine University/University of Saint Thomas School of Social Work in Saint Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility and basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the University Institutional Review Board, implement the project, and publicly present the finding of the study. This project is neither a Master's Thesis nor a dissertation.

Abstract

Adults diagnosed with an intellectual disability are three to four times more likely than the general population to be diagnosed with a mental disorder. There are traditionally four classifications of intellectual disability: mild, moderate, severe, and profound. Each classification has characteristics that limit the cognitive functioning and abilities of the individual affected. This qualitative research was developed to explore the question of what might constitute some emerging best practices used in modifying psychotherapy when working with adults with a diagnosed intellectual disability and mental disorder. Five current and former psychotherapists and one psychiatrist served as respondents for the project. The psychotherapists were all asked the same semi-structured questions; however the questions most specifically geared toward the psychotherapists were modified for the interview with the psychiatrist. After the interviews were transcribed and coded, four initial themes emerged. These themes spoke to strengths, collaboration and the caregiving process, the role of groups, and “a variety of approaches used.” The respondents agreed that looking for clients’ strengths and collaborating with caregivers, family and guardians of their clients were the most important aspects of finding effective ways to work with adult clients diagnosed with a co-occurring intellectual disability and mental disorder. Other findings are explored as well and suggestions for future studies are offered to build upon this pilot.

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According to the Centers for Disease Control and Prevention (CDC) adults diagnosed with an intellectual disability have a three to four times greater risk than the general population of having a mental disorder (www.cdc.gov). *The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM 5)* characterizes intellectual disabilities by deficits in reasoning, problem solving, planning, judgment and academic learning (American Psychiatric Association, 2013). These deficits result in impairments of adaptive functioning. This results in the individual with an intellectual disability failing short on the standards of independence and social responsibility in areas that affect daily life including communication, academic or occupational functioning, and personal independence at home or in the community (American Psychiatric Association, 2013).

An intellectual disability is a category of disorder that is characterized, in part, by its onset during the early developmental period of an individual's life (i.e. typically arising in utero or between birth and age 18). In order for an individual to be diagnosed with an intellectual disability, the following three criteria need to be met:

- A. "Deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing
- B. Deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards of personal independence and social responsibility. Without ongoing support, the adaptive deficits limit functioning in one or more of the activities of daily life, such as communication, social participation, and independent living, across multiple environments, such as home, school, work and community

C. Onset of intellectual and adaptive deficits during the developmental period” (before age 18) (American Psychiatric Association, 2013).

According to the National Dissemination Center for Children with Disabilities, approximately 6.5 million individuals in the United States have an intellectual disability. There are four classifications of intellectual disabilities. The classifications of intellectual disabilities are mild, moderate, severe, and profound.

According to the DSM-IV, mental disorder refers to “disorders generally characterized by dysregulation of mood, thought, and/or behavior” (www.cdc.gov). The National Institute of Mental Health reports estimate that 26.2% of all Americans age 18 and over suffer from a diagnosed mental disorder in any given year. The most common classes of mental disorders in the United States are mood, anxiety, and personality disorders (www.nimh.gov).

Adults with intellectual disabilities have a three to four fold greater risk of having a mental disorder than the general public. These adults meeting the criteria for both an intellectual disability and a mental disorder are often referred to as people with “dual diagnoses”. The term dual diagnosis is usually used when speaking about individuals diagnosed with a mental illness and a substance abuse issue; however, it is also used to describe a child or adult with “lifelong developmental disorders along with co-occurring mental illness and behavioral difficulties” (Tang, Bynre, Friedlander, McKibbin, Riley, & Thibeault, 2008). According to an article published in *Social Work Today* it is estimated that 33% of all adults with an intellectual disability also have a diagnosed mental illness (Quintero & Flick, 2010). Even though there is such a high rate of diagnosed mental disorder in the intellectually disabled population, few mental health professionals have heard about this form of dual diagnosis (Quintero & Flick, 2010). A complicating factor when considering psychotherapy for clients diagnosed with a co-

occurring intellectual disability and a mental disorder is the client's communication skills (Quintero and Flick, 2010). This limitation makes it difficult or impossible for them to describe their symptoms and what a normal day is like for them. Other potential challenges include finding a qualified professional who is trained in working with adults dually diagnosed with an intellectual disability and a mental illness. Another challenge to consider is question of whether an adult diagnosed with a co-occurring intellectual disability and mental disorder has the intellectual capacity needed to understand the type of psychotherapy they are about to embark on.

When treating adults diagnosed with a co-occurring intellectual disability and mental disorder, psychotherapy is often recommended. Psychotherapy is a term used for treating mental health issues by talking to a psychiatrist, psychologist, or other mental health professional. Psychotherapy is useful in treating a wide variety of mental health conditions including anxiety, mood, and personality disorders and in some cases can be seen as effective as medications such as antidepressants. Optimal treatment generally involves prescribing medications in conjunction with psychotherapy (www.mayoclinic.com). There are several different types of psychotherapy used in treating the many different types of mental disorders. The main factor in deciding which therapy that will work for the individual is the specific diagnosis the individual has.

Because of the unique challenges that adults with a diagnosed intellectual disability and mental disorder face, psychotherapy for this client population often needs to be modified. The modification is necessary to get the best result for the client and so the mental health professional is better able to understand the special needs of the client. Literature to date lacks consistent recommendations as just how psychotherapy may need to be modified for this population in order to maximize benefit. For this project clinicians using several different types of

psychotherapy were interviewed to see what modifications, if any, are being used when working with adults with a co-occurring diagnosed intellectual disability and mental disorder in the context of outpatient psychotherapy. For this project, the following research question was addressed: What are the emerging best practices used in modifying psychotherapy when working adults diagnosed with a co-occurring intellectual disability and mental disorder?

Literature Review

The DSM-IV-TR uses the term mental retardation to mark individual differences in cognitive abilities. Throughout history, there have been many definitions and names for this condition. In the mid-nineteenth century other terms including idiot, imbecile and feeble-minded were used. During the mid-twentieth century the terms of mental deficiency, feeble-mindedness, mental sub normality, and mental handicap were used to describe these individuals. Although these terms seem objectionable in the 21st century, in their time they were clinical and commonly acceptable terms. The terms used to describe people have changed over time. Most recently, the term mental retardation has been replaced by the term intellectual disability (Fletcher, Loschen, Stavrakaki & First, 2007).

Intellectual Disability

The American Psychiatric Association (2013) utilizes four classifications for adults with intellectual disabilities. The first is mild. An adult with a mild intellectual disability has an IQ between 50 and 70 and most often has difficulties in abstract thinking, planning and prioritizing as well as short-term memory, and functional use of academic skills including reading, writing, and math. These individuals also lag behind their peers socially.

An adult with a moderate intellectual disability usually has an academic skill level that is at the elementary school level. Their IQ is between 35 and 49. There are significant differences

in the communication levels of adults with a moderate intellectual disability and their peers. In these individuals social judgment and decision making skills are limited. After an extended teaching period, adults with a moderate intellectual disability can become independent in the areas of personal care including bathing, eating, dressing, and hygiene.

An individual with a severe intellectual disability generally has limited understanding of written language and concepts including money, numbers, and time (American Psychiatric Association, 2013). These individuals also have a limited spoken vocabulary and require support in all areas of activities of daily living including; meal prep, bathing, dressing, and toileting. The IQ of these individuals is between 20 and 34.

The final classification of intellectual disability is profound. An individual with a profound intellectual disability usually uses objects to communicate with, have a very limited understanding of speech and are completely dependent on all aspects of daily care, health, and safety. The IQ of these individuals is under 20.

There are several different diagnosed intellectual disabilities. According to the Centers of Disease Control and Prevention and the National Information Center for Children with disabilities the most common types of the intellectual disabilities diagnosed in the United States are Autism Spectrum Disorders (ASDs), Down's Syndrome, and Attention Deficit Hyperactivity Disorder(ADHD).

According to Bradford (2010), the prevalence of ASDs is on the rise. Bretani, de Paula, Bordini, Rolim, Sato, Portolese, Pacifico, & McCracken (2013) also noted in their article on the diagnosis and treatment of ASDs that the prevalence of ASDs is on the rise. They found that studies conducted after the 1990s detected ASDs prevalence between 10 and 16 per 10,000 people (Brentani et al, 2013).

Emerging research suggests many professional are misdiagnosing ASDs. To help professionals to better diagnose these disorders and become better members of treatment teams, Bradford offers a brief overview of ASDs. Autism Spectrum Disorders occur in approximately 1 of 150 children in the United States and are four times as common in boys as girls (Bradford, 2010). In Bradford's review of recent literature, evidence was cited that Asperger's disorder and autism were not "qualitatively distinct disorders" rather different qualitative manifestations of similar disorders. Asperger's disorder was first described by Hans Asperger from Austria in 1944 and autism was first described by Leo Kanner in 1943. Asperger described what would be later called Asperger's disorder as a "pattern of behavior and abilities including low empathy, little ability to form friendships, absorption to special interests and clumsiness" (Bradford, 2010). Kanner described patterns similar to Asperger's disorder in what today is known as autism. These patterns included "social deficits, echolalia, avoidance of people, and obsessive and repetitive behaviors" (Bradford, 2010).

Autism Spectrum Disorders can be missed or misdiagnosed because of the wide variations in the impairments in the areas of communication, cognitive abilities, and behavior patterns (Bradford, 2010). Another reason that ASDs sometimes get missed or misdiagnosed is because the behaviors associated with them can be seen in isolation and not associated to a pervasive developmental disorder. These researchers also noted that diagnosis of ASDs requires an approach that is comprehensive, systematic, and structured. When diagnosing ASDs the goal of the assessment is make sure that the correct diagnosis is being made and providing important information about the relative strengths and weaknesses of the child that is being assessed (Brentani et al, 2013)

Early detection of ASDs is crucial because of the evidence that early intervention can mean quantifiable gains in positive outcomes (Bradford, 2010). Brentani et al noted that doctors in the United States are recommended to perform specific ASDs screening on all children at 18 and again at 24 months of age. The signs and symptoms of ASDs are marked by “developmental deviations” in social interaction and both verbal and nonverbal communication (Bradford, 2010). Individuals with ASDs usually appear physically normal, but have oddities of social interaction which makes people who observe them see them as abnormal (Bradford, 2010). Individuals with Autism and Asperger’s Disorder each have signs and symptoms that affect them in many different areas of functioning. In the DSM-5 the diagnosis of Asperger’s Disorder is no longer differentiated, but placed under the ASD classification. These areas include social, cognitive, communication, behavioral, and physical. The degree to which they are impaired in each of these areas makes the diagnosis of either Asperger’s Disorder or Autism possible. Many professionals describe Asperger’s Disorder as a mild form of Autism (Bradford, 2010). However it is interesting to note that in their overview of the diagnosis and treatment of ASDs, Brentani et al. (2013) explain that delayed speech and cognitive impairment are not signs of a diagnosis of Asperger’s syndrome like they are with a child with a diagnosis of Autism. In the DSM-5 the diagnosis of Asperger’s syndrome is subsumed under a range of pervasive developmental disorders whereas in the DSM-IV-TR it was its own separate diagnosis.

Another intellectual disability diagnosis is Down syndrome. According to the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) (2013)

Down syndrome is described as a set of cognitive and physical symptoms that result from an extra copy or part of an extra copy of chromosome 21. Common physical signs of Down syndrome include decreased or poor muscle tone, a short neck with extra skin at the back of the neck, flattened facial profile and nose, small head, ears, and mouth, upward slanting eyes, white spots in the part of the eye, wide, short hands with short fingers, a single deep crease across the palm of the hand and a deep groove between the second and third toe.

The type of error that happens is called nondisjunction. In nondisjunction, something goes wrong and both chromosomes from one pair go into one cell and no chromosomes for that pair goes to the other cell (www.nichd.nih.gov).

According to the CDC, approximately 6,000 babies in the United States are born with Down syndrome annually. This accounts for about 1 out of every 691 live births. The age of the mother when she gives birth also plays a factor in the risk of a baby being born with Down syndrome. The risk factor ranges from 1 in 1,300 when a mother is 25 to 1 in 25 when a mother is 49 (www.nichd.nih.gov). This suggests that age may be an important or relevant variable.

There is no standard treatment for Down syndrome. Treatments are based on each individual's physical and intellectual needs. There are early intervention programs that are proving successful with children with Down syndrome. There are also a variety of treatment therapies that can be used during early intervention program and throughout the life a person with Down syndrome to improve their quality of life. These treatment therapies include physical therapy, speech-language therapy occupational therapy and emotional and behavior therapies (www.nichd.nih.gov).

According to the CDC, ADHD is one of the most common types of neurobehavioral disorders of childhood (www.cdc.gov). Signs of ADHD include having trouble focusing and behavior that cannot be grown out of that causes difficulty at school, home or with friends. Some of the symptoms of ADHD include daydreaming several hours a day, forgetting or losing many things, squirming or fidgeting, talking too much, making careless mistakes or taking unnecessary risks, having a hard time resisting temptation, having trouble taking turns, and having trouble getting along with others.

According to the DSM-5, there are three different types of ADHD. The first is predominantly inattentive presentation. In this type of ADHD, it is hard for the individual to organize or finish a task, to pay attention to details or to follow instructions. The second type of ADHD is predominantly hyperactive-impulsive presentation. This person fidgets a great deal and is unable to sit still for long periods of time, feels restless and has trouble with impulsivity (American Psychiatric Association, 2013). The third is called combined presentation. This is when the symptoms of both of the other two types are ADHD are equally present in the person (American Psychiatric Association, 2013).

Scientists are studying the risk factors and causes of ADHD. The causes and risk factors of ADHD are unknown, but research shows that genetics play an important role. Scientists are also studying other possible causes and risk factors including brain injuries, environmental exposure, alcohol and tobacco use during pregnancy, premature delivery and low birth weight (www.cdc.gov). Pheula, Rohde, and Schmitz (2011) noted in their study that low family cohesion and low family relationship index are factors that contribute to ADHD inattentive type. Pineda et al found that presence of major genes interacting with environmental factors is the cause of ADHD. In their study, the researchers looked at 200 children with ADHD and 286 healthy controls to see what risk factors including prenatal, neonatal, and early risk factors they may have. This was done by mothers and grandmothers filling out surveys (Pineda et al, 2007). The risk factors for ADHD as noted in the study included miscarriage symptoms, premature delivery, viral infection, moderate to severe illness in the mother during gestation, neonatal seizures, asphyxia or anoxia, mild speech retardation and moderate brain injury. It is also noted in the study that these environmental risk factors must be included when future studies are conducted on the risk of developing ADHD (Pineda et al, 2007).

Diagnosis of ADHD is a several step process. This is because there is no single test to detect ADHD. One of the steps of the process involves having a medical examination which includes hearing and vision tests. This is done to rule out other problems with symptoms similar to ADHD. Other parts of the diagnosis of ADHD is complete a checklist for rating the ADHD symptoms and taking a history of the child from teachers, and sometimes the child. In most cases, treatment for ADHD is best done with a combination of medication and behavior therapy (www.cdc.gov).

Mental Disorders

The most common classes of mental disorders in the United States are mood, anxiety and personality disorders. Mood disorders affect approximately 20.8 million adults in the United States (www.cdc.gov). The median age of onset for a mood disorder is 30 (www.cdc.gov). Some of the common diagnoses in this category include major depressive disorder, dysthymic disorder, bipolar disorder, and schizophrenia. Major depressive disorder affects approximately 14.8 million Americans and is the leading cause of disability in the United States for adults 18-44. Anxiety disorders affect approximately 40 million Americans age 18 and over. Common types of anxiety disorders include panic disorder, post-traumatic Stress Disorder (PTSD), obsessive-compulsive disorder, generalized anxiety disorder, and social phobias. When an individual has, a diagnosed anxiety disorder often times it co-occurs with a depressive disorder and/or substance abuse issues (www.nimh.gov). Individuals with an anxiety disorder usually have their first onset by the age of 21.

The prevalence of a personality disorder in the United States is 8.1%. Common personality disorders include Antisocial Personality Disorder and Borderline Personality Disorder. Antisocial personality disorder is characterized by an individual disregarding social rule and

cultural norms and affects approximately 1% percent of all Americans age 18 and over.

Individual with borderline personality disorder are seen to have pervasive patterns of unstable interpersonal relationships and have marked impulsivity. Borderline Personality affects approximately 1.8% of Americans age 18 and older (www.nimh.gov).

Co-occurring Diagnoses of Intellectual Disability and Mental Disorder

Adults with an intellectual disability are three to four times more likely to have a mental disorder than the general population (www.cdc.gov). According to the *Diagnostic Manual-Intellectual Disability(DM-ID)*, individuals with an intellectual disability can exhibit a full range of psychiatric disorders including anxiety disorders, personality disorders, affective disorders in addition to several other disorder clusters (Fletcher, Loschen, Stavrakaki & First, 2007). The purpose of the DM-ID is to obtain a more accurate psychiatric diagnosis for individuals with intellectual disabilities. People with intellectual disabilities have long been under diagnosed or misdiagnosed due to limitations in the areas of expressive and receptive language skills.

According to Holmes (personal communication, October 1, 2013), as a person's functioning decreases, the prevalence of having a mental illness increases. She noted that the mental disorders seen in adults with an intellectual disability at a greater rate than the general population are: dysthymic disorder, depressive reactions to life events, and personality disorders in adults with a mild or moderate intellectual disability (Holmes, 2013). Adults with intellectual disabilities have similar rates of diagnosis of major depression, bipolar disorder, and anxiety disorder as the general population (Holmes, 2013). Adults with an intellectual disability are diagnosed with panic disorder and obsessive-compulsive disorder at a lower rate than that of the general population (Holmes, 2013).

Risk factors for an adult with an intellectual disability to be diagnosed with a mental disorder include: Fragile X, limited emotional and regulation skills, developmentally inappropriate environments, including substandard housing, poor mental health care, developmental problems, and poor social skills (Holmes, 2013). Special considerations must be made when trying to diagnose a mental disorder in an adult who already has a diagnosis of an intellectual disability (Holmes, 2013). The mental health professional doing the assessment must have the skill, experience, and patience to do an accurate and thorough assessment. They should also use multiple informants including family members, social workers, care providers, and the adult client they are working with (Holmes, 2013). When diagnosing the adult with an intellectual disability with a mental disorder, the mental health professional also needs to pay attention to the behavior changes, the lack of concrete thinking and possession of limited communication skills (Holmes, 2013). Mental health professionals working with adults with an intellectual disability must also be aware of nonverbal behaviors that may indicate the client is experiencing psychosis. These behaviors include: staring to the side or into corners and nodding as if they are holding a conversation, brushing unseen material off the body, wearing multiple layers of clothing, covering eyes or ears, placing wrappings around ankles, sleeves or neck, glaring with intense anger at strangers or people they previously liked, wearing costumes, inspecting or refuses food with fear or other intensity, grimacing as though tasting or smelling something foul (Holmes, 2013).

Psychotherapy with adults diagnosed with a co-occurring intellectual Disability and a Mental Disorder

There are several hundred different types of psychotherapies practiced by outpatient therapists today. For this section of the literature review, the book *Psychotherapy with Individuals with an Intellectual Disabilities* (Fletcher, 2011) was used to identify the different psychotherapies most often used in treating adults with a diagnosed co-occurring intellectual disability and mental disorder. These included: Cognitive Behavioral Therapy (CBT), Dialectical Behavior Therapy (DBT), Behavioral Relaxation Training (BRT), and Mindful-based psychotherapeutic practices (Fletcher, 2011).

Cognitive Behavioral Therapy is a common form of psychotherapy in which the client works with the therapist in a structured way for a limited number of sessions. This type of psychotherapy is most useful in treating mental disorders such as depression and anxiety (www.mayoclinic.com). Cognitive behavior therapy is used to treat a wide variety of mental disorders. It is often the preferred type of psychotherapy for clients because it can quickly help the client understand their mental disorder and how to cope with challenges that their diagnosis presents them with (www.mayoclinic.com). Cognitive behavior therapy is also useful in helping to address emotional challenges. Examples of these challenges include managing symptoms of the diagnosed mental disorder, preventing a relapse of symptoms (www.mayoclinic.com).

Dialectical Behavior Therapy (DBT) was developed by Dr. Marsha Linehan, who had been using cognitive behavior therapy to treat those who were suicidal and individuals with self-harming tendencies (Cooper & Parsons, 2010). Dialectical Behavior Therapy was developed to work with adults diagnosed with Borderline Personality Disorder. DBT has a number of assumptions and principles that are at its core and has been adopted for multiple mental health

issues. One of these principles is the importance of the paradigm of the dialectical approach (Cooper & Parsons, 2010). In a dialectical approach, it is stated “there is no absolute truth as perspectives change and shift” (Cooper & Parsons, 2010). This approach allows for gaining a new understandings and the striving for synthesis in opposites and extremes (Cooper & Parsons, 2010). Further assumptions of DBT include the utilization of biosocial factors in understanding emotional lability (Cooper & Parsons, 2010). Therapists using DBT utilize these principles to help address problems in their client’s processing of emotions (Cooper & Parsons, 2010).

Relaxation training is an intervention aimed at decreasing the frequency of tension and anxiety “via inhibition of the beta sympathetic nervous system and reduction of the peripheral muscle activity” (Fletcher, 2011). Behavioral Relaxation Therapy (BRT) was developed by Schilling and Poppen. These two professionals noted that clients who completed progressive muscle relaxation (PMR) displayed a set of behaviors that co-occurred with self-reported and physiologically-measured relaxation (Fletcher, 2011). Examples of these behaviors included slowed breathing, loose jaw, absence of swallowing and closed eyes (Fletcher, 2011). BRT has been evaluated for use with a diverse range of conditions and disorders. These include hyperactivity, stress management, and Huntington’s disease (Fletcher, 2011). BRT is seen to be useful when working with adults with an intellectual disability because it does not rely on verbal reports of internal state and can be used even with persons who are not verbal (Fletcher, 2011).

Mindfulness-based psychotherapy is a type of psychotherapy that combines Buddhist mindfulness techniques with Cognitive-Behavioral Therapy. Mindfulness-based psychotherapy was founded by Segal, Teasdale, and Williams (2003). It is adapted from a program on mindfulness based stress reduction by Kabat-Zinn. The goal of mindfulness-based psychotherapy is to increase relaxation and happiness by developing a greater self-awareness, introspection, and

compassion for yourself and others. Mindfulness based psychotherapy “utilizes self-regulative practices to enhance attention, awareness and acceptance and emotion regulation” (Robertson, 2011, p. 91). Mindfulness-based psychotherapy has been found to be an effective treatment or secondary treatment for many mental health concerns including anxiety, trauma, and emotional dysregulation. Mindfulness-based psychotherapy generally takes eight weeks to complete and consists of weekly two hour sessions working directly with a trained psychotherapist, with assigned homework to be completed between sessions. The therapists will attempt to bring clarity to the client about compulsive or negative thoughts and ideas (Robertson, 2011).

Mindfulness-Based Psychotherapeutic Practices

Mindfulness-Based Stress Reduction (MBSR) is an eight week semi-structured group format that incorporates meditation, gentle yoga and relaxation exercises. This technique was developed by Jon Kabat-Zinn who established the Center for Mindfulness. According to the center, there are no published reports on modifying MBSR for adults with an intellectual disability; however, in 2008 MBSR was modified for parents and caregivers of individuals with an intellectual disability through a 2008 pilot study conducted in association with Westside Regional Center in Culver City, California.

Modification of Psychotherapy for an adult diagnosed with a co-occurring intellectual disability and a mental illness

There is a little evidence of research done in the area of modifying different types of psychotherapy used in treating adults with a co-occurring intellectual disability and a mental disorder. This may suggest that the modification of different psychotherapies used when an outpatient therapist works with an adult diagnosed with a co-occurring intellectual disability and mental illness is done on an individual client basis and little is being written as to the *process* of

the modification of the different types of psychotherapy used to treat this client population. While at least one meta-analysis has been conducted offering evidence that psychodynamic, cognitive behavioral, and behavioral psychotherapies have been used successfully with adults with intellectual disabilities (producing small to medium effect sizes), the literature points to little evidence of a consensus among practitioners as to a “more effective” theoretical orientation and little research in this area in general.

Because of there is little evidence of research on how different types of psychotherapy were being modified when working with an adult diagnosed with a co-occurring intellectual disability and a mental disorder this researcher wanted to know what is being done by therapists to help this client population. Are therapists taking a “blind” approach to practicing different types of psychotherapies when working with an adult diagnosed with a co-occurring intellectual disability and a mental disorder or are there certain steps being taken to modify the different types of psychotherapies used when working with these adults? Do therapists tend to use a certain type of psychotherapy with an adult diagnosed with a co-occurring intellectual disability and a mental illness? Do they modify the therapy in some similar ways or is it done on an individual client basis? This Qualitative research project attempted to explore the question: what are the emerging best practices used in modifying different types of psychotherapy used when working with an adult diagnosed with a co-occurring intellectual disability and a mental disorder?

Conceptual Framework

Dennis Saleebey, in the Book *the Strengths Perspective in Social Work Practice*, writes about the idea of building on clients’ strengths. He discusses how textbook authors, social work

educators and practitioners are all embracing this important principle. The strengths perspective has several key concepts that shape its core. These concepts are: empowerment, membership, regeneration, synergy, dialogue, and suspension of disbelief (Saleebey, 1992).

The empowerment agenda is about discovering the power within people. To discover that power “we must subvert and adjure pejorative labels; provide opportunities for connection to family, institution, and community; assail the victim mindset; forswear paternalism (even in its benign guises); and trust people’s intuitions, accounts, perspectives, and energies” (Saleebey, 1992, pg. 8). Empowerment is aimed at both reducing the sense of and the reality of individual and community powerlessness but it is also aimed at helping a person discover the power within themselves, their families, and their neighborhoods. In order to pursue an empowerment agenda, a person needs to have a deep belief in the necessity of democracy and that all people have the ability to participate in the decisions and actions that will affect their world (Saleebey, 1992).

Membership refers to the idea that having a communal place and identity is requisite to realization for distributive justice (Saleebey, 1992). People find themselves without membership because they are strangers in the community or have been torn from their geographical roots and are very vulnerable (Saleebey, 1992). The strengths orientation proceeds from a recognition that all the people social workers serve are like them in that they are members of the same species and are entitled to the respect, dignity, and responsibility that comes with that membership (Saleebey, 1992). When an individual is thought of as a stranger or is otherwise estranged from their group, their rights and access to resources within the group they were a member of becomes legitimized. As helpers of individuals who might have a loss of absence of group membership certain things are required of them at the outset. These include: instigating a collaborative stance, giving voice to, and acknowledging that each individual’s story, values, and beliefs have

authentic meaning, recognizing individuals' efforts and successes despite not having any roots or membership in a particular community or group, and making sure that they help individuals make links to possible community or groups of interest that may be able to become members of in order to gain and use their individual strengths are respected and can flourish (Saleebey, 1992). People with intellectual disabilities may experience themselves as lacking membership, and at times even a "stranger" status as Saleebey describes.

Saleebey uses several specific terms likely relevant to this study. These include regeneration, synergy, dialogue and collaboration, and suspension of disbelief. He defines regeneration as the process of renewal, restoration and growth that makes individuals resilient to events that cause disturbance or damage (Saleebey, 1992). In the strengths perspective this concerns an individual's ability to cope with change and bad events in their life. With each catastrophic life event an individual and their ability to regenerate is increased.

The synergistic perspective assumes that when people and other phenomena are "brought into interrelationship, they create new and often unexpected patterns and resources that typically exceed the complexity of their individual constituents" (Saleebey, 1992). In varying degrees over time a synergistic community will develop certain qualities that include a practical sense and accounting of renewable and expandable resources within the community and a sense that the individuals or families are part of a larger community (Saleebey, 1992). This will help the individuals and communities build stronger and more lasting relationships with institutions outside the community (Saleebey, 1992).

Dialogue and collaboration deal with humans beings coming into being only through creative and emergent relationships with others in the external world. "Without these collaborations, an individual will not have tested their powers or know of their knowledge or

become better aware of their own internal strengths. An individual needs to have dialogue with others to help build lasting relationships in order they can understand what internal strengths they have” (Saleebey, 1992, pg. 12). Psychotherapy, itself, involves dialogue and relationship.

Suspension of disbelief centers on the client’s word in the realm of professionalism. The idea of suspension of disbelief may have resulted from the overspreading of scientific thinking throughout our culture and in professions such as social work (Saleebey, 1992).

The strengths perspective was chosen as the conceptual framework for this project because of its potential fit with psychotherapy done by outpatient therapists with this population. Outpatient therapist can work with adult clients diagnosed with a co-occurring intellectual disability and mental disorder to find out their strengths and therapy goals. The specific psychotherapy used with a client can be based on these strengths and goals in order that the client can be helped (in Saleebey’s language – empowered) to the best of the outpatient therapist’s ability to create a better and more fulfilling life for the client, with a greater sense of community and belonging. Saleebey’s concepts above were chosen as potential “sensitizing concepts” to listen for in the interviews conducted.

Methodology

Research Design

The research design for this paper was qualitative. According to the literature reviewed there is little research done on how therapists modify different types of psychotherapy used when working with adults diagnosed with a co-occurring intellectual disability and mental disorder. Because of this lack of research in the area of modification of different psychotherapies used with this client population, questions for the interviews were constructed based on present literature in other areas related to the psychotherapeutic approaches authors

such as Fletcher and Robertson (2011) recommend using with this population. A sample of outpatient clinicians who identify working with this population was asked about this and also about their experiences working with the adult client population diagnosed with a co-occurring intellectual disability and mental disorder. This study was exploratory in nature in order to help begin to explore the research question for this study. It was decided to only interview outpatient psychotherapists who specialize in or who work significantly with adults diagnosed with a co-occurring intellectual disability and mental disorder. This is because they would have the education and training needed to answer questions relating to the diagnosis of, psychotherapy for, and modification of the specific psychotherapy or therapies that they use in their practice. The psychiatrist who was interviewed for the project was chosen in that psychiatrists often serve an important role in outpatient mental health treatment teams.

Population and Sample

The sample for this study consisted of five outpatient therapists and one psychiatrist, all of whom have a great deal of experience working with adults who have a co-occurring diagnosis of an intellectual disability and mental disorder. Each of the outpatient therapists interviewed practice some form of psychotherapy as the method of treatment that they use with their clients. The psychiatrist who was interviewed uses a domains model which can be called a refinement of a bio-psychosocial model. The outpatient therapists were all master or doctoral level clinicians and licensed as a mental health professional in the state where they practice. Examples of Mental Health Professionals are Licensed Independent Clinical Social Workers (LICSW), Licensed Psychologists (LP), Licensed Professional Clinical Counselors (LPCC) or Licensed Marriage and Family Therapists (LMFT). A preference in this study was given to professionals with a Master of Social Work (MSW) degree and a professional license of a LICSW. The reason for

the MSW and LICSW preference for this study is to use this project as a way to offer findings that might inform the practice of clinical social workers as the largest number of mental health therapists in the United States. It also focused the sample and was done in order to potentially offer some disciplinary specificity.

For this study four current and one former outpatient therapist were interviewed. A psychiatrist who works with adults diagnosed with a co-occurring intellectual disability and mental disorder was also interviewed for this project. The respondents for this project were found two different ways. The researcher had knowledge of one of the respondents and snowball sampling was used in order to find additional respondents. Snowball sampling was done by the researcher to see if either of the committee members for the project knew of any mental health professionals, preferably outpatient psychotherapists who work with adults diagnosed with a co-occurring intellectual disability and mental disorder who might be willing to be interviewed for this project. Two of the respondents were found this way. The other two respondents were professionals who were found through a national website that works with adults diagnosed with a co-occurring intellectual disability and mental disorder. The reason that this sample was decided upon is due to the fact that outpatient therapists who specialize working with this specific client population would have the expertise to answer the specific questions for the study and also ease of accessing respondents who may have similar expertise in a difficult to access sample. Once the outpatient therapists and psychiatrist were identified and contacted, the study was explained to them by way of an email in order to see if they were interested in being a study respondent.

Protection of Human Participants

A consent form was created using a template provided by the University of Saint Thomas. The form consists of a summary of the research questions, procedures for the interview

and the interview's voluntary nature. Also included in the consent form are the contact information for the researcher and the faculty advisor for the project (See Appendix A). The consent form was reviewed and approved by the chair of the research and the committee prior to conducting the interviews with the respondents. Prior to audio recording of the interviews, both the researcher and respondents reviewed, signed, and dated the consent form. One copy of the consent form will be kept by the researcher and one copy was provided to the respondent before the interview began. The researcher thanked the respondent for considering participating in the study and remind of the voluntary nature of the study before the interview began.

Interviews were set up at a date and time convenient to both the respondent and the researcher. None of the interviews were conducted locally. Because of this freeconferencecall.com was used for all the interviews.

Data Collection

The interviews were conducted one on one, audio taped and recorded using freeconferencecall.com. Freeconferencecall.com also transcribed four of the interviews for this project. Another transcription service, Speakwrite, transcribed the other interview. This service was used to transcribe one of the interviews for this project because initially when the researcher signed up for an account on freeconferencecall.com it was not set up for transcription service. The final interview was unable to be recorded because of the way the researcher called in for the conference call when this respondent was interviewed.

The format of the interview was semi-structured. There were eleven prepared questions for the interview, most of which have room for elaboration (See Appendix B). The respondents were asked questions about their experiences and education level associated with working as an outpatient psychotherapist or psychiatrist with adults with a diagnosed co-occurring intellectual

disability and a mental disorder. The interview questions ask about how the therapist approaches diagnosis, the psychotherapy they specialize in, and their sense of the emerging best practices used in modifying that psychotherapy to best help treat their adult client diagnosed with a co-occurring intellectual disability and mental disorder.

The interviews that were recorded on freeconferencecall.com were transcribed and all records of the study will be kept confidential. Transcripts were kept in a locked file at the researcher's residence so that no one else would have access to the information. The transcriptions that were done by freeconferencecall.com or Speakwrite were sent to the researcher via email and are stored on a password protected computer. Identifying information was removed from the transcripts and results section so that it would be difficult to identify any individual respondent. Findings from these interviews are being used for academic purposes only. All recording from the interviews will be digitally deleted by January 1, 2016. The modified transcripts without identifying information will be kept indefinitely by the researcher in a home file for future educational purposes only.

Data Analysis

Open coding was done for the analysis of the data of this project. Open coding is the idea of finding themes in the interviews without using information found in the review of the literature or other sources to bias the researcher in finding themes that may not be present (Padgett, 1998). After all of the interviews were completed, then the transcription and coding took place. Open coding was done initially by the researcher to find common themes in the data. However, this was difficult. The researcher next looked at the interview questions to see if any themes or information from the interviews stood out based on the interviews questions. After the

open coding and coding based on the interview questions was done, the researcher identified four main themes which are discussed below in the Results section.

Strengths and Limitations

The primary strength of this study consists of the professional experience of the outpatient therapists working with adult clients diagnosed with a co-occurring intellectual disability and mental disorder. These initial findings can be useful in future research in order to learn if there is an emerging pattern to the best practices of modifying different types of psychotherapies used when treating adults diagnosed with a co-occurring intellectual disability and a mental illness.

Even though there are strengths to this study, there are also limitations as well. The small sample size can be seen as a limitation because the data collected cannot be seen as representing enough of the overall group of outpatient psychotherapists that specialize in working with this adult client population. Until more research is done on this topic it will not be known for sure if the majority of outpatient therapists using a specific psychotherapy are modifying it in similar way(s) to help the adult clients diagnosed with a co-occurring intellectual disability and a mental disorder who they are working with. Finally, because a lack of research was found in the area of the modification of different types of psychotherapies used to treat adults diagnosed with a co-occurring intellectual disability and a mental disorder the questions associated with modifications were not tested. This means that the researcher did not find other studies that used similar questions in the area of modification of psychotherapy like the questions used in this study. This limits the questions about modifying the different types of psychotherapies for this population.

Timeframe

In order to ensure this project would stay on track and be completed on time this researcher adhered to a timeframe. In November, 2013, this researcher met with his research committee in order to have the project reviewed. After this meeting, the paper was amended in order to be approved by the research committee. After approval of the proposal by the research committee, application to the University of Saint Thomas Institutional Review Board (IRB) was made in order to get approval for the project to be completed. This application was submitted on December 14th. The IRB requested that modifications be made before the research project could be conducted. The resubmitting of the project to the IRB took place in the middle of January. The IRB application of this research project was then accepted. Possible respondents were contacted at the end of January in order that interviews could be set up. Many individuals were not responding or did not know anyone worked in the field of outpatient therapy with adults diagnosed with a co-occurring intellectual disability and mental disorder. The individuals who were contacted were clinical directors from community mental health centers in the state of Minnesota along with individuals on a list of names the researcher was given access to. All of the interviews were conducted by the end of February and the transcriptions were done in March. After the transcriptions were done, the coding was completed. The coding took place in March and the writing of the results and discussions sections took place in April. The final draft of this research project was done in the middle of April in order to have a final research committee at the end of April. The findings were disseminated (presented publicly) in May, 2014.

Results

For this project the research question that is to be addressed is: what are the emerging best practices used when modifying psychotherapy used when working with an adult with a co-occurring intellectual disability and mental disorder? To accomplish this, outpatient psychotherapists who work with or specialize in working with adults diagnosed with a co-occurring intellectual disability and mental disorder were interviewed. The researcher completed six interviews for the project. The professionals who were interviewed were four outpatient psychotherapists that currently work in the field, one former outpatient psychotherapist who currently is an executive of a national organization that supports individuals diagnosed with a co-occurring intellectual disability and mental disorder, and one psychiatrist who works with many adults diagnosed with a co-occurring intellectual disability and mental disorder. Each of the respondents was a seasoned professional having more than ten years of work experience with this client population. These respondents were found in a variety of ways. One of the respondents the researcher had knowledge of through a former professional position and because the researcher and this respondent had former clients in common. This respondent also helped the researcher find another respondent through snowball sampling. Two of the respondents were found through one of the researcher's committee members. The final two respondents for the project were found through contacting a national website on the dual diagnosis of an intellectual disability and mental disorder. One of the executives of this website allowed the researcher to use the names of professionals who work in the field of psychotherapy with individuals with dual diagnoses who contributed to the book that he edited.

The interviews were conducted using an 11 question format. The five current or former outpatient psychotherapist respondents were all asked the same questions. However, the

questions were specific to outpatient psychotherapists. In the case of the psychiatrist who was interviewed, the questions specific to the type of psychotherapy and the modification of the psychotherapy used in practice were omitted. After the interviews were conducted and transcribed, coding was done to bring out the most prominent themes throughout the six interviews. This was done initially by using open coding. Prominent themes were initially challenging to find; however it was suggested to this researcher that looking at the interview questions might be a good way to help with the coding process. Between the open coding and looking at the interview questions four prominent themes emerged. Some tentative, beginning themes stood out as being very important across all of the interviews. These themes included: strengths, collaboration, and the role of groups. Because there were many topics brought up in each of the interviews that did not match up across the six interviews, a fourth theme titled “a variety of approaches used” was included as a theme in this results section in order to capture some of the particulars of what individual practitioners are trying and doing that they have found successful. The variety of responses in many ways points to this as an emerging area of practice, with approaches being used and being more akin to “emerging best practices” than empirically supported treatments. These findings are offered with the goal of helping practitioners begin to have some broader context as to what professionals who have developed practices in this area are doing and which approaches hold promise or are worth further exploration.

Strengths

The idea behind asking questions regarding the role of clients’ strengths was to ascertain to what extent the respondents for this project worked overtly with the strengths of the clients that they worked with before deciding what type of psychotherapy that they were going to use with

a specific client. The respondents brought up some interesting ideas related to the topic of working with strengths.

One of the respondents talked about how she asks about the strengths of the client and how she uses that in therapy practice with this client population. She mentioned the “health and social history” questions she has on the intake forms. This is brought out in the following quote: “Well as part of our health and social history, we have a question that says what your strengths are. So we ask it directly. Strengths... I will look some practical kinds of things. If they have a strength in reading, you know, I gonna do a lot more writing with words. If they have strength in some sorta activity, for example, I will often use it as a rapport building piece”. As this quote suggests, it is noteworthy here that these practitioners explicitly used clients’ strengths in the service of building an alliance with clients.

One of my respondents talked about how the assessment process of the client plays a large role in figuring out the strengths of the client. This was brought out in the following quote: “It is all part of doing a good clinical interview and, really like with any therapy whether the person has a disability or not you’re assessing all of the time. In the beginning it is a lot of assessing. ...continually evaluating what a person can and can’t do in their strengths and needing so, again I think it is a very critical judgment”. While this is something that, as the respondent suggests is important with all clients, this kind of functional assessment was described as particularly important in working with adults with intellectual disabilities.

Another of the respondents for this project talked about how she similarly uses the assessment process to find the strengths of her clients. This was brought out in the following quote:

“Well I try to assess whether or not I think they have the skills to understand or learn verbally. So I would have to know that they have a certain level of comprehension”. That is, she emphasizes client comprehension, specifically as an important part of her assessment.

One of the respondents emphasized the importance of looking at strengths when working with a client diagnosed with a co-occurring intellectual disability and mental disorder. He spoke to using *the family* as an important collaborating source in order to find those strengths that might be latent, that a client might not verbally offer in the office. He described how:

“You’re always trying to look for strengths. Talk to the family, talk to [people or caregivers] where they are staying. Get some sense of what’s going on with them. Yeah I think the more you can communicate with the providers, your parents, around what they’re good at, what they’re not good at, they’ll give you quite a bit of information, also time”. Again, while this balanced attention to clients’ potential strengths and vulnerabilities is important broadly in practice, it was described by these providers as important in practice here. Clinicians in the sample reminded other practitioner of the need to seek out collaborative sources to speak to strengths and deficits that the client might not readily be able to articulate. They offered a reminder to involve not only the family, but who might be described as a surrogate family for those living in supportive home settings.

Lastly, another one of the respondents for this project echoed the importance of this point, by speaking about how he goes about finding the strengths of the clients in this category: “Speaking to the individuals and getting collateral information from family or caregivers is a good way to find out the strengths of these clients”.

This researcher found that the theme of “looking for and working with strengths” to be a prominent one throughout all of the interviews with the respondents. A question asking

specifically about the strengths was thought to be a good way to bring in the conceptual framework for this study.

Collaboration and the Importance of the Caregiving System

Each of the respondents interviewed for this project thought that collaborating with family members, caregivers, and case managers of their client diagnosed with a co-occurring intellectual disability and mental disorder was important to the overall therapy process. Once she received a referral, one of the respondents discussed how she talks with the person doing the referral to see who would be coming with the client to the therapy appointments. She talked about how many of the individuals who she sees in therapy from this client population have a guardian and therefore she will invite the guardian to come to the first therapy session in order to have the consent form signed. This respondent also talked about it is good to talk to whoever brings the clients in order that everyone is on the same page with addressing the issues that are going on with the client. This was brought out in the following quote:

“I will often invite the collaborative support person, whoever that might be, into the session. And I’ll say from the beginning, I say sometimes it is helpful to do this together and so I will ask who will be bringing the client... I’ll say you know if we could talk, I would invite them back into the office with the client...but say, you know we can talk a little bit together, about what’s been going on, what concerns, what’s the progress in what we’ve been talking about and workin’ on ... Sometimes I would bring them back into the session and say you know, we were workin’ on this, could you help this person with this. You know the whole point of, well, part of the point of doin’ the collaborative contact is that then you’ve got a support of the generalization of whatever you’re workin’ on; that you got somebody at the home or at work or somewhere else to help

them implement coping skills for example or choosing different ways of addressing a problem, and as such, and you've got somebody to help them carry it over.”

Another of the respondents talked about collaborating with the guardian in order to get consent. This was brought in the following quote:

“Well first we determine whether that person is their own legal guardian or not. If the person is not their own legal guardian of course we have to have them in to consent to the treatment and they or may not be involved in their treatment...we continually try to assess how what's going on with the care giving system”.

One of the respondents talked a great deal about how he works a great with residential facilities. Because of this, he does a great deal of collaborating with staff members of these facilities. This was evident in this quote:

“Well, many of them [residential facilities] demand a notebook that we have some sort of communication back and forth for their records. So I have a couple who come in with a notebook. This tells me how they've been over the last week or two. Others I may go to their annual meetings. We also do a quarterly review on all of our clients and send that to their like social workers, guardian and group homes and most of them do not come alone. So if I have some concerns or they have some concerns, they will come in and sit for the first few minutes and let me know what has been going on.”

Another of my respondents compared working as an outpatient psychotherapist with an adult diagnosed with a co-occurring intellectual disability and mental disorder to working with a child as it relates to the collaboration process. Whereas the these professionals understand that their clients are adults, because of their level of functioning and having to get consent for

treatment because some of their clients were not their own legal guardian, it felt sometimes like working with a child. This was brought out in the following quote:

“It would be impossible to treat them without doing so. It is similar to working with a child. You, you wouldn’t work with a child without working with their parents. So I do collaborate from beginning to end with the whole treatment team...sometimes individuals who work directly with them will have questions for me about how to deal with behaviors or how to approach a situation...But yeah, I have ongoing and even the initial session, they have to be accompanied by someone because as you probably guess people with developmental disabilities can’t even complete my paperwork”.

The psychiatrist who was one of the respondents for this project talked about how important it is from the beginning to collaborate with the caregivers and family members of your clients. This was brought out in the following quote:

“We would be including family or caregivers from the beginning to get their input on what they’ve observed. Then we would gather as many outside records as possible, and so that requires their knowledge and consent, and then most of my appointments then I will most often meet with an adult patient who has an intellectual disability in the presence of their escort because I wanna make sure that questions are understood and directions about medications and medical tests are understood. With our therapists most we most of them would include a guardian, parent or escort in the first few minutes and last few minutes of the therapy appointment”.

The Role of Groups

The role group therapy plays when working with adults diagnosed with a co-occurring intellectual disability and mental disorder was an important theme that came up in interviews

with the respondents. Many of the respondents thought that showing this client population they are not alone in their struggles was important and several reported that they used group work as part of their practice. This was a way of achieving a sense of universality or shared experience.

One respondent made the recommendation that more group therapy should be used with this population. He talked about how group therapy can be particularly helpful for adult clients dually diagnosed in order to understand that they are not alone.

Another of the respondents who spoke to this theme talked about approaches that she has found particularly useful when working as an outpatient psychotherapist. She described a particular type of group approach she called “interactive behavioral therapy:” “Yeah like the group therapy model using interactive behavioral therapy I think is really uniquely helpful when people have a diagnosis [like this] there is a greater opportunity for growth for them, as time goes on”.

Interactive behavioral therapy is a group therapy approach that uses four stages. The first stage is the orientation stage where group members are asked to introduce themselves and then one member is given the responsibility of explaining what confidentiality is. After the nature of confidentiality is explained, then new members are asked to repeat back what was said in order to check for their understanding. The person who explained confidentiality then makes sure that all of the new members understand what the term confidentiality means.

The second stage of interactive behavioral therapy involves a “warm up and sharing.” In this stage group members take turns sharing what they would like to work on in the session that day. This is usually referred to as a check-in. Usually during this stage the group facilitator will ask who would like to begin the check-in. If two people seem to both want to begin, they will leave it up to the two members to compromise and to negotiate who will go first. If these two

members cannot compromise, it is up to the rest of the group members to decide who will begin the check-in.

The third stage of interactive behavioral therapy is called enactment and takes place after all of the members in the group have had the opportunity to check in. The term enactment is the “name given to the third stage of the session in which a member’s issue is explored in depth and moved into action through the use of psychodramatic techniques” (Fletcher p. 202). During this stage the group member’s issue that is developed needs to have the support of the other group members in order that the work done on this issue is beneficial to both the facilitator and group members.

The final stage after enactment in the interactive behavioral therapy process is affirmation. In this stage each member is given feedback about the strengths and growth he or she exhibited during group that day. Not only does the facilitator give feedback to each of the group members, but each of the group members are also given the opportunity to give feedback to fellow members about their strengths and growth they have exhibited during the day’s session.

A Variety of Approaches Used

When analyzing the interviews, several approaches are being used by these professionals that seemed important to the researcher. While these approaches are important to note, not all of the respondents mentioned these. When mentioning these approaches, an explanation of why the researcher felt they were important will be noted.

For instance, it was a good contrast in this research to hear about the diagnostic process the psychiatrist interviewed used because it was different from the way that the outpatient psychotherapists did their diagnosing and it offered a point of thematic divergence within the data.

The Domains Model

The psychiatrist interviewed spoke to the importance of a functional assessment, using the language of domains. She described how:

“We use something we call a domains model, which I guess you could [call] a refinement of a bio-psychosocial model. So we spend a lot of time designing the current problem that brings them in and trying to understand the frequency, severity, you know the duration, what has been tried in the past and then we move from there to understand the neutral development”.

This respondent talked about how her diagnostic process is different when working with a client presumed to have a co-occurring intellectual disability and mental disorder than a client without an intellectual disability. In keeping with the mental health therapists interviewed, when in the diagnostic process with adults with a presumed intellectual disability and a mental disorder, she uses quite a bit more information from collateral sources rather than solely from the patient.

It was surprising to this researcher that the concept of IQ was only brought up explicitly by one of the respondents. It was thought by the researcher all of the respondents would want to know the IQ of every client diagnosed with a co-occurring intellectual disability and mental disorder with whom they work. It is possible that these clinicians are indeed assessing for IQ, implicitly or explicitly. It simply was not raised in the interviews by most. The idea of the respondent wanting to know about the IQ when working with this client population surfaced explicitly when one respondent was asked about the modification of psychotherapy in the following quote:

“Well you’re always gonna have to modify it but yet part of it is for some folks with intellectual disabilities you know if their scores get pretty low then, then you really are doing some simple

basic stuff so I, usually try to find some kind of IQ, assessments at some point in their life cause then you can look at their scores”.

The results of the data collected through the interview process with the respondents suggest that collaborating with family members and caregivers along with assessing the strengths and deficits (attention to a functional assessment) of these clients goes a long way to aid in the therapy process. By understanding their client’s strengths and vulnerabilities they will build better rapport with their clients. This in turn will help them decide what type of psychotherapy or other techniques they will use as clinicians to help their clients better be able to manage their mental health symptoms.

Discussion

Summary of Findings

The findings of this project were somewhat inconclusive. The mental health professionals who were interviewed had a variety of ideas of how to best go about completing psychotherapy when working with adults diagnosed with a co-occurring intellectual disability and mental disorder. Although many of the respondents discussed how finding out the strengths of their clients and getting as much background information from collateral sources about their clients is important, there was no a true consensus about how best to go about achieving this.

First of all, many of professionals who were interviewed discussed how it is important to know the strengths of the client that they are working with in order to best help them with the situation that is before them. However, these professionals did not agree on how to best use these strengths to help their clients to the best of their ability. The professionals discussed how they use strengths of their adult clients diagnosed with a co-occurring intellectual disability and

mental disorder to come with a plan to provide psychotherapy services; however, there was some inconsistency on how and when to use these strengths. One respondents talked about how as a therapist one always needs be looking at the strengths of the adult client diagnosed with a co-occurring intellectual disability and mental disorder, whereas another respondent talked about the importance of getting as much collateral information as possible from sources including family, case managers, and caregivers in order to better understand the strengths and vulnerabilities of their clients.

These professionals also did not necessarily agree upon the best diagnostic practices used when working with this client population. Some of the professionals either did no formal diagnosing of their clients at all (this may reflect their setting) and others gave a variety of techniques for diagnosis they used. However, it did seem that no matter what the situation, these psychotherapists did make sure that they used some sort of diagnostic assessment tool in their practice. One of the therapists who was interviewed for this project uses the most recent diagnostic assessment she can find for the newly referred client. Usually she uses a diagnostic assessment that is within the last six months of the client being referred for outpatient psychotherapy services. This therapist does not do any diagnostic testing with any of her clients and has not for many years. She feels tests can be redundant if the client also has a psychiatrist.

Also when discussing the topic of diagnosis and assessment, it was helpful to get the point of view of the psychiatrist who was interviewed for this project. Because she is coming from the perspective of a medical doctor, her explanation of how she goes about diagnosing and assessing her adults clients with an intellectual disability and mental disorder was different from the outpatient psychotherapists who were interviewed for this project. She discussed the importance of completing a functional assessment with her clients. As previously mentioned,

she uses a domains models which a refinement of the bio-psychosocial model to complete her assessment.

When working with this client population, each of the mental health professionals interviewed agreed that collaboration with guardians, family members, case managers, caregivers and other support staff is important. This is because many times these clients are not able to adequately express themselves or to understand the concepts that the therapist is trying to explain to them. Also the collaboration is done for a variety of reasons. These reasons include: getting consent for treatment, getting a release of information signed, obtaining background information on the client, and learning about the strengths and vulnerabilities of the client. Sometimes when working with a an adult client diagnosed with a co-occurring intellectual disability and mental disorder, the outpatient psychotherapist will have a guardian, family member or caregiver of the client come to therapy session with the client in order get another perspective on how things are going with the client. The individual will sit in on one or more therapy sessions with the client in order that the psychotherapist can more fully understand how things are going on at home and can speak to the severity and frequency of the client's mental health symptoms. Also, if the outpatient psychotherapist wants the client to work on an assignment between sessions such as working on a coping skill or writing down every time they have a panic attack or anxiety, the person accompanying the client to the outpatient therapy appointment can help the client work on the assignment to make sure it gets done. This is done to help the client get the best outcomes possible out of the therapy sessions they are attending. Many of the mental health professionals who were interviewed for this study discussed how collaborating with sources such as guardians, family members, case managers, and other support staff can help in the rapport building with clients they are serving. This is because the outpatient

psychotherapist has another source to consult with regarding where the client is at and where they have come from in regard to the emotional and mental health state of their client. The therapist will also learn why the client was brought to therapy in the first place. Sometimes the client does not have the ability to communicate effectively and getting information from another source is beneficial in helping the client succeed in therapy. This was done in a number of creative ways, including the use of journals when a staff or family member could not attend a session in person.

The idea of tending to strengths when working with this client population appeared to be the most prominent theme. Because there was an interview question specifically related to finding the strengths of the clients when deciding what type of psychotherapy to use, the respondents talked a great deal about how strengths guides them in their outpatient psychotherapy practice. One of the respondents discussed how he is continually assessing and looking for the strengths in the clients from this population that he works with. This in itself is consistent with Saleebey's (1992) strengths perspective. Another respondent discussed how knowing what her clients are good at helps her decide if she will do more written or talking exercises in her therapy. Other respondents discussed that they like to know the strengths of the clients from this population to in order to know if the client is going to understand the concepts discussed in the therapy sessions with the individual. All of the respondents discussed that obtaining collateral information from many sources such as guardians, family members, case managers, caregivers, and other support staff is important when assessing the strengths of the adult client diagnosed with a co-occurring intellectual disability and mental disorder. These mental health professionals discussed how collaborating with multiple people who are involved in the client's life is essential in order to assess all of the strengths that the client has. This can

make deciding on what type of psychotherapy and other therapeutic techniques and the modifications needed for these therapies easier to establish.

Many of the professionals agreed that group therapy plays an important role in outpatient psychotherapy when working with an adult diagnosed with a co-occurring intellectual disability and mental disorder. One of the respondents recommended that group work be used more with this client population. Another of the respondents discussed how she focuses on the group model and what she called “interactive behavioral therapy” when working with this client population. She discussed how this is unique and how the client is able to show particular growth in group therapy sessions. Both of these respondents discussed how group therapy can be effective with this client population because clients can understand they are not alone in their struggles. In addition, the clients diagnosed with a co-occurring intellectual disability and mental disorder can support each other through the group process in order that the best possible outcomes are achieved.

Because of the cognitive abilities of the individuals in this population and in order to obtain background information on the client being served, the mental health professionals who were interviewed for this project all agreed that collaboration with outside sources such as guardians, family members, caregivers, case managers and other support staff is very important. In addition, these mental health professionals described getting information about the strengths and vulnerabilities of their clients in order to aid in rapport building and to help the adult diagnosed with a co-occurring intellectual disability and mental disorder see the best outcomes in their therapy sessions as possible.

The “variety of approaches used” theme in the results sections was used to bring to light the interesting approaches mental health professionals are using to diagnose and treat dually

diagnosed clients that were not discussed elsewhere. One of the ideas brought up in this section was IQ. Only one respondent talked about how he likes to know the score of the clients he is working with. Knowing the IQ score was brought out when this respondent was asked about modifying psychotherapy used when working with this client population.

Relationship of the Findings to the Literature Review and Conceptual Framework

Dennis Saleebey's articulation of the strengths perspective (1992) was used for this project. One of the questions for the project was: how do you look for the strengths of the client you are working with before deciding on what psychotherapy to treat the client when working with a client with an intellectual disability?

The conceptual framework of the strengths perspective was easy to bring out in the analysis of the interviews as the question about the strengths of the clients was asked in the interviews. The psychotherapists all agreed that the strengths of the clients need to be considered when working with members of this client population. Respondents spoke to the importance of making sure that the clients' strengths are taken into consideration when deciding on how to proceed with whichever method of psychotherapy or treatment was going to be used with the client. Most of the respondents did not speak specifically to theoretical orientations they gravitated toward. In keeping with the literature, no one psychotherapeutic orientation "rose to the top" across this group of providers.

Two central texts emerged in my review of the literature that are worth referring back to: Fletcher's (2011) *Psychotherapy for Individuals with Intellectual Disabilities* and the *Diagnostic Manual-Intellectual Disability (DM-ID)* edited by Fletcher, Loschen, Stavrakaki, and First (2007). Fletcher's book was introduced in the literature review to discuss the different types of psychotherapies that are most often being used in field of outpatient psychotherapy with adults

with an intellectual disability. The DM-ID was referenced as a text in the literature to let the reader know that there are criteria specific to adults with an intellectual disability to be taken into consideration before diagnosing them with a mental disorder. The fact that there is a DM-ID shows that services for adult clients with a co-occurring intellectual disability is an emerging area in the field of outpatient mental health care and this co-occurring diagnosis needs to be given more attention.

For the most part the data collected from the interviews for this project did not provide much information explicitly as to what psychotherapy the respondents specialized in when working with this client population. This made comparing the psychotherapies recommended to be used in Fletcher's book and the techniques used by the respondent difficult. However, one of the psychotherapists noted that she uses cognitive behavior therapy in her practice. The other therapists who were respondents for the project did not mention that they specialized in one type of psychotherapy over another. One of the respondents did mention that she focuses on the group work model and, in particular, on interactive behavioral therapy. This respondent uses this therapy model with survivors of trauma who have an intellectual disability. There was one chapter (9) in Fletcher's 2011 book *Psychotherapy for individuals with intellectual disability* that talked about group work with trauma survivors, and authors such as Razza, et al. (2011) and Razza & Tomasulo (2004) have described this treatment model and its application to adults with intellectual disabilities in detail. There was a recommendation made by one of the respondents that was also brought out in Fletcher's edited text. Both recommended more psychotherapists try mindfulness-based psychotherapy when working with adults diagnosed with a co-occurring intellectual disability and mental disorder. It is also beneficial to mention that Behavioral Relaxation Training (BRT) was also mentioned in Fletcher's book, but not by any of the

respondents as a therapy technique that they use. It was thought that because BRT is seen to be useful when working with adults with an intellectual disability (because it does not rely on verbal reports of internal states and can be used even with persons who are not verbal) that one of more of the respondents for this research would have mentioned it or might be currently using it in practice. This, however, was not the case and it was not brought up by any of the respondents in the interviews.

When looking at the diagnoses that were mentioned as being worked with by the outpatient psychotherapists interviewed for this project, only autism and depression were specifically mentioned. Anxiety and sexual inappropriateness were conditions that were also mentioned that the therapists who were respondents for this project were dealing with in their practice. Both of these are areas that merit attention in future studies. Through a conversation with one of my respondents before the project began, it was discovered that she uses the DM-ID in practice to assist her in working with adults with a diagnosed co-occurring intellectual disability and mental disorder. However it is unclear how many of the other mental health professionals who were interviewed for this project use or know about the DM-ID. The DM-ID is a useful tool in the mental disorder diagnosis of adults with an already diagnosed intellectual disability. It is a resource for clinicians working with this population to consider. Sometimes because of cognitive disabilities or other impairments, the verbal communication skills are lacking in individuals with an intellectual disability. Having a diagnostic manual specific to adults with an intellectual disability is helpful to mental health professionals in addition to using the DSM-5.

Implications for Social Work Practice

How does this project potentially impact the field of Social Work? It holds promise to help mental health psychotherapists to begin to better serve this client population. It is an important topic because adults with intellectual disabilities can be a forgotten client population that needs to be better served. It is a population that students and practitioners need to be made aware of in the field of Social Work. Similarly, little research appears to have been done in this area. This is evidenced by a number of potential interview respondents noting their perception that many practitioners either avoid or feel ill-prepared to work with these clients.

The client population of adults diagnosed with co-occurring intellectual disability and mental disorder risks being “forgotten.” Many outpatient psychotherapists working in the field either do not know about this client population or choose not to work with this population. This may be, in part, because of the complexity these individuals may present with. When an individual has both of these co-occurring disorders, many factors including the strengths and limitations of the individual, along with what specific diagnoses the client has, need to be taken into consideration when finding the most effective treatment for these clients. The cognitive ability, lack of communication skills, and insight into the co-occurring diagnoses can also make psychotherapy with these individuals challenging. This may prove to be a challenge that not all psychotherapists are willing to undertake because of the difficulty of diagnosing and treating this client population.

Working with the client population of those diagnosed with a co-occurring intellectual disability and mental disorder can be a challenging process. This is because this client population needs extra attention to understand exactly what is going on in every step of the therapy process. This is due to having cognitive challenges that make understanding concepts of the therapy

process potentially more difficult. However, clinicians interviewed showed ways of working with these challenges adeptly.

Strengths and Limitations

This project has several strengths. The first and perhaps most obvious strength is that it brings attention to an area of practice that remains not well understood. It begins, even as a pilot, to raise questions about what clinicians are or are not doing with clients that present with this complexity. It gives voice to and begins to advocate for what clients may need in the context of psychotherapy. Studies like this hold the potential to begin to offer an emerging and eventual “expert consensus” model. This study is strong in that it surveys the perspectives of practitioners with genuine expertise in this area of practice. Similarly every study has its associated limitations. This study may suffer from or reflect the lack of existing literature in this area. This study is a pilot, with a small, but national sample. Other limitations of this study include the small sample size and also the lack of more developed literature on this area. The sample size for this project was small because of this being a “hard to reach” group of outpatient psychotherapists who specialize in working with adult clients who have a diagnosed co-occurring intellectual disability and a mental disorder.

Suggestions for Future Research

There are several parts of this project that could be replicated in future studies. These parts include the methods section and how the interviews were arranged. The researcher had a clear sense of how the project was going to be set up and what the researcher was looking for in terms of who was needed as potential respondents for the project.

Another part of the project that was clear was the section that dealt with the questions that were used in the interviews and the transcriptions of the interviews. The use of an explicit

conceptual framework is also worth considering using in future studies. Saleebey's Strengths Perspective (1992) seemed to work well in this study. Respondents showed clear evidence of not only using strengths, but seemed to make the most of use of Saleebey's (1992) sensitizing concepts of: membership, dialogue and collaboration. From the responses that were received, other potential frameworks that could be used in the future include functional models such as the domains model suggested by the psychiatrist that was interviewed. One respondent referred to the fact that there is limited research on the topic of modifying psychotherapy used when working with an adult diagnosed with a co-occurring intellectual disability and mental disorder. He pointed out that even the existing literature on this topic that has been done has been limited due to potentially faulty methodologies. By this, he meant that the designs for existing studies had problems and seemed to suggest new approaches in research on this topic need to be completed. There seems to be a broad agreement that additional research is needed. Future researchers in this area might consider quantitative or mixed methods research, to survey a larger number of general practitioners and mental health providers about the modifications they make to psychotherapy and could ask more specifically about their theoretical orientations. These could be compared with the edited work by Fletcher, et al. (2011) that outlines a number of potential theoretical perspectives practitioners use that might be modified in ways to used successfully with this population.

Working as an outpatient psychotherapist with an adult diagnosed with a co-occurring intellectual disability and mental disorder can prove to be effective. Looking at the strengths of the clients and collaborating with guardians, family members, case managers, caregivers and other support staff is important in understanding and building rapport with adult clients diagnosed with a co-occurring intellectual disability. Once the client is understood and the

strengths and vulnerabilities are identified, the outpatient therapist can use their expertise and training to help identify the most effective psychotherapy possible to treat adults diagnosed with a co-occurring intellectual disability and mental disorder in order that these clients get the treatment they deserve.

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CONSENT FORM
UNIVERSITY OF ST. THOMAS
GRSW682 RESEARCH PROJECT
MODIFYING DIFFERENT PSYCHOTHERAPY WHEN WORKING WITH AN
ADULT DIAGNOSED WITH A CO-OCCURRING INTELLECTUAL
DISABILITY AND MENTAL DISORDER

I am conducting a study about modifying different types of psychotherapy used when working as an outpatient therapist with adults diagnosed with a co-occurring intellectual disability and a mental illness. I invite you to participate in this research. You were selected as a possible participant because you are an outpatient psychotherapist who specializes in working with adults who are diagnosed with a co-occurring intellectual disability and a mental illness. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Jesse Virgil Buchner, a graduate student at the School of Social Work, St. Catherine University/University of St. Thomas and supervised by Dr. David Roseborough, an associate professor at the same school of Social Work.

Background Information:

The purpose of this study is: to explain the question: What are the emerging best practices used when modifying psychotherapy used when working with adults diagnosed with a co-occurring intellectual disability and mental disorder?

Procedures:

If you agree to be in this study, I will ask you to do the following: Answer questions that I ask from a predetermined set of questions. The interview will be anywhere from 30-60 minutes in length and will be audio recorded. The interview will be transcribed and interpreted by myself. After that is done an oral presentation will be completed based on the interview with you and other study respondents for a single public presentation at the University of Saint Thomas for both current students and community practitioners.

Risks and Benefits of Being in the Study:

The study has no known risks.

The study has no direct benefits.

Confidentiality:

Records will be kept in a locked file at my home. They will take the form of audio tapes and written transcriptions. I will not publish any of this material. Research records will be kept in a locked file at my home. I will also keep the electronic copy of the transcript in a password protected file on my computer. I will delete the file off my computer on January 1, 2017. Direct quotes may be used in the single public presentation, but you will not be named, nor will your practice location. Your quotes will be de-identified enough that no one will know who you are. I will delete any highly or potentially identifying information from the transcript. Findings from the transcript will be presented to my research seminar and during the Social Work Presentation Day on May 19, 2014. The audiotape and transcript will be destroyed by January 1, 2017.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the interview at any time. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. If you decide to participate, you are free to withdraw at any time without penalty. Should you decide to withdraw, data collected about you will not be used. Please just let me know if you would like your materials not to be used. I would need to know by a week after your interview. I can be contacted by email at buch5470@stthomas.edu or by phone at xxx-xxx-xxxx

Contacts and Questions

My name is Jesse Virgil Buchner. You may ask any questions you have now. If you have questions later, you may contact me at xxx-xxx-xxxx. If you have further questions you can also contact my professor, David Roseborough, PhD, LICSW, ACT at xxx-xxx-xxxx You may also contact the University of St. Thomas Institutional Review Board at xxx-xxx-xxxx with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study and to be audiotaped.

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date

Appendix A

Interview Questions

Brief Demographic Questions:

What is your title, educational background and professional licenses?

What is your client specialty in the area of outpatient therapy?

Could you tell me how long you have worked in this field and how you came to work with adults with intellectual disabilities (IDs)? What type of psychotherapy do you focus on or specialize in?

Interview Questions:

This project focuses on modifying psychotherapy when working with adults diagnosed with a co-occurring intellectual disability and mental disorder. Could you reflect a bit on clients you have worked with who have had both an intellectual disability and a mental disorder?

What type of psychotherapy do you focus on or specialize in generally and then when you work with adults with an Intellectual Disability?

How do you get referrals for the clients that you see in your practice?

How do you go about diagnosing your clients with an intellectual disability and/or a mental disorder? How is this similar or different from other clients you might see without an intellectual disability?

How do you collaborate with family members, case managers or caregivers of your clients in order to get additional information that might be helpful in the treatment process when working with adults with an intellectual disability and a mental disorder?

How do you decide on modification needed for a certain psychotherapy that you will use to help treat your adult clients diagnosed with a co-occurring intellectual disability and mental disorder? That is, what do you similarly/differently when working with adults in this group? Are there any particular theories or approaches/techniques especially helpful here?

How do you look for the strengths of the client you are working with before deciding on what psychotherapy to treat the client when working with a client with an intellectual disability?

Are there professional guidelines or best practices in place already that you are aware of that are recommended to be used when deciding to modify a specific psychotherapy in order to help the client diagnosed with a co-occurring intellectual disability and a mental disorder? If not, are you aware of what other colleagues working with this group do that they have found especially helpful/important?

Any there any other recommendations you have as the emerging best practices that should be used when modifying a specific psychotherapy used when treating an adult with a diagnosed intellectual disability and mental disorder that you would like to share with me?