

5-2012

Adapting Dialectical Behavior Therapy for Clients with Developmental Disabilities and Borderline Personality Disorder

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Recommended Citation

Seavey, Maija, "Adapting Dialectical Behavior Therapy for Clients with Developmental Disabilities and Borderline Personality Disorder" (2012). *Master of Social Work Clinical Research Papers*. Paper 132.
http://sophia.stkate.edu/msw_papers/132

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Adapting Dialectical Behavior Therapy for Clients with Developmental Disabilities and
Borderline Personality Disorder

Submitted by Maija Seavey, LSW
May, 2012

MSW Clinical Research Paper

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with 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 their findings. This project is neither a Master's thesis nor a dissertation.

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Abstract

The purpose of this study was to explore the research question: how should clinicians adapt and provide therapeutic interventions within the framework of Dialectical Behavior Therapy (DBT) while engaging in clinical practice with individuals diagnosed with both Borderline Personality Disorder (BPD) and a Developmental Disability (DD)? Using a qualitative design, seven participants from a Minnesota Department of Human Services *Certified DBT Provider* agency were interviewed. A semi-structured interview of twelve formal questions was used based on the literature review to further explore 1) occurrences of clinicians having clients with the identified co-morbid diagnoses, 2) barriers to treatment of this population, 3) attitudes and/or beliefs by clinicians of individuals diagnosed with this co-morbidity and 4) clinicians perceived effectiveness with this population. Findings suggest an overall positive regard towards individuals diagnosed both with a Developmental Disability and Borderline Personality Disorder. Additionally, clinicians overall provided positive belief and supporting evidence that DBT is effective and can be provided to this population. This study's findings indicate a need for further exploration and research with this population to better serve the needs of individuals with intellectual impairments and Developmental Disabilities in the mental health system.

Acknowledgements

I have many amazing individuals to thank that have played an essential role in my having gotten this far. First I want to thank my mom, “Mootie”, for not only believing in me but also for all those unspoken sacrifices you and dad have made to make this a reality. I want to thank my dad because without you I would not have the sense of humor to get through the harder times. To Marty, my husband: words cannot describe how supportive you have been. Whether it was making dinner, running to the store in the middle of the night for last minute school supplies, coping with my crazy hours or listening to my nonsense you stood by me and I am forever grateful.

I want to thank all my friends; especially Dee, Faith, Melanie and Amanda. I don’t think I would have survived this without your sisterhood. Angie, without you I don’t think I would have made it this far. Thank you for your empathy, time and being there for me during the more stressful of times.

Thank you, Valandra, my chair. I am very grateful to have had you because of your critical eye, open mind and love of mutual learning. To my committee members, Amy and Brooke; without your knowledge and experience this paper would not have made it to full fruition. Thank you for your critical feedback and all that you have done. Amy, you went above and beyond your role as a committee member and as a supervisor. Thank you for your never-ending support and for all of your understanding.

Finally, I want to thank the clients that have let me into their homes and into their lives. You are the inspiration behind this paper and continue to inspire me and the work that I do.

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Introduction

This research project is intended to answer the question: how should clinicians adapt and provide therapeutic interventions within the framework of Dialectical Behavior Therapy (DBT) while engaging in clinical practice with individuals diagnosed with both Borderline Personality Disorder (BPD) and a Developmental Disability (DD)?

The co-morbidity of a developmental disorder and psychopathology are emerging concepts in clinical practice (Flynn, Matthew & Hollins, 2002). Newer research strongly suggests a need for a paradigm shift among clinicians to increase knowledge and assessment capacity when working with the co-morbid population of individuals diagnosed with both DD and BPD (Barnhill, 2008).

The prevalence of individuals with a developmental disability is approximately 2 percent of the population, or 4,132,878 individuals based on the National Health Interview Survey's Disability Supplement (NHIS-D) that studies the non-institutionalized population of the United States (Larson, Lakin, Anderson, Kwak, Lee & Anderson, 2000). The Developmental Disabilities Assistance and Bill of Rights Act defines DD as a "severe, chronic disability" that includes "mental" and/or "physical" impairments that are "likely to continue indefinitely" (Larson, S., Lakin, Anderson, Kwak, Lee & Anderson, 2000, p.1)

BPD is characterized as a serious mental illness, affecting approximately two to four percent of the general population (NIMH, 2011; Gunderson, 2011; Jones, 2009). BPD is defined by the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR) (2000) as an individual having a pervasive pattern of instability in interpersonal

relationships, self-image, and affects, and marked impulsivity that begins by early adulthood and is present in a variety of contexts.

Initially, the term “borderline” was used to describe symptoms being atypical, or “bordering” between other mental health disorders because many individuals with severe BPD have experienced intermittent psychotic episodes along with the observation that several individuals with the diagnosis often would test borders, or limits being placed (NIMH, 2011; Linehan, 1993a; Gunderson, 2011). Individuals with this disorder have a high likelihood of engaging in self-injurious and suicidal behaviors and have completed suicides (Linehan, 1993a). Recent research has indicated that BPD can be treated and that individuals with this illness can improve with effective treatment (NIMH).

Research suggests there are similar developmental pathways of people diagnosed with BPD and DD (Judd, 2005; LeGris & van Reekum, 2008). Individuals diagnosed with DD and mental illness have overlapping symptoms; the predispositions of each also maintain significant similarities such as frontal lobe damage along with psychological vulnerabilities including low self-esteem, social impairments/stigma and poor interpersonal skills and relationship development (Vander-Schie-Bezyak; 2003). The co-morbidity of an intellectual disorder and psychopathology are emerging concepts in clinical practice (Flynn, Matthew & Hollins, 2002). Newer research strongly suggests a need for a paradigm shift among clinicians to increase knowledge and assessment capacity when working with the co-occurring population of individuals diagnosed with both DD and BPD (Barnhill, 2008).

In one study it was determined that thirty-nine percent of patients admitted for challenging behaviors who were admitted with a diagnosis of a mild to moderate learning disability also met criteria for a Personality Disorder (Judd, 2005). Similarly, other research founded similar dysfunctional behavior development between individuals with BPD and DD due to the hypothesis that both populations in the formative years had “invalidating, traumatic, or abusive” environments (Wink, Erickson, Chambers & McDougle, 2010, p. 278).

In DBT cognition is not a primary factor in the growth process. “DBT presumes that the intensity of affect is caused by dialectical conflict between self and environment defined as inadequate compromises between competing needs and wants, attachment, trauma and loss experience of the patient or genetic kindling effects” (Marra, 2005, p. 6). When working with individuals diagnosed with DD the utilization of DBT is plausible, and was tested in 2006 and proved similar outcomes to individuals with a primary diagnoses of BPD without any other developmental impairments (Lew, Matta, Tripp-Tebo, & Watts; 2006). The study of Lew and colleagues (2006) also proved that DBT can be adapted while maintaining adherence to the practice created by Dr. Linehan, the founder of the model, when working with this population.

Separately, individuals with a diagnosis of either DD or BPD can be difficult for clinicians to meet his/her needs. Further research and addressing of this topic is important to the social work profession due to the ethical obligation as a profession to help all individuals in need and address social problems (National Association of Social Workers, 1999). It is imperative that clinical social workers provide ethical, effective and appropriate treatment to address the needs of this specialized population to reduce treatment recidivism as well as aid in improving the quality of the individual’s life. It is also imperative to increase research and knowledge to aid in improving the retention of clinicians who serve this population.

Literature Review

Definitions

Borderline Personality Disorder

BPD is characterized as a serious mental illness, affecting approximately two to four percent of the general population (NIMH, 2011; Gunderson, 2011; Jones, 2010). It is also important to note that individuals with BPD have a high likelihood of having a co-morbid diagnosis, such as depression, anxiety disorders, substance abuse and eating disorders (NIMH). Individuals with this disorder have a high likelihood of engaging in self-injurious and suicidal behaviors and have completed suicides. Approximately ten percent diagnosed have committed suicide and seventy five percent diagnosed engage in intentional self-injurious behavior (NIMH, 2011; Gunderson, 2011). Recent research has indicated that BPD can be treated and that individuals with this illness can improve with effective treatment (NIMH, 2011).

BPD is defined by the DSM-IV-TR (2000), as an individual having a pervasive pattern of instability in interpersonal relationships, self-image, and affects, and marked impulsivity that begins by early adulthood and is present in a variety of contexts. Initially, the term “borderline” was used to describe symptoms being atypical, or “bordering” between other mental health disorders because many individuals with severe BPD have experienced intermittent psychotic episodes along with the observation that several individuals with the diagnosis often would test borders, or limits being placed (NIMH, 2011; Linehan, 1993; Gunderson, 2011).

The etiology of BPD is similar to other major mental illnesses, which is caused by a combination of biopsychosocial factors (Gunderson, 2011). Research on the risk factors for BPD are still in early development stages; however, at this point in time it is presumed that

environmental and genetic factors play a significant role (NIMH, 2011). The onset of BPD usually begins in early adulthood, though studies also indicate that some symptoms begin to manifest as early as childhood (Gunderson, 2011).

Research suggests there are similar developmental pathways of people with BPD and DD (Judd, 2005; LeGris & van Reekum, 2008). The term ‘borderline’ originated from an original assumption that the diagnosis shares features of both psychosis and neurosis (Judd, 2005; p 1177). BPD has also been described as an axial diagnosis that is bordering on three other psychiatric disorders including schizophrenia, mood disorders and impulse control disorders (LeGris & van Reekem, 2008). Diagnostic features of the disorder include paranoid ideation and disassociation which was added to the criteria after several studies concluded significant cognitive impairments in adults with BPD (Judd, 2005).

Developmental Disability

The prevalence of individuals with a developmental disability is approximately two percent of the population, or 4,132,878 individuals based on the National Health Interview Survey’s Disability Supplement (NHIS-D) that studies the non-institutionalized population of the United States (Larson, Lakin, Anderson, Kwak, Lee & Anderson, 2000). The Developmental Disabilities Assistance and Bill of Rights Act defines DD as a “severe, chronic disability” that includes “mental” and/or “physical” impairments that are “likely to continue indefinitely” (Larson, et. al., 2000, p.1). Furthermore, the Encyclopedia of Counseling defines DD as an “umbrella term” that refers to a grouping of chronic physical or cognitive impairments that can be identified best by the absence or delay of one person reaching various developmental milestones of a normal developing person (Leong, 2008, p.294).

Mental Retardation (MR), Developmental Disability (DD), and Intellectual Disability (ID) are the primary terms and categorization utilized for the population included throughout the literature reviewed. Each identification maintains a very similar definition and is used interchangeably throughout the research to identify individuals with a cognitive disability. Each term identifies and maintains separate diagnostic criteria and characteristics, however the utilization of all listed have been identified throughout the research to describe one or all of these sub-populations. This includes the generalized requirements to include there being functional impairments in cognition, self-care capacity, social and behavioral adaptability, and language deficits (AAID, 2011; AAMR, 2003; Hope Enterprises, Inc, n.d.).

Co-Morbidity of Individuals with BPD and DD

In medicine, co-morbidity is defined as the presence, or existence of one or more diseases, or conditions that co-exist, and may or may not have direct causal factors for one another. In this study the term co-morbidity is used to identify individuals with a diagnosis of BPD and a DD.

The research of Judd, while noting significant amounts of sources, found that there are connections between BPD and a wide range of developmental and learning disabilities including Attention Deficit Hyperactivity Disorder (ADHD) with both child and adult populations (2005; p. 1182). She further noted in her publication that one study reviewed concluded that nearly eighty-eight percent of a sampled group with BPD had either acquired or had a DD.

Furthermore, another inpatient hospitalization study cited by Judd (2005) concluded that there is a significantly plausible connection between DD and this sample also meeting criteria for a personality disorder. In this study it was determined that 39 percent of patients admitted for

challenging behaviors who were admitted with a diagnosis of a mild to moderate learning disability also met criteria for a Personality Disorder (PD). “There was also a significant association between PD and early child maltreatment potentially supporting the link between cognitive problems and psychosocial factors in the development of PD in general (Judd, 2005, p. 1182).” Other studies noted in Judd’s research (2005) from a 1997 study by Kan, Cowan & Roy, founded further evidence supporting a connection or similar pathways of PD and learning disabilities with reporting findings of a study that concluded thirty one percent of community service users met criteria for both PD and a learning disability.

Invalidating environment

Similarly, other research has founded similar dysfunctional behavior development between individuals with BPD and DD due to the hypothesis that both populations in the formative years had “invalidating, traumatic, or abusive” environments (Wink, Erickson, Chambers & McDougle, 2010, p. 278). The term invalidating environment was coined by Dr. Marsha Linehan when describing individuals with BPD, however it is suggested that this is also true for individuals with a DD (Lew, Matta, Tripp-Tebo & Watts, 2006). Lew, Matta, Tripp-Tebo & Watts (2006) also note that individuals with DD “have the increased likelihood of being invalidated due to histories of abuse and institutionalization” eluding to significant similarities of having an invalidating environment, providing evidence that the utilization of treatment modalities for BPD can be helpful for individuals with DD (p. 2).

Research suggests that parents with children of disabled children struggle to validate the child’s experiences and eludes to an increased likelihood of providing an invalidating environment due to conscious and/or unconscious disregard to the child’s needs. Wink and

colleagues (2010) suggested this invalidating environment has a significant impact in a child's development and inflexibility of managing emotions.

Individuals with DD and mental illness have overlapping symptoms; the predispositions of each also maintain significant similarities such as frontal lobe damage along with psychological vulnerabilities including low self-esteem, social impairments/stigma and poor interpersonal skills and relationship development (Vander-Schie-Bezyak; 2003). Additionally, individuals with a DD typically experience significant stigma related to his/her disability such as rejection from peers, and an overall lack of control over ability which Vander-Schie-Bezyak (2003) suggests significantly contributes to an increased likelihood of developing a mental illness.

The co-morbidity of a developmental disorder and psychopathology are emerging concepts in clinical practice (Flynn, Matthew & Hollins, 2002). Newer research strongly suggests a need for a paradigm shift among clinicians to increase knowledge and assessment capacity when working with the co-occurring population of individuals diagnosed with both DD and BPD (Barnhill, 2008). Barnhill (2008) further identified a need to eliminate the clinical mindset of the individual being diagnosed either with a mental health diagnosis or a cognitive disability, as opposed to the need to consider both. Hurley and colleagues (1998) reported the results of one researcher who surveyed graduate clinical psychology and counseling psychology students. The findings concluded seventy five percent of clinical and sixty seven percent of counseling programs did not include DD in the curriculum (Hurley, Tomasulo & Pfadt, 1998). Hurley and colleagues (1998) reported "few mental health clinicians feel adequately prepared to treat individuals with DD and to treat them using psychotherapy" (p.366). This is significant for

the implications for clinical social work practice, due to the ethical duty of delivering competent clinical interventions to all populations and to address the specialized needs of each.

Dialectical Behavior Therapy

Dialectical Behavior Therapy (DBT) is the primary treatment and therapeutic intervention chosen for individuals diagnosed with Borderline Personality Disorder. DBT in the simplest of terms is a modification of Cognitive Behavior Therapy (CBT) that has evolved and expanded to meet the therapeutic needs of individuals diagnosed with BPD. DBT goes a step further from traditional CBT by emphasizing the importance of acceptance of the situation along with behavior modification. It also incorporates Zen practice, eastern psychological and spiritual practices along with traditional western treatment strategies (Linehan, 1993b).

There are four primary targeted stages and goals of treatment. Stage I begins by emphasizing the need for the individuals to move from not having any control of his/her behavior to being in control. The focus of stage II is to move from avoiding or blocking emotion to being able to experience emotions fully. Stage III and IV include target goals that incorporate building mastery of skills to allow the individual to build an ordinary life and find fulfillment within it (Behavioral Tech, LLC, 2011).

DBT further differentiates itself as it also is based upon the biosocial model which is a theory that presents emotions as being triggered by genetic inheritances, physiological feedback systems, cognitive schemas, environmental triggers, previous learning history, brain neurochemistry and feedback between each of these factors that is intended to increase or decrease emotions being experienced (Linehan, 1993a; Marra, 2005). DBT shares and derives from many traditional therapeutic theories and/or frameworks (Marra, 2005). DBT also differs

itself from other therapeutic interventions by maintaining the theory of attaining affect regulation will foster the ability to change behaviors, whereas traditionally CBT maintains the stance that changing or managing thoughts fosters behavioral change. In DBT cognition is not a primary factor in the growth process. “DBT presumes that the intensity of affect is caused by dialectical conflict between self and environment defined as inadequate compromises between competing needs and wants, attachment, trauma and loss experience of the patient or genetic kindling effects” (Marra, 2005, p. 6).

There are four areas of emphasis in DBT which include (1) acceptance and validation of behavior as it is in the moment, (2) treating therapy-interfering behaviors of both the client and the therapist, (3) the emphasis on the therapeutic alliance and its essential role to treatment and (4) the dialectical process of acceptance and validation (Linehan, 1993b).

In DBT the therapist engaged the client through both psychoeducation and psychotherapy; foundational principles borrowed by DBT typically only maintain one of these primary interventions. Psychoeducation differs in that the therapist’s primary goal is to teach, explain and review specific concepts and skills sets. In DBT the primary skill sets include meaning making, mindfulness, interpersonal effectiveness, emotion regulation, distress tolerance and strategic behavior management (Linehan; 1993a). In the psychotherapy process it is the therapist’s role to provide validation of the client’s experience, while also following a procedural hierarchy that is intended to reduce target behaviors, increase behavioral skills, reduce post-traumatic stress and increase self-respect and establishing and achieving individual goals (Linehan, 1993b).

It is also important to note the eight basic assumptions of DBT that differs from other treatments (Linehan, 1993a). Linehan (1993b) identifies these basic assumptions to be (1) clients are doing their best, (2) clients want to get better, (3) clients “need to do better, try harder and be more motivated to change”, (4) even though clients may not have created all of their problems they need to resolve them, (5) the individual with BPD is miserable living his/her life as it currently is, (6) clients need to learn new behaviors applicable to any environment, (7) client cannot “fail” in therapy, and (8) the therapists providing treatment also need support during the intervention process (p.106).

Empirical support for DBT

There is significant empirical evidence supporting the effectiveness of DBT when working with individuals with BPD, however it has also been utilized more recently for treating other mental disorders and is also an effective modality for working with people with intellectual disorders (Hurley, Tomasulo, & Pfadt, 1998; Lew, et al., 2006). DBT has been implemented and empirically studied since 1991; this treatment has been tested in multiple settings including inpatient, outpatient, and other various community settings (NREPP, 2006). Outcomes measured noted to date include efficacy of reduction of suicide attempts, non-suicidal self-injurious behavior, psychosocial adjustment, treatment retention, drug use and symptoms of eating disorders (NREPP, 2006). Treatment retention outcomes concluded a higher retention rate for DBT participants, ranging between sixty three and one hundred percent, in comparison to those receiving treatment as usual, or an alternate treatment which resulted in a rate of twenty three to seventy three percent retention (NREPP, 2006). Evidence also supports DBT due to participants engaging in fewer suicidal and non-suicidal self injurious behaviors. NREPP (2011) reported from its analysis of independent and Randomized Control Trials (RCTs) individuals who

completed one year of DBT treatment reported nearly half as many suicidal attempts and experienced fewer non-suicidal self injurious behaviors in comparisons to other receiving alternate treatment, or treatment as usual. DBT treatment has also proven effective in improving psychosocial adjustment; within seven RCTs it was noted there was a sustained effectiveness 16 to 18 months post treatment as well as reports of reduced anger twenty four months post DBT participation (NREPP, 2006). Furthermore, the analysis of these RCTs proved a reported improvement in some form of psychological, social or global adjustment in comparison to individuals who received alternate treatment or treatment as usual (NREPP, 2006). This may also suggest DBT can also assist in a reduction in treatment recidivism.

Utilization of DBT

There is limited research that has a primary focus on both individuals diagnosed with BPD and DD. However, there is significant evidence supporting further research as indicated by currently existing publications. When working with individuals diagnosed with DD the utilization of DBT is plausible, and was tested in 2006 and proved similar outcomes to individuals with a primary diagnosis of BPD without any other developmental impairment (Lew, et al., 2006). This study also proved that DBT can be adapted while maintaining adherence to the traditions created by Dr. Linehan, the founder of the model, when working with this population. Common adaptations suggested throughout literature that does not impact the traditional DBT model includes limiting sessions to two thirty minute sessions each week as opposed to the traditional sixty to ninety minute sessions due to the natural cognitive limitations and attention capacity of individuals with DD (Lew, et. al, 2006: Hurley, et. al, 1998).

In addition, monitoring and adapting language to more simplistic terms along with finding ways to engage in activities beyond traditional psychotherapeutic conversation is also

proven to be effective when working with this population (Hurley, et. al., 1998). Furthermore, skills training groups are a primary identified support when working with individuals with DD. Traditionally support is limited for this population. Psychotherapy is helpful in providing a direct support and caring support to this population, especially when there is a co-occurring mental illness (Hurley, et.al, 1998). Although not mentioned in research, this may be aided by teaching of any individual staffing providers how to encourage and engage these individuals in the practice of DBT.

Researchers are currently in the process of adapting DBT curriculum for children with DD (Charlton, M., 2006). Charlton and Dykstra wrote an unpublished manuscript in 2003 titled *Dialectical Behavior Therapy Skills Training; Adapted for Special Populations* which included changes, or adaptations that are suggested to assist with the efficacy of DBT with persons who have a DD diagnosis, targeting primarily children as a piloted study. Although these adaptations are initially suggested primarily for children, they reinforce what other studies have found and are encompassing enough for all ages. (Lew, et al., 2006; Hurley, et. al, 1998)

Suggestions for adaptations include changing language that individuals with DD would be able to understand. This includes simplifying terms and breaking down the concepts so that this specialized population would better understand and be able to apply the material (Charlton, 2006). Also, for this pilot study handouts were also rewritten and reformatted in order to improve understanding and attention to the primary concepts of DBT skills. Repetition is the final point emphasized within the methods being implemented in this pilot study. This includes allowing additional time to practice skills within the group setting, as opposed to traditional DBT skills groups that primarily have the participants practice outside of group. Charlton and Dykstra hypothesize that this will provide a supportive environment to practice skills immediately

following their learning (Charlton, 2006). Charlton further emphasized the need information needs to be broken down and provided in a variety of forms such as more interactive versions that include audio or visual methods in order to adapt therapeutic interventions for individuals with DD (Charlton, 2006). It is also suggested that activities be interactive and structure be maintained (Charlton, 2006). The results of this pilot study are not yet published.

Conceptual Framework

The purpose of this section is to describe the conceptual framework that has guided the literature review and the research. The primary lenses in which the research questions and data collected are rooted from the framework of DBT and practice experience of the researcher.

Dialectical Behavior Therapy

Dialectical Behavior Therapy (DBT) is the primary treatment and therapeutic intervention chosen for individuals diagnosed with Borderline Personality Disorder. DBT in the simplest of terms is a modification of Cognitive Behavior Therapy (CBT) that has evolved and expanded to meet the therapeutic needs of individuals diagnosed with BPD (Linehan, 1993b). DBT goes a step further from traditional CBT by emphasizing the importance of acceptance of the situation along with behavior modification (Linehan, 1993b). It also incorporates Zen practice, eastern psychological and spiritual practices along with traditional western treatment strategies (Linehan, 1993b).

Practice Experience

The researcher has worked primarily for community based mental health centers throughout her practice experience. The beliefs and assumptions made by the researcher are

based in part from practice experience providing community and residential based rehabilitative services to individuals diagnosed with a severe and persistent mental illness and/or chemical dependency. The researcher has adopted beliefs from practice experience to include clients having a right to receive evidence-based treatment and services while also factoring cultural needs and differences. Additionally, the researcher maintains a value that clients should be treated and respected as an individual.

The researcher has predominantly maintained caseloads working with individuals diagnosed with a personality disorder, a chemical health diagnosis with approximately seventy-five percent also having a history of developmental disabilities and/or impairments. The researcher is currently employed with an agency that supports and promotes DBT as a primary treatment modality for the population being researched. The researcher also maintains a view on mental illness from practice experience and has adopted the mission and values of her current employer. This mission states that “serious and persistent mental illness is a brain disease. It is neither a choice nor a character weakness. Each consumer is an individual with specific strengths, vulnerabilities, and clients can become their own best expert on their illness”: (Jones, 2010; south-metro.org).

The researcher also abides by the National Association of Social Workers (NASW) code of ethics which maintains the core values to include dignity and worth of the person, service, social justice, integrity, competence and the importance of human relationships (NASW, 2008). The NASW also states in the preamble the primary mission of the social work profession is “to enhance human wellbeing and help meet the basic human needs of all people, with particular attention the needs and empowerment of people who are vulnerable, oppressed, and living in poverty” (NASW, 2008).

Method

This section includes the rationale for the methodology utilized for this study including proposed design, sampling, recruiting of participants, the Internal Review Board (IRB) process and the interview process.

Research Design

This study is a qualitative and exploratory research design with the intention of gathering further data and insight on how clinicians adapt and intervene in a DBT model when working with individuals diagnosed with BPD and DD. Through the literature review the researcher noted the majority of data obtained was through a qualitative form. This presented to be appropriate for this design as it provided more descriptive, in-depth information in reference to the research question.

A semi-structured interview was conducted with participants that required approximately one hour of their time. The researcher asked twelve questions designed based on themes identified in the literature review (Appendix D). The interview had face and content validity.

Subjects

Preliminary guidelines for choosing subjects was determined by the utilization of the Minnesota Department of Human Services (DHS) guidelines for clinicians identified as a “DBT Certified Provider” (Appendix E).

A purposeful sampling method was the primary modality of obtaining participants for this study. The initial stages of recruitment included obtaining a list of *DBT Certified Providers* from the Minnesota DHS website (2011). The researcher then made initial contact with each

agency by utilizing a phone script introducing the purpose of the research and requested contact with the primary coordinator of the agency's DBT programming (Appendix B). The researcher then made contact with the referred person utilizing a second standard phone script further detailing the purpose of the study, participant requirements and summary of procedure of the research study process (Appendix C). The researcher initially established a goal of completing ten to twelve interviews total throughout the process, with the intention of maintaining a minimum that seventy five percent of the sampled population be clinical social workers. Upon completion of the recruitment process seven clinicians elected to participate and two were licensed clinical social workers.

Protection of Human Subjects

The researcher completed the St. Catherine's University IRB requirements, including the consent form (Appendix A). The researcher provided each participant a copy of the consent form in addition to discussing and reviewing prior to conducting each interview. Each participant will be required to sign providing consent to the research process. Each participant was given the right to withdrawal consent and participation from the interview/research study at any time. Any data collected by a participant that withdraws were destroyed and not utilized.

Confidentiality was maintained and discussed throughout the research process. All voice recordings, transcripts, and field notes were only be accessible by the researcher. All research data will be kept in a locked file cabinet in the researcher's home. The researcher will destroy all audio recordings by May 20, 2012.

Data Collection

In order to provide ability to replicate the data obtained, the researcher compiled a set of fourteen interview questions based on information and/or gaps found within the literature review conducted. These questions are provided as Appendix D. Throughout the interview process, data collection was completed by obtaining consent, and recorded each interview along with the researcher having maintained individual field notes for each interview conducted. The recorded data was then transcribed utilizing transcription software. The researcher will utilize standard content analysis and code based on prominent themes chosen prior to beginning this process.

The researcher contacted all referred individuals by telephone utilizing the telephone script that informed them the purpose of the study (Appendix C). The researcher additionally utilized e-mail in the recruiting process when prompted by agencies during the initial recruitment phase. The researcher requested participants meet at a reserved conference room at the library of St. Catherine's University. In order to preserve confidentiality the researcher provided directions to each participant and provided a designated meeting location to prevent the participant from needing to identify him/herself to any university students, faculty, or staff at throughout the process. When participants provided consent and invitation to meet at his/her office location the researcher discussed the potential level of disclosure during the time of recruitment. Participants were provided with a consent form (Appendix A) which will be signed by each participant and the researcher prior to beginning the interview process. Each participant was offered the right to end the interview at any time and all data collected was destroyed and omitted within this research.

Data Analysis

Content analysis was the method used for data analysis of this research study. The researcher recorded and then transcribed each interview and will utilize a content analysis format to analyze data (Berg, 2001). Field notes were utilized throughout the interview process noting observations and themes identified during each interview.

The researcher coded transcriptions based on themes identified prior to initializing the interview process. The identified themes are (1) occurrences of having clients with the identified co-morbid diagnosis, (2) barriers in treatment of this population, (3) attitudes and/or beliefs by clinicians of individuals diagnosed with this co-morbid condition, and (4) clinicians' perceived effectiveness with this population. This was used as a start list when performing the coding process. Other themes were considered and noted throughout the content analysis as they emerged.

All data required coding each individual transcript. A color code for each theme was assigned prior to beginning the analytic process. Each theme was designated a specified color and when new themes emerge an additional color was assigned. The intention of content analysis was to reduce researcher bias as well as better break down data obtained into the themes chosen based on the literature review.

Findings

The researcher conducted a total of seven individual interviews in order to examine the research question: how should clinicians adapt and provide therapeutic interventions within the

framework of DBT while engaging in clinical practice with individuals diagnosed with both BPD and DD? Of the seventeen DBT Certified Providers contacted the researcher received responses from ten agencies. Five agencies elected to participate in the study.

Twelve questions were asked of each participant in a semi-structured interview in order to obtain the information being analyzed. Each participant met criteria outlined in the study design and provided full acknowledgement and consent to participate. All interviews were coded analyzed and coded based on the codes that were derived from the themes identified within the literature review. The themes coded in each interview were 1) occurrences of having clients with the identified co-morbid diagnoses, 2) barriers in treatment of the population, 3) attitudes and/or beliefs by clinicians of individuals diagnosed with this co-morbid condition, 4) clinician's perceived effectiveness with this population, and 5) barriers to maintaining adherence with this population. This section identifies the findings of each code used to analyze the data obtained.

Occurrences of having clients with the identified co-morbid diagnosis

The researcher coded for occurrences and frequency of having clients with a co-morbid diagnosis of BPD and DD when a reference was made to the number of years working with this population and number of clients the participant identified meeting this criteria. Participants that were interviewed presented with a range of experience from six months to fourteen years. Of the seven participants two identified themselves as DBT skills trainers, one day treatment therapist and four identified themselves as DBT individual therapists with three also participating in the delivery of skills group. Two participants also identified themselves as having experiencing working with the co-morbid population in an Adult Foster Care setting where DBT was a supported therapeutic intervention utilized.

Three participants reported that they serve the co-morbid population. Two participants stated that they work more with clients with a diagnosis of BPD and other psychiatric diagnoses. Participants' responses varied from some having the co-morbid population being the dominant population they serve. Others identified having fewer clients with both diagnoses of DD and BPD in comparison to working with clients that have a diagnosis of BPD with other psychiatric diagnoses identified such as Major Depression, Attention Deficit Hyperactivity Disorder and so forth. One participant reported that "the majority of the clients that I work with are developmentally disabled...I would say probably about 50-70% of them." Another practitioner reported having "a handful" of clients meeting criteria for DD and BPD and another reporting "having much more experience working with clients with BPD and average or above average intellectual functioning". Another participant reported that she began working with this population in 1979 and stated "the first group of people I worked with for a year and a half were extremely low functioning and physically handicapped, then I worked for people who were mentally ill and mentally retarded". This participant additionally reported having started working with this co-morbid population prior to the existence of DBT. Other participants identified working with participants that are "lower functioning with BPD and they may not be termed Developmentally Disabled, but have a harder time learning". An additional participant included Borderline Intellectual Functioning within their agency's criteria. When asked how criteria for DD is determined the majority of participants reported that this was determined predominantly from the client's history. One participant reported:

We don't work with people in this program who have a traumatic brain injury of history of learning disorder. That's not sufficient to be within the program and so generally we are consulting with other providers in their treating team, case

management, social workers, housing staff to say ‘what is the level of cognitive impairment? Is this something that would benefit them?’.

Barriers in treatment of the population

Barriers in treating this population were coded and identified when reference was made by participants of explicit and implicit challenges. Common themes within this code included statements made by participants in reference to insight, apparent competency, environmental factors, clients’ ability to identify emotions and identifying ways to deliver the information in a concrete, retainable manner. A participant reported “it can be difficult to treat Borderline Personality Disorder when it is co-morbid with DD because there is not always the level of insight into behavior patterns, into kind of the dialectics that are being addressed by DBT”. Another participant reported “some of the differences in how you can present information, the ability to take in abstract information and then also to generalize what is being taught” as an identified challenge. One practitioner elaborated on this and reported additional observations of barriers related to clients’ apparent competency issues.

One of the biggest challenges I found is apparent competency. That is, often times these clients appear with a high level of apparent competency come in and say ‘yep I get it’ and it’s difficult to assess their actual levels of understanding the skills that I am teaching and that’s again, where applying skills in the group is way to test out if they’re getting the information. That is one of the big challenges. That and making DBT concrete enough for them to be able to use the

skills and understand. Finding a way to introduce the whole theory behind DBT, why we're using the skill but in a concrete way.

One participant reported "one of the most difficult things as far as skills training is the language used and keeping that adherent to what the skills are and what they're trying to teach while at the same time coming up with ways that it makes sense to them." This participant also reported struggles with structure of sessions stating "an hour session is way too long because of focus and attention is limited".

The two participants that identified themselves as DBT skills group trainers reported similar struggles. One stated "with the lower functioning needs, we have to find different ways of getting the information to them... The lower functioning group might take 3 different times going through the module before they even understand what mindfulness is."

A seasoned with fourteen years of experience additionally identified the primary challenges to include apparent competency and the clients' ability to identify his/her emotions. She reported "in some ways [DBT] is actually easier because its straight forward, but sometimes its making sure that people are understanding what it is that I am talking about...like really breaking down the emotions. It's really coming up with very concrete examples...and making sure they're getting the concept."

It was also identified through this research that clients with co-morbid diagnoses of DD and BPD can struggle more with identifying emotions. A participant describes this by reporting "I find that those clients can be more resistant to talking about emotions and to experiencing emotions because their emotions are so intense and so the exposure to emotions is a very process

and is often difficult because they've been through so many traumatic events." She later stated in the interview:

I feel like a lot of with the DD clients they struggle to find the emotions in between 0 and 5, like it's either a 0 or a 5. I think that's a symptom of black and white thinking of normal BPD, but getting them to understand why that's important to feeling these in between emotions can be really difficult.

The majority of participants also identified environmental factors playing a role in barriers to treatment, as well as playing a significant role in this population's needs in delivery of DBT. One participant reported "I think there has to be some environmental adaptations. With a lot of the clients that I get that have behavioral issues or emotional outbursts, their staff do not know how to handle it. So I think the staff, just like with adolescents, the parents need to be trained on how to do the skills, staff really need to be encouraged to learn the skills and how to help coach their clients too." Another participant described her experience of environmental factors to include having a group home staff member involved in a client's individual skills training sessions. Other environmental factors noted special to this population included a higher frequency of clients having conservators or guardians and how this impacted the delivery of DBT treatment. One participant noted "sometimes my clients' goals are different than what their guardian's, or what their conservator's are and then you have to do more navigating and I think that's where you sometimes have to do a bit more environmental intervention." Another participant reported similar observations stating:

...many of the clients are not their own guardian which can be complicated because the clients will ask for one type of treatment or ask for treatment goals that the guardians may

not be on board with and so when there are differences between what the client wants and what the treatment team wants that can be difficult.

A final environmental factor noted throughout this research was the adaptations being made to specific examples used when teaching skills. One participant reported “sometimes I look at those examples and create something that they would encounter in their everyday lives.” She described one example of a skill being “if you’re borrowing your friend’s car and you spill something in it you might feel guilty or ashamed and your emotions might be extreme. I don’t know if that’s necessary applicable, I know not a lot of them drive so we use an example like medical transportation and the frustrations with medical transportation.”

Attitudes and/or beliefs by clinicians and clinicians’ perceived effectiveness

The general attitude and perceived effectiveness in reference to working with this population was reported to be positive even though barriers were identified by each of the participants. Several statements about focusing on this population’s abilities and strengths were noted throughout coding of this theme. One participant stated “One of the big things that I really emphasize when working with this population is really recognizing their capabilities. That these are people who are very capable of learning and understanding what we are providing them and it’s about recognizing that they can do this and helping empower them to do it.” Another stated “I feel like within the structure of DBT there has to be the flexibility of working with clients that are so different...you have to be creative in how you do that, especially with developmentally delayed clients.” The same participant later stated “one thing that is really important to know about DBT and the DD diagnosis is that they can definitely learn DBT. It’s not just for the people of average intelligence.” Further enlightening statements from participants included one

stating “I was pleasantly surprised the first person I tried to teach mindfulness to got it ‘like that’ which I thought ‘there was no way she was going to get it’ and she had an IQ of about 80, or 85.”

One variable noted within this theme was whether the participant had primary experience working with this population. The participant with the most experience and training also started her clinical career working with the DD population. She reported “I think I have been lucky because I started out with a DD population and so I got familiar with how do you help people change behaviors and I think that’s helped a lot with delivering [DBT].”

Barriers to maintaining adherence with this population

Maintaining adherence to DBT when working with this co-morbid population presented with various finding throughout the exploratory research process. One participant reported difficulty maintaining adherence due to not having skills group established for their population and identified not doing coaching calls for this specific population. She also identified difficulty within their program of how to do diary cards and how to structure the skills group to meet the needs of this co-morbid population. Another participant stated “we’re not strictly adherent to DBT the way that Linehan presents it.” She described her program’s efforts to maintain adherence by stating “we still use things like behavior chains, but they’re slightly modified to address insight issues and address more acute behavioral issues that otherwise would be kind of looked at as the ‘small fires’ that aren’t necessarily addressed in DBT.”

Other clinicians that participated reported adherence is possible and maintained within their practice but reported adaptations were necessary. One participant stated “I think it is really repetitiveness of what’s adherent and explaining it in a language that they understand.” She also stated that consultation and “checking in with other therapists ‘is this within the model of DBT

or am I straying from it?” emphasizing the importance of consultation when making adaptations. A skills trainer that participated in this study reported that her primary way of maintaining adherence to the DBT model when working with this population was to practice the skills in addition to engaging in weekly DBT consultation groups.

The participant with the most noted experience reported “I don’t think there is necessarily a problem with staying adherent as far as delivering it the way it’s supposed to be” beyond noting clients with significant physical impairments, with the example given of a client who is deaf and blind and therefore could not engage in phone coaching or skills group because of these physical limitations. She later stated “my suggestions would be to learn the model to adherence first with standard practice, secondly know behavior therapy inside and out and then don’t ‘dumb it down’, just give more concrete examples of what to do and how to do it.”

When exploring adherence the identification of governmental agencies beginning to monitor DBT services of this specific population with *Certified DBT Providers* in the state of Minnesota was brought to light. When asking one participant in this study the questions related to making adaptations and challenges she stated the following:

You have to make sure you are using several different methods of teaching so that you can get to the visual, the audio the hands on. One of the criteria for the state of Minnesota to be in a DBT program the person has to be developmentally capable of understanding so you have to be clear that there is a way that you can provide that treatment. When we do authorization requests they actually ask that same question ‘is this person cognitively capable?’ and if they have a lower IQ, or difficulty with that you have to identify how it I you’re going to get them the information right on the authorization.

An additional finding to this research included over half the participants identifying *The Skills Manual Instructor's Guide: An Emotion-Regulation Skills Curriculum for All Learning Abilities* by Julie Brown, an individual from Behavioral Tech, the overseeing agency of DBT trainings. She recently published this skills training manual that four of the participants acknowledged utilizing for supplemental material when working with this population. Participants emphasized that this manual is not intended to replace any of the DBT skill sets, but to assist in adapting how DBT skills are presented and/or to provide additional practice.

Discussion

The researcher conducted a total of seven individual interviews in order to explore the research question: how should clinicians adapt and provide therapeutic interventions within the framework of DBT while engaging in clinical practice with individuals diagnosed with both BPD and DD? Though current literature specific to the research question is limited, the researcher's findings of this study are consistent with the existing literature. Each participant of this study had a general knowledge and experience base working with this population and had experience delivering DBT as a primary therapeutic modality. The general consensus of what was determined to fit the umbrella term of DD was matched between research participants and the literature. The overall belief and attitudes of participants was that DBT can be effectively adapted to meet the needs of individuals diagnosed with both DD and BPD.

The current literature reports a prevalence of individuals with a DD is approximately two percent of the population, or 4,132,878 individuals based on the National Health Interview Survey's Disability Supplement (NHIS-D) that studies the non-institutionalized population of the United States (Larson, Lakin, Anderson, Kwak, Lee & Anderson, 2000). Of the participants

interviewed in this study the prevalence of individuals with DD is concurrent with the current literature. Participants also described their clients with DD with similar characteristics as that of the Developmental Disabilities Assistance and Bill of Rights Act which defines DD as a “severe, chronic disability” to include “mental and/or physical impairments that are likely to continue indefinitely” (Larson, et. Al, 2000, p.1). Participants described their clients’ limitations to include physical and mental impairments such as reading ability, comprehension, Mild Mental Retardation and other cognitive impairments. One difference from the literature is that some participants reported within their program working with individuals with noted lower functioning that may not have a diagnosis of DD and/or other intellectual impairments. Three participants included Borderline Intellectual Functioning within their agencies’ criteria. When asked how criteria for DD is determined the majority of participants reported that this was determined predominantly from the client’s history.

According to the literature examined the primary identified barriers with DBT treatment are related to the generalized requirements of DD to include the functional impairments in cognition, self-care capacity, social and behavioral adaptability and language deficits (AAID, 2011; AAMR, 2003; Hope Enterprises, Inc., n.d.). Barriers and adaptations identified in the literature are congruent with those reported by research participants. Areas not mentioned in the research identified by participants included issues related to apparent competency. Adaptations made by participants including utilizing repetitiveness, going at a slower pace and modifying language used are also addressed within the literature. Common adaptations suggested throughout literature that does not impact the traditional DBT model includes limiting sessions to two thirty minute sessions each week as opposed to traditional sixty to ninety minute sessions along monitoring and adapting language to more simplistic terms along with finding ways to

engage in activities beyond traditional psychotherapeutic conversation, utilization of repetition (Hurley, et. al., 1998; Charlton, 2006).

One participant described her interventions to address these barriers by comparing a client with DD and BPD with other clients reporting “We have to break it up sometimes with playing different games, [her] focus and attention is so limited so it’s a different type of session than with my other clients.” She went on to state “She likes to draw on the white board too” and described how breaking up her sessions to include more interactive activities to learn and deliver the DBT concepts and skills.

The literature also made note to the significance of skills training groups being a primary identified support when working with individuals with DD. When exploring this further with research participants it was found to vary based upon the availability of resources to the participants’ agency as well as the level of functioning of the participants’ clients. One participant described the available skills group with her agency to include individuals of all levels of functioning stating “In this group one goes to St. Olaf, one is in a Master’s program in math and so we have a range of those types of clients all the way down to clients that are living in a group home.” This participant reported taking her client with Borderline Intellectual Functioning out of this group and began working with her on an individual basis to perform the skills teaching component. Other participants identified having a group catered specifically to individuals with lower cognitive functioning and reported effectiveness being comparable to their agency’s other DBT skills groups reporting “it is tailoring the coaching interventions to something that they can more easily understand. It might be using the pictures, they work really good with a visual....repetitive teaching where you are teaching it, then reviewing it again.”

There is limited research that has a primary focus on both individuals diagnosed with BPD and DD. However, existing publications note that when working with individuals diagnosed with DD the utilization of DBT is plausible and was tested in 2006 and proved similar outcomes to individuals with a primary diagnosis of BPD without any other developmental impairment (Lew, et. al, 2006). Participants in this study overall noted positive regard towards the utilization of DBT and found that maintaining adherence has its challenges, but is plausible when working with this population. One participant who has been practicing adherently for eight years stated “I don’t think it’s any more difficult than with anybody else in maintaining adherence. It’s just delivering the information that click for people, but it’s not an adherence issue.”

Implications for Social Work Practice, Policy and Research

The researcher made contact with several potential participants that declined to participate in this study because of their limited knowledge and experience of working with this population. Current literature suggests a need for a paradigm shift among clinicians to increase knowledge and assessment capacity when working with the co-occurring population of individuals diagnosed with both DD and BPD (Barnhill, 2008). “Few mental health clinicians feel adequately prepared to treat individuals with DD and to treat them using psychotherapy” (Hurley, Tomasulo, & Pfadt, 2008, p.366). When evaluating the outcomes of participants that responded the researcher’s findings are congruent to the literature of there being a need for more research and clinical education to better prepare clinicians to meet the needs of individuals with a developmental disability and mental health diagnoses.

There is limited published research on the effectiveness of DBT and individuals with a DD diagnosis as well as individuals with DD and mental health. A participant stated it best when she stated:

“I don’t think someone with a Developmental Disability is any less deserving than somebody that doesn’t and its incumbent on us as providers to figure out how to deliver the treatment that they can benefit from it as much as anybody else. They shouldn’t be punished because they have a more difficult time understanding things.”

Further research and addressing of this topic is important to the social work profession due to the ethical obligation as a profession to help all individuals in need and address social problems (National Association of Social Workers, 1999). It is imperative that clinical social workers provide ethical, effective and appropriate treatment to address the needs of this specialized population to reduce treatment recidivism as well as aid in improving the quality of the individual’s life. It is also imperative to educate clinicians that this modality of treatment can be effective and further research needs to be implemented to increase awareness and validity of what current clinicians are doing effectively and adherently with this population.

Strengths and Limitations

Strengths of this study include the researcher’s ability to interview only providers who are certified based upon MNDHS standards that maintain significant expectations of adherence to the DBT model which then in turn provided very knowledgeable and experienced interview participants. This study also provided the opportunity to build on the current research that currently exists on a subject that has not yet been significantly explored.

Primary limitations of this study included a small size of the sample. This disallows for any potential generalizing of data collected by the researcher. All participants were within a metro area so generalization and ability to speak for all of DBT Certified Providers throughout the state was not possible. Time was also a significant limitation as the researcher could possibly have obtained more rich information and collected further data from more possible participants if the time parameters were extended. Furthermore, the knowledge and experience of the researcher could be perceived as a hindrance as well as strength due to having had past practice experience and academic knowledge of DBT and its theoretical constructs. A smaller sample than initially anticipated also proved for some limitations; however, the researcher noted in findings that outcomes are very similar among all the seven participants interviewed.

References

- American Association on Intellectual and Developmental Disabilities. (2011). *Definition of intellectual disability*. Retrieved from http://www.aaidd.org/content_100.cfm?navID=21
- American Psychiatric Association. (2000). *Diagnostic Statistical Manual-IV-TR* (4th ed.).
- Barnhill, L.J. (2008). The diagnosis and treatment of individuals with mental illness and developmental disabilities: an overview. *Psychiatric Quarterly*, 79 (3), 157-170. doi: 10.1007/s11126-008-9076-0
- Behavioral Tech, LLC. (2008). *Dialectical behavior therapy frequently asked questions*. Retrieved from: http://behavioraltech.org/downloads/dbtFaq_Cons.pdf
- Berg, L.B. (7th ed.). (2009). *Qualitative research methods for the social sciences*. Boston, MA: Allyn & Bacon.
- Chapman, A.L; Turner, B.J.; Dixon-Gordon, K.L. (2010). To integrate or not to integrate dialectical behaviour therapy with other therapy approaches. *Clinical Social Work Journal*, 39 (2), 170-179. doi: 10.1007/s10615-010-0283-4
- Charlton, M. (2006). Dialectical behavior therapy for children with developmental disabilities. NADD Bulletin, IX, article 1. Retrieved from NADD website: <http://www.thenadd.org/cgi-bin/checkmember.pl?page=pages/membership/bulletins/v9n5a1>
- Di Nuovo, S.F. & Buono, S. (2007). Psychiatric syndromes comorbid with mental retardation: differences in cognitive and adaptive skills. *Journal of Psychiatric Research*, 41, 795-800. Retrieved from <http://www.sciencedirect.com/science/article/>

- Flynn, A., Matthew, H. & Hollins, S. (2002). Validity of the diagnosis of personality disorder in adults with learning disability and severe behavioural problems: preliminary study. *The British Journal of Psychiatry*, 180, 543-546.
doi: 10.1192/bjp.180.6.543
- Gunderson, J.G. (2011). A BPD brief: An introduction to borderline personality disorder. *The New England Journal of Medicine*, 364 (21)
- Hope Enterprises, Inc. (n.d.) Introduction to mental retardation. Retrieved from:
http://www.heionline.org/docs/training/introduction_to_mental_retardation.pdf
- Hurley, A. D., Tomasulo, D.J. & Pfadt, A.G. (1998). Individual and group psychotherapy approaches for persons with mental retardation and developmental disabilities. *Journal of Developmental and Physical Disabilities*, 10 (4), 365-386. Retrieved October 8, 2011 from doi: 10.1023/A:1021806605662
- Jones, A. (2010). *Clinicians' attitudes toward self-injury in individuals diagnosed with borderline personality disorder*. Research paper (M.S.W.) St. Catherine University ; University of St. Thomas (Saint Paul, Minn.), 2010.
- Judd, P.H. (2005). Neurocognitive impairment as a moderator in the development of borderline personality disorder. *Development and Psychopathology*, 17, 1173-1196. doi: 10.1017/S095405050558

- Larson, S., Lakin, C., Anderson, L, Kwak, N, Lee, J. & Anderson, D. (2000). Prevalence of mental retardation and/or developmental disabilities: Analysis of the 1994/1995 NHIS-D. MR/DD Data Brief, 2(1). Retrieved from The college of Education and Human Development, University of Minnesota website: <http://rtc.umn.edu/docs/dddb2-1.pdf>
- LeGris, J. & van Reekum, R. (2008). Nuerocognitive impairment in borderline personality disorder. *Psychiatric Times*, 25 (1), p. 66-96. Retrieved from http://go.galegroup.com.ezproxy.stthomas.edu/ps/i.do?&id=GALE%7CA180317161&v=2.1&u=clic_stthomas&it=r&p=EAIM&sw=w
- Lew, M., Matta, C., Tripp-Tebo, C., & Watts, D. (2006). Dialectical behavior therapy (dbt) for individuals with intellectual disabilities: A program description. *Mental Health Aspects of Developmental Disabilities*, 9 (1), p. 1-13. Retrieved from: <http://gra.midco.net/pdkolstoe/MHS/DownloadResources/MHADD06-DBT-IDDPgmDesc.pdf>
- Linehan, M.M. (1993a). *Cognitive-behavioral treatment of borderline personality disorder*. New York, New York: Guilford Press.
- Linehan, M.M. (1993b). *Skills training manual for treating borderline personality disorder*. New York, New York: Guilford Press.
- Merra,T. (2005). *Dialectical behavior therapy in private practice: A practical & comprehensive guide*.Oakland, CA: New Harbinger Publications, Inc.

Minnesota Department of Human Services (2011). Bulletin: *DHS issues guidance on dialectical behavior therapy intensive outpatient programs*. #11-53-01. Retrieved from:

http://www.dhs.state.mn.us/main/groups/publications/documents/pub/dhs16_162345.pdf

National Association of Social Workers. (2008). *Code of ethics of the national association of social workers*. Retrieved from: www.socialworkers.org/pubs/code/code.asp

National Institute of Mental Health. (2011). *Borderline personality disorder*. Retrieved from:

http://www.nimh.nih.gov/health/publications/borderline-personality-disorder/borderline_personality_disorder_508.pdf

National Registry of Evidence-based Programs and Practices (NREPP). (2006). *Dialectical Behavior Therapy*. Retrieved from:

<http://nrepp.samhsa.gov/ViewIntervention.aspx?id=36>

Prout, H. & Strohmer, D.C. (1998). Issues in mental health counseling with persons with mental retardation. *Journal of Mental Health Counseling*, 20 (2), 112. Retrieved from

EBSCOhost at

<http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=keh&AN=564229&site=ehost-live>

South Metro Human Services. (2011). *Mental illness*. Retrieved from: <http://www.south-metro.org/mi/>

- Tulloch, R. (2009). Dealing with personality disorders in individuals who have learning disabilities. *Learning Disability Practice*, 12 (10), 22-25. Retrieved *Expanded Academic ASAP at*
http://go.galegroup.com.ezproxy.stthomas.edu/ps/i.do?&id=GALE%7CA215324877&v=2.1&u=clic_stthomas&it=r&p=EAIM&sw=w
- Vander-Schie-Bezyak, J.L. (2003). Service problems and solutions for individuals with mental retardation and mental illness. (2001 NRA Graduate Literary Award Winner). *The Journal of Rehabilitation*, 69(1), 53+. Retrieved from
http://go.galegroup.com.ezproxy.stthomas.edu/ps/i.do?&id=GALE%7CA98253977&v=.1&u=clic_stthomas&it=r&p=EAIM&sw=w
- Wink, L. K., Erickson, C. A., Chambers, J. E., & McDougle, C. J. (2010). Co-Morbid Intellectual Disability and Borderline Personality Disorder: A Case Series. *Psychiatry: Interpersonal & Biological Processes*, 73(3), 277-287. Retrieved from
<http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=keh&AN=55150236&site=ehost-live>

Appendix A

Adapting Dialectical Behavior Therapy when working with Co-Morbidity of Developmental Disabilities and Borderline Personality Disorder

RESEARCH INFORMATION AND CONSENT FORM

Introduction:

You are invited to participate in a research study investigating best practices and adapting interventions of Dialectical Behavior Therapy when working with individuals who have both a diagnosis of a Developmental Disability and Borderline Personality Disorder. This study is being conducted by Maija Seavey, Professor Valandra in the Graduate Social Work Program at St. Catherine University. You were selected as a possible participant in this research because of your knowledge and experience in this field and have been identified from the Minnesota Department of Human Service's list of agencies qualified as a *Certified DBT Provider*. Please read this form and ask questions before you decide whether to participate in the study.

Background Information:

The purpose of this study is intended to gather further data and insight on how clinicians adapt and intervene in a DBT model when working with individuals with a co-morbidity of developmental disability and borderline personality disorder. Approximately 10 to 12 people are expected to participate in this research.

Procedures:

If you decide to participate, you will be asked to participate in a onetime interview with the researcher in a private location. This interview will take approximately one hour of your time.

Risks and Benefits:

The study has minimal risks. All interview content is based on your practice experience and knowledge. The researcher requests no specific client information or data be shared and your name and agency/practice will remain confidential throughout the research process.

There are no direct benefits to you for participating in this research.

Compensation:

There is no compensation or incentive offered for participating in this study.

Confidentiality:

Any information obtained in connection with this research study that could identify you will be kept confidential. In any written reports or publications, no one will be identified or identifiable and only group data will be presented.

I will keep the research results in a password protected computer and/or a locked file cabinet in my private home and only I will have access to the records while I work on this project. I will finish analyzing the data by May 20, 2012. I will then destroy all original reports and identifying information that can be linked back to you. All audio recordings will not be shared with any others and will be destroyed by May 20, 2012.

Voluntary nature of the study:

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with St. Catherine University in any way. You have the right to refuse any questions asked throughout the interview process. If you decide to participate, you are free to stop at any time without affecting these relationships, and no further data will be collected.

Contacts and questions:

If you have any questions, please feel free to contact me by phone at (218)591-1037 or by email at swan2727@stthomas.edu. You may ask questions now, or if you have any additional questions later, the faculty advisor, Valandra at (651) 690-6704, will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact Lynne Linder, SCU IRB Administrative Assistant llinder@stkate.edu, 651-690-6203.

You may keep a copy of this form for your records.

Statement of Consent:

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study at any time and no further data will be collected.

I consent to participate in the study. I agree to be audio taped during the interview process.

Signature of Participant

Date

Signature of Researcher

Date

Appendix B

Initial Agency Contact Telephone Script

Hello, my name is Maija Seavey. I am a student at St. Catherine University/University of St. Thomas MSW program and I am in the process of conducting my clinical research paper. My focus is to further explore effectiveness, and treatment adaptations of Dialectical Behavior Therapy when working with individuals who have a co-morbidity of Developmental Disability/Intellectual Disorder and Borderline Personality Disorder. Your agency was provided on the Minnesota Department of Human Services website as a *DBT Certified Provider*. I am currently looking to interview clinicians that provide DBT therapy within your agency. Would you be willing to direct me to someone that I can speak with further and possibly invite to participate in my research?

If Yes:

Great, thank you.

Proceed to Utilize Appendix C if able to make contact with referred participant during initial phone contact. If needing to leave a message Researcher will provide contact information and brief description of research and participation requirements. The researcher will request the potential participant to return call if interested in participating.

Appendix C

Clinician Contact Telephone Script

Hello, my name is Maija Seavey. I am a student at St. Catherine University/University of St. Thomas MSW program and I am in the process of conducting my clinical research paper. My focus is to further explore effectiveness, and treatment adaptations of Dialectical Behavior Therapy when working with individuals who have a co-morbidity of Developmental Disability and Borderline Personality Disorder. I received your name from _____(name)_____ at your agency who identified you as a DBT provider within your agency.

I am conducting a qualitative exploratory study where I will be interview 10 to 12 participants in a semi-structured process. The interview questions will include obtaining your background experience and knowledge of working with this population including training, perspective and treatment modalities utilized including any adaptations.

I am wondering if you would like to be a part of this study?

(If yes)

Great, thank you. Before we schedule a time to meet I will explain the process in brief terms.

We will meet in person and I will provide you with a consent form that we will both review and sign prior to beginning the interview. The interview will last approximately one hour and we will meet in a private setting to maintain your confidentiality.

I would like to suggest we meet at the University of St. Catherine's library. Do you have any other preference for a meeting place? (If different locations establish availability of privacy with participant).

Can you give me some times, or availability to interview? Do you have any further questions for me at this time?

Appendix D

Interview Questions

- 1) What is your level of licensure?
- 2) What is the main setting of treatment unit you work in? What is your title?
 - a) Private Practice
 - b) Outpatient Clinic
 - c) Day Treatment
 - d) Inpatient
 - e) Residential
 - f) Other – Please specify: _____
- 3) How long have you practiced DBT?
- 4) Have you had many clients with a co-morbidity of a developmental disability and BPD?
Please describe.
- 5) Tell me about your experience with this co-morbid population within DBT treatment.
- 6) What do you find to be the most effective treatment approach working with this population?
- 7) What is your experience working with individuals with Borderline Personality Disorder?
- 8) What are the major challenges of working with this population under a DBT treatment modality?
- 9) How do you maintain adherence to the DBT model when working with this co-morbid population?
- 10) Tell me your perspective on how to better serve individuals with this co-morbidity. What are some suggestions, or treatment interventions you would recommend further?

- 11) Are there any ethical considerations when providing DBT to this specified population?
- 12) Is there anything you would like to add related to this topic that may be useful for research purposes?

Appendix E

Certified DBT Providers

DBT has been added as an Intensive Outpatient Program (IOP) to those who are eligible under the Minnesota Behavioral Healthcare guidelines and maintains standard requirements to be considered a Certified DBT provider. According to the Minnesota Department of Human Services (MNDHS), a certified provider must provide DBT based on and maintain the following initial guidelines that determined those sampled for this study:

...the principles of the research-based model and as a comprehensive treatment using the three modalities of individual therapy, group skills training and telephone coaching by a team of trained providers. The targeted treatment group is individuals for whom empirical evidence supports its effectiveness; individuals who are suicidal, engaging in self-harm behaviors, and/or diagnosed with a borderline personality disorder. DBT as a treatment is based in cognitive, behavioral and dialectic principles and incorporates both clinical and rehabilitative interventions. Programs must determine that a client meets the eligibility requirements for this intensive service by providing a thorough assessment, including a functional assessment and by conducting the necessary treatment readiness protocol described by the evidence based practice and defined in Minnesota Rule 9505.0372 Subp.10 (pending publication).

(MNDHS, 2011)