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Efficacy, Risks, and Ethics of Aversive or Positive Therapy in Identical Twins

Jacqueline Salerno
Walden University

Walden University

College of Social and Behavioral Sciences

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Jacqueline Salerno

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Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
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MA, Long Island University, 1999

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

Aversion therapy has reemerged as a treatment for self-injurious behavior (SIB) but remains unpopular, as it is perceived to be unethical. The purpose of this mixed-methods sequential explanatory study was to investigate the effectiveness of positive therapy and aversion therapy in the treatment of twins with SIB as well as to understand the lived experiences of their caretakers regarding treatment ethics. The frameworks used included classical and operant conditioning as well as utilitarian ethics theory. Quantitative research questions focused on changes in SIB, aggressive and prosocial behaviors with treatment, while the qualitative research question focused on the perceptions of caretakers regarding treatment. The quantitative component used a case study design and archived data from 2 U.S.-based treatment centers. The qualitative component included essay-type questionnaires for family members and caretakers regarding perceptions of the different therapies. The quantitative data that was obtained measured different behaviors that were not comparable. The twin in aversion therapy demonstrated aggressive behaviors that decreased with treatment, while the twin in positive therapy demonstrated positive behaviors that showed little to no change. Caretaker and family reports were consistent with the quantitative data, and family members considered aversion therapy ethical because they perceived it to be effective in treating SIBs. They also perceived it as ethically preferable to the use of large amounts of medication. Findings suggest that aversion therapy may be effective and ethical. Implications for positive social include potential continued research on aversion therapy to enhance treatment outcomes for individuals with SIB, and possible changes in public perceptions of aversion therapies.

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Chapter 1: Introduction to the Study

Self-injurious behavior (SIB) is a potentially life-threatening chronic behavioral problem that can be difficult to treat with either conventional psychotherapies or nonaversive behavioral therapies (Wolff, Hazlett, Lightbody, Reiss, & Piven, 2013). In the past, providers used aversion therapy, which involves the pairing of an aversive stimulus (e.g., electric shock) with an undesirable behavior (e.g., head-hitting self-injury) in order to reduce or eliminate the undesired behavior, to successfully treat individuals (including individuals with intellectual and/or developmental disabilities) exhibiting SIBs (Linscheid, Iwata, Ricketts, Williams, & Griffin, 1990; Ricketts, Goza, & Matez, 1992). However, ethical controversies arose due to the associated with the use of aversion therapy (Dickinson, 2010). In recent years, aversion therapy has had a resurgence, particularly in the area of alcohol and drug addiction treatment (Staiger, Richardson, Long, Carr, & Marlatt, 2013; Verendeev & Riley, 2012). Success in this area suggests that it is time to reconsider the potential for aversion therapy to effectively treat SIBs, especially in cases where other therapies have failed and the SIBs are chronic and potentially life-threatening, as can be the case in persons with intellectual and developmental disabilities (IDDs).

This chapter includes background information pertaining to aversion therapy, the purpose and problem statements, the research questions (RQs) that formed the basis of this study, the theoretical framework, and the nature of the study. Additionally, Chapter 1 contains key definitions and the assumptions, scope and delimitations, and limitations of

the research. I conclude the chapter by discussing the significance of this study and providing a summary and transition to Chapter 2.

Background

Classic Aversion Therapy

Linscheid et al. (1990) described the case of Johnny, an 11-year old who spent most of his school day confined to a beanbag chair and wearing a special protective helmet. The confinement and helmet offered Johnny some protection against the damage he inflicted when hitting himself in the head an average of 1,800 times per school day (Linscheid et al., 1990). Four months after wearing a special device configured to deliver a mild electric shock contingent upon any head-hitting activity, Johnny's rate of head hitting had fallen to fewer than 17 hits per school day (or less than 1% of his baseline rate; Linscheid et al., 1990). The four other individuals (two adolescents and two young adults) in the Linscheid et al. aversion therapy study also showed dramatic reductions in their SIBs.

Linscheid et al.'s (1990) study is considerably dated. According to my review of the literature, there are very few recently published studies on the topic of classic aversion therapy. At the time Linscheid et al. reported that there were improvements in the SIB of Johnny and other patients, ethical concerns had already resulted in aversion therapy being out of favor (Jacob-Timm, 1996). Prior to the study involving Johnny and the four other individuals receiving aversion therapy, several national organizations had come out strongly against the practice because of the view that such treatment was a form

of corporal punishment (Maurer, 1983) and that these individuals were unable to give informed consent to the aversive procedures (Jacob-Timm, 1996; Sherman, 1991).

Aversion therapy, which is also sometimes referred to as aversive counter-conditioning, fits within the theoretical framework of classical learning principles when the aversive stimulus is paired with the problem or undesired behavior (Groden & Cautela, 1981). The aversion therapy described in the case of Johnny (involving the delivery of electric shock immediately following head-hitting rather than simultaneously with head-hitting) fits within the theoretical framework of operant learning principles (Groden & Cautela, 1981). Whether subsumed within operant or classical learning theory terms, the central objective of aversion therapy, as Dirks (1974) summarized, "is to develop a conditioned aversion to formerly positively reinforcing stimuli by presenting or eliciting them contiguously with aversive consequences" (p. 1329). Although there are many possible aversive stimuli, major categories of aversion therapy include chemical/pharmacological aversion therapy (including the use of emetics to cause nausea); electrical (use of electric shocks) aversion therapy; and imaginal aversion (the subject imagines the aversive stimulus as well as the target behavior), known as covert sensitization (Cautela, 1967; Dirks, 1974; Quinn, Patten, Barker, Whitlock, & Allen, 1964).

Contemporary Aversion Therapy

Although contemporary aversion therapy is associated with the development of behavior modification therapies in the early and mid-20th century, aversion therapy has a long history (Kraft & Kraft, 2005, p. 202). In an early record of aversion therapy, the

Roman encyclopedist Pliny the Elder described a technique to discourage drunkenness that involved placing spiders in the bottom of wine bottles (Howard, 2001). Modern references to the use of aversive stimuli in medical or psychological treatment for a variety of disorders date back to the 1840s (Kraft & Kraft, 2005). Modern scientific interest in aversion therapy can be traced to the early 20th century and Watson and Reyner's (1920) experimental study demonstrating that pairing an aversive stimulus with a neutral object led to withdrawal (a conditioned response). In the 1930s, variations of chemical or pharmacological aversion therapies were used to treat alcoholism in various clinical studies and treatment facilities in Europe, the United States, and Russia (Howard, 2001; Lemere, 1987). In the United States, clinicians at the Shadel Sanitarium (subsequently named the Schick Shadel Hospital) spearheaded research on and clinical application of aversion therapy for the treatment of alcoholism in Seattle, Washington, beginning in 1935 (Howard, 2001).

Aversion therapy peaked in popularity in the 1950s and 1960s when aversive procedures were widely used in the treatment of alcohol and drug addiction, sexual deviance (including homosexuality, which at the time was labeled as sexual deviance), behavioral problems, and challenging behaviors (including self-injury) among intellectually and developmentally disabled children and adults (Cautela, 1967; Griffin, Locke, & Landers, 1975; King, Smith, & Bartlett, 2004; Lemere, 1987; Linscheid & Cunningham, 1977; MacCulloch & Feldman, 1967; Nord, Wiesler, & Hanson, 1991; Quinn et al., 1964). The treatments that were used were largely considered successful, especially in the treatment of juvenile exhibitionism (MacCulloch, Williams, & Birtles,

1971), sexually deviant behavior (Raymond, 1956), and alcoholism (Elkins, 1975). However, most of the research that was published at that time consisted of case reports. For example, MacCulloch et al. (1971) reported a successful reduction in a 12-year-old male's exhibitionistic behavior, deviant masturbatory fantasy, and sexual orientation towards older women, following eighteen 20-minute aversion therapy treatment sessions. Follow-up at 5 months revealed that behavior change had been maintained. According to Raymond (1956), a married man aged 33 years was referred after he had attacked a baby carriage, after 11 previous similar incidents. Nineteen months after he started aversion therapy, he appeared to be maintaining behavior change (Raymond, 1956). Furthermore, according to Elkins (1975), more than 35,000 alcoholics had received chemical aversion (emetic therapy) in at least 75 settings worldwide from the 1930s to the 1970s. Elkins also found long-standing evidence of treatment effectiveness in the results of 75 private hospitals, which had consistently produced 1-year abstinence rates approximating 60% in case series and chart review studies.

However, voiced criticisms of aversion therapy that led to its decline. In terms of effectiveness, Rachman (1977), Lowenstein (1998), and Nathan (1985) reported that treatment results did not last in the long term for juvenile behavior, fetishes, and alcoholism diagnoses, respectively. In addition, significant ethical concerns over the use of conversion therapy for homosexuality after it was no longer considered a mental illness contributed to the downfall of aversion therapy (Dickinson, Cook, Playle, & Hallett, 2012).

By the 1980s and 1990s, aversion therapy had largely fallen out of favor. Aversion therapy also seemed increasingly out of step in an era of positive reinforcement and nonintrusive methods. The use of aversive procedures with children also ran afoul of the nationwide movement against the use of corporal punishment (Jacob-Timm, 1996; Maurer, 1983; Pickering, Morgan, Houts, & Rodriguez, 1988). Disabled rights groups and children's rights groups also raised concerns about the use of "punitive" procedures with persons who were unable, by virtue of age or mental competency, to give informed consent for the use of the aversive procedures (Jacob-Timm, 1996; Sherman, 1991). Others argued that aversive procedures were on their face unethical in that they represented a clear breach of the ethical principle of beneficence and the duty to do no harm (American Psychological Association [APA], 2010; Maurer, 1983; Sherman, 1991). Finally, even those who conceded that aversion therapy might be an effective treatment for certain difficult behaviors warned that aversion therapy and its associated procedures were subject to considerable abuse, and that the potential for such abuse was an argument against widespread application of the therapy (Eikeseth, Lovaas, & Holden, 2006; Holden, 1990; Nord et al., 1991). As a result of all of these criticisms, there are very few published studies reporting the use of aversion therapy from 1999 to 2012 for any diagnosis (Furniss & Biswas, 2012).

Aversion therapy starts to reemerge. Despite mounting opposition to the use of aversion therapy in the late 20th century, advocates argued that aversion therapy offered the best and most efficacious treatment option in some cases and the only remaining treatment option in other cases (Eikeseth et al., 2006; Holden, 1990; Lerman & Vorndran,

2002; Maurer, 1983; Sherman, 1991). In the first decade of the 21st century, aversion therapy reemerged as a promising treatment modality, particularly in the area of alcoholism and addiction treatment (Bordnick, Elkins, Orr, Walters, & Thyer, 2004; Gaval-Cruz & Winshenker, 2009; "Schick Shadel," 2011). Although most of the clinical applications of aversion therapy in the past decade have focused on drug and alcohol abuse treatment, a number of researchers and some clinicians have begun to revisit the utility and efficacy of aversion therapy in the treatment of a broad range of problem and challenging behaviors, including SIB in children and adults (Matson, Neal, & Kozlowski, 2012; Prangnell, 2009; Ringdahl & Falcomata, 2009).

Some of the reemergence of aversion therapy has stemmed from caregivers' experiences treating individuals with behavior that they cannot control (Ter Mors, van Heugten, & Harten, 2012). For example, in a study of electrical aversion therapy for individuals with traumatic brain injuries, caregivers reported feeling overwhelmed with the challenges of caring for individuals whose traumatic brain injuries had caused them to have inappropriate aggressive and sexual behavior, but the caregivers were reluctant to have these patients committed to psychiatric institutions because of concerns that their charges were not receiving the most adequate care and management (Ter Mors et al., 2012). Dickinson et al. (2012) reported that mental health nurses were split in terms of opinions of treating individuals with aversion therapy. Some nurses empathized with their patients, seeing aversion therapy as a negative force within their patients' lives, while others demonstrated "a distinct lack of empathy and sensitivity to this patient group" (p. 287). Additionally, the authors noted that to "make the administration of brutal treatments

tolerable, the role of morality had to be limited" (Dickinson et al., 2012, p. 289). There is no published literature examining the lived experiences of both family and professional caretakers considering the issues of ethics and effectiveness of aversion therapy together, and this study sought to fill in that gap by considering the experiences of those who take care of one twin who is treated with aversion therapy and another treated with conventional standard treatments.

Self-Injurious Behavior

SIBs are intentional acts of self-harm (Sandman, Kemp, Mabini, Pincus, & Magnusson, 2012). SIB can take numerous forms, including head banging, cutting, biting, hitting, hair pulling, face slapping, pinching, eye-poking, and the ingestion of foreign objects. It can have a broad range of clinical presentations including stereotypy, tic, compulsion, ritual, and self-stimulation among others (Ernst, 2000). Within the general (nondisabled) population, SIB occurs commonly and usually in a self-limiting fashion in infancy and early childhood (usually expressed as head-banging and self-injury associated with tantrums). In addition, SIB may, in mild forms such as nail biting or skin picking, be viewed as relatively normal behavior among adolescents and adults (Ernst, 2000, p. 447).

Conversely, SIB can also be expressed as a chronic and sometimes life-threatening condition, as well as a behavior that may have profound, life-changing consequences (e.g., blinding oneself, inflicting permanent damage and disfigurement, etc.; Linscheid et al., 1990). The scope, purpose, motivating factors behind, and consequences of SIB vary widely: given the wide scope of behavior and the

heterogeneity of populations who engage in SIB, it is difficult to operationally define for the purpose of research. This study focused on two identical twins who are intellectually disabled and have engaged in serious, health-threatening SIB.

SIBs are associated with a number of different clinical syndromes, including autism, mental retardation, developmental disorders, Tourette's disorder, obsessive-compulsive disorder, borderline personality disorder, chronic pain, major depression, Lesch-Nyhan disease, Cornelia De Lange syndrome, and Prader-Willi syndrome (Ernst, 2000; Sandman et al., 2012). Although severe, chronic SIBs are typically found among a small proportion of the population (generally among persons [children and adults] with severe intellectual disabilities and/or pervasive developmental disorders); milder forms of SIB as well as less chronic forms of SIB are found across a fairly broad spectrum of the population. Hamza, Willoughby, and Good (2013) reported that "among clinical inpatient samples, as many as 21% of adults and 30 to 40% of adolescents" engage in SIBs (p. 1). Moreover, these authors note that "as many as 12-38% of young adults report lifetime history" of SIBs (Hamza et al., 2013, p. 1). Kakhnovets, Young, Purnell, Huebner, and Bishop (2010) also cited estimates of SIB prevalence ranging from 12% to 28% among American adolescents and young adults (p. 310).

SIB, particularly the severe and chronic manifestations of SIB, is often quite difficult to treat, as reported by multiple researchers over a wide array of studies, including studies with children with autism and mental retardation, research on the etiology, development, and phenomenology of SIB in people with intellectual disorders, and clinical evaluations of SIB inhibiting systems (Eikeseth et al., 2006; Furniss &

Biswas, 2012; Holden, 1990; Linscheid et al., 1990; Ricketts et al., 1992; Zanarini et al., 2009). Conventional psychological therapies may be unsuitable for persons with intellectual impairment and/or severe developmental disorders due to the fact that nonaversive behavioral treatments seem to offer some relief of symptoms, although implementing the procedures can be cumbersome and time consuming and the effects of such interventions are often short-lived, with relapse in SIB occurring soon after treatment stops (Eikeseth et al., 2006; Furniss & Biswas, 2012). This has been found to be true across multiple studies, including those on SIB in children with autism and intellectual disability (Eikeseth et al., 2006), SIB in individuals with intellectual disabilities (Furniss & Biswas, 2012), reviews of clinical evaluations of SIB inhibiting systems (Linscheid et al., 1990), and decade-long observational research regarding SIB in individuals with borderline personality disorder (Zanarini et al., 2008).

Eikeseth et al. (2006) reviewed the educational, therapeutic, ethical, and scientific contexts in which aversion therapy is used, and opined that aversion therapy should only be used when all other measures have failed. Eikeseth et al. also asserted that aversive techniques should only be used when nonrestrictive interventions have been attempted and proven ineffective, when baseline data on the aberrant behavior has been collected, when caretakers have been informed, when peer review has been completed, when doctors have obtained informed consent from the client or client's caretakers, and when the procedure is scientifically validated. Additionally, medical assistance should be on hand and the procedures must be socially acceptable (Eikeseth et al., 2006).

Furniss and Biswas (2012) conducted a review of the etiology, development, and phenomenology of SIB in people with intellectual disabilities. In their review, the authors found only nine articles published between 1999 and 2012 detailing the development of SIB within children, 29 studies on the risk factors of SIB in older children and adults, and four studies focusing on the relationship between SIB, sleep disorder, and pain. The study by Furniss and Biswas (2012) is of particular importance to the present research in that it detailed the scarcity of research related to SIB not classified as nonsuicidal self-injury (NSSI) in various populations.

Although there has been a recent increase in the use of aversion therapy for SIB, most of this research has been with adolescents engaging in NSSI (Franklin, Puzia, Lee, & Prinstein, 2014; Glenn, Kleiman, Cha, Nock, & Prinstein, 2015; Reitz et al., 2015). Franklin et al. (2014) reported that both low implicit aversion, which is involuntarily formed and remains typically unknown, and explicit aversion, which is deliberately formed and is easy to self-report, to self-cutting stimuli were significantly negatively associated with future NSSI, and that these associations were unique from several other theoretically important predictors.

Franklin et al. (2014) found that important predictors of NSSI included prior NSSI, number of NSSI methods, implicit identification with self-cutting, self-prediction of future NSSI, emotion dysregulation, and therapy status in a group of healthy individuals (Franklin et al., 2014). While the findings were informative, they failed to capture the entirety of studies on SIB, in that Franklin et al. did not examine individuals with intellectual disabilities or those who were institutionalized.

Additionally, Glenn et al. (2015) examined implicit self-identification with NSSI, which is hard to detect and is involuntarily formed, in a large sample of middle school students in a longitudinal prospective study. Adolescents who engaged in NSSI exhibited stronger implicit self-identification with NSSI than adolescents who did not engage in NSSI, meaning that it would be difficult for other individuals to tell that these adolescents were involved in SIB. Moreover, implicit NSSI identification was stronger in adolescents who engaged in cutting, frequent NSSI, and recent NSSI. A reciprocal association was observed between NSSI frequency and implicit NSSI identification over 1 year. Notably, implicit NSSI identification uniquely and prospectively predicted engagement in NSSI over the subsequent year (Glenn et al., 2015). Similar to Franklin et al.'s (2014) study, Glenn et al.'s study provided an expansive outlook on the case of NSSI and SIB in various individuals; however, much like Franklin et al. study, Glenn et al.'s study also failed to demonstrate rates of SIB within institutionalized and intellectually disabled individuals.

As such, the majority of scholarly publications on the topic of SIB in disabled populations in recent years are reviews or theoretical articles (e.g., Cautela, 2013; Luiselli, Matson, & Singh, 2012), while many researchers have focused on the topic of NSSI in adolescents (Franklin et al., 2014; Glenn et al., 2015). In contrast, almost no attention has been paid to aversion therapy for SIBs in developmentally disabled populations. Given the historical demonstration of effective aversion therapy treatment in this population (e.g., Linscheid et al., 1990; Ricketts et al., 1992), and the recent resurgence of interest in the use of aversion therapies (Staiger et al., 2013; Verendeev &

Riley, 2012), there is a need to conduct research investigating the gap in the literature regarding the use of aversion therapy in comparison to conventional psychological treatment modalities (specifically focused on positive behavior support) in the treatment of SIBs in a pair of intellectually disabled twins, and also to gain the subjective lived experience of the relatives and caretakers regarding the efficacy and ethics of those therapies. There is a paucity of recent research on the use of aversion therapy for the treatment of SIB in persons with IDDs (Langdon, 2015). Moreover, existing research on the use of aversion therapy for the treatment of SIBs in the intellectually and/or developmentally disabled population lacks methodological rigor (Langdon, 2015; J. Robertson, Hatton, Baines, & Emerson, 2015). This research was designed to address some of the existing shortcomings in the research literature.

Problem Statement

SIB is a commonly occurring and potentially life-threatening chronic behavioral problem that can be extremely difficult to treat with either conventional psychotherapies or nonaversive behavioral therapies. In the past, clinicians used aversion therapy to successfully treat individuals (including individuals with intellectual and/or developmental disabilities) exhibiting SIB (Linscheid et al., 1990; Ricketts et al., 1992). Controversies over the use of aversion therapy have limited its application, not only for the treatment of SIBs but also for the treatment of other behaviors. However, in recent years, aversion therapy has made a resurgence, particularly in the area of alcohol and drug addiction treatment (Staiger et al., 2013; Verendeev & Riley, 2012). Success in this area suggests that it is time to reconsider the potential for aversion therapy to effectively

treat SIBs, especially in cases where other therapies have failed, and the SIBs are chronic and potentially life-threatening, as can be the case in persons with IDDs who exhibit SIBs.

The problem that was addressed in this research was the need to find effective treatment for the life-threatening SIB of individuals with intellectual and/or developmental disabilities and the perception of aversion therapy as unethical. As discussed in the Background section, most SIB research has been with adolescents involved in NSSI (Franklin et al., 2014; Glenn et al., 2015; Reitz et al., 2015). Even though a number of scholarly review and theoretical publications on the topic have appeared in recent years (see Cautela, 2013; Luiselli et al., 2012), very little attention by researchers has been paid to the use of aversion therapy for SIBs in developmentally disabled populations. According to Langdon (2015), there has been a paucity of recent research on the use of aversion therapy for the treatment of SIB in persons with IDDs. Moreover, existing research on the use of aversion therapy for the treatment of SIBs in the intellectually and/or developmentally disabled generally has lacked methodological rigor (Langdon, 2015; J. Robertson et al., 2015).

In this study, I attempted to fill the gap in the literature by examining the efficacy of aversion therapy in comparison to therapy that focuses on positive reinforcement. The findings may contribute to the literature by providing insight on the lived experiences of those who care for the intellectually disabled individuals undergoing this treatment: Their voices have not been included in prior studies, and, as discussed earlier in this chapter,

there is very little research that has focused on how caregivers weigh these therapies in terms of effectiveness and ethics.

Purpose of the Study

The purpose of this mixed-methods study was to investigate the effectiveness of aversion therapy in comparison to conventional psychological treatment modalities (specifically focused on positive behavior support) in the treatment of SIBs in a pair of intellectually disabled twins. I also wanted to gain insight on the subjective lived experience of the relatives and caretakers regarding the efficacy and ethics of those therapies. I used archival data in a single-case design in the quantitative component to determine treatment effectiveness, examining one case that involved aversion therapy and another that involved conventional behavior modification methods. The data were drawn from archival data from U.S.-based clinical psychiatric and psychological treatment centers. The qualitative component was prospective and involved essay-type questionnaires I administered to the family members and caretakers of the participants from the quantitative study. The participants in the qualitative component were two people who are related to twins receiving different treatment for SIBs and two additional individuals who were each responsible for the caretaking of a different twin.

Research Questions

I sought to answer five RQs: four for the quantitative part of the study and one for the qualitative part.

Quantitative Study

RQ1: Are there significant differences in trends of behaviors of aggression (i.e., biting, hitting, kicking, pushing, grabbing, and head butting) towards others recorded for an intellectually and developmentally disabled individual treated with applied behavior analysis (ABA), which includes aversion therapy, and trends of behaviors of aggression towards others recorded for his identical twin who has been treated with conventional positive behavior therapy (PBT)?

RQ2: Are there significant differences in trends of behaviors of self-aggression behaviors that may cause physical or emotional harm to self (i.e., hitting self, biting self, picking skin to cause bleeding, picking inside of the nose to cause bleeding, or forcefully scratching to cause breaking of skin) recorded for an intellectually and developmentally disabled individual treated with ABA, which includes aversion therapy, and the frequency of behaviors of self-aggression recorded for his identical twin who has been treated with conventional PBT?

RQ3: Are there significant differences in trends of destructive behaviors (involving the intentional breaking or destruction of property) recorded for an intellectually and developmentally disabled individual treated with ABA, which includes aversion therapy and trends of destructive behaviors recorded for his identical twin who has been treated with conventional positive behavior therapy?

RQ4: Are there significant differences in trends of positive, prosocial behaviors (i.e., completing daily living skills, maintaining a neat appearance, and practicing appropriate hand shaking) recorded for an intellectually and developmentally disabled

individual treated with ABA therapy that includes aversion therapy, and trends of positive, prosocial behaviors recorded for his identical twin who has been treated with conventional PBT?

Qualitative Study

RQ5: What are the experiences and perceptions of the family members and caretakers of twins with IDDs who were treated with different approaches (conventional vs. aversion therapy) in terms of outcome and ethical implications?

Theoretical Framework

The theoretical framework for the quantitative analysis of results consisted of the behavioral theories (e.g., classical conditioning, operant conditioning) that underpin aversion therapy and ABA (Cautela, 1967; Groden & Cautela, 1981; Pavlov, 1927; Watson & Reyner, 1920; Wolpe, 1958). These theories, combined with an ethical framework of utilitarianism, were used to assist in the evaluation of the effectiveness and appropriateness of the use of aversion therapy in this study (APA, 2010). The goal of utilitarianism and the sole moral duty, according to this ethical theory, is to "maximize utility" by producing "as much pleasure as possible (positive utilitarianism) or to decrease as much pain as possible (negative utilitarianism)" (Knapp, 1999, p. 384).

The theoretical framework used for the twin exposed to conventional PBT treatment for SIBs was operant or Skinnerian conditioning. In conventional behavior therapy of SIB, the target SIB is reduced or eliminated through reinforcement schedules that may reward alternative behaviors, reward stopping the undesirable behavior,

negatively reinforce the behavior, or punish the target behavior (Ringdahl & Falcomata, 2009; Rojahn, Schroeder, & Hoch, 2008; Wilkins & Matson, 2009).

The theoretical framework that was used for the twin exposed to aversion therapy was primarily the classical (Pavlovian) learning/conditioning paradigm. Based on the work of Pavlov (1927), classical conditioning involves pairing a neutral stimulus (conditioned stimulus or CS) with an automatic or unconditioned stimulus (UCS) that already produces an unconditioned response (UR) so as to eventually cause a conditioned response (CR) to the CS (Hadley, 1985; Rescorla, 1988; Timberlake, 2004). Historically, aversion therapy has been placed within the theoretical framework of classical conditioning. It is generally acknowledged that most aversion therapy protocols will necessarily include both classical and operant conditioning procedures (Hadley, 1985, p. 35).

Of primary concern is that the treatments that were used in the cases of these young men were supported by the ethical principles and standards of the APA's (2010) *Ethical Principles of Psychologists and Code of Conduct.* For the purposes of this research, the ethical theory framework that was used for the qualitative component was utilitarian ethical theory. Contemporary understanding and application of utilitarian theory reflects the idea of the Enlightenment philosophers, Jeremy Bentham (1748-1842) and John Stuart Mill (1806-1873; Gandjour & Lauterbach, 2003; Knapp, 1999; M. Robertson, Morris, & Walter, 2007). This research used Ganjour and Lauterbach's (2003) definition of utilitarianism as "a moral theory according to which an action is right if and

only if it produces more utility (or welfare or well-being) for all people than any alternative" (p. 230).

Classical or act utilitarianism has four important characteristics related to its application: (a) it is consequentialist theory (to determine morality, one is concerned with the consequences or outcomes of the behavior versus motivations); (b) it is hedonistic, in that happiness or maximum utility (however defined) is the goal; (c) it involves welfarism, in that in evaluating consequences one must consider the welfare of the subject; and (d) it is universal, in that the happiness of others (society in general) is as important as the happiness of the individual (Gandjour & Lauterbach, 2003, p. 231; Knapp, 1999, p. 384).

For the qualitative element of this research, I applied utilitarian ethical theory to consider the outcomes of both conventional PBT and aversion therapy, while also taking into account the consequences for the twins exposed to the treatments as well as the consequences for the participants, therapists, and society in general. There are a number of objections to and problems with utilitarianism, including practical difficulties in predicting and calculating the ultimate consequences of actions, difficulties in evaluating pleasure or happiness, and the lack of concern with individual rights and minority interests (Gandjour & Lauterbach, 2003; Knapp, 1999). Rules and guidelines for decision-making can be used to address some of the problems with act (versus rule-based) utilitarianism (Gandjour & Lauterbach, 2003). Such decision-making rules/guidelines should not be confused with the behavioral/moral rules of rule utilitarianism.

Strict application of utilitarian theory may prove problematic in clinical or research situations involving persons with limited or compromised mental capacities (Knapp, 1999; M. Robertson et al., 2007). In the present study, the patients undergoing therapy for SIB may have displayed a strong preference for self-injury, thus suggesting that the consequences of SIB include pleasure or happiness for these individuals. At the same time, however, utilitarianism includes a mandate for welfarism, so in calculating utility, the welfare of those individuals must be considered and, in doing so, it is clear that SIB is harmful to their welfare. Moreover, it is assumed that prevention or reduction of SIB increases happiness in the family-member participants.

For the present study, utilitarian theory served to guide the interview questions for the qualitative component of the study. Family-member participants were asked to consider the costs and benefits of treatment, and to make judgments as well as voice opinions about the ethical nature of treatment given those costs and benefits.

Nature of the Study

I used archival data in a single-case design in the quantitative component that determined treatment effectiveness, examining one case that used aversion therapy and another that used conventional behavior modification methods. The data were drawn from archival data from two U.S.-based clinical psychiatric and psychological treatment centers. The qualitative component was prospective, in the form of essay-type questionnaires I administered to the family members and caretakers of the participants from the quantitative study. This questionnaire was used to address the participants' perceptions and views of the effectiveness of both aversion therapy and conventional

therapy, as well as their thoughts about the ethics of using each type of therapy. These responses helped answer the RQs that focused on the ethics of using aversion therapy in individuals who have experience with both types of treatment (the family members). The participants in the qualitative component were two people who are related to twins receiving different treatment for SIBs, and two additional individuals who are each responsible for the caretaking of a different twin.

For the quantitative portion of the present study, I used a single-case study analysis given the small sample size of two.

A sequential explanatory design is appropriate when using qualitative techniques to further substantiate quantitative findings (Sandelowski, 2000). Visual analysis was implemented to examine change in behavior over time in each case. Fisher et al. (2003) designed a visual inspection procedure called the conservative dual criterion (CDC). The CDC technique measures the effectiveness of treatment by analyzing the number of data points that fall above the established linear regression trend line. The dependent variables to be examined include (a) aggression behaviors (intentional behaviors that may cause physical or emotional harm or significant discomfort to others); (b) health dangerous behaviors (those that are self-injurious or may cause physical or emotional harm to the participant or his health); (c) destructive behaviors (behaviors that involve the intentional breaking or destruction of property); and (d) major disruptive behaviors (behaviors that occur at such frequency or intensity to significantly disrupt the social environment); and (e) positive social behaviors (completing daily skills, maintaining a neat appearance, practicing appropriate hand shaking).

Definition of Terms and Abbreviations

Conceptual and operational definitions of the major terms and abbreviations used in this study are provided in this section. These definitions specifically refer to the meaning of the term for the present study. The parenthetical notes following some of these definitions represent the acronyms and abbreviations commonly used in the literature and in this study.

Aggressive behavior: The *Merriam-Webster.com Dictionary* ("Aggressive," n.d.) defines aggressive as "a) tending toward or exhibiting aggression; b) marked by combative readiness" (para. 1; e.g., biting, hitting, kicking, pushing, grabbing, and head butting).

Applied behavior analysis (ABA): ABA practitioners systematically apply interventions based on behavioral analysis and principles of learning and behavior theory (Ringdahl & Falcomata, 2009, p. 31). ABA is not a single treatment, but rather an approach to treatment based on behavior theory and principles (Ringdahl & Falcomata, 2009). Although not a single treatment, ABA is generally acknowledged to have several defining characteristics or dimensions, including a focus on problems of social and/ or psychological importance (applied), direct measurement of behaviors (behavior), and the use of analytical procedures and methods to document evidence of behavior change (analysis; Lerman, Iwata, & Hanley, 2009, p. 82).

Aversion: The *Merriam-Webster.com Dictionary* ("Aversion," n.d.) defines aversion as:

> a) feeling of repugnance towards something with a desire to avoid or turn from it; b) a settled dislike; antipathy; and c) a tendency to extinguish a behavior or to avoid a thing or situation and especially a usually pleasurable one because it is or has been associated with a noxious stimulus. (para. 1-3)

All three definitions fit with the concept of aversion as discussed in the present study and as the "aversion" in aversion therapy. Umberg and Pothos's (2011) conception of aversion as "the state opposite of reward" also conveys the concept as it was used in this study.

Aversion therapy: Aversion therapy is a form of behavior modification therapy grounded in classical learning (conditioning) theory that involves the pairing of an aversive stimulus (one which stimulates the feelings and reactions of aversion as defined above) with an undesirable behavior in an effort to condition an aversive response to the undesirable behavior, and in this way reduce or eliminate the behavior (Dirks, 1974; Groden & Cautela, 1981).

Although aversion therapy is historically grounded in classical learning theory, both classical and operant conditioning elements may be present in aversive protocols. Hadley (1985) drew on Lovibond's definition of aversion therapy as "a behaviorally oriented treatment that utilizes an aversive or noxious stimulus, such as faradic shock, to eliminate undesirable behaviors" (p. 29). Although this study uses the term *aversion therapy*, it is also known as *aversive therapy*, *aversive conditioning*, and *aversive counter-conditioning*.

Aversive stimulus: An aversive stimulus is defined as a "stimulus from which the subject will learn to escape, if given the opportunity" (Hadley, 1985, p. 29).

Aversives: Aversives are any substances or stimuli (e.g., electric shock) used as a stimulus intended to provoke an escape response in aversion therapy (Dirks, 1974; Hadley, 1985).

Cognitive behavioral therapy (CBT): CBT is a category of psychotherapeutic interventions that emphasize the important role played by thinking (cognition) in individuals' behaviors and actions (Wilkins & Matson, 2009, p. 14).

Conditioned stimulus (CS): In classical conditioning, the CS is the stimulus that comes to elicit the target response, following the use of classical conditioning procedures (Hadley, 1985; Rescorla, 1988).

Conditioned stimulus response (CSR) or *conditioned response (CR)*: This represents the CR to the conditioned stimulus (Hadley, 1985; Timberlake, 2004).

Covert sensitization: Developed by Cautela (1967), covert sensitization is a form of imagined aversion therapy. Cautela (1967) labeled the process covert because "neither the undesirable stimulus nor the aversive stimulus is actually presented" (p. 459). Instead of being presented, the undesirable and aversive stimuli are both imagined by the individual undergoing covert sensitization. The "sensitization" component in covert sensitization refers to its purpose, which Cautela (1967) said was to "build up an avoidance response to the undesirable stimulus" (p. 459).

Destructive behavior: The *Merriam-Webster.com Dictionary* ("Destructive," n.d.) defines destructive as "a) causing destruction; b) designed or tending to hurt or destroy" (para. 1-2).

Developmental disability: For the present study, developmental disability is defined as any severe, chronic disability in an individual aged 3 or older that is caused by a mental and/or physical impairment, which results in significant functional limitation in areas such as language, learning, self-care, and capacity to live independently (Wilkins & Matson, 2009). For the present study, *pervasive developmental disorders*, including autism, are included under the general category of developmental disability (Rojahn et al., 2008; Wilkins & Matson, 2009).

Dialectical behavior therapy (DBT): This psychotherapeutic intervention is a form of CBT that combines principles of Zen Buddhism with problem solving and skills training (Muehlenkamp, 2006).

Differential reinforcement (DR): DR is a behavioral procedure with two components: (a) contingent reinforcement of one response class, and (b) withholding reinforcement for another response class (Ringdahl & Falcomata, 2009, p. 39). There are a number of major variations of DR, as noted below.

Differential reinforcement of alternative behavior (DRA): DRA, as its name implies, involves the contingent reinforcement of a specified behavior different than the behavior targeted for reduction or elimination. In DRA, the alternative behavior need not be incompatible with the target behavior (Ringdahl & Falcomata, 2009, p. 39).

Differential reinforcement of incompatible behavior (DRI): DRI involves the contingent reinforcement of an alternative behavior that is incompatible with the behavior that has been targeted for reduction or elimination (Ringdahl & Falcomata, 2009, p. 40).

Differential reinforcement of other behavior (DRO): DRO involves "the delivery of reinforcers contingent on the absence of identified problem behavior for a specified time period" (Ringdahl & Falcomata, 2009, p. 42).

Extinction: Often combined with DRA or other behavioral procedures, extinction involves achieving reduction or elimination of behavior through the deliberate absence of reinforcement (Groden & Cautela, 1981, p. 177).

Functional analysis and functional assessment: Functional analysis and functional assessment are procedures used to identify the factors that maintain a targeted behavior (Rojahn et al., 2008, p. 106). Both are often used to assist in the development of treatment plans for individuals with SIB. Functional analysis, also called experimental or analogue analysis, "involves systematically varying antecedent conditions . . . and consequent events . . . in the context of a single-subject experimental design and examining changes in self-injurious behavior rates as a result of those manipulations" (Rojahn et al., 2008, p. 41). In functional assessment, no manipulation is carried out. Instead, information is gathered through direct and indirect assessment procedures (Rojahn et al., 2008, p. 106).

Intellectual and developmental disabilities (IDD): A broader term than *intellectual disability*, this term also encompasses developmental disabilities (Rojahn et al., 2008; Wilkins & Matson, 2009).

Intellectual disability: *Intellectual disability* has replaced mental retardation as the term used to describe persons with significant limitations in intellectual and adaptive abilities, generally with an age of onset prior to age 18 years (Wilkins & Matson, 2009, pp. 3-4).

Negative reinforcement: Often confused with the concept of punishment, negative reinforcement "refers to an increase in the performance of a behavior when that behavior results in escape from or avoidance of an aversive event" (Groden & Cautela, 1981, p. 176). Iwata (1987) explained that negative reinforcement usually "involves the removal, reduction, postponement, or prevention of stimulation" (p. 362).

Nonsuicidal self-injury (NSSI): Generally distinguished from the type of repetitive SIB seen among developmentally disabled and/or intellectually disabled children and adults, NSSI refers "to the direct and deliberate destruction or alteration of bodily tissue in the absence of suicidal intent" (Hamza et al., 2013, p. 1). Also sometimes referred to as parasuicide, NSSI behaviors commonly include self-cutting, burning, carving, and hitting.

Positive behavioral therapy (PBT): Developed in the 1980s in reaction against aversive techniques, PBT emphasizes "nonaversive behavioral interventions with increasing respect, improving interpersonal relationships, and building personal competency" (Matson et al., 2012, p. 589).

Positive reinforcement: One of the most widely used behavioral therapy procedures, positive reinforcement "refers to an increase in the frequency of a behavior that is followed by a positive reinforcer," with *positive reinforcer* defined as "an event

following a behavior that increases the frequency of that behavior" (Groden & Cautela, 1981, p. 175). Positive reinforcement and reward are not equivalent or even analogous concepts (Ringdahl & Falcomata, 2009, p. 35).

Problem-solving therapy (PST): This is a CBT-based psychotherapeutic intervention that assumes that dysfunctional coping behaviors, including self-injury, "result from a cognitive or behavioral breakdown in the problem-solving process" (Muehlenkamp, 2006, p. 16).

Punishment: Punishment is defined as the presentation (positive punishment) or withdrawal (negative punishment) of a stimulus/operation following a behavior leading to a decrease in or elimination of the behavior (Ringdahl & Falcomata, 2009, p. 32). The case vignette drawn from Linscheid et al.'s (1990) study of aversion therapy for SIB among persons with developmental disabilities provided an example of the application of aversion therapy as a form of positive punishment (the electrical shock was delivered immediately following the self-injurious head banging behavior). A frequently used example of negative punishment is the "time-out," short for time-out from reinforcement (Groden & Cautela, 1981, p. 176).

Self-injurious behavior (SIB): There are a variety of definitions of SIB found in the literature. Key shared components in these definitions include these elements: they are self-inflicted, nonaccidental, not consciously suicidal, and they produce bleeding, bruising, or other temporary or permanent injury to self (Kakhnovets et al., 2010; Prangnell, 2009). This definition of SIB excludes deliberate suicide attempts, suicides, and bodily mutilation or alteration for fashion or other personal reasons (e.g., tattooing,

piercing). Some examples of SIB include hitting, biting, picking the skin to cause bleeding, picking the inside of the nose to cause bleeding, forcefully scratching to cause breaking of skin, and head banging.

Self-injurious behavior inhibiting system (SIBIS): SIBIS was developed by Linscheid et al. (1990). It is an electrically charged sensory device that provides automatic detection of self-injurious blows to the head, response-contingent delivery of electric shocks to the arm or leg of the person wearing the device, and automatic recording of the SIBs and shock responses (Linscheid et al., 1990, p. 55).

Social behavior: The *Merriam-Webster.com Dictionary* ("Social," n.d.) defines social as "a) marked by or passed in pleasant companionship with friends or associates; b) sociable; c) of, relating to, or designed for sociability" (para. 2). Also identified as appropriate "replacement" or alternative behaviors (e.g., functional communication: speaking in a clear/low tone of voice, maintaining a neat appearance, and practicing appropriate hand shaking to greet a person).

Unconditioned stimulus (UCS): In classical conditioning, the UCS is the stimulus that naturally and instinctively elicits the response (e.g., meat powder was the UCS in Pavlov's bell tone conditioning experiment with dogs; Rescorla, 1988; Timberlake 2004).

Unconditioned stimulus response or unconditioned response (UR): The UR is the natural or instinctive response to the UCS (e.g., in the Pavlov's experiment, dogs' salivation constitutes the UR; Hadley, 1988; Rescorla, 1988; Timberlake, 2004).

Assumptions

I assumed that the archival data used in the quantitative portion of the present study were accurate and valid, and that the behaviors that were assessed were assessed accurately using the operational definitions for each behavior. It was also assumed that the behaviors measured as dependent variables were assessed in a roughly equivalent fashion across and within cases. The behaviors in each individual were compared to themselves over time in each case rather than across cases to account for disparity. In addition, it was assumed that all qualitative study participants were able to understand the questionnaire items and answer them honestly and to the best of their ability.

Scope and Delimitations

In the present study, I used a sequential explanatory mixed-methods approach. I drew on archival data for the quantitative component and narrative case study for the qualitative component to investigate the effectiveness and experience of aversion therapy compared to conventional psychological treatment modalities in the treatment of SIB in two adult, identical twin brothers. One of these individuals experienced exposure to aversion therapy to treat his SIB, while the other (his twin brother) underwent conventional psychological treatment for his SIB.

The results of the present study were not generalized beyond the participants, but they may provide a foundation for future studies. The nature of the topic of aversion therapy is sensitive at this time, and hope is that small-scale studies such as this one will encourage more research and conversation about the efficacy and ethical nature of

aversion therapy. Social change can be encouraged in this manner, and perhaps larger scale research as well.

Limitations

The quantitative component of the present study was limited in the use of existing databases. Data were not collected prospectively; therefore, I was limited to the use of variables and information that had been collected in the past. This study was also limited to a comparison of ABA, including aversion therapy, and conventional PBT in two genetically identical individuals with similarly SIB patterns. Due to this unique sample of an identical twin pair for the present study, results may not be generalizable beyond these individuals. Most notably, researchers have encountered problems with generalizability of the treatment effects, as well as sometimes reporting the individuals exposed to aversive stimuli may eventually (sometimes only after a few sessions) adapt to the shock or other stimulus and recover the SIB (Corte, Wolfe, & Locke, 1971; Matson & Taras, 1989; Tanner & Zeiler, 1975). The qualitative component of the present study was limited by the participants' direct knowledge and/or accurate recollection and reporting of the study twins' behaviors and perceived response to aversion therapy, including ABA or conventional PBT for their SIB.

Significance

A half century ago, aversion therapy was viewed as a promising and effective behavioral treatment modality for a range of clinically defined disorders involving problem or undesirable behavior, including SIB, among intellectually and developmentally disabled children and adolescents (Furniss & Biswas, 2009; Hadley,

1985; Kahng, Iwata, & Lewin, 2002; Linscheid & Cunningham, 1977; Linscheid et al., 1990; Matson & Taras, 1989).

Over the next couple of decades, profound social changes affecting the classification of some behaviors for which aversion therapy was commonly used, as well as psychologists' and the general public's view of the acceptability of what were widely perceived as punitive techniques, led to the discrediting of aversion therapy (Dickinson, 2010; Holden, 1990; Timoshin, 2009). Aversion therapy was largely abandoned despite evidence of its effectiveness in the treatment of a range of behavioral disorders (Eikeseth et al., 2006; Nord et al., 1991). The recent resurgence in the use of aversion therapy in the treatment of drug and alcohol addiction has provided further evidence of the effectiveness of this treatment modality.

Aversion therapy seems to have the potential to provide effective treatment for potentially life-threatening SIB in addition to addiction and alcoholism (Bordnick et al., 2004; Lemere, 1987). Moreover, previous research suggests that aversion therapy may be particularly suitable for use in the treatment of SIB in persons with intellectual and/or developmental disabilities (Matson et al., 2012; Prangnell, 2009; Ringdahl & Falcomata, 2009). However, the possible potential of aversion therapy is likely to remain unrealized unless contemporary researchers provide additional evidence of its effectiveness as well as its ethical and practical appropriateness for use in contemporary clinical psychology practice.

If aversion therapy is effective in reducing behaviors that endanger health in individuals who do not respond to other treatments, its dismissal as a treatment option

may be considered unethical. If the costs in terms of human suffering are higher with aversion therapy than the gains in the reduction of self-injury, the recent increase in its application is unethical. The questions of effectiveness and ethics need to be considered side-by-side in order to address the cost-versus-benefit assessments that need to be made in cases of disabled individuals with SIB. Single-case research design coupled with qualitative narrative research can provide a detailed examination of the data that can be used to determine how to explore this complex issue.

Most recent SIB research has been with adolescents involved in NSSI (Franklin et al., 2014; Glenn et al., 2015; Reitz et al., 2015), and even though scholarly reviews and theoretical publications on the topic of SIB have appeared in recent years (e.g., Cautela, 2013; Luiselli et al., 2012), very little attention has been paid to aversion therapy for SIBs in developmentally disabled populations, thereby demonstrating a paucity of recent research on the use of aversion therapy for the treatment of SIB in persons with IDDs (Langdon, 2015). Moreover, existing research on the use of aversion therapy for the treatment of SIBs in the intellectually and/or developmentally disabled population lacks methodological rigor (Langdon, 2015; J. Robertson et al., 2015).

The present research is designed to address some of the existing shortcomings in the research literature. A major shortcoming in the existing research concerns the lack of controls or directly comparable cases. Another critical shortcoming is the absence of qualitative data. The question of ethics cannot be addressed thoroughly with quantitative study and requires narrative account. The family members and caretakers of those undergoing treatment can provide such data. The present study addressed these

shortcomings through the reliance on identical twin participants, both of whom are severely intellectually disabled and who exhibit a similar range of SIBs, and who have undergone different treatments (one aversion therapy, one nonaversive conventional treatment modality) for several years. The mixed-methods design of the present study helped to address gaps related both to the lack of empirical evidence on aversion therapy effectiveness and in the richness of the case data addressing the ethical issues connected with aversion therapy.

Summary

Chapter 1 consisted of an overview of the key facets of the research, including the purpose and problem statements, the theoretical framework of the study, the key methodological aspects of the study, as well as how this study is significant in the current academic sphere. Additionally, the chapter included a list of definitions for the study, and the assumptions, limitations, and delimitations that will affect this study. Chapter 2 will present a historical perspective of the literature in regard to the issue of aversion therapy and SIB, providing a deeper understanding of the theoretical framework and key concepts related to this study as a whole.

Chapter 2: Literature Review

The purpose of the present study was to investigate the effectiveness of the use of aversion therapy in comparison to a psychological treatment modality that does not involve the use of aversion in the treatment of SIB. The complexities, controversies, and variations associated with both aversion therapy and SIB necessitate a discussion and review of underlying theory, as well as prior studies on the use of aversion therapy for the treatment of SIB. In this chapter, I review the research on aversion therapy and SIB as it relates to this study. The chapter begins with an overview of my literature search strategy and the theoretical framework for my investigation.

The first part of Chapter 2 provides a general overview of aversion therapy, aversive stimuli, and aversive states. The theoretical basis of aversion therapy is discussed with reference both to its behavioral and its neurobiological foundations. Following this, the major types and components of aversion therapy are considered, along with evidence of its effectiveness for treatment of various conditions other than SIB. As noted in Chapter 1, recent research on and clinical interest in aversion therapy have centered primarily on its application in the treatment of alcoholism and addiction. In this chapter, I review this literature to provide an overview of the current status of aversion therapy as well as evidence of its effectiveness and increasing acceptance in clinical practice for some applications. A discussion of the ethical issues in aversion therapy is also provided later in this chapter.

The literature review of Chapter 2 also includes a review of research on SIB and the therapies used to treat it, with a strong focus on aversion therapy. Although a brief

background on the range and scope of SIB is provided, the primary focus of this review is SIB as it occurs in intellectually and developmentally disabled children and adults. This type of SIB includes stereotypy, head banging, and various forms of self-aggression (e.g., head slapping, eye poking, self-biting, skin scratching, and gouging; Rojahn et al., 2008, pp. 22-26). The intellectually disabled adult individuals in the present study exhibit this type of severe SIB. This type of SIB may be contrasted with what is generally called NSSI, which occurs more frequently in individuals in the intellectual and developmental normative range and is often manifested by "cutting" behaviors (e.g., individuals who repeatedly cuts their wrists and/or arms, inflicting nonlethal injuries) and may be associated with personality and psychological disorders (Walsh, 2012).

The part of Chapter 2 that focuses on SIB begins with a discussion of the prevalence of SIB, followed by a review of its etiology and phenomenology as well as its behavioral and neurobiological bases. This is followed first by a brief review of nonaversive methods of treating SIB and subsequently by a more detailed review of the literature on the use of aversion therapy to treat SIB. The gaps and the weaknesses in the existing research on the use of aversion therapy to treat SIB are noted.

Following the review of SIB is a review and discussion of ethical issues. I consider the ethical issues of aversion therapy in general as well as the ethical issues specifically related to aversion therapy for SIB. Additionally, in this section, I consider the special ethical concerns related to aversion therapy and the use of aversive behavioral interventions in intellectually and developmentally disabled persons. The rationale for the use of aversive behavioral interventions and the need for methodologically sound studies

investigating the effectiveness of aversion therapy for the treatment of SIB in individuals with intellectual and developmental disorders is explored.

Chapter 2 concludes with a brief summary of the major themes and findings in the literature as they relate to aversion therapy for SIB in persons with intellectual and/or developmental disabilities. I reflect on the gaps in the existing literature. In addition, I consider the significance and contribution of the present study to knowledge on the effective and ethical treatment SIB in persons with intellectual and/or developmental disabilities.

Literature Search Strategy

I searched the literature using university library search services and databases, notably EBSCOhost, ERIC, Academic Search Premier, PsycINFO, CINAHL, SAGE, and MEDLINE. The list of search terms included *aversion therapy*, *aversive therapy*, *aversive interventions*, *aversive stimuli*, *punishment*, *behavior modification*, *self-injury*, *self-injurious behavior*, *neurotransmitters*, *reward system*, *developmental disability*, *intellectual disability*, *severe behavior*, *aggressive behavior*, *self-aggression*, *challenging behavior*, *ethics*, *ethical issues*, and *treatment protocols*.

Theoretical Framework

Theoretical Basis for Aversion Therapy

Although its history dates to ancient times and predates modern behavior theories and therapies, aversion therapy is a behavior therapy underpinned by learning theory. Bandura (1969) included aversion therapy in his seminal text *Principles of Behavior Modification* as a legitimate and potentially effective behavior therapy, albeit one that he

cautioned should be used judiciously and only within strict ethical guidelines (p. 551). Like other behavior therapies, aversion therapy is grounded in learning theory and the behavioral principles of conditioning (Bandura, 1969; Ringdahl & Falcomata, 2009; Witkiewitz & Marlatt, 2011).

Aversion Therapy as Classical Conditioning

Aversion therapy, particularly when it is used for the treatment of alcoholism, drug addiction, eating disorders, and other conditions where an aversive stimulus (e.g., electric shock, emetic, odor, etc.) is paired with an object connected to an undesirable behavior (e.g., drinking alcohol), is based on the classical (Pavlovian) learning/conditioning paradigm (Groden & Cautela, 1981, p. 179). Pavlov's dogs were conditioned to salivate at the sound of a bell after the bell was paired with meat powder (causing instinctive salivation). In a similar way, alcoholics treated with aversion therapy/classical conditioning learn to respond to the sight and smell of alcohol (prior to actually consuming it) with nausea/revulsion following conditioning in which alcoholic beverages are paired with an emetic to induce vomiting (Dirks, 1974, p. 1331). Theoretically, after repeated pairings the individual will respond to the target object (e.g., alcohol) with the same (aversive) response (e.g., nausea, repulsion, etc.) as the aversive stimulus.

Under the classical conditioning paradigm, the person who undergoes the therapy is conditioned to produce an involuntary response of nausea when presented with the alcohol stimulus. The conditioned response of nausea to the CS (the emetic) thus replaces the involuntary response of craving/desire/good feeling to the UCS (the alcohol). The

goal of the aversion therapy is to reduce or eliminate the undesirable target behavior (Groden & Cautela, 1981, p. 178).

Aversion Therapy as Operant Conditioning or Punishment

A number of authors have called into question the appropriateness of classifying aversion therapy as a type of classical conditioning, suggesting that it might be better described as a form of operant conditioning (e.g., Bandura, 1969; Iwata, 1987; Kushner, 1966; Lerman & Vorndran, 2002; Ringdahl & Falcomata, 2009). In classical conditioning, the conditioning traditionally occurs via a neutral stimulus (i.e., one that does not produce a response). Aversive stimuli, including emetics, electric shocks, unpleasant imaginings, water mists, overcorrections, and even time-outs, are hardly neutral stimuli since they typically elicit strong avoidance and stimulation escape responses. Thus, the aversive stimuli, absent of its pairing with the undesirable behavior or object, elicits a decidedly nonneutral involuntary response.

Another difficulty with classifying aversion therapy procedures as classical conditioning is that classical conditioning requires that the timing between the pairing of the neutral stimulus (or in the case of aversion therapy, aversive stimulus) and the involuntary, UR be simultaneous or nearly simultaneous. This requirement is difficult to execute in many cases. Whereas classical conditioning involves pairings or associations between a conditioning stimulus and an involuntary response or behavior, operant conditioning involves pairings between voluntary behaviors and a consequence that is contingent upon the behavior (Bandura, 1969; Ringdahl & Falcomata, 2009). In operant conditioning, desired behavior (including the reduction or elimination of undesirable

behaviors) is shaped through the use of reinforcement (positive or negative) and punishment.

Lydon, Healy, Moran, and Foody (2015) examined 368 articles published over almost five decades (between 1967 and 2013) that included an evaluation of punishment-based procedures for the treatment of challenging behavior in individuals with developmental disabilities. Lydon et al. reviewed (a) the amount of research that has utilized punishment procedures; (b) the characteristics of the participants, behaviors, and treatments included in these studies; and (c) the relative efficacy of the treatment with consideration of the inclusion of reinforcement-based components, method of treatment selection and development, and the function of the target challenging behaviors. This comprehensive analysis provides an overview of the research literature evaluating aversive procedures as a method of reducing inappropriate behavior. The authors found that since 1990, punishment procedures have been used in fewer than 10 published articles each year (Lydon et al., 2015). The authors concluded that knowledge of behavioral function has had a seemingly limited impact on the treatment efficacy of punishment procedures.

Matson and Taras (1989) conducted a similar review, albeit 26 years earlier than Lydon et al. (2015) and suggested the maintenance of treatment effects for punishment procedures was quite good, but that less research support was available for the generalization of punishment's reductive effects. They also reported that children most frequently served as research participants in studies of punishment-based interventions, and that self-injurious, aggressive, and stereotyped behaviors were the behaviors most

frequently targeted for reduction through the application of punishment. This comparison suggests few shifts in the punishment literature over the last 2 decades.

Although none of the authors in the present review categorized covert sensitization (involving imagined aversive stimuli) as punishment, a number of researchers suggest that aversion therapy involving physical aversive procedures can best be conceptualized as punishment due to its infliction on children with intellectual disabilities (Eikeseth et al., 2006), the fact that it is used to correct undesirable behavior (Horner et al., 1990), the fact that it is best understood within the behavioral framework of punishment (Kushner, 1966), and because punishment is generally understood as a change in the environment contingent on offending behavior (Lerman & Vorndran, 2002). As defined by Groden and Cautela (1981), punishment is "the presentation or withdrawal of a stimulus following a behavior when that presentation or withdrawal leads to a reduction in that behavior" (p. 176). Thus, the therapist who utilizes the SIBIS device to deliver an electric shock to an individual's arm or leg immediately following the individual's head-banging behavior in an attempt to reduce or eliminate head banging is utilizing an aversion therapy procedure that clearly falls under the framework of punishment.

Like reinforcement, punishment may be classified as either positive or negative. Since positive punishment entails the addition of a contingent aversive stimulus following the target response, most aversion therapy procedures, including the foregoing example of the electric shock following the head-banging behavior, would comprise positive punishment. In negative punishment, a reinforcer is contingently removed

following occurrence of the target behavior or response, again in an effort to reduce or eliminate the target behavior (Ringdahl & Falcomata, 2009, p. 33). Although it would not be common practice to do so, aversion therapy could be structured as negative punishment. For example, the therapist who wished to reduce or eliminate rocking behavior might expose the rocking individual to loud, irritating noises and then stop the noises when the individual stopped the rocking behavior.

Commonly used forms of mild punishment that fit within the general theoretical framework of aversion therapy (but are typically delivered by parents and/or teachers versus professional therapists) include time-out from reinforcement, response cost, and overcorrection (Eikeseth et al., 2006; Groden & Cautela, 1981; Lerman & Vorndran, 2002; Ringdahl & Falcomata, 2009). Time-out, or time-out from reinforcement, involves either the removal of positive reinforcers or the lack of access to positive reinforcers for a specified period of time (Ringdahl & Falcomata, 2009, p. 33). Another commonly used negative punishment procedure is the *response cost*, which often involves a penalty or the loss of a positive reinforcer (Groden & Cautela, 1981, p. 177). For example, the response cost punishment for teenagers who have broken curfew could be loss of use of their cell phone for a certain amount of time.

Overcorrection is an aversive/positive punishment developed by Foxx and Azrin (1973). Foxx and Azrin initially developed the procedure as a means of rapid toilet training as well as for controlling aggressive and disruptive behavior among intellectually disabled and brain-damaged children. The original procedure was soon modified and developed and used to decrease or eliminate a wide range of behaviors, including self-

stimulation, mouthing, biting, hair pulling, nail biting, thumb sucking, stealing, public disrobing, eye poking, body rocking, an arrange of aggressive and antisocial behaviors, and SIBs (Miltenberger & Fuqua, 1981, pp. 125-127). As explained by Foxx and Azrin, overcorrection is a two-stage procedure involving (a) restitution (involving overcorrection of the inappropriate act); and (b) intensive, positive practice (the offender has to repeatedly and intensively practice performing correct forms of the behavior/positive behaviors). Among these three commonly used forms of punishment, overcorrection, a form of positive punishment, is most closely aligned with aversion therapy.

Psychology and Neurobiology of Aversive States

As previously noted, the goal of aversion therapy is to reduce or eliminate the target (undesirable) behavior through aversive conditioning. Behavior is changed through the production of a response to the aversive stimuli. This response is described as being either an avoidance behavior (the individual seeks to avoid the aversive stimulus) or as an escape behavior (the individual seeks to escape from the aversive stimulus; Bandura, 1969; Groden & Cautela, 1981; Lerman & Vorndran, 2002; Umberg & Pothos, 2011; Watson & Reyner, 1920).

Behavioral studies in animals and humans demonstrate that from the perspective of motivation, both appetitive and aversive stimuli can be either excitatory or inhibitory (Seymour, Singer, & Dolan, 2007, p. 302). While appetitive motivation is characterized by actions aimed at increasing the probability of an outcome (e.g., a rat pressing a lever to get food), aversive motivation is characterized by actions aimed at reducing the

probability of an outcome (e.g., avoidance of an electrified grid in response to a warning light; Watson & Reyner, 1920). An excitatory aversive stimulus is associated with the motivational state of fear, whereas an excitatory aversive stimulus is associated with the motivational state of relief (Seymour et al., 2007, p. 302).

Behavioral models of motivational action in Pavlovian learning are relatively straightforward, with the responses/actions directly associated to the unconditioned or conditioned stimulus, representative of "hardwired" behavior (Bandura, 1969; Pavlov, 1927; Seymour et al., 2007; Skinner, 1935). The models for instrumental learning and motivational action are more complex, as they are adaptive rather than hardwired (Bandura, 1969; Konorski & Miller, 1937; Seymour et al., 2007; Skinner, 1935, 1945, 1950). Authors of models of instrumental learning acknowledge the contribution of varied and sometimes unknown factors, including social influences, observational learning, cognition, and neural responses and feedback (Bandura, 1969; Hebb, 1955; Witkiewitz & Marlatt, 2011).

Bandura's (1969) view on the underlying psychology of aversion therapy is somewhat different from either the classical or the operant conditioning view. Rather than viewing conditioning as an automatic learned response, Bandura has stressed the importance of cognition and self-control/self-efficacy influences. Bandura's (1969) "alternative view of counterconditioning" holds that "stimuli acquire the capacity to activate a self-stimulation mechanism which, in turn, produces the aversion reactions" (p. 507). Bandura (1977) has argued that in aversion therapy, individuals do not come to view previously neutral or pleasurable stimuli as aversive, but rather they learn "to

anticipate aversive consequences" because the formerly neutral/positive stimuli have been converted into predictive stimuli that reliably predict bad consequences (p. 209). Bandura (1969) also argued that the predictive stimuli become perceived threats that activate defensive behavior, which in turn is reinforced by success in preventing or reducing aversive events.

The underlying neurobiology of aversion therapy and aversive-based learning is less well studied and less well understood than their underlying behavioral psychology (Lerman & Vorndran, 2002; Seymour et al., 2007; Umberg & Pothos, 2011). Considerable progress has been made in understanding the neurobiology of behavior since Lashley (1930) lamented following his examination of the then current state of knowledge in the field: "In reading this literature I have been impressed chiefly by its futility" (p. 1). At the same time, it should be noted that the existing knowledge of the neurobiology of behavior in general and of aversive states in particular is still quite limited and largely speculative.

The neurobiology of aversive states can be considered within the broader framework of the neurobiology of reward systems, as aversion or the avoidance of painful or unpleasant stimuli is the opposite of reward or pleasure-seeking behavior (Dichter, Damiano, & Allen, 2012; Hayes & Northoff, 2012; Higgins & George, 2013). Higgins and George (2013) observed, "Voluntary behavior in animals is motivated by the avoidance of pain and the pursuit of pleasure" (p. 136). An understanding of the neurobiology of reward systems is also useful as a foundation for considering the neurobiology of a broad range of psychiatric illnesses, neurodevelopmental disorders, and

genetic syndromes that are associated with dysfunctions in reward systems (Dichter et al., 2012, p. 19).

More than a half-century of research using animal models has enabled neuroscientists to map the basic neuroanatomy of reward systems. The neurotransmitter dopamine is the key actor in mammalian (including human) reward systems. The primary neurobiological structures of this reward system are the mesolimbic dopamine systems. The key pathways in the mesolimbic dopamine systems include neurons in the ventral tegmental area and nucleus accumbens at the base of the brain (Higgins & George, 2013, p. 138). Human neuroimaging studies conducted over the past 2 decades have demonstrated the similarity between human and other mammalian reward systems and confirmed dopamine as the primary neurotransmitter involved in the neurobiology of the human reward system (Hayes & Northoff, 2012, p. 63). Moreover, it is now known that the dopamine systems are also primarily implicated in aversive states as well as pleasure/reward states. Dichter et al. (2012) reported that "it is clear that these DA [dopamine] systems affect not only reward processing, but a number of related functions, including punishment, decision-making, cognition, reward prediction, and reward valuation" (p. 21).

From a neurobiological perspective, it is useful to distinguish between acute and chronic aversive states based on evidence of differences in neurobiological pathways in acute versus chronic aversive states. Whereas animals and humans may recover (both from a psychological and from a neurochemical perspective) quickly from an acute aversive state following the cessation of the aversive stimuli (or the individual's escape

from the aversive state), chronic aversive states are associated with chronic psychological and neurochemical conditions (Umberg & Pothos, 2011, pp. 70-71). Likewise, the neurotransmitter dopamine is affected differentially by acute and chronic aversive states. Acute aversive states, such as immediate pain and acute stress, are associated with an increase in dopamine, while depression, learned helplessness, and other conditions associated with chronic aversive states are characterized by decreased dopamine activity. The general pattern of response appears to be that acute aversive states and/or short-term aversive stimuli lead to an increase in dopamine activity, but over time (as the aversive state persists), "the brain adapts to counteract these dopamine surges by downregulating dopaminergic transmission" (Umberg & Pothos, 2011, p. 73).

The most prevalent human neurotransmitter, acetylcholine (ACh) is also profoundly influenced (often in conjunction with dopamine) by aversive states. It is thought that ACh, which acts as a neuromodulator in both the central nervous system and the peripheral nervous system, "may interact with dopamine to modulate approach and avoidance behaviors in the reward-aversion spectrum" (Umberg & Pothos, 2011, p. 73). Specifically, Umberg and Pothos (2011) reported that while increases in dopamine facilitate reward states, ACh release in the nucleus accumbens is associated with chronic aversive states. Research on the neurobiology of drug addiction has shown that dopamine and ACh seem to have a reciprocal/complementary relationship on the reward/aversion spectrum, with the latter (ACh) particularly associated with aversive states (Dichter et al. 2012; Hayes & Northoff, 2012; Umberg & Pothos, 2011). For example, while many drugs that are abused (e.g., cocaine, nicotine, amphetamines) are associated with an

increase in dopamine, ACh is known to inhibit some drug-seeking behavior. Some types of drug withdrawal (including alcohol and nicotine) are associated with increased levels of ACh. Additionally, both dopamine and ACh neurotransmitters are affected by opioid receptors, which have a modulating effect on dopamine and ACh (Higgins & George, 2013; Umberg & Pothos, 2011).

Although many of the same neurotransmitters and neural structures are involved in each, the specific neural pathways and neurobiology of aversive states have not been as clearly mapped as the neural pathways and neurobiology of reward states. An interesting question, especially as it relates to aversion therapy, is whether all aversive states are similar from a neurobiological perspective, or whether these states can be differentiated based on variations in aversive stimulus and/or environment. Based on their research drawing on animal models and neuroimaging studies of humans, Hayes and Northoff (2012) argued that there is a "core aversion-related circuit involved in processing aversive stimuli regardless of whether they are painful or non-painful" (p. 61). The implication of this finding is that from a neurobiological perspective, the aversive state produced by an electric shock should be very similar to the one produced by a nonpainful aversive stimulus, such as water mist or odor. At the same time, it may be premature to draw this inference. Hayes and Northoff found that while there seemed to be a single, core neurological aversive processing system for all types of aversive stimuli, their neuroimaging studies also demonstrated that some brain regions appear to be differentially associated with either painful (associated with the sensory cortex) or nonpainful (associated with the amygdala) aversive stimuli and processing.

Aversion Therapy, Clinical Practice, and Research

Types of aversive stimuli. In both research and clinical practice, a wide variety of aversive stimuli have been utilized in behavioral training. Types of aversive stimuli mentioned in the literature include facial screens, emetics, bitter tasting substances, water mist, electric shock (including the related SIBIS delivery system), various chemicals and pharmaceuticals stimulating aversive responses, noxious odors, painful or irritating sounds, excessively bright lights, aromatic ammonia, time-outs, response cost, and overcorrection (Eikeseth et al., 2006; Jacob-Timm, 2006; Lerman & Vorndran, 2002; Nord et al., 1991; Rice & Kohler, 2012; Ricketts et al., 1992; Sherman, 1991). In addition to these physical or actual aversive stimuli, imagined aversive stimuli (i.e., an imagined version of an aversive stimulus, such as imagining feeling nauseous) have been used in covert sensitization (Cautela, 1967). Although overcorrection, time-out, and response cost are probably the most widely used forms of aversive stimulants/punishments in clinical and educational settings, aversion therapy is most often associated with two main types of direct physical aversive stimuli, namely, chemicals/pharmaceuticals and electric shock, as well as one type of imagined aversion therapy (covert sensitization).

***Pharmacological or chemical aversion*.** Chemical or pharmacological aversives have been used extensively in the treatment of alcoholism and drugs of abuse, including cocaine, opioids, nicotine, and other substances (Bordnick et al., 2004; Dirks, 1974; Howard, 2001; Lemere, 1987). As defined by Bordnick et al. (2004), chemical aversion therapy "involves pairing chemically induced nausea using emetic agents (e.g., emetine hydrochloride) with the sight, smell, taste and thought of the desired substance" (p. 3).

Although the drug naltrexone (an opioid receptor antagonist) has also been extensively used in the treatment of alcoholism (it takes away the pleasurable feelings from drinking and reduces cravings for alcohol), the most commonly used chemical/pharmacological agent in the treatment of alcoholism is an emetic (a drug designed to induce nausea and vomiting), usually emetine hydrochloride (Howard, 2001; Lemere, 1987; Symons, Thompson, & Rodriguez, 2004).

The aversion procedure used in Schick Shadel Hospital includes the use of emetine hydrochloride and is designed to be a classical conditioning procedure. Hospital officials reject the charge that the procedures used at the hospital constitute punishment or operant conditioning (Lemere, 1987;Smith, Frawley, & Polisser, 1991). The intention at Schick Shadel is "to create a true conditioned reflex aversion to the sight, taste, smell and thought of alcoholic beverages" (Lemere, 1987, p. 257).

The chemical treatment protocol requires a brief (approximately six hour) fast prior to treatment. After giving informed consent, patients are escorted to a room that features shelves with many kinds of alcohol as well as alcohol advertising and other paraphernalia. Patients are seated in chairs and provided with emesis basins. Several minutes after drinking an oral solution of emetine, patients become nauseous. Just before the expected onset of nausea, a nurse pours the patient's alcoholic drink of choice, mixing the alcohol with warm water to enhance the odor. Patients are instructed to first smell the beverage, and then to take a small amount into the mouth, swish it around, and spit it out. The process of smelling and tasting but not swallowing the alcohol allows the patients time to develop a strong aversion to it. Patients are instructed to actually drink the

alcoholic beverage when they are just on the verge of vomiting, and as soon as they swallow vomiting commences.

The process is repeated over the next 30 to 40 minutes. The course of treatment is generally 10 days, with conditioning taking place every other day ("Schick Shadel," 2011, p. 2). Voegtlin, cofounder with Shadel of the Seattle Sanitarium and the scientist who developed the chemical aversion therapy program, spent 5 years (1935-1940) perfecting the conditioning procedures at the hospital. Voegtlin stressed the importance of precise timing: the "onset of nausea from the emetine must occur exactly at the same time that the alcoholic drinks are exhibiting" (Lemere, 1987, p. 258). Voegtlin cautioned against allowing patients to drink the alcohol too soon, because if they did, the intoxicating effects would nullify the conditioning effects. He also cautioned against allowing the patients to drink the alcohol too late, warning "the association of nausea and imbibing is not properly correlated in the patient's mind" (Lemere, 1987, p. 258).

Probably the strongest evidence of the effectiveness of aversion therapy comes from studies of the use of classical conditioning aversion therapy paradigms (mainly using chemical aversion, but also including electric shock methods) for the treatment of alcoholism. Reporting from Schick Shadel Hospitals, Lemere (1987) indicated that the hospitals had treated more than 30,000 patients between 1935 and 1987 and experienced a success rate (defined in terms of 6- and 12-month posttreatment abstinence from alcohol) of 60% to 75% (p. 257). Lemere noted that while other treatment facilities and clinicians have encountered difficulties (which he attributed to lack of attention to proper classical conditioning procedures as well as to poorly controlled studies) in replicating

Schick Shadel's success record, there had been at least two incidences of Schick Shadel training representatives from other facilities (an English treatment facility in the 1960s and a Boston-based hospital in the 1950s and 1960s) with good results (posttreatment abstinence rates of 60% or greater).

Controlled, methodologically sound studies from Schick Shadel Hospital demonstrate the effectiveness of aversion therapy versus nonaversive treatment of alcohol as measured by 6- and 12-month abstinence rates (Smith et al., 1991, 1997). Smith et al. (1991) reported that patients ($n = 249$) treated with aversion therapy had significantly higher ($p < 0.01$) alcohol abstinence rates at 6 and 12 months than a group of matched inpatients who underwent individual and group counseling treatment for alcohol abuse (p. 862). Drinkers undergoing aversion who were male, over age 35, and/or daily drinkers showed more dramatic gains from aversion therapy, with 6- and 12-month abstinence rates among these subgroups significantly different from the matched group at the $p <$ .001 level (Smith et al., 1991, p. 862). In a subsequent study, Smith et al. (1997) compared treatment outcomes in 249 patients (the same patient group as the previous study) treated with either chemical or faradic (electrical) aversion with 249 matched inpatients from a treatment registry who had undergone individual and group counseling, considering whether there were any differences in outcomes between the chemical and the faradic aversion groups.

Howard (2001) reported on the successful treatment of 82 hospitalized alcoholics with a chemical aversion therapy procedure modeled on the Schick Shadel method (five sessions over a 10-day period). Pre- and postassessments provided support for the case

that pharmacological aversion therapy produces conditioned alcohol aversion and significantly improves outcomes as well as increases patient confidence that drinking can be avoided in high-risk situations (Howard, 2001, p. 561). Measures included questionnaires, standardized psychophysiological assessments and alcohol/drug screening and dependency tests, and structured interviews. The effectiveness of aversion therapy was assessed with paired *t* tests and repeated measures of analysis of variances of pre-post measures. Stepwise multiple regression analysis of factors related to alcohol dependence measures was used to examine prediction of conditioning. The paired sample *t* tests demonstrated significant pre-post changes on four items. Specifically, patients' self-reported level of current desire to drink as well as their estimated difficulty in reducing alcohol consumption were both significantly ($p < .001$) reduced by the end of treatment. In addition, patients' confidence that they would continue to reduce alcohol consumption (even in stressful, high-risk situations) at 2 and 6 months posttreatment was significantly increased ($p < .001$; Howard, 2001, p. 574). The multiple regression factor analysis revealed that "antisocial propensities, greater severity of alcohol dependence, and more extensive prior exposure to nausea and vomiting" appeared to reduce patients' susceptibility to chemical-aversion treatment protocols (Howard, 2001, p. 583). The finding that lifetime frequency of nausea and vomiting while drinking was inversely related to effective aversive conditioning suggests that these patients experienced a preconditioning effect that reduced the effectiveness of a chemical-based aversion therapy aimed at creating a nausea response to alcohol.

Bordnick et al. (2004) evaluated the effectiveness of aversion therapy as a modality to reduce craving among 70 cocaine abusers. The participants were randomly assigned to 1 of 3 aversion therapy groups (faradic, chemical, covert sensitization) or a control relaxation therapy group. Scenarios and physical props involving pseudococaine were used. Patients for the study were recruited from a population of newly admitted inpatients at an Augusta, Georgia inpatient alcohol- and drug-treatment facility. Each group received a total of 12 treatments. Pre- and posttreatment assessments of patients' level of drug craving were conducted. Patients were asked to report, on a scale of 0 (for no craving) to 10 (for maximum possible level of craving) their level of craving for cocaine.

Results indicated that aversion therapy (all methods) was more effective in reducing drug craving than relaxation therapy or conventional group counseling treatment in treating cocaine abuse. The results were most impressive for the emetine aversion therapy group: by the end of the eighth session, 100% of the patients in this group reported a craving level equal to zero. Seventy-eight percent of the patients in the electric shock and covert sensitization groups reported zero-level craving at Session 8 (Bordnick et al., 2004, p. 18). Bordnick et al. (2004) noted that electric or covert sensitization were viable aversion conditioning alternatives for patients unable to participate in emetic-based aversion treatment for medical or other reasons. The researchers noted that covert sensitization might be preferable to electric shock methods for both safety and ethical reasons. Additionally, it is worth noting that the electric shock aversion therapy modality actually seemed to increase patients' cocaine craving slightly after each treatment

session, suggesting that “the electrical stimulation does not provide a strong enough unconditioned stimulus during treatment” to overcome the “strongly reinforcing properties of cocaine” (Bordnick et al., 2004, p. 17).

In addition to alcohol and drug abuse, chemical aversion therapy has been successfully used to treat a variety of other maladaptive behaviors. For example, Nissani (2000) described the use of an aversive taste procedure to reduce bruxism (teeth clenching) in dental patients, providing a case study of a 52-year-old man with a 12-year history of severe bruxism. A mouth-guard device designed to emit a taste aversive when it detected bite pressure was worn for 8 months (on a declining schedule). The man was able to completely stop the bruxism by the end of the study (Nissani, 2000, p. 51).

***Faradic (electrical) aversives*.** Case reports document the use of electric shock aversion in the treatment of alcoholism and sexual “disorders” (including homosexuality, which was categorized as a disorder at the time) beginning in the late 1950s and early 1960s in both Britain and the United States (King et al., 2004; Quinn et al., 1964). Schick Shadel Hospital began using electric shock (and calling it “faradic,” the name for alternating current, to avoid the stigma associated with shock treatments) aversion treatment as an alternative modality on patients for whom the use of emetics was contraindicated (e.g., persons with gastrointestinal disorders). As with its chemical aversion therapy, Schick Shadel configured its faradic aversion therapy as classical conditioning, pairing the electric shocks with the smell, sight, and taste of the alcohol (Smith et al., 1997). Quinn et al. (1964) described the use of electrical aversion therapy (using a modified electroconvulsive therapy device that delivered shocks to the soles of

the feet) with inpatient alcoholics using both classical conditioning (pairing the sight of alcohol with shock) and operant conditioning (shock following alcohol consumption) procedures (p. 436).

Researchers have cited the ability to precisely time the delivery of shocks, the ability to deliver shocks remotely or through automated systems, as well as the capacity to closely control the strength of the shock delivered as among some of the key advantages to this form of aversion therapy compared with chemical/pharmaceutical aversion procedures (Dirks, 1974; Eikeseth et al., 2006; Linscheid et al., 1990; Quinn et al., 1964). Another advantage cited for electrical aversion therapy relates to the fact that it is possible to deliver a shock as a single, brief, discrete event compared to the often-lingering effects of chemical or pharmaceutical aversives (Linscheid et al., 1990, p. 56). At the same time, the use of electrical aversion is generally contraindicated in patients with cardiac disorders and has been found to be less effective among patients with peripheral neuropathy or other disorders that reduce sensitivity in the extremities (Bandura, 1969, p. 504).

Another concern, depending upon the device used to deliver the shocks and the handling of the devices, is the possibility of causing electrical burns or cardiac fibrillation (Maurer, 1983, p. 272). There is also evidence that there is an "anesthesia effect" when an area of skin is repeatedly shocked, so that shocks to the same area become progressively less effective (Ducker, Hendriks, & Schroen, 2004, p. 104). In addition, it has also been suggested that some individuals adapt to the pain and require progressively more intense shocks. Ducker and associates (2004) remarked that there is individual

variability in sensitivity to electrical shocks, thus making it difficult to standardize delivery of the stimulus.

A variety of devices have been used to deliver electrical shocks in aversion therapy, including modified ECT machines, modified graduated electronic decelerator device (GEDs), shock rods, and specially developed devices (Dirks, 1974; Maurer, 1983; "New Chapter," 2010; Quinn et al., 1964).

Haq and Ghaziuddin (2014) reported on the treatment of two adolescent patients with autism who presented with severe aggression, one of whom also engaged in repetitive SIB. With ongoing treatment with maintenance ECT, dramatic reduction in aggression and SIB were noted, allowing both patients a reasonable quality of life in their own homes (p. 64). ECT is used in the treatment of aggression and SIB in the adult population. The few published case reports since 1999 have documented that ECT may successfully treat catatonia in patients with autism, including catatonia that presents with repetitive aggression and/or SIB (Haq & Ghaziuddin, 2014). Based on the experiences of Haq and Ghaziuddin, it was determined that withdrawing of maintenance ECT in autistic and catatonic patients precipitated a faster, more predictable relapse in symptoms than in the onset treatment of mood disorders. Further research is necessary to identify ideal parameters for maintenance ECT in this population. Above all, ongoing advocacy and educational efforts about this potentially life-saving treatment modality are important (Haq & Ghaziuddin, 2014).

One of the better-known and more widely used specially developed devices is Linscheid et al.'s (1990) SIBIS, an electrical aversion therapy device for use in persons

with SIB. The SIBIS includes a sensor/impact detector worn on the head to detect potentially self-injurious blows (the sensitivity of the detector can be adjusted and set to particular levels), a stimulus module (worn on the arm or leg) that includes a radio receiver (to receive transmissions from the head sensor), microelectric circuitry for the generation and timing of the electrical stimulus, and a recorder/counter to count the number of shocks delivered (Linscheid et al., 1990, pp. 56-57). The stimulus module is configured in such a way to ensure that the electrical shock is precisely delivered and localized to the site on the arm or leg to eliminate the risk of the electrical current passing through the body, reaching the heart, and causing cardio-electrical problems (Linscheid et al., 1990, p. 56).

Bordnick et al.'s (2004) previously discussed study comparing the effectiveness of chemical, electrical, and covert sensitization aversion therapy for cocaine addiction and abuse was one of the few published examples of electrical-based aversion therapy for non-SIB related conditions. Reports from Schick Shadel Hospital on aversion therapy treatment of alcoholism indicate that electrical-based aversion therapy is sometimes used as an alternative to the hospital's traditional chemical-based aversion therapy program with patients for whom emetic exposure is contraindicated (Howard, 2001; Smith et al., 1991, 1997). However, in general, it appears that researchers and clinicians prefer nonelectrical aversive stimuli unless there are compelling reasons to use this modality (i.e., other modalities have proven ineffective, or other modalities are contraindicated). Several studies involving the use of electrical-based aversion therapy in the treatment of SIB will be discussed in a later section of this chapter.

Covert sensitization (imagined aversion). Covert sensitization is a form of imagined aversion therapy developed by Cautela (1967) as an alternative modality for treating maladaptive behavior built on theories and procedures from Wolpe's (1958) systematic desensitization as well as aversion therapy. In this treatment, the aversive stimulus and the undesirable behavior stimulus are both imagined rather than physically present. The imagined components represent the "covert" aspect of the treatment. Cautela (1967) used the term "sensitization" to refer to the procedure's purpose of building up "an avoidance response to the undesirable stimulus" (p. 459). In other words, this procedure uses imagined aversive stimuli to condition an aversion to the undesirable behavior.

Covert sensitization can be configured as a classical conditioning aversion therapy procedure (with precise pairing of the conditioned stimulus and the unconditioned stimulus). Kraft and Kraft (2005) presented six case studies in the use of covert sensitization for the treatment of alcoholism, nail tearing, cigarette smoking, cannabis smoking, overeating, and chocolate "addiction" (as classified by the researchers) using what they described as a classical conditioning procedure to build an aversion to the craving for the target behavior (versus the behavior itself). However, Cautela (1967) characterized covert sensitization as falling under the operant conditioning paradigm, specifically as punishment. Cautela (1967) described his procedure as follows (note that Cautela first referenced drinking, as this was his first treatment trial; however, he described an analogous procedure for use in the treatment of other behavior problems):

> Since the individual is asked to imagine an aversive situation as soon as he has thought of drinking or is about to drink, this is a punishment procedure. An aversive stimulus is made to follow the response to be reduced. . . . The aversive stimulus should be presented on a continuous basis, at least initially . . . the level of punishment should be clearly noxious but not so intense as to immobilize the organism. . . . Since the patient is usually told that . . . he feels better as soon as he turns away from the undesirable object (e.g., beer, food, homosexual), this is analogous to an escape procedure. . . . Eventually, avoidance behavior occurs. (Cautela, 1967, pp. 460-461)

Covert sensitization has been used an aversion therapy treatment for a broad range of maladaptive or problem behaviors, including alcoholism, drug abuse, obesity, eating disorders, and cigarette smoking. Compared with chemical/pharmaceutical and/or electrical aversion therapy, covert sensitization carries obvious advantages in terms of safety, side effects, risks, cost of implementation, and ethics (Cautela, 1967; Eikeseth et al., 2006; Kraft & Kraft, 2005; Rice & Kohler, 2012; Sherman, 1991). Compared to other physical forms of aversion therapy (including chemical/pharmaceutical and electrical), covert sensitization has disadvantages, including those related to the need for patients who are willing and able to participate; difficulties in measurement, control, and standardization; and the requirement for a highly skilled therapist/guide (Bandura, 1969; Cautela, 1967; Dirks, 1974).

The literature on covert sensitization indicates that this can be a powerful form of aversion therapy treatment in some cases, while at the same time suggesting that overall,

it may be less powerful than other physically based aversive modalities (e.g., electrical, emetic; Bandura, 1977; Bordnick et al., 2004; Cautela, 1967; Kraft & Kraft, 2005). In his original article detailing the procedure, Cautela (1967) described his use of covert sensitization in successfully treating alcohol problems, obesity, homosexuality, and juvenile offenders and speculated that "one of the reasons for its effectiveness is probably the sense of control the individual feels over his own behavior" (p. 467). At the same time, Cautela (1967) was already aware that this new procedure sometimes yielded low success rates and that some behavior problems would be less amenable to treatment with covert sensitization than others. Notably, Cautela (1967) reported that treatment of alcohol problems was especially difficult, speculating that this was a result of the strength of the alcohol habit and its possibility of a large number of reinforcements on a daily basis as well as "drive-reducing properties of alcohol" related to the substance's effect on the nervous system (p. 467).

Bordnick et al.'s (2004) study of the use of three types of aversion therapy (covert sensitization, chemical, and electrical) and relaxation to reduce cocaine craving among cocaine abusers found that the covert sensitization treatment group required more sessions (eight sessions versus one to three for the other aversion treatments) to produce a significant reduction in cocaine craving. Although his discussion focused on imagined aversive stimuli used in systematic desensitization procedures versus covert sensitization, Bandura (1977) noted the superiority of participant modeling and real-world exposures (e.g., an actual spider for spider phobias) to imagined stimuli (p. 197).

Kraft and Kraft (2005) presented six case studies examining the value of covert sensitization for the treatment of a 20-year old man with chronic fingernail tearing, a 24-year old woman with an addiction to smoking cannabis, a 13-year old girl with an overeating problem, a 34-year old woman with a smoking habit, a 41-year old woman manifesting an "addiction" to chocolate, and a 52-year-old female alcoholic patient. In these studies, Kraft and Kraft aimed at reducing the individual's craving for the substance, and thus paired the imagined craving for the maladaptive behavior with an imagined noxious stimulus (in all cases nausea, vomiting, headache). In all but the alcoholism case, the researchers reported success (free of the behavior on follow-up after 3 to 6 months posttreatment) with only two to four treatment sessions. The alcoholic patient, however, proved more difficult and required three sessions plus another three booster sessions after an initial relapse of the behavior. Although these case studies seem to strongly endorse the use of covert sensitization, it should be noted that these researchers, in fact, combined covert sensitization with a hypnosis procedure (participants were hypnotized and given their images, and then later coached on self-hypnosis techniques).

There is considerable evidence from case studies and clinical reports supporting the effectiveness of aversion therapy in the treatment of a wide variety of different undesirable and/or maladaptive behaviors (Bordnick et al., 2004; Cautela, 1967; Howard, 2001; Kraft & Kraft, 2005; Smith et al., 1991, 1997). As discussed earlier, there is a much smaller body of evidence on aversion therapy effectiveness that can be drawn from controlled studies or even from studies with a modest degree of methodological rigor.

Lerman and Vorndran (2002) reviewed the evidence on the effectiveness of operant conditioning-based aversion therapy (which they labeled as punishment) and found strong evidence that various aversive procedures (e.g., shocks, noise, time-out, blasts of air) produced rapid decrease in target behavior frequency in both animals and humans. Moreover, they noted that improvements seen through aversive procedures were frequently superior to that achieved through other behavior methods, including extinction, satiation, and DR. Lerman and Vorndran went on to note that their review indicated the benefit of punishment in treating intractable problem behaviors, including those for which less invasive treatments had proven ineffective. At the same time, the authors noted significant limitations in the existing research, including lack of adequate research on factors influencing the conditioning process, the use of conditioned punishers in treating problem behavior, the methods to develop and maintain the conditioned punishers, and the role of reinforcement schedules among other factors. A major limitation in Lerman and Vorndran's review was their failure to specify (other than indicating "problem behaviors" and "aggressive and disruptive behaviors") the type of behavior targeted in the studies reviewed, or the type of population exposed to the aversive interventions. By failing to specify the type of population exposed to interventions, the research is not clearly interpretable or generalizable. Interventions that may succeed with problematic, aggressive, and disruptive individuals may not work with individuals who do not demonstrate these behaviors, such as those with substance abuse issues.

Miltenberger and Fuqua (1981) provided a structured review of the literature on the use of overcorrection to treat a variety of behavior problems. They examined more than 95 studies published between 1975 and 1981 that described the use of overcorrection procedures on the behavioral problems of children, adolescents and adults. The behaviors targeted for overcorrection in the studies included tics, bed wetting, self-stimulation, toileting accidents, eye contact, drooling, aggressive behaviors, body rocking, stealing, and swearing (as well as an assortment of SIBs). Although Miltenberger and Fuqua noted many methodological shortcomings in the studies and criticized the lack of analytical research, they found that in the vast majority of studies reviewed, overcorrection had a "decelerative effect on behavior" (p. 136). However, Miltenberger and Fuqua also noted that there were two distinct drawbacks to overcorrection, citing specifically the amount of staff time that was required to apply the procedure as well as potential difficulties related to the size of the individual receiving overcorrection, with larger individuals representing more of a potential danger to themselves and staff.

Limitations in effectiveness. Although the literature suggests that aversion therapy may be appropriate for treating a broad range of behavioral problems, research studies and clinical evidence to date suggests that aversion therapy may be inappropriate and/or ineffective for some people. Dirk's (1974) case study, for example, is a seminal work that has been frequently referred to in the literature. Dirk reviewed archival reports from Schick Shadel hospital, as well as data from a London group that used aversion therapy in the treatment of inpatient alcoholics, as part of his research on the potential for using aversion therapy in a correctional setting. Severely limiting the potential usefulness

of aversion therapy in a correctional setting was the finding that aversion therapy does not appear to be effective when it is involuntary: only patients who willingly submitted to aversion therapy and were middle to upper class appeared to benefit from it (Dirks, 1974, p. 1334).

Literature Review Related to Key Variables and/or Concepts

Self-Injurious Behavior and Its Treatment

Prevalence. SIB prevalence rates vary widely across different epidemiological studies and reports. The studies in this review that included reference to prevalence rates yielded estimates of lifetime prevalence in community samples ranging from 1.5% to more than 20% and lifetime prevalence in clinical populations (institutionalized or community-based) ranging from 5% to more than 75% (Furniss & Biswas, 2012; Hamza et al., 2013; Kakhnovets et al., 2010; Klonsky, 2011; McCloskey, Ben-Zeev, Lee, & Coccaro, 2008; Oliver & Richards, 2010; Richards, Oliver, Nelson, & Moss, 2012; Rojahn et al., 2008; Totsika, Toogood, Hastings, & Lewis, 2008; Walsh, 2012; Xeniditis, Russell, & Murphy, 2001; Yates, 2004). Unfortunately, there is still much that remains unknown in regard to prevalence rates of SIB, because most organizations do not collect information on the phenomena. For example, the Centers for Disease Control and Prevention (2016) compiles statistics regarding SIB prevalence nationwide, but fails to distinguish how much of it occurs within clinical populations, especially among intellectually disabled individuals. There are a number of reasons for the wide variation in SIB prevalence estimates. Although SIB often occurs in conjunction with specific psychological, psychiatric, and developmental disorders, there is no standard *DSM*

operational definition for SIB, despite it being examined with various scales, such as the Lifetime Self-Destructiveness Scale, from index admission to 2-year follow-up periods (Zanarini et al., 2008), and from questionnaires paired with a functions index (Hamza et al., 2013). Different sampling strategies, settings, population reference points, and assessment methods further complicate the task of accurately assessing prevalence of SIB (Klonsky, 2011; Oliver & Richards, 2010; Rojahn et al., 2008; Totskika et al., 2008).

Some researchers' attempts to provide population-wide estimates of SIB include a very broad-based definition of SIB encompassing a wide range of nonlethal, nonsuicidal SIBs in the intellectually normative population as well as a range of nonlethal and potentially lethal SIBs in the intellectually and/or developmentally disabled population (Moran et al., 2012). Some researchers focus predominantly on the intellectually normative, community-dwelling population when making their estimates, while other researchers focus on SIB prevalence estimates for intellectually and/or developmentally disabled persons (Hinshaw, 2015). Even in instances where the population is clearly defined, such as Klomek et al.'s (2016) cross-sectional study on SIB in bullied teens in Europe, often authors fail to specify the behaviors included in the definition of SIB. In other cases where the population is not clearly defined, such as Brunner et al.'s (2014) correlational study of SIB in European adolescents, SIB may be grouped together with a range of other ill-defined challenging or problem behaviors that may or may not include SIB

Another methodological concern with existing prevalence estimates is the likelihood of underreporting, given that people who engage in SIB may attempt to hide

their behavior. Different sampling strategies, settings, population reference points, and assessment methods further complicate the task of accurately assessing prevalence of SIB (Klonsky, 2011; Oliver & Richards, 2010; Rojahn et al., 2008; Totskika et al., 2008).

Methodological considerations aside, there is a general agreement that the prevalence of SIB is higher among intellectually and/or developmentally disabled populations than among intellectually normative populations. Klonsky's (2011) recent study of NSSI among intellectually normative, community-dwelling American adults provides one of the more methodologically rigorous estimates of SIB prevalence among the intellectually normative population found in the literature. Based on a random sample of 439 adults (age range from 19 to 92 years, mean age of 55), Klonsky estimated 12-month prevalence of 0.9% and lifetime prevalence of 5.9%, including 2.7% reporting five or more incidents of self-injury (p. 1981). The average reported age of onset for self-injury was 16 years. The specific types of self-injury reported included cutting/carving, burning, biting, scraping/scratching skin, hitting, and skin picking.

The focus of the present study is SIB in two persons with IDDs. As previously noted, SIBs are associated with a number of different clinical syndromes. SIB as it occurs among nonintellectually disabled persons is associated with obsessive-compulsive disorder, borderline personality disorder, chronic pain, and major depression as well as other clinical syndromes (Ernst, 2000; Walsh, 2012). In intellectually and/or developmentally disabled populations, SIBs are associated with autism, mental retardation, developmental disorders, fragile X syndrome, Down syndrome, attention deficit hyperactivity disorder, intermittent explosive disorder, Lesch-Nyhan disease,

Cornelia de Lange syndrome, and Prader-Willi syndrome (Ernst et al., 2008; Oliver & Richards, 2010; Rojahn et al., 2008; Xeniditis et al., 2001).

Various SIB prevalence rates have been reported in association with specific clinical syndromes among persons with intellectual and/or developmental disabilities. Based on structured interviews with 276 adult subjects diagnosed with intermittent explosive disorder, McCloskey et al. (2007) reported a SIB prevalence rate of 7.4%, a suicide attempt rate of 12.5%, and a "self-aggression" rate of 16% (p. 248). SIB was defined as a "physically self-damaging act with the conscious intent to hurt one's self, but not to end one's life" (McCloskey et al., 2007, p. 251). Neither attempted suicide nor "self-aggression" were operationally defined in this study. Richards et al. (2012) estimated prevalence rates of SIB in samples of youth with diagnosed autism spectrum disorder (n = 149), fragile X syndrome (n = 132), and Down syndrome (n = 49) to be 50% (autism), 54.5% (fragile X), and 18.4% (Down syndrome; p. 476).

Minshawi et al. (2014) examined the epidemiology of SIB in children with autism spectrum disorder, factors that predict the presence of SIB in this population, and the empirically supported behavioral treatments available for SIB. The researchers defined SIB as a class of behaviors that the individual inflicts upon himself/herself that have the potential to result in physical injury, more specifically tissue damage (Minshawi et al., 2014). Minshawi et al. found that children with autism spectrum disorder demonstrate SIB at high rates. The authors noted that punishment-based strategies have a long history of use in the treatment of SIB (Minshawi et al., 2014). The application of electric shock is

the most extreme application of negative stimuli (one should note that this is distinctly different than electroconvulsive shock therapy; Minshawi et al., 2014).

Reliable estimates of the prevalence of SIB in intellectually and/or developmentally disabled persons overall are difficult to find. Rojahn et al. (2008) commented, "The state of the art in the epidemiology of intellectual disabilities in general is woeful due to lack of standardized research methods and widely varying definitions of the targeted behavior" (p. 25). The authors noted that among the studies of SIB they reviewed, "it was the exception to find inclusion or exclusion criteria" of the behaviors classified or not classified as SIB (p. 26). Given these considerable limitations, the authors estimated overall prevalence rates of between 4% and 9.3% (p. 25).

Although reliable overall prevalence rates for SIB in intellectually and/or developmentally disabled persons are difficult to find, it is possible to make a range of research-based characterizations about SIB in this population. In general, the more severe the disability, the higher the rate of SIB (Richards et al., 2012; Rojahn et al., 2008; Xeniditis et al, 2001; Yates, 2004). Likewise, lower levels of intellectual and/or behavioral functioning are associated with higher prevalence and frequency of SIB (Minshawi et al., 2014). Rates of SIB are much higher in institutionalized persons than persons residing in nursing homes, community care, parental homes, or disabled persons living independently (they have the lowest rate of SIB; Magagna, Emilia, Vargas, Lozano, & Cabezas, 2013). NSSI in community-dwelling, nonintellectually disabled persons is several times more prevalent among women than men (Rizzo et al., 2014); however, among intellectually and developmentally disabled persons, there is no clear

relationship between gender and SIB, with the exception of SIB linked to specific genetic syndromes such as Lesch-Nyhan and fragile X (Schroeder et al., 2014). Although adults with IDDs are much more likely to exhibit SIB than nonintellectually disabled adults, in both population groups there is a higher rate of SIB among younger (teenage) persons (Repp, Felce, & Barton, 1988; Rojahn et al., 2008; Wolff et al., 2013).

Etiology and phenomenology. Among the many factors that must be considered in developing behavior therapy treatment plans are the antecedents and etiology of the specific behaviors targeted for treatment (Bandura, 1969; Watson, 1913). There are two main perspectives on the etiology and development of SIB, particularly SIB emerging in childhood or adolescence. The dominant view, and one that has both informed and supported behavioral-based treatment, is a behavioral model of SIB as "a response to environmental or social stressors," wherein individuals injure themselves in order to escape from social demands or situations, gain attention, or to relieve anxiety (Sandman, et al., 2012, p. 516). The behavior model for SIB gains empirical support from numerous studies demonstrating the effectiveness of behavioral interventions (especially including aversion interventions; Furniss & Biswas, 2012, p. 454). The behavioral model for SIB conceptualizes the development and maintenance of SIB as operant conditioning entailing social-negative reinforcement, social-positive reinforcement, and automatic reinforcement (Furniss & Biswas, 2012; Iwata, 1987; Repp et al., 1988).

Repp et al. (1988) characterized SIBs among persons with severe intellectual and/or developmental disabilities as "common forms of maladaptive responding" (p. 281). Iwata (1987) argued, based on review of studies on behavioral treatment of SIB,

that self-injury is primarily a negatively-reinforced behavior, with negative reinforcement (related to escape from demands and avoidance) playing a much greater role in shaping SIB than positive reinforcement (including attention-seeking; p. 365-368).

The second major model of SIB theorizes that this behavior has a biological basis (Carr & Smith, 1995; Davenport, Lutz, Tiefenbacher, Novak, & Meyer, 2008; Dichter et al., 2012; Furniss & Biswas, 2012; Sandman et al., 2012; Symons, 2011). Within this biological model, SIB is seen as a consequence of biological system imbalance or dysregulation (Furniss & Biswas, 2012, p. 454). As Sandman et al. (2012) explained, the biological model of SIB hypothesizes that "SIB is motivated by an underlying biological disturbance either in the pain and pleasure system or in the dissipation or generation of arousal" (p. 517). The biological model of SIB is also known as the homeostasis function or self-stimulation model, wherein the individual's self-stimulating SIB is seen both as a function of and as an attempt to correct homeostatic imbalance (Ernst, 2000, p. 448).

The association between SIB and certain metabolic (Lesch-Nyhan disease) and neurological (Cornelia de Lange syndrome) disorders tends to support the biological model (Wolff et al., 2013). Besides these two major models of SIB etiology, alternative explanations include self-injury as part of a ritual or compulsion, self-injury as a response to chronic pain, self-injury as a failure in development, self-injury as part of a reflex syndrome, and self-injury as self-punishment and/or as part of a psychoanalytic model (Carr & Smith, 1995; Ernst, 2000; Sandman et al., 2012; Thompson, Symons, Delaney, & England, 1995; Yates, 2004). Recent studies using animal models as well as neuroimaging studies with humans have begun to identify possible neurobiological

mechanisms and structures involved in SIB. Included among these are disruptions in the reward system, the disruptions/malfunctions in pain signaling and perception, stress responses, and the role of endogenous neurotransmitters (Davenport et al., 2008; Muehlmann, Wilkinson, & Devine, 2011; Peebles & Price, 2012; Stanley et al., 2010; Veinante, Yalcin, & Barrot, 2013).

Treatment of Self-Injurious Behavior: Methods Other Than Aversion

Treatment of self-injurious behavior in the intellectually normative population. Behavioral interventions, specific behavior therapies, and cognitive behavior therapies are predominant in the treatment of SIB in both the intellectually normative population and the intellectually and/or developmentally disabled population. Only two articles regarding a nonbehavioral or non-CBT approach to treating SIB in the intellectually normative population have been published, and both of these are not empirical research reports. In addition, both advocated the use of behavioral or CBT techniques in conjunction with the nonbehavioral therapies used by the authors (Bratter, Esparat, Kaufman, & Sinsheimer, 2008; A. C. Healey & Craigen, 2010).

Bratter et al. (2008) discussed the rationale and described the implementation of reality therapy-based confrontational therapy in the treatment of gifted adolescents who engaged in self-destructive (including self-injurious) behavior at the John Dewey Academy in Great Barrington, Massachusetts. Confrontational therapists, as its name suggests, confront patients with their failings and bad behavior and demand accountability, not to please others, but to demonstrate self-respect. Patients are confronted about their maladaptive behaviors in individual and group sessions. Bratter et

al. (2008) reported that at the John Dewey Academy, confrontational therapy is integrated with DBT.

A. C. Healey and Craigen (2008) advocated the development and use of an Adlerian feminist approach integrated with established cognitive behavioral methods for treating SIB in adolescent and adult females, particularly women diagnosed with borderline personality disorder and engaging in cutting SIB. In this approach, the therapist moves away from labeling the patient as borderline, and works to establish an egalitarian, empowering alliance in which the client can "participate in redefining herself or himself in conjunction with her or his current coping behavior" (A. C. Healey & Craigen, 2010, p. 376). Neither of these approaches appears to be relevant for intellectually and/or developmentally disabled individuals with SIBs.

Treatment approaches using cognitive behavioral therapy and dialectical behavior therapy. Van Vliet and Kalnins (2011) described the use of compassion-focused therapy, a form of CBT, in the treatment of adolescents and young adults with SIB. Van Vliet and Kalnins focused on patients with psychological/psychiatric disorders but no significant intellectual disability and who engaged in what they characterized as NSSI. No specific case data were presented. Rather, the authors discussed compassion-focused theory (characterized by caring and concern and empathy) and its promise for promoting emotional regulation among adolescents and young adults engaged in SIB.

Developed originally for the treatment of severe behaviors (including NSSI and suicidal behavior) in persons diagnosed with borderline personality disorder, DBT has been shown to reduce SIB in normal intellect adolescents and adults (Harned, Jackson,

Comtois, & Linehan, 2010; Muehlenkamp, 2006). DBT includes a range of CBT and problem-solving interventions, as well as skills training (focused on the development of effective coping skills), and stresses the importance of finding a balance between change (changing behavior) and self-acceptance (Muehlenkamp, 2006, p. 171).

Harned et al.'s (2010) study evaluated the efficacy of DBT in reducing SIB among 51 adult female suicidal and/or self-injuring women with diagnosed borderline personality disorder and some symptoms of post-traumatic stress disorder. All participants received standard DBT involving weekly (1 hour) individual psychotherapy, weekly (2 and one-half hours) group skills training, and as-needed phone consultation with a licensed therapist and researcher. Assessments were made at pretreatment and at 4-month intervals through the 1-year treatment period. Results indicated that DBT had a significant effect on reducing suicidal and SIB, with the percentage of clients deemed to be at "imminent risk" of suicide falling from 28% before treatment to 0% posttreatment, and the percentage of clients exhibiting self-injury falling from 96.2% at pretreatment to 29.2% at posttreatment (Harned et al., 2010, p. 424).

Muehlenkamp (2006) reviewed the literature for evidence of the efficacy of two different interventions: DBT and PST in the treatment of NSSI in adolescents and adults. Muclenkamp reviewed 16 studies using DBT to treat NSSI, including randomized clinical trials, intervention studies, case studies, and clinical case reports. The author's conclusion was that the "studies reviewed suggest that DBT is effective in reducing NSSI, particularly among individuals with BPD [borderline personality disorder]" (p. 173). At the same time, Muehlenkamp noted the relative lack of controlled studies (only

four of the review studies were randomized clinical trials), the overall failure to identify and study the particular elements of DBT that lead to its effectiveness, and the possibility that the result could not be generalized to individuals without BPD, as most of the research has involved clients with this diagnosis. Muehenkamp also looked at the evidence for the efficacy of the use of PST in the reduction of NSSI. The underlying theory of PST is that the self-injurious and other maladaptive behaviors reflect dysfunctional coping behaviors and a "cognitive or behavioral breakdown in the problem-solving process" (Muhlenkamp, 2006, p. 165). Overall, Muehlenkamp assessed the evidence on PST's effectiveness in reducing NSSI as "inconclusive" based not only on conflicting findings, but also on the limited number of studies and methodological flaws in the research (pp. 169-170).

Treatment of self-injurious behavior in intellectually or developmentally disabled persons. Behavior-based treatments dominate the nonaversive therapy approaches to treating SIB in the intellectually and/ or developmentally disabled population Three studies described the use of extinction interventions in the treatment of SIB. Yang (2003) described the use of extinction combined with nonintrusive restraint to reduce SIB (severe head scratching) in two institutionalized female adolescents with profound intellectual and physical disabilities. Both individuals had been wearing (for 2 years) mechanical restraints (mittens, elbow braces) to prevent injury from SIB. Functional analysis indicated that social attention reinforced and maintained their SIB.

At the start of each session, the therapist directed the individual's hands to touch and manipulate activity materials for 30 seconds. The individual's hands were then

released to start the procedure. During the extinction procedure, no attention was directed towards any attempted or actual SIB, although the therapist engaged in limited noncontingent social interactions about topics unrelated to SIB. To reduce the risk of injury, the individual's fingernails were cut short and filed and head hair was cut short. To further reduce risk of injury, petroleum jelly was applied to their fingertips as well as to each individual traditional target areas for self-injury (i.e., forehead, chin, top of head, ears). Target scratching behaviors were eliminated over the course of 14 to 17 30-minute sessions and 6-month follow up confirmed that neither individual had resumed scratching behavior (Yang, 2003, p. 109).

Oliver, Petty, Ruddick, and Bacarese-Hamilton (2012) evaluated the independent association between adaptive behavior, communication and repetitive or ritualistic behaviors and self-injury, and aggression and destructive behavior to identify potential early risk markers for challenging behaviors. Data were collected for 943 children aged 4 to 18 years with severe intellectual disabilities. The authors reported that 153 (17%) of the total sample engaged in SIB, 356 (39.5%) demonstrated aggressive behavior, and 267 (29.6%) demonstrated destructive behavior. Children with autism demonstrated higher levels of self-injury and stereotyped behavior, and poorer impulse control (Oliver et al., 2012). Oliver et al. stated that a higher prevalence of autism spectrum disorder is evident in those with more severe intellectual disability and compromised communication is associated with both severe intellectual disability and autism spectrum disorder.

Luiselli (1988) presented a case study of a 6-year old boy's self-injurious arm biting using two different response-contingent deceleration procedures (physical

immobilization, drinking a distasteful solution) and two forms of sensory extinction (wearing tennis wrist bands or orthoplas protective cuffs). The results indicated that only the sensory extinction procedure that included protective cuffs significantly reduced arm biting.

Finally, Banda, McAfee, and Hart (2012) presented the results of a clinical case study involving fading restraint and a fixed reinforcement schedule with extinction to reduce SIB (severe head hitting) in a 14-year old boy diagnosed with severe autism and Tourette's syndrome. The boy in this case had a 2-year history of severe SIB (he hit his head with his hands an average of 3 times per minute during daily activities) and a more recent history of self-restraint (wrapping his hands tightly in blankets, putting a blanket over his head). To protect from injury, the boy consistently wore a padded boxing helmet and light boxing gloves. The study used an ABAB design with two baselines and two intervention phases. During the first baseline, the boy wore boxing helmet and gloves, but had no access to blankets. Researchers collected data in 5-minute sessions while a teaching assistant presented tabletop activities, praised the student for completion of the activities, and blocked SIB using existing classroom procedures of verbal cautions and physical blocks.

During the first intervention, the student had access to one large blanket (and continued to wear helmet and gloves). The teaching assistant used social attention reinforcement on a fixed interval schedule (10 seconds) as long as the student was not hitting himself. The teaching assistant turned away and did not speak for 10 seconds anytime the student hit himself. The second baseline measurements were taken using the

same procedures as the first baseline. The second intervention phase followed the procedures of the first and because of reduced rates of SIB, parents volunteered to discontinue the use of helmet and gloves. During the final fading phase, the student did not wear helmet or gloves. The student was given access to one blanket for the first four sessions (procedures were the same as in the first intervention) and then, after rates of SIB had dropped to near zero, the blanket was systematically cut (0.1 to 0.3m were removed from the horizontal and vertical edges of the blanket) seven times over 33 sessions. Use of the blanket was discontinued entirely after 28 sessions of zero or near-zero SIB. SIB dropped from more than 30 arm bites per hour at baseline to less than five per hour after 15 sessions. SIB increased at first during restraint fading and was eventually brought to zero by session 52. Follow-up found the student free from SIB several months posttreatment (Banda et al., 2012, p. 173).

In a study demonstrating one of the longest sustained successes in the behavioral treatment of SIB, Jensen and Heidorn (1993) detailed the behavioral interventions used to reduce SIB (eye gouging, head slapping, scratching) in a 27-year old profoundly retarded blind man (he blinded himself with eye gouging) and presented 10-year follow-up data. The intervention combined mild restraint with positive social and food reinforcers. After six months of behavioral intervention, the frequency of the patient's SIB was reduced to near zero. During the first 6 months posttreatment, SIB occurred less than once per day (versus dozens of times during baseline) and during the last 4 years of follow-up, there were no incidents of SIB (Jensen & Heidorn, 1993, p. 277).

Konarski and Johnson (1989) evaluated the use of brief arm restraint plus DRA to treat SIB in two inpatients (one age 31 and one age 19) with multiple mental and physical disabilities. Social (praise and touching) and food (milk) were provided as reinforcers. During the study, the SIB of one client dropped to 2% of baseline, while appropriate behavior climbed from 18% to 100%; the second client's SIB reduced to 9% of baseline after treatment, while appropriate behaviors increased from 26% at baseline to 99% posttreatment (Konarski & Johnson, 1989, p. 45).

To explore what types of behavior interventions might be most effective in reducing SIB (self-punching and slapping) in a 21-year old male with profound intellectual disability and autism, J. J. Healey, Ahearn, Graff and Libby (2001) conducted an extended functional analysis with two experiments in reducing SIB. The first experiment began with a multielement phase that involved exposing the individual to five different alternative conditions in rapid succession. After the initial multielement phase, a series of six (the initial five conditions plus a sixth condition) one-condition assessment phases were carried out. The first condition was called "attention," and involved the experimenter and the individual in a room with available leisure materials. The experimenter did not attend to the individual unless SIB occurred, and then the experimenter voiced concern or disapproval and provided brief physical contact.

In the second condition, called "edible," the experimenter and the individual were seated across from each other at a table in an otherwise empty room. Prior to data recording, the experimenter delivered a small quantity of food to the individual at 15-second intervals, with a 5-second hold following any occurrence of SIB. Food was then

removed from the individual's reach but kept within eyesight. When SIB occurred, the experimenter delivered a small quantity of food. In the third condition, called "demand," the individual and experimenter were again seated at a table in a room empty except for task materials. Every 15 seconds, the experimenter verbally instructed the individual to perform a range of difficult (for his ability level) tasks. Responses completed without prompting resulted in brief verbal praise.

When SIB occurred, all instructions/demands were terminated, and task materials removed for 15 seconds. In the fourth condition, called "alone," the individual sat alone in an otherwise empty room and was observed. There were no programmed consequences for SIB or any other behavior. In the fifth condition, or "play," the individual was given access to a variety of his preferred leisure materials. The experimenter delivered social attention (verbal praise, touching) at 15-second intervals, with a 5-second delay for occurrences of SIB. Based on results during the first five conditions, a sixth condition, called "sensory," was added. In this condition, the individual was observed while he was alone in a room that contained a number of highly preferred sensory toys (providing a range of auditory, vibratory, tactile and olfactory simulation) that were not available in other experimental conditions or in the individual's regular environment.

In Experiment 2 (J. J. Healey et al., 2001), a sensory treatment procedure combining elements of the edible and sensory conditions from Experiment 1 was deployed. The most preferred sensory (three items) and edible (two items) elements were identified and used in the experiment. In the sensory treatment phase of the experiment, the individual had response-independent access (via a pocketed waist belt) to the sensory

items. The experimenter delivered edible items paired with verbal praise on a fixed 30-second schedule. There was a 5-second changeover delay for occurrences of SIB. These 15-minute sensory treatment sessions alternated with 15-minute nonsensory treatment periods. During the nonsensory treatment, the sensory waist belt was removed. Instructional demands were paired with a DRA procedure. Correct responses were reinforced with the presentation of a preferred food item and social praise, with a 5-second hold of both food and praise for any occurrence of SIB. Measured across several months, the frequency of SIB decreased 55.3% from baseline measures during the daily treatment hours, while increasing 7.3% during nontreatment comparison hours (J. J. Healey et al., 2001, p. 191).

Steege et al. (1990) used negative reinforcement to treat SIB in two profoundly mentally retarded children (a girl aged 5 and a boy aged 6) who exhibited hand/wrist biting SIB primarily associated with grooming activities (both children were completely dependent upon others for self-care, including grooming). A functional assessment confirmed that negative reinforcement (escape from grooming activities) was the main reinforcer for SIB. The treatment intervention for both individuals combined negative reinforcement (brief escape from grooming contingent upon occurrence of the alternative behavior of pressing a microswitch that triggered a message saying “Stop!” to play) with guided compliance (hand-over-hand guidance on the grooming task). The experimenter stopped the grooming activity for 10 seconds when the child pressed the microswitch. If the child did not voluntarily press the switch, the experimenter physically prompted the

child to do so and then, contingent on the child's cooperation with grooming activities, allowed 10 seconds avoidance of grooming activities.

The guided compliance strategy was implemented whenever the child engaged in SIB. The efficacy of the negative reinforcement was tested in a design that measured baseline SIB over four sessions, followed by five treatment sessions, two baseline measurements, five treatment sessions, four baseline measurements, and six treatment sessions. Instructors and parents were trained in implementing the treatment in school and home environment. Follow-up studies were conducted at 6 and 12 months. The treatment led to a significant decline in SIB for both children, with SIB rates dropping from 60% to 80% of baseline observations and 5% to 12% during negative reinforcement treatment (Steege et al., 1990, p. 463). SIB rates spiked to near original baseline levels during the second and third baseline measurements for the female child. Second and third baseline SIB levels also increased over treatment level SIB for the male child, but not to original baseline level.

At follow-up, one child (the boy) manifested low rates of self-injury (8% of observations) and an increase in task-related appropriate behaviors. The other child (the girl) had high rates (80%+) of SIB related to all grooming tasks. Steege et al. (1990) noted that the boy's parents and instructors had continued to implement treatment, while the girl's parents and instructors had declined to implement treatment during the follow-up period. Overall, the study results seem to indicate the short-term efficacy of negative reinforcement as a treatment for SIB,but call into question its long-term usefulness, as it

seems treatment must be continually maintained in order to keep SIB rates from quickly returning to baseline levels.

Reviews. Prangnell (2009) provided a systematic review of the 2000 to 2009 literature on behavioral interventions for SIB. The review covered 425 studies encompassing a total of 861 participants, with 41% of the papers reviewed including persons under 18 years old (Prangnell, 2009, p. 261). The majority of the studies reviewed were single-case designs or a series of four or fewer cases, and only one study included a control group. In addition to aversive interventions and punishment, the approaches represented in Prangnell's review included functional communication training, noncontingent reinforcement, DR (including DRA and DRO, with the latter the most widespread intervention cited), desensitization and recent fading, desensitization combined with education and blocking, and response cost (which was not classified as punishment in this review). Not surprisingly, given the variety of approaches represented and the lack of methodological rigor, Prangnell concluded that the efficacy of the various behavioral interventions was highly variable.

Matson et al. (2012) reviewed best evidence practice for the treatment of challenging behaviors (including SIB) in adults with intellectual disabilities. Aside from pharmacological treatments, Matson and associates focused on various behavioral treatments. Positive behavioral support, a treatment approach developed in the 1980s reportedly in an effort to provide an alternative to aversive techniques, emphasizes "nonaversive behavioral interventions with increasing respect, improving interpersonal relationships and building personal competency" (Matson et al., 2012, p. 589). Matson et

al. reported strong empirical support for the use of various DR interventions, with DRO and DRA having the most research support. Although there is empirical support for various DF interventions in treating intellectually disabled adults with challenging behaviors, including SIB, Matson et al. cautioned that research results confirmed the importance of individualizing reinforcement (e.g., a hug or other display of physical affection may provide effective positive reinforcement for some individuals and have no effect or a negative effect on other individuals).

Aversion therapy treatment of self-injurious behavior. A search of PsychLit and other scholarly databases using the combined keywords *aversion therapy* or *aversive* and *self-injurious behavior* or *self-injury* yielded only a handful of articles published within the past dozen years and only a small number published within the past 25 years, with that number dwindling as the years progress. There were 506 articles identified in the literature search on this specific topic published in the past 5 years. It should be noted that none of those articles are an in-depth, all-encompassing review of the collected studies on SIB and aversion therapy within the intellectually and developmentally disabled.

Within that same time frame, studies on aversion therapy for individuals involved in NSSI amount to 1,170 articles. As previously stated, most recent SIB research has been with adolescents involved in NSSI (Franklin et al., 2014; Glenn et al., 2015; Reitz et al., 2015). Comparatively little attention has been paid to aversion therapy treatment for SIBs in developmentally disabled populations, as opined by Langdon (2015). Moreover, a significant proportion of these are analytical and/or discussion articles focusing on the

ethics and controversies surrounding the use of aversives in the treatment of SIB rather than studies on aversion therapy for SIB. Systematic and analytical reviews of behavioral treatment of self-injury, including behavioral treatment of SIB in developmentally disabled children, adolescents, and adults (the population in which aversion therapy for self-injury has been most thoroughly used and researched) indicate that aversion therapy has been in declining use since the early 1980s, with positive behavioral support methods becoming the dominant behavioral intervention over the past 3 decades (J. J. Healey et al., 2001; Kahng et al., 2002; Matson & Taras, 1989; Matson et al., 2012; Snell, 2005).

The historical literature does provide support for the effectiveness of the treatment of SIB with aversion therapy. Matson and Taras (1989) reviewed 23 relevant peer-reviewed journals covering the period 1967 to 1987 and selected 382 studies on punishment/aversive-based and other alternative (predominantly behavioral) treatment of severe behavior problems, including SIB, among developmentally disabled persons. Many of the behavioral studies included a mixture of aversive and nonaversive interventions, although there were a few purely aversive studies and a larger number that used no aversive stimuli. Overall, Matson and Taras concluded that most behavioral interventions (aversive, nonaversive, and combination) were effective in reducing the frequency of SIB. Studies that included an aversive component (or studies that used only aversive stimuli) showed higher success rates (success defined as measurable, significant reduction in SIB) than studies using purely nonaversive interventions. To date, there have been no updated reviews of the literature related to aversion therapy in treating

intellectually and developmentally disabled individuals with SIB, and the Matson and Taras review remains the most recent publication on the topic.

Matson and Taras (1989) also refuted claims made by opponents of aversion therapy that although such treatment results in short-term reductions in SIB, it does not lead to long-term suppression of SIB. On the contrary, they noted that all of the aversion-based studies reporting follow-up data "showed significant maintenance of treatment gains" (Mason & Taras, 1989, p. 85). An additional concern is the paucity of follow-up data in most of the studies and the related difficulty in drawing conclusions about the long-term success of aversive interventions.

Kahng et al. (2002) conducted a quantitative analysis of behavioral treatment of SIB across 35 years from 1964 to 2000. Kahng et al. identified 396 studies involving a total of 706 participants, most of who were diagnosed with severe/profound intellectual disability. Studies (including single-subject design research) using any behavioral intervention (alone or in combination) as a treatment for SIB were included. Studies using pharmacological interventions alone or in combination with behavioral or other treatment were excluded from the analysis. Treatments included in the review were categorized broadly into reinforcement based, punishment based (aversion therapy), or other (including restraint, response blocking, antecedent based). The most common type of SIB in the studies was head-banging/hitting (49% of participants). Kahng et al. estimated treatment effectiveness by using the last five data points from the baseline and the treatment phases. In the case of studies reporting multiple replications, final phase data were analyzed.

Kahng et al.'s (2002) analysis of treatment effectiveness found that most treatments demonstrated an 80% reduction in SIB from baseline level, although reinforcement-based interventions used alone or in conjunction with response blocking had lesser rate of SIB reduction (73%) in these studies (Kahng et al., 2002, p. 212). Very few studies included in this review included follow-up data, so it was not possible to draw conclusions about the long-term effectiveness of the interventions. Moreover, Kahng et al. observed numerous flaws in the study designs and methodologies and their pooled data, noting a great deal of variability in the differences in study quality.

Miltenberger and Fuqua's (1981) systematic review of studies using overcorrection interventions to treat maladaptive behavior included four studies involving a total of 30 participants (a mixture of children, adolescents, and adults, all with moderate to severe intellectual disabilities and developmental disorders). Overcorrection procedures produced large, immediate (within a few days) reductions (usually to zero) of SIB. Follow-up data were provided in one of the studies (a single-subject study) and showed sustained complete suppression of SIB for 6 months posttreatment (Miltenberger & Fuqua, 1981, p. 127).

Electric shock has been one of the more frequently used aversive stimuli in aversion therapy protocols aimed at reducing severe, long-standing SIB. Concerns about risks of severe cardiac events, electrical burns, inconsistency in the timing and intensity of the shock, and abuse of shock delivery schedule led to Linscheid et al.'s (1990) development of the previously described SIBIS. Linscheid et al. presented a clinical evaluation of the SIBIS based on five cases of severe and previously unmanageable SIB

in one child, two adolescents, and two young adults. All the individuals were severely or profoundly intellectually disabled and two were additionally diagnosed as autistic. All individuals had experienced severe injuries as a result of their SIB, and previous attempts to treat the SIB had been unsuccessful. Reversal and/or multiple baseline designs were used. In all five cases, the SIBIS-based aversion therapy resulted in rapid, nearly complete reversal of the SIB while the SIBIS was worn. The results also demonstrated that the suppression of SIB could be generalized to multiple locations outside of the original treatment area (but again, only when the SIBIS was in place).

Although follow-up data were provided in 4 of the 5 cases, Linscheid et al. (1990) noted "stimulus generalization, whether or not SIBIS could be removed or faded while maintaining a therapeutic effect, was not addressed systematically" (p. 75). Anecdotal reports suggested that the removal of the SIBIS led to a fairly rapid "rebound" in SIB, at higher-than-baseline levels in two cases, while in two other cases, lower-than-baseline frequencies and intensities of SIB were maintained for as long as 2 weeks. The analysis indicated that in 4 of the 5 subjects, there was no evidence of habituation to the electric shocks, although in one case the subject appeared to require more shocks and higher intensity shocks to effect reduction in SIB.

Corte, Wolf, and Locke's (1971) study compared the effectiveness of three treatment approaches (elimination of all social consequences, DRO, and electric shock aversion) to eliminate the SIB (face slapping, face banging, hair pulling, face scratching, and finger biting) of four institutionalized, profoundly retarded adolescents. The first two treatments (elimination of social consequences and DRO) were attempted with the two

individuals who manifested less severe SIB (so that the experiment could run longer without risking severe injury). For the elimination of social consequences procedure, Individuals 1 and 2 were observed (via a one-way mirror) 1 hour per day each for 12 consecutive days. They were alone in a room and no social stimulation was available. There was no measureable decrement in either subject's SIB. For the DRO procedure, after an initial 14 baseline sessions (15 minutes each) with no contingencies, the individuals were given a bite of food (candy) for any behavior other than SIB for the next 10 sessions. Three observers counted SIB responses during the sessions. Neither showed any decrease in rate of SIB. The procedure was continued for 25 more sessions with the first individual and 10 more sessions with the other, with a change in the food reinforcer (instead of a bite of candy, they were spoon-fed a thick malt) and under conditions of food deprivation (lunch was withheld on the days that the experiment was conducted).

Under these conditions, the first individual's SIB rate declined rapidly from the 20 responses per session during baseline and 22 responses during the no-deprivation procedure to zero for the 25 deprivation sessions with the malt reinforce (Corte et al., 1971). The second individual exhibited no decrease in rate of SIB. Throughout all DRO experiments, the rate of interobserver reliability was very high (98% to 100%). Electric shock aversion procedures (shocks were delivered contingent on SIB) were used with all four individuals. In an effort to encourage generalization of results, shock procedures were carried out in three different locations, conducted by three different observers, and delivered under "seen" and "hidden" (the individual could not see the observer/experimenter) conditions. The electric shock aversion procedure eliminated SIB

(the rate reduced to zero by the third to fourth session in each series) in all cases and in all "seen" observed conditions in all settings. However, the results did not readily generalize to new settings or new observers/experimenters (Corte et al.,1971). As Corte et al. (1971) noted, "the effects of the punishment were usually specific to the setting in which it was administered" (p. 201). Contrary to their expectations about the capabilities of intellectually deficient individuals, the individuals in this study were clearly able to discriminate not only between settings (different rooms) but also between adults. The researchers noted that this finding implied that when treating SIB with aversive stimuli, it is important to "include the active generalization of the effects through a planned program of treating the behavior under as many different conditions as necessary to produce a generalized effect" (Corte et al., 1971, p. 212).

Ricketts et al. (1992) reported the results of a single-subject case study examining the relative effectiveness of two treatments for SIB in a 25-year-old man with profound intellectual disability and epilepsy. Treatment 1 consisted of the opiate antagonist naltrexone delivered in single daily dosages and Treatment 2 combined naltrexone treatment with SIBIS-based aversion therapy. The results indicated a 32% reduction in SIB when naltrexone alone was used. The reduction was maintained for 4 weeks but then increased to baseline levels during weeks 10 to13 (Ricketts et al., 1992, p. 322). The addition of SIBIS to the treatment intervention resulted in a dramatic increase in SIB behavior. Moreover, SIB continued to increase with the use of the SIBIS (which had been tested as a single-intervention strategy in this individual and was shown to be very

effective) as the dose of naltrexone increased. The researchers were unable to determine why the addition of SIBIS to the treatment protocol led to increased SIB.

In an early, well-designed, single-subject study, Griffin et al. (1975) described the aversion therapy for treatment of SIB (face-slapping, hand/wrist biting) in a blind, profoundly retarded adult male. The researcher tested the efficacy of multiple forms of punishment/aversion, including hair pulling and hair tug with electric shock using various ratios and different restraint designs. Partial suppression of SIB was achieved through the hair pulling only punishment. Full suppression of SIB was achieved with the hair tug plus electric shock treatment. Treatments were applied daily through 6 months in sessions ranging from 30 minutes to 8 hours in duration. Posttreatment follow-up demonstrated total suppression of SIB in all settings in which the individual regularly functioned for 3 years (Griffin et al., 1975, p. 458).

Tanner and Zeiler (1975) reported on an experiment using punishment with aromatic ammonia to eliminate SIB (head and face slapping) of a 20-year–old, severely autistic institutionalized woman. Aromatic ammonia capsules were selected as the aversive stimulus based on their relative safety (no lasting damage to mucosal structures), low cost (less than three cents per capsule), and small size (which made the capsules easy to conceal and to distribute to all staff). Observation periods were 3 to 5 minutes in length (researchers did not believe it was safe to leave the individual without her protective helmet for longer than this).

In the first phase of Tanner and Zeiler's (1975) experiment, the experimenter applied the ammonia capsule under the individual's nose when she slapped herself and

withdrew the capsule when slapping stopped. Tanner and Zeiler noted that she reacted violently to the ammonia and commented that it might be difficult to use this particular aversive stimulus with a physically stronger or more agile person. After the intervention, the rate of slapping decreased from a mean of 38.4 per minute to 1.3 per minute. During the last three sessions of this experimental phase, the experimenter applied the ammonia whenever the individual brushed her hair back from her forward, a behavior shown to be a precursor of slapping. The rate of slapping declined to zero through four observation periods. Upon return to baseline, the rate of slapping increased to a mean of 42.5 slaps per minute (Tanner & Zeiler, 1975, p. 55).

During Tanner and Zeiler's (1975) second experimental phase, the SIB was immediately eliminated and follow-up 21 days after the last experimental session found no occurrences of the SIB. Nursing staff were supplied with ammonia capsules and instructed on applying ammonia whenever she slapped herself. Although there was no observation or recording of the number of face slaps or ammonia applications outside of the experimental sessions, staff reported that the SIB had been substantially reduced from preintervention levels. It was also noted that SIB could have been reduced further had staff been consistent about applying the ammonia at each face slap (sometimes staff approached the individual but did not apply the ammonia, sometimes staff forgot to carry the capsules, etc.). It is notable that suppression of SIB occurred only so long as frequent and ready application of the ammonia was possible. Tanner and Zeiler commented, "It appeared that punishment would have to be continued indefinitely in order to control the slapping" (p. 57).

In contrast to Tanner and Zeiler's (1975) finding regarding the need for continuous punishment, Lerman, Iwata, Shore, and DeLeon's (1997) study suggested that in some cases of SIB, it may be possible to gradually thin an aversive/punishment schedule from continuous to intermittent. Lerman et al. (1997) reported the results of a study investigating punishment schedule thinning in the treatment of SIB (hand mouthing and head hitting) in five institutionalized adults with profound mental retardation. Functional analysis indicated that the individuals' SIB was not maintained by social consequences and that it was most likely maintained by automatic reinforcement. Treatment with continuous schedules of time-out (one individual) or contingent restraint (four individuals) produced "substantial reductions" (the researchers did not quantify the reductions) in SIB. When these individuals were exposed to intermittent schedules of punishment (fixed interval of 120 seconds or 300 seconds), SIB for all but 1 of the 5 returned to pretreatment levels.

Lerman et al. (1997) then attempted to gradually (no quantification for "gradually" was provided) thin continuous punishment schedules for the four individuals who did not maintain SIB suppression with a sudden switch from continuous to intermittent punishment. The procedure was successful in 2 of the 4 individuals. Intermittent punishment proved ineffective in suppressing SIB in the other two cases, despite repeated attempts to thin the schedule. The study thus appears to demonstrate the value of thinning from continuous to intermittent punishment schedules for some people with SIB, and at the same time illustrates that intermittent punishment schedules may be ineffective in suppressing SIB in others.

Singh, Watson, and Winston (1986) reported on three experiments comparing the effectiveness of a water-mist spray aversive, facial screening, or forced arm exercise in the treatment of SIB and related behaviors in a three profoundly retarded, institutionalized 17-year old females. The young woman in Experiment 1 had a 7-year history of face slapping. The purpose of the experiment was to compare the efficacy of water-mist spray and facial screening on her face slapping. Twice-daily 30-minute sessions were divided into 180 ten-second intervals and the number of SIB responses recorded by two trained observers. Following 5 days of baseline observations, two treatment interventions were introduced: (a) the individual's face was sprayed with 0.5 to 0.75 cc of water immediately after each face-slapping occurrence, and (b) a terrycloth bib was tied around her neck and pulled over her face and firmly held for 5 seconds. The mean number of SIBs during water-mist spray sessions was 5.6 (versus 21.9 in baseline), and the mean number of SIBs during facial screening was 4.2 (Singh et al., 1986, p. 404). In a second phase, facial screening was applied in both daily treatment sessions and SIB decreased further to a mean rate of 0.9 responses per session.

The young woman in Singh et al.'s (1986) second experiment had a 10-year history of low-rate and relatively mild (in intensity) SIB (finger licking, face punching, jaw hitting, and self-biting). Experiment 2 compared the same two procedures (water mist and facial screening) as in Experiment 1 with her SIB of excessive finger licking. This experiment also investigated replication of treatment effects across different therapists. Results indicated that facial screening was more effective than water mist for reducing SIB (the SIB rate fell from a mean of 3.7 per minute in baseline to 2.8 per minute with

water mist and 0.2 for facial screening). Results were successfully replicated across therapists and through a 6-month follow-up. In addition, associated SIBs (jaw punching) also decreased in frequency and an increase in appropriate social interaction was noted (Singh et al., 1986).

The individual in Singh et al.'s (1986) Experiment 3 had a 10-year history of face slapping and ear rubbing. Experiment 3 compared the efficacy of water mist spray with another aversive intervention, forced arm exercise (the therapist grabbed her wrist before she touched her ear, extended her arm and "pumped" the arm up and down 25 times at a rate of one pump per second) in eliminating the ear-rubbing SIB. The forced arm exercise was more effective at suppressing SIB: SIB occurred in 9.2% of observed intervals when forced arm exercise was applied, versus 22.7% in water-mist spray condition and 98.4% in baseline (Singh et al., 1986, p. 408). In both Experiments 2 and 3 the water-mist aversive was deemed to be effective in suppressing in SIB but not as effective as less intrusive alternatives. Singh et al. also found that in each experiment, the subjects' adaptive social behavior increased with the suppression of the SIB.

Paisey and Whitney (1989) provided evidence of the long-term effectiveness of aversion therapy in their study of the treatment of life-threatening pica in an institutionalized, 16-year old male with "profoundly retarded collateral self-injurious and aggressive conduct" (p. 191). The individual's pica was nonspecific, very severe, and frequently life threatening because of his ingestion of potentially lethal objects, including broken glass and cleaning fluid. As a result of consuming large quantities of lead-based paint in early childhood, he had chronic lead poisoning, and years of consuming a broad

range of inedible, sharp, and toxic items had resulted in multiple corrective surgeries and a range of pica-related medical conditions.

Paisey and Whitney's (1989) study involved two directly aversive stimuli: contingent water mist (delivered by an observer contingent on pica and accompanied by a loud "No!") and contingent lemon juice (contingent on pica, an observer grasps his jaw and delivered a squirt of concentrated lemon juice directly into his mouth, while saying a loud "No!"). A third indirect aversive was the use of a contingent mesh hood (placed on his head contingent on pica) that prevented him from ingesting (but not from attempting to chew) food edibles. The experiment involved placing "bait" (potential pica items) in front of the individual, as well as allowing unlimited access (except when the mesh hood was in place) to food edibles. Full treatment (with various schedules and in various settings) continued for 18 months, with the different aversives gradually withdrawn over the next 4 months.

Paisey and Whitney's (1989) analysis showed that the lemon juice aversive, but not the water-mist aversive, immediately suppressed pica. The water mist provided additional suppression of pica, however, when used as a punishment for an antecedent to pica (wandering into unsupervised areas). Functional assessments, behavioral analysis, and analysis of data over a 4-year period led Paisey and Whitney to conclude that "pica suppression was primarily a function of the introduction, maintenance, and withdrawal of aversive contingencies, rather than of concurrent schedules of positive reinforcement" (p. 191).

Arntzen and Werner (1999) reported on a study investigating the effectiveness of a water-mist punishment to reduce self-injurious and aggressive behavior in a 50-year-old woman with severe intellectual disability. Prior to this study, clinical staff had tried DRI, DRO, time-out and overcorrection for the woman's problem behavior. Although overcorrection resulted in a modest, short-term reduction in SIB and aggressive behaviors, none of the less invasive procedures had met with any success. The water-mist punishment took the form of a focused direct stream of cold water sprayed into her face first in response to aggressive behaviors and later in response to SIB. The targeted aggressive behaviors were reduced to 5% of baseline activity within 16 days (Arntzen & Werner, 1999, p. 92). However, during this first phase of the study, the SIB increased as more aggressive behaviors were targeted in different settings. After the introduction of the water-mist punishment, SIB was reduced to less than 5% of baseline within a few weeks. There were no observed negative side effects to maintenance of the aversive procedures over 18+ months, and the treatment effect was maintained with both categories of problem behavior (aggressive and SIB) at less than 10% of baseline throughout the study period. Without warning and against advice of the researchers, authorities terminated the procedure after 19 months and the rate of SIB rapidly climbed to more than 3 times baseline (Arntzen & Werner, 1999, p. 92).

Reflections on the Aversion Therapy Literature

Decades of clinical data from Schick Shadel and other alcohol/drug treatment facilities using aversion therapy, combined with independent research studies comparing aversion therapy with other approaches in the treatment of alcoholism and other

addictions, provide strong evidence that aversion therapy is an effective treatment for alcohol and some other addictive behaviors in the intellectually normative population (Bordnick et al., 2004). The clinical data and research on aversion therapy for addiction have also provided important information about the strengths and weaknesses of different aversive interventions (e.g., electrical versus emetics), the importance of intervention scheduling, and the potential effectiveness of imagined aversive intervention (covert sensitization) in some cases (Bordnick et al., 2004; Howard, 2001).

The recent resurgent interest in aversion therapy for the treatment of addiction and alcoholism has not sparked recent interest in or investigation of aversion therapy for other behavior problems, including SIB. Indeed, the review of literature clearly profiles a movement away from the use of aversive interventions and towards increasing reliance on PBT for most problematic behaviors and in most populations, including SIB and the intellectually and/or developmentally disabled population. The review of the literature on SIB prevalence highlighted the close positive association between severity of intellectual and/or developmental disability and the prevalence and frequency of SIB (Richards et al., 2012; Rojahn et al., 2008; Xeniditis et al., 2001; Yates, 2004).

The review of literature on the etiology and phenomenology of SIB revealed a dominant behavioral model of SIB that conceptualizes the development and maintenance of SIB as operant conditioning entailing social-negative reinforcement (Furniss & Biswas, 2012; Iwata, 1987). An emerging biological model conceptualizes SIB as a consequence of biological system imbalance or dysregulation (Furniss & Biswas, 2012;

Sandman et al., 2012). Both the behavioral and the biological models of SIB provide theoretical support for the use of aversive interventions to treat SIB.

The literature on nonaversive approaches to treating SIB in the intellectually normative population suggested that a variety of behavioral, CBT, and alternative therapies might provide at least partial effectiveness in the treatment of SIB (mainly the type characterized as NSSI) in the intellectually normative population (Bratter et al., 2008; Harned et al., 2010; Van Vliet & Kalnins, 2011). It seems unlikely, however, that the CBT and alternative approaches would be very useful in treating intellectually and/or developmentally disabled individuals with SIBs because of limitations in their cognitive and communicative abilities.

Behavior-based interventions, including extinction and various types of DR comprise the dominant nonaversive approach to treating SIB in persons with intellectual and/or developmental disabilities. A number of the studies reviewed demonstrated that a programmatic application of negative reinforcement and various DR interventions led to significant decreases in SIB among the intellectually and/or developmentally disabled individuals in the study (J. J. Healey et al., 2001; Jensen & Heidorn, 1993; Konarski & Johnson, 1989; Steege et al., 1990). Many of the studies showing the most significant and lasting reductions in SIB combined some type of physical restraint (itself arguably an aversive intervention) with the nonaversive behavioral interventions (Jensen & Heidorn, 1993; Konarski & Johnson, 1989). An important lesson or take away from these studies is the critical role of functional assessments and/or functional analyses prior to the development of a behavioral intervention (aversive or nonaversive) plan to treat SIB in

intellectually and/or developmentally disabled individuals (J. J. Healey et al., 2001; Steege et al., 1990).

Although there was support for the use of nonaversive behavioral interventions in the treatment of SIB in the intellectually disabled population, the review of literature also pointed to problems and shortcomings in this treatment approach, including the need for personalized reinforcers and reinforcement schedules, the rapidly "wearing off" of treatment effects after intervention ceases, and the danger of a substantial rebound in SIBs after intervention stops (Steege et al., 1990).

The vast majority of research on this topic was published more than 20 years ago, and a considerable portion of the literature on aversion therapy treatment of SIB in the intellectually disabled population dates from the 1970s and 1980s. However, there were 14 studies published in the last 20 years, including a literature analysis published in 2017. It is noteworthy to mention, one study in 2008 involved 60 subjects and included M, and one study in 2010 involved seven subjects, respectively. Although there were a number of relatively methodologically sound studies (including experimental studies) included in the review, the literature on aversion therapy for SIB in the intellectually and/ or developmentally disabled population is dominated by single-case studies, anecdotal reports, and analytical reflections. Notwithstanding this limitation, the preponderance of evidence drawn from systematic reviews, meta-analysis, experimental and quasiexperimental studies, and other research studies indicates that aversion therapy is a potentially effective (and found to be more effective than nonaversive behavioral interventions in some studies) treatment for SIB in intellectual and/or developmentally

disabled individuals (Corte et al., 1971; Griffin et al., 1975; Lerman et al., 1997; Linscheid et al., 1990; Miltenberger & Fuqua, 1981).

The review of the literature on aversion therapy for SIB in intellectually disabled individuals highlighted strengths and weaknesses in different types of aversive interventions (e.g., the superiority of electrical aversive stimuli for controlling the timing and intensity of the intervention), problems related to individuals' adaptation to aversive stimuli and the wearing-off effect, and difficulties in generalization of response effect and the need to plan for active generalization (Arntzen & Werner, 1999; Corte et al., 1971; Linscheid et al., 1990; Ricketts et al., 1992; Tanner & Zeiler, 1975).

Taken as a whole, the literature on aversion therapy in the treatment of SIB in intellectually and/or developmentally disabled persons suggests that aversion therapy can be quite effective quickly (much more quickly than other approaches) and significantly reduces target SIBs in this population (Corte et al., 1971; Kahng et al., 2002; Lerman et al., 1997; Linscheid et al., 1990; Paisey & Whitney, 1989). Notwithstanding this general finding, there are severe weaknesses and gaps in the literature on the use of aversion therapy for SIB in intellectually and/or developmentally disabled persons. These problems include a reliance on single-case designs, a lack of use of controls and/or comparable cases, designs complicated or confused by the use of multiple different aversive interventions, designs complicated or confused by the inclusion of multiple participants with different SIBs, differing levels of SIB severity, and different personal characteristics, as well as the lack of follow-up.

The present study aimed at addressing some of the weaknesses noted in the literature as well as providing potentially unique contributions to the field. No other studies located in this review drew on a study population of identical twins. Moreover, the twins participating in this study are both severely intellectually disabled, both in an institutional setting, and exhibit closely similar SIBs in terms of type, severity, and frequency. Although the two individuals in this study received similar treatments during childhood and adolescence (holding therapy), since the age of 21 (they are now 42 years of age), they have received different treatment approaches: one conventional therapy (PBT and psychotropic medication) and the other, ABA, including electric shock-based aversive therapy. The present study thus offers a unique opportunity to compare one type of aversion therapy with the conventional treatment in two individuals who are genetically identical and have closely similar intellectual disabilities and SIBs.

Ethical Issues Related to the Use of Aversion Therapy

Controversies and ethical issues: General concerns. Throughout its contemporary history, aversion therapy has been tainted by controversies and haunted by ethical concerns (Jacob-Timm, 1996; King et al., 2004; Leslie, 1997; Maurer, 1981; Nord et al., 1991; Rice & Kohler, 2012; Sherman, 1991). The aversion therapy controversy is more than just a public image problem. Many psychologists, including behavioral theorists, have voiced ethical concerns about its use (Bandura, 1969; Barron, 2007; Corte et al., 1971; Eikeseth, et al., 2006). As Corte et al. (1971) observed, "The calculated application of painful stimuli, albeit without injury, always involves important ethical consideration" (p. 202).

Among psychologists' ethical concerns raised by aversion therapy are the ethics of using punitive and/or invasive/intrusive procedures when positive reinforcement and nonintrusive procedures could be used instead (Bandura, 1969; Barron, 2007; Holden, 1990; Horner et al., 1990; Jacob-Timm, 1996; Jones & McCaughey, 1992; Michaels, Brown, & Mirabella, 2005). Moreover, some have argued that researchers and therapists are ethically bound to focus on the development of more effective nonaversive behavioral treatments rather than investigating or expanding the use of aversive behavioral treatments (Horner et al., 1990; Michaels et al., 2005). There are also concerns that the patient may be physically harmed by the aversive procedures (e.g., get electrical burns, suffer cardiac effects from electrical aversion, suffer side effects from chemical aversion, etc.) as well as concerns that the patient may be psychologically and emotionally harmed by aversive procedures (Barron, 2007; Eikeseth, et al., 2006; Maurer, 1983).

The potential for abuse of aversive therapy and its procedures is another major problem (Holden, 1990; Jacob-Timm, 1996; Maurer, 1983; Rice & Kohler, 2012; Sappington, Rice, Bulison, & Gordon, 1981). As with any psychological treatment, there are ethical concerns related to the need for informed consent, and there are particular ethical concerns when a patient is unable to provide informed consent (Jacob-Timm, 1996; Sherman, 1991). Finally, there are concerns regarding the longer-term psychological effects of punishment. Aversion therapy may have the potential to cause longer-term psychological problems in patients undergoing treatment (Jacob-Timm, 1996; Rice & Kohler, 2012; Rojahn et al., 2008).

Given these concerns, even the staunchest aversion therapy advocates warn that its use should be carefully monitored and controlled. A commonly stated position is that aversion therapy should be used only after treatment with noninvasive methods (including behavioral and other methods) has failed (Corte et al., 1971; Holden, 1990; Jacob-Timm, 1996; Singh et al., 1986). Others argue that it would be unethical not to use aversion therapy as a first-line treatment for conditions where it has been shown to be among the most effective form of treatment or when it has the potential to stop or reduce life-threatening self-injury (Eikeseth et al., 2006; Holden, 1990; Matson & Kazdin, 1981; Matson & Swiezy, 1990).

Ethical concerns with aversion therapy treatment in SIB. The controversies and ethical concerns with aversion therapy are amplified in the case of aversion therapy for SIB. Unlike aversion therapy for alcoholism or drug addiction, aversion therapy for SIB has frequently involved minority-aged patients and/or adults who cannot give informed consent because of the nature of their condition. The use of punitive interventions in children is inherently controversial and raises unique ethical dilemmas related to the treatment of persons who are not old enough to provide consent, even if they were intellectually capable of providing consent (Drotar, 2008; Jacob-Timm, 1996; Rice & Kohler, 2012; Sherman, 1991). The use of aversive interventions with children has also historically led to intense and often bitter conflicts between parents/guardians, educators, and clinicians about what level of invasive treatment is appropriate (Jacob-Timm, 1996; Pickering et al., 1988).

Regardless of the age of the persons undergoing aversion therapy for SIBs, there are often questions about the competency of such individuals to provide consent. As noted, there is a close association between severe SIB and severe IDDs (Jacob-Timm, 1996; Rice & Kohler, 2012; Rojahn et al., 2008). These individuals, regardless of age, are unable to provide consent (Adams & Boyd, 2010; Bentley, 1987). Legal guardians (individuals or institutions) generally provide consent for treatment. When patients or research participants are unable to provide informed consent, imbalances of power between patient and therapist or participant and researcher are exacerbated, and the potential for therapist/researcher abuse of power increases (Adams & Boyd, 2010; Bentley, 1987; Iacono, 2006).

Like prisoners, people with severe intellectual disabilities and/or limited cognitive capabilities are inherently vulnerable to abuse (Adams & Boyd, 2010; Iacono, 2006). Because of these individuals' limited cognitive capabilities and severe restrictions in communication abilities, they are not able to express pain, frustration, and other objections to aversive treatment to the extent that intellectually normal individuals can. Therapists and researchers get only limited feedback on how the aversive treatment affects these individuals. This may lead the therapist or researcher to incorrectly conclude that the treatment does not really harm the patient or research participant when in fact it does (Adams & Boyd, 2010; Iacono, 2006). The lack of clear feedback from the patient or participant may lead the therapist or researcher to treat the individual as less than human and to perhaps ignore obvious signs (e.g., screaming, extreme avoidance behavior) that the individual is experiencing significant physical and/or psychological

pain (Adams & Boyd, 2010; Bentley, 1987; Feudtner & Brosco, 2011; Sappington et al., 1981).

In considering the ethics of using aversive treatments for the SIBs of persons with profound intellectual disabilities, it is also important to reflect on the therapist's or researcher's perspective on and reactions to the intellectually disabled person with SIBs. The display of severe SIB is alarming to most observers, including those with professional training. Revulsion and a strong desire to stop the behavior are common responses (Rojahn et al., 2008). A range of other behaviors often accompanies SIB, including pica, coprophagia, and extreme aggression, which may also provoke responses of revulsion and a desperate desire to stop the behavior. These feelings might make it easier for a therapist or researcher to rationalize the use aversive techniques as the quickest means of stopping the behavior. These responses might also result in the further dehumanization of the patient from the perspective of the therapist or researcher.

Another ethical problem for therapists and researchers treating intellectually disabled individuals with aversive therapy for SIBs is that there is not yet a full understanding of the psychological and physiological functions of SIB. If, as some researchers have suggested, SIB represents the individual's attempt to address or respond to pain, does the elimination of SIB through painful aversive stimuli actually impair the individual's capacity to address unseen painful stimuli?

The major advocate groups for persons with IDDs are unilaterally opposed to the use of aversive procedures to treat SIB or any other condition or problem in persons with IDDs (Iacono, 2006; Sajwaj, 1977; Stoltz, 1977). The American Association on

Intellectual and Developmental Disabilities (AAIDD, 2012) condemns all aversive procedures and "urges their immediate elimination" (p. 1), arguing that aversive procedures cause physical pain, have potential or actual physical side effects, and dehumanize the individual. The joint position statement of the AAIDD and the Association for Retarded Citizens on behavior supports states that the organizations are "opposed to all aversive procedures", arguing that "behavioral supports should be individually designed and positive" (AAIDD, 2010, p. 1).

A search of the literature revealed no clear consensus among behavioral therapists regarding the ethical use of aversive treatments for SIB in persons with intellectual and/or developmental disabilities. There is a split between those therapists who join with the AAIDD and Association for Retarded Citizens in categorically rejecting aversive treatments and those who argue that aversion therapy treatment of severe SIB is, in some cases, the optimal treatment (Feudtner & Brosco, 2011; Horner et al., 1990; Matson & Kazdin, 1981; Matson & Swiezy, 1990). Among the latter group, there is no established guideline or algorithm for parsing the ethical appropriateness of using aversion therapy for the treatment of SIB in persons with intellectual and/or developmental disabilities.

In general, analysts who have made the ethical case for aversion therapy treatment of SIB have taken a utilitarian approach, weighing the potential costs of the treatment (e.g., pain, discomfort, etc.) against the benefits of the treatment results (e.g., reducing or stopping the SIB, improving positive behavioral and social functioning, etc; Bentley, 1987; Matson & Kazdin, 1981). In cases where the SIB is mild or does not pose significant risk of severe injury, the threshold for permitting aversion therapy must be

higher than in cases where the SIB is severe and potentially life threatening. For most persons, a reasonable approach is to weigh the discomfort/risks/costs against the potential benefits in deciding when to undergo or approve the treatment (Israel, Blenkush, von Heyn, & Rivera, 2008). However, before weighing the costs against the benefits of aversion therapy treatment, the therapist or researcher first needs to ask if there is a nonaversive alternative that could be tried first.

In cases of destructive behaviors, the treatment of a person with destructive behaviors often involves many components including nonantipsychotic medication, a range of behavioral procedures, as well as other treatments (Blenkush, 2017). If it is determined that all positive or nonaversive alternatives have been exhausted, the therapist/researcher is ethically obligated to apply the type of aversive stimuli based on the severity of the behavior and to conduct the treatment in a way that minimizes harm risk. Regardless of how mild the aversive stimulus, multiple safeguards need to be put into place to ensure consistency of treatment and safety of procedures as well as to protect against therapist/researcher abuses (Bentley, 1987; Corte et al., 1971; Feudtner & Brosco, 2011). Finally, throughout the research and/or therapy process, the researcher/therapist is ethically obligated to treat the individual/patient with respect and dignity, and to avoid taking any action that dehumanizes them.

My present study involved a comparison of aversion therapy, including ABA and conventional PBT, in two severely intellectually disabled genetically identical male adults with a lifelong history of closely similar behaviors. The twins in this study have extremely challenging and dangerous (potentially life-threatening) behaviors, including

head banging. From the perspective of the ethical framework discussed, the use of invasive aversive interventions in these cases can be justified given the individuals' risk of severe injury or death as a consequence of their SIBs and given the potential (based on research evidence) for aversion therapy to significantly reduce the frequency of the SIBs.

The unique design of this study (offering a direct retrospective comparison of two different approaches in genetically identical individuals with similar SIBs) also can be ethically justified based on its potential to advance understanding of effective treatment of severe SIB in intellectually and/or developmentally disabled individuals. In addition, I addressed ethical issues in the qualitative component of the study by gathering the lived experiences of the family and caretakers of the individuals who are in treatment. Their perspective of the ethics of treatment also adds to the literature on this topic in a substantive manner by helping researchers understand how those close to individuals in treatment understand this aspect of therapy.

Summary

The general trend over the past 2 decades in behavioral treatment for any type of behavioral problem, including SIB, has been to move away from aversive/punitive stimuli and towards positive behavior supports, or at least towards commitment to using the least aversive/invasive intervention possible. The trend has been to use behavioral interventions involving aversive stimuli only when all other nonaversive treatment alternatives have been exhausted. Until-positive-only procedures are able to treat individuals with very severe behavior problems effectively, and without disabling and harmful psychotropic drugs, it is only prudent and humane to keep available the option of

supplementing positive procedures with aversives when required (Israel, Blenkush, von Heyn, & Sands, 2010). A notable exception has been in area of alcohol and drug addiction, where there has been renewed interest in and application of aversion therapy by prominent alcoholism treatment facilities (Bordnick et al., 2004; Howard, 2001; Smith et al., 1991, 1997). Clinical evidence from these treatment facilities, combined with research studies on the use of aversive interventions for the treatment of addictions, speaks to the potential effectiveness of aversion therapy in the treatment of a broad range of problematic behaviors (Bordnick et al., 2004). Yet, with the exception of studies involving aversion therapy treatment of alcoholism and addiction, few researchers have investigated aversion therapy as a treatment modality over the past 3 decades.

The present literature search and review did not uncover any recent (past 15 years) studies of aversion therapy treatment of SIB. In recent decades, there has been a strong reluctance to use aversion therapies or to conduct aversion therapy research with children and/or with adults who have intellectual and/or developmental disabilities. Indeed, many advocates for persons with IDDs firmly reject the use of any type of aversive treatment or intervention in such persons, arguing that it is never ethically acceptable to use aversive techniques in this population.

There is little doubt that the strong tide of public and professional opinion condemning the use of aversive interventions has discouraged research on aversion therapy treatment of SIB (in any population). However, it should be noted that even prior to the sharp turn away from the use of aversive interventions seen in recent decades, the existing literature on aversion therapy in the treatment of SIB in intellectually and/or

developmentally disabled individuals was fraught with gaps, limitations, and weaknesses. The vast majority of the literature on this topic is comprised of single-case reports and anecdotal reports. There is overall an absence of controls, randomization, and long-term follow-up. In some of the studies with multiple participants, the use of different types of aversive stimuli, an assortment of intervention scheduled, and inclusion of participants of different ages, genders, intellectual capabilities, and different SIB targets and level of severity makes it difficult to draw any conclusions about aversion therapy effectiveness.

Using aversion therapy techniques with any human population for any treatment purpose raises ethical issues related to causing harm, coercion, patient autonomy, and informed consent. The type of SIB under investigation in this study is generally manifested in persons with intellectual and/or developmental disabilities. Research on the prevalence and distribution of SIBs demonstrates that both the prevalence and severity of SIBs increase with the severity of intellectual and/or developmental disability (Richards et al., 2012; Rojahn et al., 2008; Yates, 2004). In other words, severely intellectually and/or developmentally disabled persons are especially likely to exhibit severe, life-threatening SIBs and hence, are potentially likely to benefit from aversion therapy for SIB.

Although many questions still remain to be answered, recent research on the neuropsychobiology of SIB has advanced understanding of the etiology and phenomenology of SIB. The emergence of a biological model of SIB might possibly offer additional information on how to effectively use aversion therapy for SIB (e.g., perhaps the aversive intervention could be viewed as a noninjurious substitute for the SIB used to

achieve homeostatic balance; Ernst, 2000; Furniss & Biswas, 2012; Sandman et al., 2012; Symons, 2011). Meanwhile, further research on the etiology of SIB, combined with the results of functional analyses and functional assessments of SIB in intellectually and developmentally disabled individuals confirms the relevance of the behavioral model of SIB to the use of aversion therapy treatment of SIB in the intellectually disabled population. Specifically, a number of the studies included in this review that included a functional analysis or functional assessment of the research participants' SIB concluded that negative reinforcement (related to escape from demands and avoidance behavior) shaped individuals' SIB to a much greater degree than positive reinforcement (including attention-seeking behavior; Iwata, 1987; Lerman et al., 1997). This finding suggests the greater potential efficacy of aversive interventions versus positive reinforcement in the treatment of SIB in the intellectually and/or developmentally disabled population.

The use of aversive techniques to treat SIB or any other condition in persons who are not competent to provide informed consent based on intellectual or developmental disabilities should be challenged on ethical grounds. Nevertheless, the case can be made that the life-threatening nature of severe SIB demands the use of the fastest, most effective treatment possible. Research to date demonstrates that aversion therapy for SIB has been effective in reducing the frequency and intensity of SIB at statistically significant levels over pretreatment SIB baseline and in achieving these results usually over a few weeks.

A variety of methods have been utilized in experiments, including the water-mist punishment to reduce SIB and aggression (Arntzen & Werner, 1999); social

consequences, DRO, and electric shock to eliminate face slapping, face banging, hair pulling, face scratching, and finger biting in severely retarded children (Corte et al., 1971); hair pulling/tugging with electric shock with various restraint designs to eliminate SIB (Griffin et al., 1975); contending with life-threatening pica wherein a patient ingested broken glass and window cleaner (Paisey & Whitney, 1989); naltrexone treatments for SIB in individuals with intellectual disability and epilepsy (Ricketts et al., 1992); the effectiveness of water-mist punishment, facial screening, or forced arm exercise to correct SIB (Singh et al., 1986); and the use of aromatic ammonia to eliminate face slapping (Tanner & Zeiler, 1975). Moreover, researchers have demonstrated that it is possible to provide safeguards and systemize the delivery of aversive stimuli (e.g., through SIBIS) in a way that minimizes the potential for abuse on the part of the therapist/researcher as well as minimizes the potential for treatment-related harm to the patient or research participant (Linscheid et al., 1990; Lerman & Vorndran, 2002; Ricketts et al., 1992). Technological advances since the time of the development of the SIBIS may offer the potential for developing more effective safeguards and controls in the application of aversive behavioral interventions.

In addition to the ethical concerns, the evidence supporting the use of aversion therapy in the treatment of SIB must be weighed against the evidence concerning the limitations and problems associated with aversion therapy for SIB. Most notably, researchers have encountered problems with generalizability of the treatment effects, as well as sometimes reporting that individuals exposed to aversive stimuli may eventually (sometimes only after a few sessions) adapt to the shock or other stimulus and recover the

SIB (Corte et al., 1971; Maston & Taras, 1989; Tanner & Zeiler, 1975). The lack of any recent studies on aversion therapy treatments of SIB as well as the paucity of follow-up studies and the absence of studies investigating the long-term maintenance possibilities for aversion treatment of SIB have left considerable gaps in the literature. Notwithstanding these concerns and limitations, it is apparent that aversion therapy for SIB works, and in many cases, works better than alternative, less invasive interventions. Moreover, the literature suggests that aversion therapy for SIB may be especially appropriate when it is not possible to identify specific reinforcers for the SIB (i.e., when it is likely that the SIB is maintained through automatic reinforcement; Iwata, Pace, Kalsher, Cowdery, & Cataldo, 1990; Lerman et al., 1997).

The present study helps to address the need for recent research on the use of aversion therapy for the treatment of SIB in intellectually and/or developmentally disabled individuals. Because I included a comparison of the effects of aversion therapy versus standard psychological treatment (PBT) through a retrospective case review in this study, I also took steps to address the gaps in the existing literature related to the need for control or comparative cases as well as the need for longer-term follow-up studies. In addition to addressing some of the gaps in the existing literature on aversion therapy for the treatment of SIB in the intellectually and/or developmentally disabled population, my research makes a unique contribution to the literature. As previously noted, the majority of studies to date have involved just one case. Moreover, when more than one individual has been included in the study design, the individuals are often not directly comparable either in terms of their personal characteristics (e.g., age, gender, level of disability, etc.)

or their type and severity of SIB. Even in studies where efforts have been made to develop matched comparative groups or individuals, there are important differences between the individuals and their SIB conditions that may have influenced study outcomes.

Another difficulty with some of the previous studies has been the reliance on a mish mash of different aversive interventions. In contrast, the my study compared two different approaches (electric shock-based aversion therapy and psychological treatment not using aversion methods) for treatment of similar SIB type and severity in two severely intellectually disabled genetically identical individuals (identical twin brothers) over an extended period of time. This research thus offers the potential not only to more clearly assess the relative effectiveness of aversion therapy versus conventional treatment for SIB in intellectually disabled persons, it also offers the potential to expand understanding of the phenomenology of SIB in intellectually disabled persons along with the facilitating and limiting factors in the use of aversion therapy for SIB.

Chapter 3: Research Method

One purpose of this mixed-methods study using a sequential explanatory strategy was to investigate the comparative effectiveness of PBT and aversion therapy in the treatment of SIB in a pair of intellectually disabled twins. A sequential explanatory design is appropriate when using qualitative techniques to further substantiate quantitative findings (Sandelowski, 2000). A second purpose was to derive the self-report of caregivers and family members regarding their experiences of the ethics and effectiveness of treatment using essay-type questionnaires. I used archival data in a single-case design in the quantitative component to determine treatment efficacy in meeting specific behavioral goals. I compared a case that used aversion therapy and another that used conventional behavior modification methods. The quantitative data were drawn from archival data from two different U.S.-based clinical psychiatric and psychological treatment centers. The qualitative component was prospective, in the form of essay-type questionnaires administered to the family members and caretakers of the twins. The participants in the qualitative component were two close relatives of the twins who were receiving treatment for SIBs, as well as two additional individuals who are each responsible for the caretaking of a different twin.

The use of a sequential explanatory design allowed for more objective examination of quantitative data regarding effectiveness, which were then supplemented with data encompassing participants' personal experiences about the effectiveness and ethics of the processes under study. This design allows for both objective data and subjective experience to be integrated. A potential limitation of the design is that the

objective and subjective information regarding effectiveness may conflict. However, this conflicting information may also be useful to explore with potential to fuel future research.

In this chapter, I will describe the research design and the rationale, the research methodology, and the sample selection. I also will describe the procedure used in designing the instrument and collecting the data. The chapter also includes a discussion of the role of the researcher and the methods I used to examine the data.

Research Design and Rationale

For this study I used a mixed-methods research design and a sequential explanatory strategy. The three basic research methods are qualitative, quantitative, and mixed method. A mixed-methods design is a procedure for collecting, analyzing and "mixing" both quantitative and qualitative data at some stage of the research process within a single study in order to understand a research problem more completely (Creswell, 2002). The rationale for mixing is that neither quantitative nor qualitative methods are sufficient by themselves to capture the full information needed to address the RQs. When used in combination, quantitative and qualitative methods complement each other and allow for more complete analysis (Green, Caracelli, & Graham, 1989).

In quantitative research, an investigator relies on numerical data (Charles & Mertler, 2002). Quantitative researchers utilize positivist claims for developing cognizance, such as cause and effect constructions, reduction to categorical variables, hypotheses and questions, utilization of quantification and observation, and the test of theories. Researchers isolate variables and relate them to determine the magnitude and

frequency of that relation. In addition, researchers determine which variables to investigate and choose instruments that will yield highly reliable and valid scores.

Alternatively, qualitative research is "an inquiry process of understanding" where the researcher develops a "complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting" (Creswell, 1998, p. 15). In qualitative research, data are accumulated from those immersed in everyday life of the setting in which the study is framed. Researchers predicate data analysis on the values that participants perceive for their world.

Researchers using a mixed-methods approach combine the methods and philosophies of qualitative and quantitative research to create a workable solution. Mixed-methods research is also an attempt to legitimize the use of multiple approaches in answering RQs rather than restricting or constraining researchers' choices (i.e., it rejects dogmatism; Johnson & Onwuegbuzie, 2004). A combination of quantitative and qualitative methods can better explain some phenomena under study. This is because the qualitative approach is better able to capture the experiences and social understanding of a case, therefore enabling substantiation of the quantitative results. A mixed-methods exploratory case study enables the researcher to utilize the same RQs and to integrate qualitative and quantitative data as complimentary and supportive of other's resulting data (Yin, 2009).

For this study I used a mixed-methods exploratory case study methodology. Case studies are employed when the researcher is asking "how" and/or "why" questions, has a bounded sample, and uses multiple sources of data (Yin, 2014). Exploratory case studies

are used to study a phenomenon that is embedded within a social setting, and thusly becomes the case under study, phenomenon to gain understanding and to pave the way for further research (Yin, 2014). To support and expand upon the quantitative results, I collected qualitative narrative essay questionnaires from the participants of the study. I used this information to expand upon and support the results of the quantitative data.

The use of an essay questionnaire enables the researcher to "discover the responses that individuals give spontaneously" (Reja et al., 2003) without influencing the participant's response. Because of the breadth of data that are generated from narrative open-ended questionnaires, there is an extensive process of data analysis. I used Braun and Clarke's (2006) thematic analysis (TA) to analyze the qualitative data that I collected. I used these resulting data to expand upon and support the results of the quantitative data. In doing so I strengthened both the credibility and confirmability of the findings by providing methodological triangulation.

Role of the Researcher

In qualitative studies, the researcher functions as an instrument, in that all the information in the study flows through the researcher (Tracy, 2013). The researcher must also work to suspend preconceptions about the nature of the phenomena so that these do not interfere with the incipient understanding. The researcher commences this process by identifying possible biases or anteriorly held opinions regarding the phenomena. The possible influences on my development of an incipient understanding of the phenomena under investigation are identified in the following paragraphs.

I did not have any differentials or relationships with participants that could have plausibly pressured them, such as being a professor or supervisor. I have a master's degree in arts. I have held positions as a behavior intervention science specialist in two major local facilities and am familiar with the vocation and the local regulations that affect the work environment. I was not employed as a psychologist in the study region at the time of data collection.

I selected aversion therapy as a dissertation topic due to my interest and credence in its consequentiality. My interest in this topic grew out of clinical experience and informal observations of the implementation of different treatment approaches in two settings (day habilitation and residential) while working as a clinician; collaboration on treatment teams with professionals from other disciplines (physicians, social workers, and occupational therapists); and extensive review of literature during 15 years as a college and graduate student of psychology. A physician of my acquaintance who is well regarded in her field of psychiatry, and who is related to the participants being studied, suggested this topic to me. Regardless of this fact, my aim was to examine the topic and learn new information to advance the field rather than advocate for any one viewpoint or position.

My place of employment had no affiliation to either of the institutions where data were collected. In order to keep my research free from bias, I practiced bracketing. Bracketing is a method that is employed to manage preconceptions that may influence the research study and the resulting data analysis. I also paid close attention to my research by examining the source material that I used, as well as being cognizant of opposing

viewpoints, the language that I used, and the expressed thoughts of my participants to make sure that I presented an unbiased version of the findings. The exclusive use of written communication between the participants and me allowed for more careful wording of unbiased questions in the essay questionnaires. In addition, I used strategies to maintain the integrity of the data that are described later in this chapter.

Methodology

Participant Selection Logic

In this study, I examined the treatment outcomes and the ethics of treatment in two adult identical twin brothers who both engage in SIB. One of these individuals experienced exposure to aversion therapy, including ABA to treat his SIB, while the other underwent conventional psychological treatment (PBT) for his SIB. I used purposeful sampling for this study, as these individuals and their caretakers provided a unique example of the case that was investigated. The family members and caretakers of these young men who gave permission to access records and be participants themselves all expressed an interest in participating in the study.

Procedures for Recruitment, Participation, and Data Collection

Quantitative study procedures. Prior to collecting data for the quantitative portion of the research, I sought permission to access data from the legal guardian of the twins, which allowed me to collect information from the two treatment centers. The legal guardian agreed to request the data directly from the two different U.S. treatment centers. Once data were released to the legal guardian, it was then given to me. Each one of these treatment centers has provided services and treatments to one twin or the other. Both of

these treatment centers are located in New England. Once permission was granted, I extracted the secondary data and compiled it into SPSS Version 22.0 for Windows. The quantitative data examination compared the effectiveness of ABA, which includes aversion therapy, and conventional psychological treatment modalities in a pair of intellectually disabled twins. I drew the data from archival records from two different U.S. treatment centers. The goal was to compare the frequencies of aggressive, disruptive, destructive, and prosocial behaviors between twins from the two treatment centers at various points in treatment to compare the effectiveness of one treatment to the other.

For the quantitative portion of the study, data were collected over a 10-year time period, between 2005 and 2015. I requested the following data from each treatment center: SIB - key shared components in these definitions include these elements: self-inflicted, non-accidental, not consciously suicidal, and producing bleeding, bruising or other temporary or permanent injury to self (Kakhnovets et al., 2010; Prangnell, 2009) (e.g., hitting, biting, picking skin to cause bleeding, picking inside of nose to cause bleeding, forcefully scratching to cause breaking of skin, head banging), aggressive behavior - physical aggression towards others (e.g. bite, hit, kick, push, grab and head butt), destructive behavior – behaviors that involve the intentional breaking or destruction of property and prosocial behavior -identified as appropriate “replacement” or alternative behaviors (e.g. functional communication, speak in a clear/low tone of voice, maintain a neat appearance, and practice appropriate hand shaking to greet a person) (Kakhnovets et al., 2010; Prangnell, 2009).

I used the requested data used to examine behavioral change over time. The data were visually interpreted by using graphs of the target behaviors. The specific target behaviors defining each dependent variable may varied between the two individuals of interest; however, I applied the operational definitions of each variable in analyzing the data. Change over time was compared for each category of behavior in each individual, and that change rate was compared between individual cases. If data for the requested time period could not be obtained by either of the treatment centers, then data were solicited from psychiatry treatment records. The legal guardian of the twins agreed to provide consent for release of psychiatric treatment records.

One of the treatment centers was required to collect data for each targeted behavior at the day program and residence, both of which are both operated under the same agency. In addition, they provide 24-hour/7 days-a-week video surveillance to ensure for safety and quality of services provided. The other treatment center does not provide 24-hour/7 days-a-week video surveillance; however, staff is required to collect data on each targeted behavior at the day program or residence operated by different agencies.

Qualitative study procedures. For this qualitative portion of the study, I recruited participants through purposeful criterion sampling. All participants were either family members or caregivers of the patients receiving treatment. Once institutional review board (IRB) approval and clearance from the facilities was obtained, I was able begin the data collection phase of the study.

The instrument used to collect qualitative data was a semistructured, open-ended, essay-type questionnaire (see Appendices A and B). The questionnaire covered three areas: (a) questions about the participant's background/relationship to the patients receiving treatment, (b) questions about the behaviors being treated, and (c) questions about the treatment effectiveness and ethical application. The use of open-ended questions aids in ensuring credibility, eases data analysis, and lessens any researcher bias (Moustakas, 1994). According to Leary (1995), there are distinct advantages in using questionnaire versus interview methodology: questionnaires are less expensive and easier to administer than personal interviews, they lend themselves to group administration, and they allow confidentiality to be assured. Robson (1993) indicated that mail surveys are extremely effective at providing information in a relatively brief time period at low cost to the researcher. Written responses also offer more time for reflection on the part of the participant and avoid the risk of transcription error. For these reasons, I chose a descriptive approach and designed a questionnaire to assess the perceptions of selected family members and direct care professionals addressing ethical issues connected with aversion therapy (see Appendices A and B).

All participants were e-mailed a copy of the informed consent form to review and sign (see Appendix B). A phone meeting was scheduled to go over and explain the informed consent, answer questions, and address concerns. The participants were informed that they are not obliged to participate in the research and could cease participation in the study at any time without any repercussion. My place of employment has no affiliation to either of the institutions where data were collected. The participants

were e-mailed the essay questionnaire to fill out and return. Once I received the data, I was able to begin analyzing this narrative information and follow up with the participants in writing via e-mail for further detail. Participants were e-mailed copies of the summaries of their data for member checking, which helped ensure the data gathered were rich and detailed and added to the dependability of the study (Tracy, 2013).

Data Analysis Plan

Quantitative data analysis. I planned an initial visual inspection of the to examine completeness and outliers. Nominal data were presented in frequencies and percentages tables. Means and standard deviations were calculated for continuous data (see Howell, 2011).

Conservative dual criterion method. Fisher et al. (2003) designed a structured procedure called the CDC for visual inspection. The CDC technique assesses the effectiveness of treatment by examining the number of data points that fall above the established linear regression trend line. Fisher et al. used the Monte Carlo validation for CDC and discovered that the visual inspection method lowered Type I and Type II error rates. Stewart, Carr, Brandt, and McHenry (2007) recognized that the CDC method significantly improved accuracy of visual inspection in comparison to more traditional methods of examining data trends.

I selected the CDC technique selected because it may have been difficult to monitor behaviors such as behaviors of aggression or destructive behaviors over a long period. In addition, examination of single-case data often violates the assumption of normality, which is a typical requirement of parametric analyses for differences such as *t*

and *F* tests. Visual analysis techniques such as the CDC method also allow for the incorporation of unique patient characteristics that is critical for case-by-case research. The CDC method has shown to assist in visual analysis and reduces Type I and II error (Fisher et al., 2003). The CDC method was the analysis that was planned to visually examine trends in behaviors of aggression, behaviors of self-aggression, destructive behaviors, and major disruptive behaviors, and positive prosocial behaviors.

Quantitative research questions. I sought to answer four RQs for the quantitative part of the study.

RQ1: Are there significant differences behaviors of aggression (i.e., biting, hitting, kicking, pushing, grabbing, and head butting) towards others recorded for an intellectually and developmentally disabled individual treated with ABA, which includes aversion therapy, and trends of behaviors of aggression towards others recorded for his identical twin who has been treated with conventional PBT?

The planned analysis was CDC visual inspection. The CDC method provides two superimposed frequency lines for behaviors of aggression. Frequency lines are created by examining behaviors of aggression for a developmentally disabled individual treated with aversion therapy and his identical twin being treated with conventional positive behavior support. Visual inspection of the frequency lines is then used to identify potential significant differences in the frequency of behaviors of aggression between identical twins.

RQ2: Are there significant differences behaviors of self-aggression behaviors that may cause physical or emotional harm to self (i.e., hitting self, biting self, picking skin to

cause bleeding, picking inside of nose to cause bleeding, forcefully scratching to cause breaking of skin) recorded for an intellectually and developmentally disabled individual treated with ABA, which includes aversion therapy, and the frequency of behaviors of self-aggression recorded for his identical twin who has been treated with conventional PBT?

CDC visual inspection was also planned to address this RQ. The CDC method provides two superimposed frequency lines for behaviors of self-aggression. Frequency lines are created by examining behaviors of self-aggression for developmentally disabled individuals treated with ABA and identical twins being treated with conventional PBT (see Appendices A & B). Visual inspection of the frequency lines are used to identify differences in the frequency of behaviors of self-aggression between identical twins.

RQ3: Are there significant differences destructive behaviors (involving the intentional breaking or destruction of property) recorded for an intellectually and developmentally disabled individual treated with ABA, which includes aversion therapy, and trends of destructive behaviors recorded for his identical twin who has been treated with conventional PBT?

CDC visual inspection was also planned to address this RQ. The CDC method provides two superimposed frequency lines for destructive behaviors. Visual inspection of the frequency lines could have identified significant differences in the frequency of destructive behaviors between identical twins.

RQ4: Are there significant differences in positive, prosocial behaviors (i.e., completing daily living skills, maintaining a neat appearance, practicing appropriate hand

shaking) recorded for an intellectually and developmentally disabled individual treated with ABA therapy that includes aversion therapy, and trends of positive, prosocial behaviors recorded for his identical twin who has been treated with conventional PBT?

Again, CDC visual inspection was the planned analysis.

Qualitative data analysis. The qualitative analysis method that was established by Braun and Clarke (2006), called TA, was used to address this RQ. TA utilizes information from questionnaires and demographic data to provide insight into caretaker and family perceptions of effectiveness and appropriateness of aversion therapy compared to conventional PBT.

RQ5: What are the experiences and perceptions of the family members and caretakers of twins with IDDs who were each treated with different approaches (standard vs. aversion therapy) of those treatments in terms of outcome and ethical implications?

The use of TA enables the researcher to explore the case under review by systematically moving through the data in recursive manner. TA is a method used to analyze qualitative data originally developed by Holton (Merton, 1975). Braun and Clarke (2006) refined the method and created a clear set of procedures to follow. One of the strengths of this method is that it is not tied to a specific theory, data collection method, or data type (Braun & Clarke, 2013). Once I collected and transcribed the data, I performed the steps required for TA.

The steps of analysis are clear and systematic, and this method enables a researcher to analyze and interpret themes that lie within the gathered data in an organized methodical manner (Braun, Clarke, & Tracy, 2014). TA consists of six steps

that are described in a linear fashion (Braun & Clarke, 2006). Although these steps are described linearly, the nature of this analysis is recursive and necessitates passage between the different stages, which causes some portions of the analysis to blur together (Braun et al., 2014).

In Stage 1, researchers read and reread the data several times to create a knowledge and understanding of participant's experiences and perceptions with the case under study. During this stage, I gained a familiarity and began to identify thoughts, patterns, and repeated words or phrases (see Tracy, 2013). During Stage 2, each of the transcripts is read, and chunks of data, which can be a word, phrase, or paragraph, can be assigned a code that represents the meaning of the data (Braun & Clarke, 2006). A good code is defined as a label that identifies the key idea expressed in that piece of the data (Braun et al., 2014). Codes can be descriptive or interpretive and are used to convey that the meaning of the data is in a manner that ensures seeing the data is not necessary (Braun & Clarke, 2006).

Gathering like codes into categories marks the beginning of Stage 3. The codes are manipulated and moved to form simple categories. These categories are then examined and grouped together until each group forms a theme that is so dense that no further reduction is required. Three main ideas to remember when creating themes are (a) will the theme provide an answer to a RQ, (b) are there enough codes and representative participants to create the theme, and (c) is there a central core idea by which the information is organized (Clark & Braun, 2014). Before moving on to the next stage each theme should be mapped out and reviewed.

I reviewed themes in Stage 4. This occurs to ensure quality and depth of analysis. At this time the data were reviewed to ensure errors have not occurred. In Stage 5, I wrote definitions and names for the themes . The name is used to capture the meaning of the theme and the theme should be direct and easy to explain (Braun et al., 2014). In the final stage, I wrote analysis and organized it for presentation.

I used the quantitative and qualitative data to address each RQ separately, and the data were also considered as a whole to examine consistency between the two methods. I used quantitative data to address RQs 1 through 4 in order to determine if there were observable differences in behaviors of aggression, behaviors of self-aggression, destructive behaviors, and prosocial behaviors between the two types of therapy (ABA with supplementary aversives and conventional PBT).

I used qualitative data to substantiate the quantitative findings by providing contextual understanding of the case under review. The qualitative data were examined with a TA of all participants' interviews. The data were then examined and explored together for supportive and conflicting information regarding efficacy and the ethics of the treatment plans for each individual. This combination of qualitative and quantitative data helped me uncover a more complex and nuanced view of the use of the two therapeutic interventions under study.

Issues of Trustworthiness

The goal of all researchers is to produce findings that are accurate and have validity. Qualitative analysis is "valid, reliable, creditable, and rigorous" (Anderson, 2010, p. 22) when it is performed correctly. Reliability and validity are important aspects

of both the archival data and the questionnaire design. It is assumed that the archival data collected from the two centers was accurate and has been validated with internal review. According to Suskie (1996), a perfectly reliable questionnaire elicits consist responses. Leary (1995) offered seven guidelines for designing a useful questionnaire:

1. Use precise terminology in phrasing the questions.
2. Write the questions as simply as possible, avoiding difficult words, unnecessary jargon, and cumbersome phrases.
3. Avoid making unwarranted assumptions about the respondents.
4. Conditional information should precede the key idea of the question.
5. Do not use double-barreled questions. (i.e., questions that ask more than one question but provide the respondent with the opportunity for only one response).
6. Choose an appropriate response format.
7. Pretest the questionnaire. (pp. 81-82)

Validity is inherently more arduous to establish within a single statistical measure. If a questionnaire is impeccably valid, it must measure in such a way that inferences drawn from the questionnaire are entirely precise. Suskie (1996) opined that reliability and validity are enhanced when the researcher takes certain precautionary steps. It is essential to have people with diverse backgrounds and viewpoints review the survey before it is administered to the participants. Doing so enables the researcher to ensure (a) each item is clear and easily understood, (b) they interpret each item in its intended way,

(c) the items have an intuitive relationship to the studies topic and goals, and (d) the intent behind each item is clear to colleagues knowledgeable about the subject (p. 59).

Considering these principles, my dissertation chair and committee, two licensed psychologists, and two psychology graduate students who had completed all requirements except for their dissertations reviewed the questions for the qualitative portion of the research. Minor edits were completed based on their reviews, and all of these professionals subsequently agreed that the questionnaire items addressed the RQs.

Ethical Procedures

Before any data were collected or any participants approached, IRB approval was obtained. As required by U.S. Health and Human Services Administration (Title 45, 2009), all methods and procedures for this study were submitted for approval of the IRB at Walden University.

Ethical principles in research are guided by the professional standards outlined by the APA (2010) and laws of the U.S. Health and Human Services Administration (Title 45 2009). Human participants in research must be treated with reverence and fairness.

The overall ethical risk of this investigation was low. Ethical issues that were faced in this study included the use of a vulnerable population, consent, privacy, and psychological distress. A consent form (see Appendix C) was signed by the legal guardian of the twins. It is a part of the guardian's responsibility to safeguard the best interests of their wards, thus they are the arbitrators of the consent decision. The researcher never made direct contact with the twins who are undergoing treatment. All data relevant to their treatment is archival and was gathered as part to the treatment

process. As the data was previously collected, there are minimal risks to the vulnerable participants.

Participants signed consent forms, and I discussed consent with each of them through a phone interview before they received the questionnaires via e-mail. They were informed that participation was completely voluntary, they may have refused to answer any questions that they did not wish to address, and they may have ceased participation in the study at any time without explanation. The confidentiality of the participants, who are the guardians and caretakers of the twins, was protected by numerically coding each returned questionnaire. I deleted from the information that I gathered as soon as data collection was completed. All data including the questionnaire is kept in a locked metal file cabinet in the researcher's office and will be destroyed 5 years after the project is completed.

I told the participants that summary data would be disseminated to the professional community, but in no way was it possible to trace responses to the individuals themselves. A copy of the study was promised to the participants if they wished to know what the findings and conclusions are. A separate e-mail address was available for the sole purpose of the questionnaire, and deleted, along with correspondence after the study was completed and the participants who wished to know about the findings are sent information.

Psychological distress was also a risk in this research given the sensitive questions that were asked of the participants. All participants were informed of their right to stop participation or refuse to address any questions they did not wish to address. They were

encouraged to discuss any distress with me and any incidents of distress were reported to the Walden IRB. In addition, I promised to supply a list of supportive organizations to obtain a referral to a mental health professional in the event that psychological distress was triggered.

Summary

The purpose of this chapter was to describe the research methodology of this study. The mixed-methods research design was identified and justified due to the fact that both quantitative and qualitative approaches are necessary to understand the case under study. Data collection procedures were outlined for the analysis of archival data and administration of questionnaires. Data analysis procedures were also described to answer the RQs through a CDC visual inspection of frequency charts and narrative analysis. Finally, threats to external validity were delineated, along with ethical considerations and steps to provide informed consent.

Chapter 4: Results

One purpose of this mixed-methods study using a sequential explanatory strategy was to investigate the comparative effectiveness of conventional PBT and aversion therapy including ABA in the treatment of SIB in a pair of intellectually disabled twins. A second purpose was to explore the lived experiences of caregivers and family members regarding their understanding of the ethics and effectiveness of treatment using essay-type questionnaires. The quantitative data component involved the examination and comparison of the data that were collected by the treating clinicians for the twins. In one case, clinicians used aversion therapy while, in the other case, they used what is considered to be conventional PBT. The qualitative component involved the examination of essay responses to questionnaires administered to the family members and caretakers of the twins. In this chapter, I will present and synthesize the findings of the quantitative and qualitative data analysis.

One of the twins (M) was exposed to GED aversion therapy to treat SIB. The treatment involved a brief electrical stimulus, or skin-shock, applied to his skin as a contingent consequence as soon as possible after a defined problematic behavior was exhibited. The purpose of this skin shock was to decrease (decelerate) the frequency of the behavior that the skin shock is made contingent upon. The treatment center where he was exposed to aversion therapy provides 24-hour/7-days-a-week video surveillance to ensure safety and quality of services provided. The other treatment center (the one that administered conventional positive therapy to the other twin, S) does not offer such surveillance. In this setting, conventional positive, nonaversive therapy involved verbal

redirection followed by praise for appropriate behaviors and token rewards that could be traded in for desired rewards. Other treatments were provided to each of the twins, including some conventional therapy and medication for M and medication treatment for S, which will be discussed later in this chapter, but the main difference between the treatments was the use of GED over a long period of time with M.

Participants

There were four participants in the qualitative component of the study, all of whom were family members or caretakers of the twins. See Table 1 for the list of participants and their relationship to the patients.

Table 1

Research Participants and Relationship to the Patients

Research participant	Relationship to the patient
Participant 1	Clinician for M
Participant 2	Care provider for S
Participant 3	Sister of M and S
Participant 4	Mother of M and S

Quantitative Data Collection and Analysis

I received two sets of data for the quantitative portion of the study, one from each treatment center where the brothers received treatment. Unfortunately, the data were not comparable in a number of ways. The data for M consisted of the frequencies of negative behaviors occurring each month over the course of 10 years from January 2008 to August

2017. The negative behaviors that were measured were (a) aggressive behaviors towards others, (b) learning interference towards others, (c) self-aggressive behaviors, (d) inappropriate verbal behaviors, (e) major inappropriate behaviors, and (f) extreme self-aggressive behavior. The data received from M's facility did not include positive behaviors with a goal to increase those behaviors. The overall emphasis of treatment appeared to be on decreasing negative behaviors, and positive behaviors were not recorded.

The data for S consisted of recorded frequency of behavioral codes for three positive behaviors. I requested data for a 10-year time frame, but the facility was only able to locate data gathered from April 2016 to November 2017. Behaviors that were included in the data were (a) staff will assist patient to shave daily, (b) patient will talk to staff daily about his feelings to resolve his frustration and disappointment when he does not get exactly what he wants from family and staff, and (c) patient is offered informal rewards for attending scheduled activities including subway rides, treats, and special attention to his daily recliner repairs. The behavioral codes were *performed entire task successfully*, *performed only part of task successfully*, and *did not perform task successfully*. The overall emphasis on S's treatment appeared to be on increasing positive behaviors, and negative behaviors were not recorded.

Given the different orientations of the two programs, it is somewhat understandable that the focus of the data keeping corresponded with the treatment approach: The treatment center using the approach focused on decreasing negative behaviors (aversion treatment) recorded exclusively negative behaviors, and the treatment

center using the approach focused on increasing positive behaviors (traditional PBT) recorded exclusively positive behaviors. Thus, the nature of the data necessitated a change in the original data analysis plan for the study. There was no possible way to test the hypotheses given the nature of the data obtained from each facility.

The analysis that I originally proposed to compare the treatment outcomes was the CDC method for visual inspection. However, to employ the CDC method for two cases, both centers would need to have measured similar variables of interest. In addition, similar time frames and units of measurement would need to be recorded. The data recorded for M were recorded over a 10-year period and each unit of measurement represented the frequency of negative behaviors over 1 month. The data for S were recorded over a 2-year period and each unit of measurement represented a behavioral code of positive behaviors for 1 day. To employ the CDC method for one case, a pretest and posttest has to be measured with the administration of an intervention. The specific date for an intervention was not identified for either brother. Consequently, I discarded the CDC method as it did not fit the data that were collected. A single-case approach was necessary.

An alternative quantitative data inspection strategy was needed because the nature of the data was such that I could not address the original quantitative RQs, rendering the hypotheses untestable. It was not possible to compare the data for the two brothers because both the nature of the data collected and the time frames they were collected in were not comparable. I determined that a visual analysis strategy was the best way to explore the trends of the brothers' recorded behaviors. Instead of comparing the brothers'

data to each other, I treated each case as a single-subject study. Researchers conducting data analyses involving single subjects do not typically incorporate inferential hypothesis testing. This strategy was the best option given that the data were not comparable in category or timeline, and that it could be graphed to determine trends over time, which can then be reviewed and summarized. The visual analysis strategy has often been used in single-case studies and tends to be a conservative approach to assessing possible treatment effects (Kratochwill, Levin, Horner, & Swoboda, 2014). Using this quantitative method also allowed me to avoid treating the data for each twin as comparable to the other twin, when it clearly was not. The visual analysis strategy calls for the visual conversion of data to summarize trends, which also limits the conclusions that can be drawn from the data as no statistical analysis or comparison takes place; however, given the poverty of the data collected, I concluded that this method was the most conservative way to present and examine the data.

Qualitative Data Collection and Analysis

I analyzed the qualitative data following Braun and Clarke's (2006) TA. TA provides a six-step process for analyzing qualitative data. The first step in this process was to familiarize myself with the data by transcribing and rereading the text provided in the surveys. In Step 2 of TA, I uploaded the data into NVivo 11 (QSR International Pty Ltd. Version 11, 2015) and coded the data from the surveys. NVivo 11 is a qualitative data analysis software that allows researchers to create codes and assign them to words and phrases in the data and to organize these codes into larger themes based on

similarities. This step involved moving from line-to-line to generate the initial codes. Examples of this process are listed in Table 2.

Table 2

Example of the Coding Process

Raw data	Assigned code
[His] aggressive behavior consists of physical aggression towards others (e.g. bite others, hit others, kick others, push others, grab others, head butt others) including all attempts to hurt others.	Aggressive behaviors toward others
In selecting treatment procedures for [him], [they] took into account the principle that it is considerably less restrictive, and more ethically defensible, to use an effective treatment procedure, such as positive reinforcement-based programming supplemented with an aversive employed a small number of times, than to use a relatively ineffective treatment procedure a large number of times.	The treatment was ethical because the benefits outweighed the risks
[He] has generally been irritable, annoyed, provocative, and sleepy. He has also had obesity and seizures and tardive dyskinesia	Disapproval of or concerns about use of psychotropic drugs

In Step 3, I analyzed for patterns and similarities to determine the relationships between the codes. Codes that shared similar characteristics were then grouped into categories that became the initial themes. Each of these categories was given a name, and I moved back and forth between the codes and the themes to determine whether other relations existed between the codes. I considered this process complete when no further relations or patterns emerged from the data. After completing the coding and creating the initial themes, these thematic clusters were grouped together based on their relations with each other and given a descriptive name. This provided the thematic structure, with

names, for further data analysis, and the sets of codes contained within each theme became the subthemes.

In the fourth step of TA, I applied the themes and subthemes from the interviews. Doing this ensured that all data from the interviews was accurately captured by the thematic structure. After establishing that the data and codes were all captured within the themes and the subthemes, the fifth step was to create the final names for the themes and subthemes. These names were based on the ideas and sentiments captured by the codes contained within them. Finally, the last step of TA was to write up the results of the data analysis, which are presented below. Each theme that emerged from the data helped to address the qualitative RQ.

Results

Quantitative Component—Data for M (Aversion Therapy)

Aggressive behaviors towards others. Aggressive behaviors towards others consisted of biting, hitting, kicking, pushing, grabbing, and head butting others. The frequencies of aggressive behaviors for M ranged from zero to five occurrences per month, with $M = 0.19$ and $SD = 0.81$ (see Figure 1). For M, most aggressive behaviors were observed during the first half of the treatment period. Over time, the frequency of negative aggressive behaviors decreased to zero and leveled off (stabilized) to no behavior occurrences by the end of the treatment period.

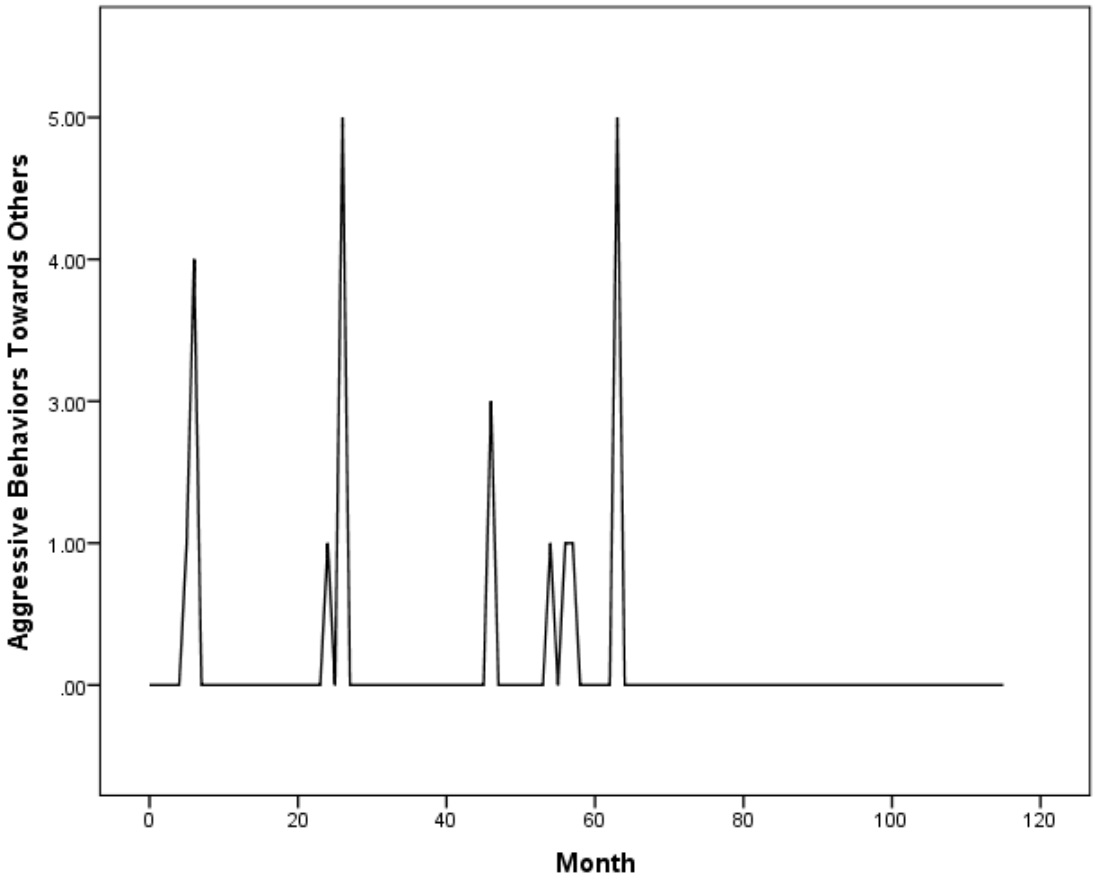

Figure 1. Aggressive behaviors towards others for M (2008–2017).

Learning interference. Learning interference consisted of behaviors such as refusing to perform learned tasks correctly, staring at hands, leaving seat without permission, rubbing fingers together, blowing on fingers, grinding teeth, leaning on side of chairs, and sitting backwards in chairs. Learning interference spiked around Month 25, with approximately 300 negative occurrences in one month. The highest frequency of behaviors was observed during the first 60 months. The frequencies of learning interference for M ranged from zero to 300 occurrences per month, with $M = 23.97$ occurrences and $SD = 38.91$ (see Figure 2).

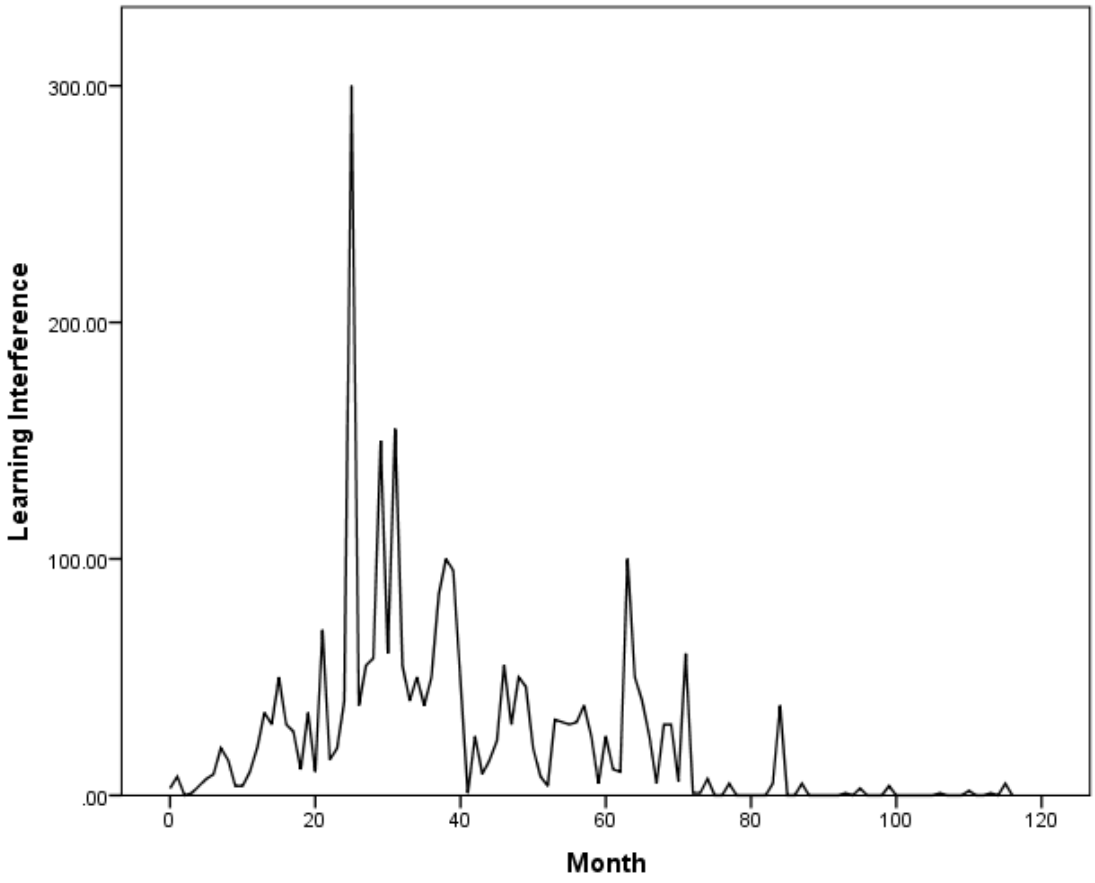

Figure 2. Learning interference towards others for M (2008–2017).

Self-aggressive behaviors. Self-aggressive behaviors consisted of behaviors such hitting self, biting self, head banging, and scratching skin forcefully. Self-aggressive behaviors increased several times during the first half of the treatment period and consequently did not occur for about 50 months. Then at the end of the treatment period, frequencies of the behavior spiked again, occurring 4 times in 1 month, before decreasing to zero by the end of the recording period. Self-aggressive behaviors for M ranged from zero to four occurrences per month, with $M = 0.27$ and $SD = 0.85$ (See Figure 3).

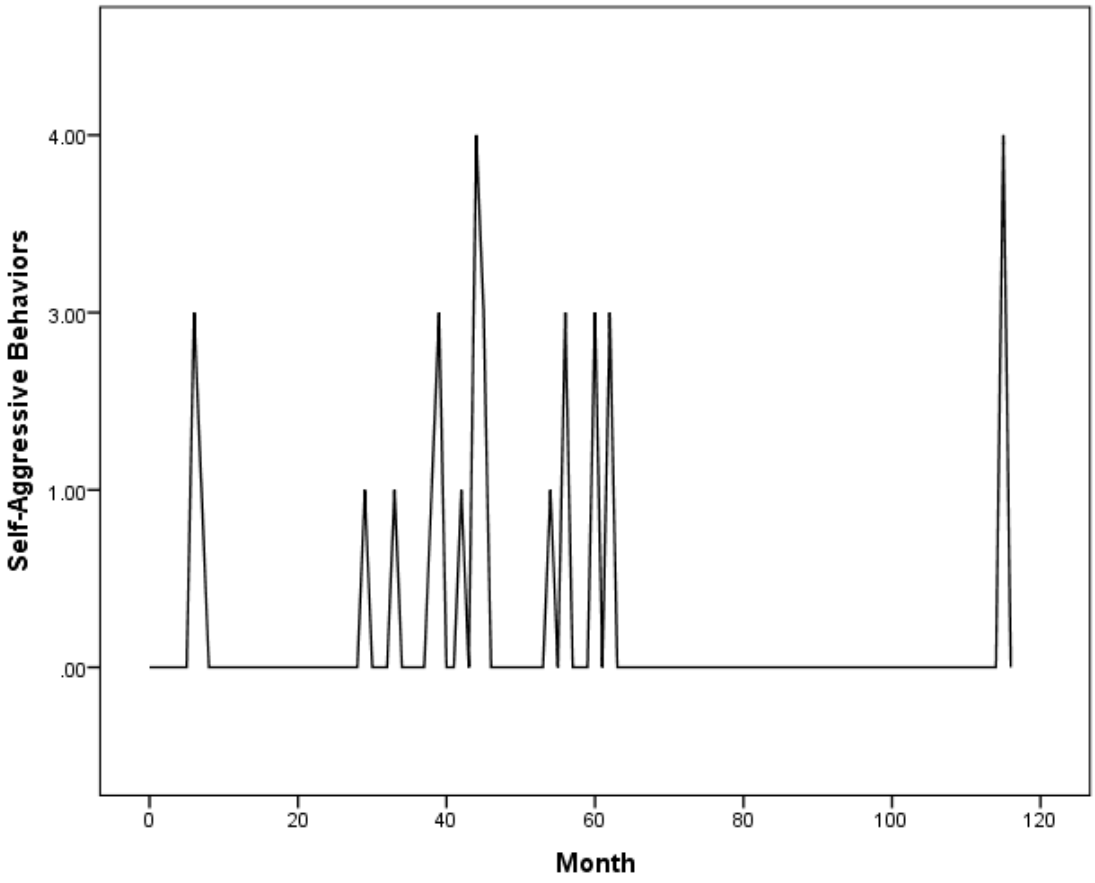

Figure 3. Self-aggressive behaviors for M (2008–2017).

Inappropriate verbal behaviors. Inappropriate verbal behaviors consisted of "nagging, and not minding own business." Inappropriate verbal behaviors were the most frequent prevalent negative behavior exhibited by the patient. The highest frequency of behaviors was observed during the first 70 months. Inappropriate verbal behaviors ranged from zero to 300 occurrences, with $M = 73.74$ occurrences and $SD = 73.68$ (see Figure 4).

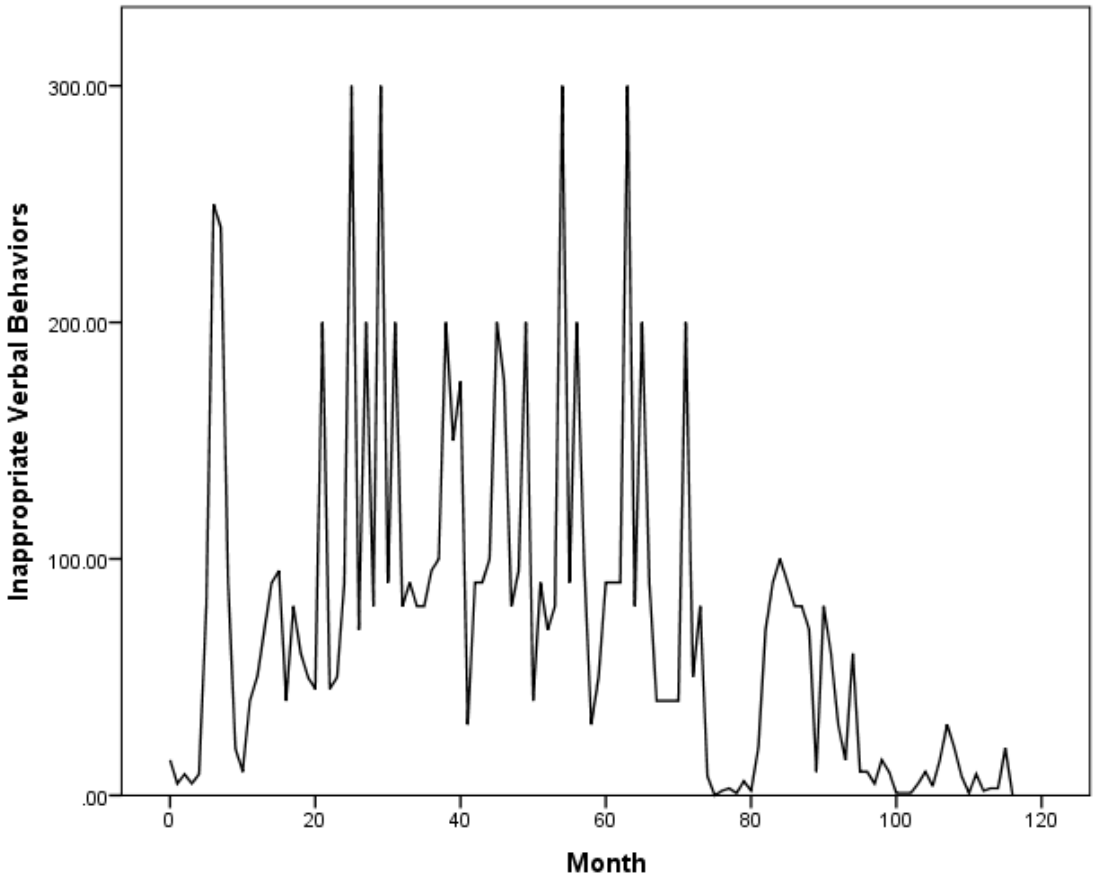

Figure 4. Inappropriate verbal behaviors for M (2008–2017).

Major inappropriate behaviors. Major inappropriate behaviors consisted of destructive, health dangerous, disruptive, and noncompliant behaviors. Major inappropriate behaviors peaked several times during the first half of the treatment period and spiked toward the end of the treatment period, similar to the pattern of self-aggressive behaviors. Major inappropriate behaviors for M ranged from zero to 25 occurrences, with $M = 1.12$ occurrences and $SD = 3.06$ (see Figure 5).

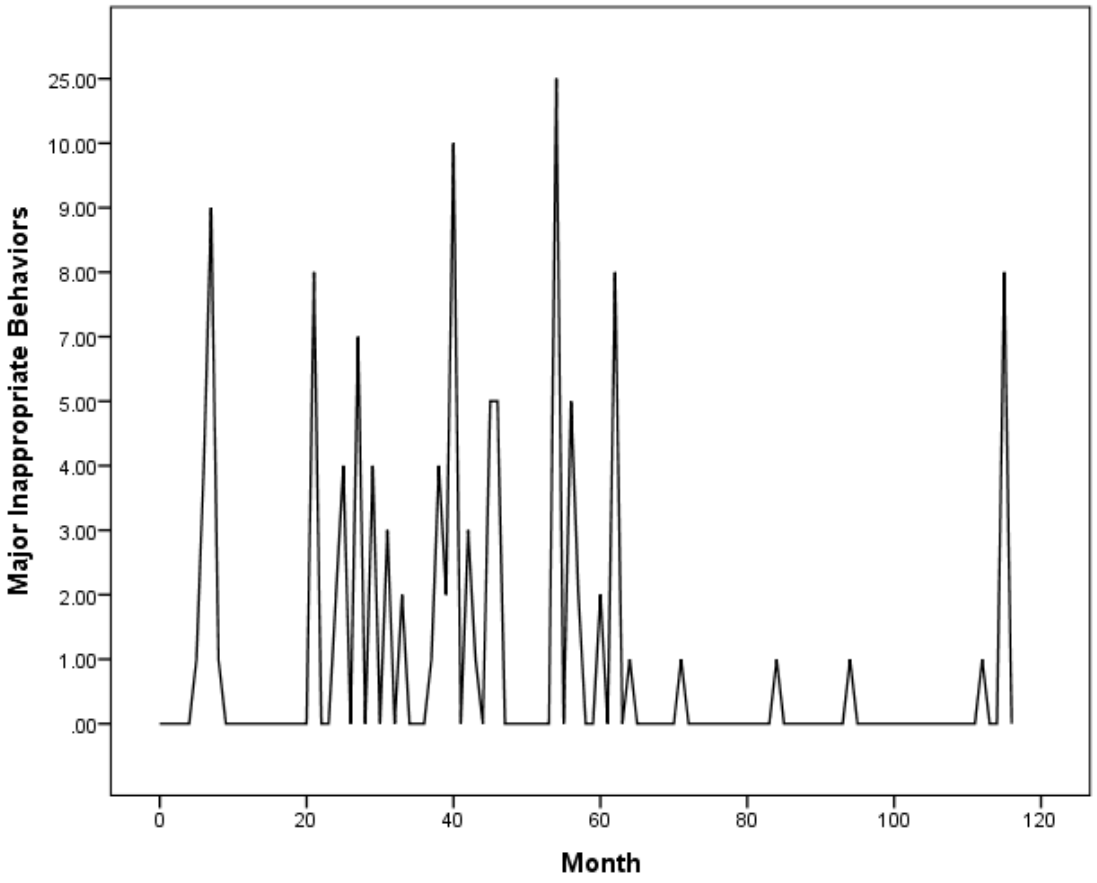

Figure 5. Major inappropriate behaviors for M (2008–2017).

Extreme self-aggressive behaviors. Extreme self-aggressive behaviors consisted of behaviors such as picking skin or forcefully scratching self to cause redness or bleeding. Extreme self-aggressive behaviors spiked several times during the first half of the treatment, before decreasing substantially and then increasing again toward the very end of the treatment period, corresponding with the increase of self-aggressive behaviors and major inappropriate behaviors. Extreme self-aggressive behaviors for M ranged from zero to five occurrences, with $M = 1.12$ and $SD = 3.06$ (see Figure 6).

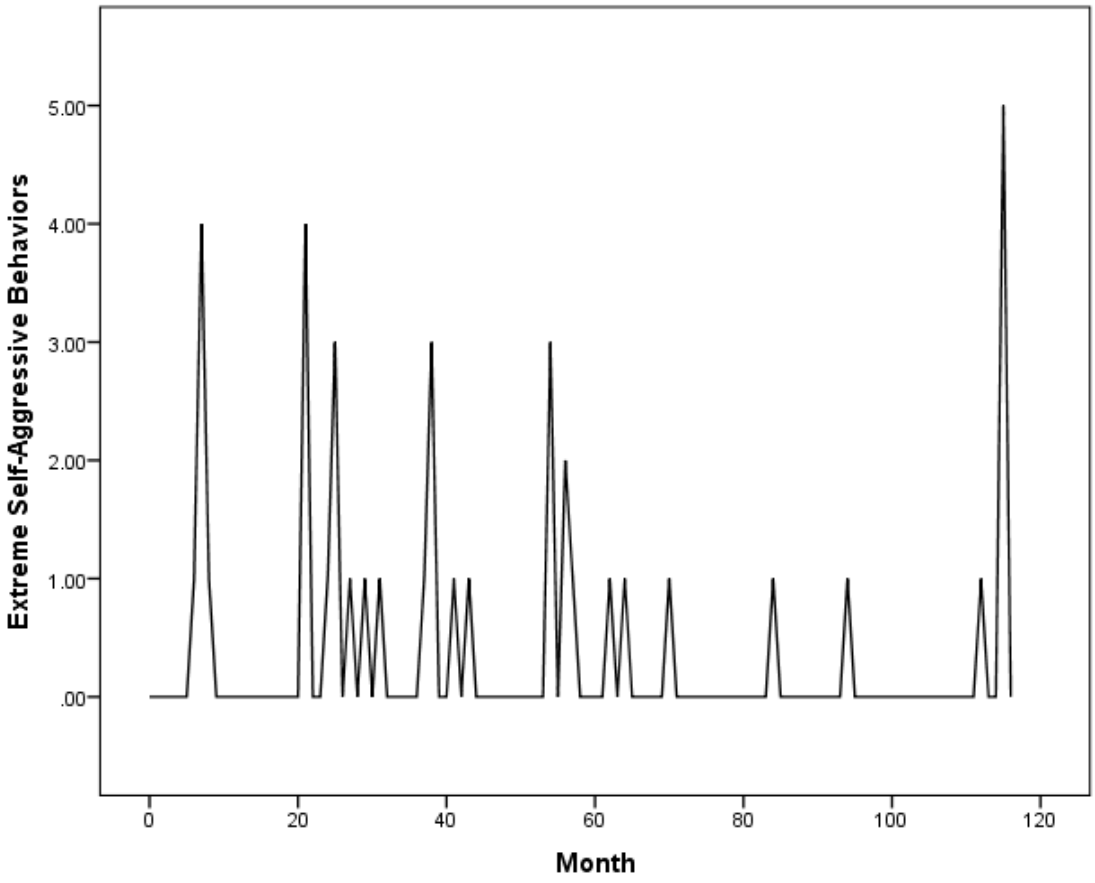

Figure 6. Extreme self-aggressive behaviors for M (2008–2017).

Overall, the negative behaviors that were recorded for M appeared to decrease over the recording period, with an increase in self-aggression and major inappropriate behaviors near the end of the recording period. That increase is a behavioral outlier; however, as this spike in negative behaviors occurred at the end of the recording period it is impossible to know if these behaviors stabilized after that time.

Quantitative Component—Data for S (Conventional Positive Behavior Therapy)

Frequencies and percentages were used to explore the trends of three tasks for S. As discussed at the beginning of the chapter, the behaviors that were recorded included (a) staff will assist patient to shave daily; (b) patient will talk to staff daily about his

feelings to resolve his frustration and disappointment when he does not get exactly what he wants from family and staff; and (c) patient is offered informal rewards for attending scheduled activities, including subway rides, treats, and special attention to his daily recliner repairs. Three behavioral codes were used, including performed entire task successfully, performed only part of task successfully, and did not perform task successfully. The data spanned from April 2016 to November 2017.

The data that I obtained from the facility was in raw form, documented once per day, including tables with hand-entered behavioral codes. Missing data varied by behavior and will be discussed below for each behavioral category. I organized the data into 3-month periods and entered into an Excel spreadsheet.

Task 1: Staff will assist patient to shave daily. S was able to at least partially complete Task 1 the majority of the time throughout the recoding period. There were some missing values in the data, including seven missing values in the first quarter, none in the second, two in the third, 11 in the fourth, 17 in the fifth, 12 in the sixth, and one in the seventh. I used only the completed data in the graph.

By far the most frequent code over the course of the recording period was that he partially complied with the task, with percentages ranging from 82.1% to 97.0% across the seven quarterly timeframes. S failed to comply at a rate ranging from 1.10% in the third quarter to 11.90% in the first quarter. Successful completion of the task was rare and occurred at a rate ranging from 1.3% in the fourth and sixth quarters to 14.6% in the seventh quarter. Although the last value demonstrates an increase in successful task completion, overall the graph represents the consistent need for some assistance in

completing the task of allowing the staff to help S shave on a daily basis. Figure 7 presents the bar chart for Task 1 by time period.

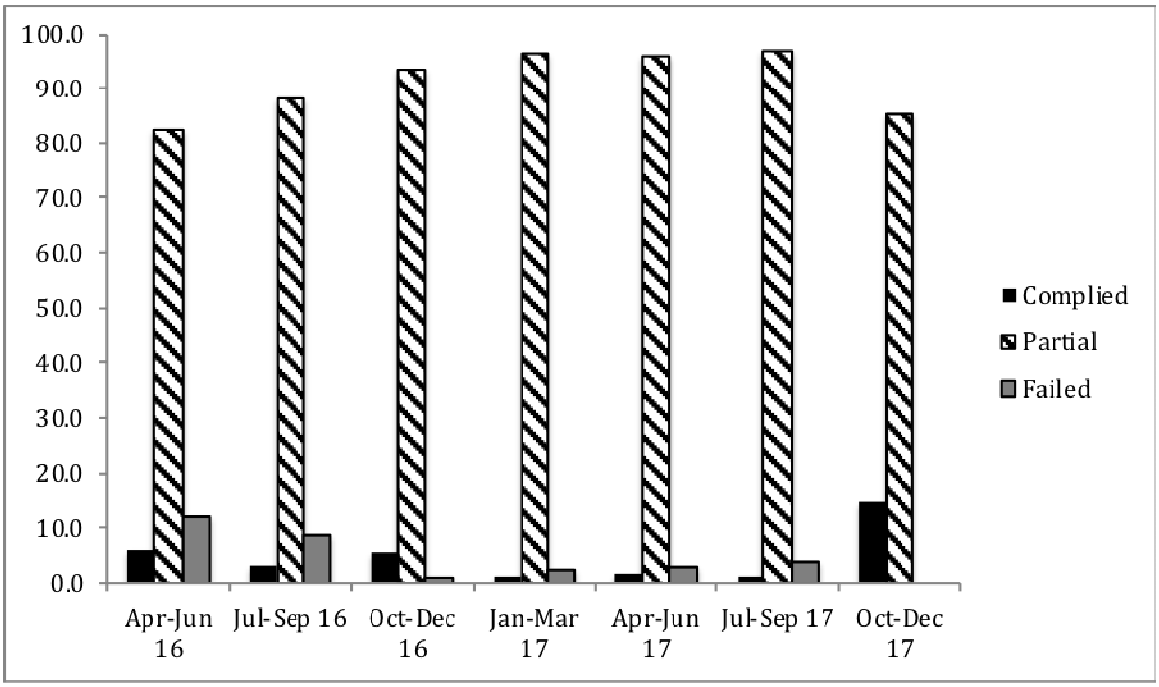

Figure 7. Percentages for Task 1: Staff will assist patient shave daily. Apr = April; Jun = June; Jul = July; Sep = September; Oct = October; Dec = December; Jan = January; Mar = March.

Task 2: Patient will talk to staff daily about his feelings to resolve his frustration and disappointment when he does not get exactly what he wants from family and staff. There six missing values in the data for this behavioral code in the first quarter, followed by three in the second, two in the third, 11 in the fourth, 13 in the fifth, 12 in the sixth, and one in the seventh.

Similar to the first task, partial compliance was the norm for this behavior across all time periods. Partial compliance varied from 65.4% in the fifth quarter to 92.1% in the

second quarter. Full compliance ranged from 3.5 % of the time in the first quarter to 28.2% in the fifth quarter. Failure to comply completely ranged from 0% in the sixth quarter to 17.7% in the fourth quarter.

Overall, S's completion of this task appeared to remain relatively steady over time, with some improvement in the fifth quarter. Figure 8 presents the bar chart for Task 2 by time period.

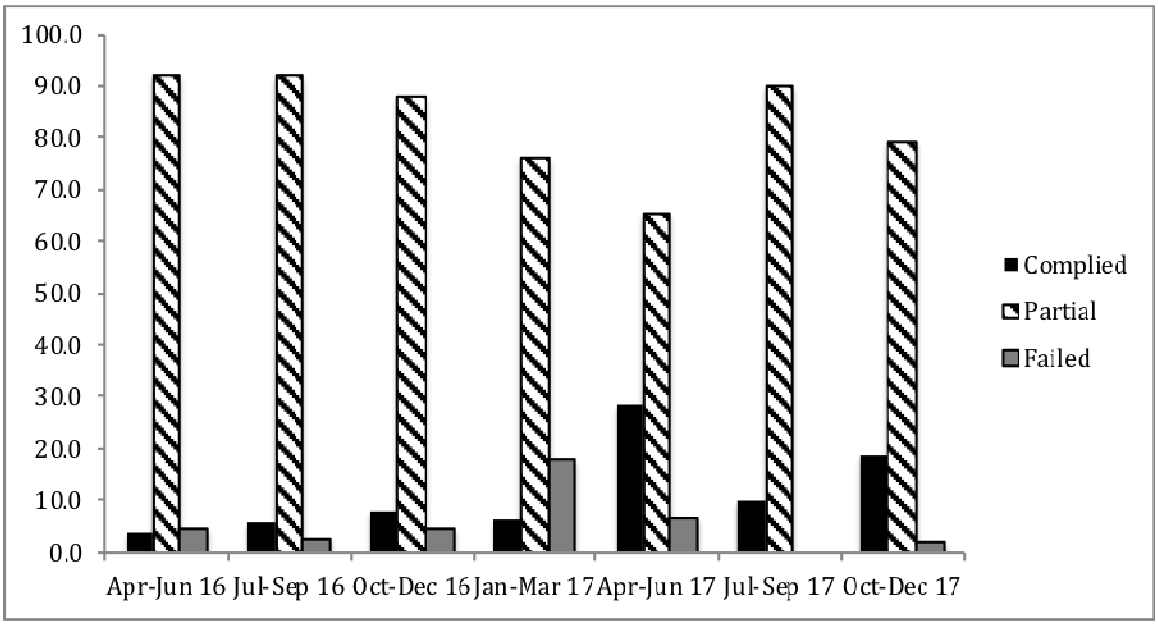

Figure 8. Percentages for Task 2: Patient will talk to staff daily about his feelings to resolve his frustration and disappointment when he does not get exactly what he wants from family and staff. Apr = April; Jun = June; Jul = July; Sep = September; Oct = October; Dec = December; Jan = January; Mar = March.

Task 3: Patient is offered informal rewards for attending scheduled activities, including subway rides, treats, and special attention to his daily recliner repairs. Similar to the other two behaviors, partial compliance was the norm throughout the recording period. Missing values for this behavior include six codes in the first quarter, two in the second, two in the third, 12 in the fourth, 13 in the fifth, 12 in the

sixth, and one in the seventh. Partial compliance in this task ranged from 54.4% in the third quarter to 98.7% in the fifth quarter. Failure to comply varied from zero in the first, third, fifth, and sixth quarters to 14.6% in the seventh quarter.

In this task, behavior varied over time, although, as mentioned, partial compliance was the norm. Attending scheduled events independently improved dramatically in the third quarter but returned to partial compliance for most of the recording period. The seventh quarter also was associated with an increase in independent attendance of scheduled activities. Figure 9 presents the bar chart for Task 3 by time period.

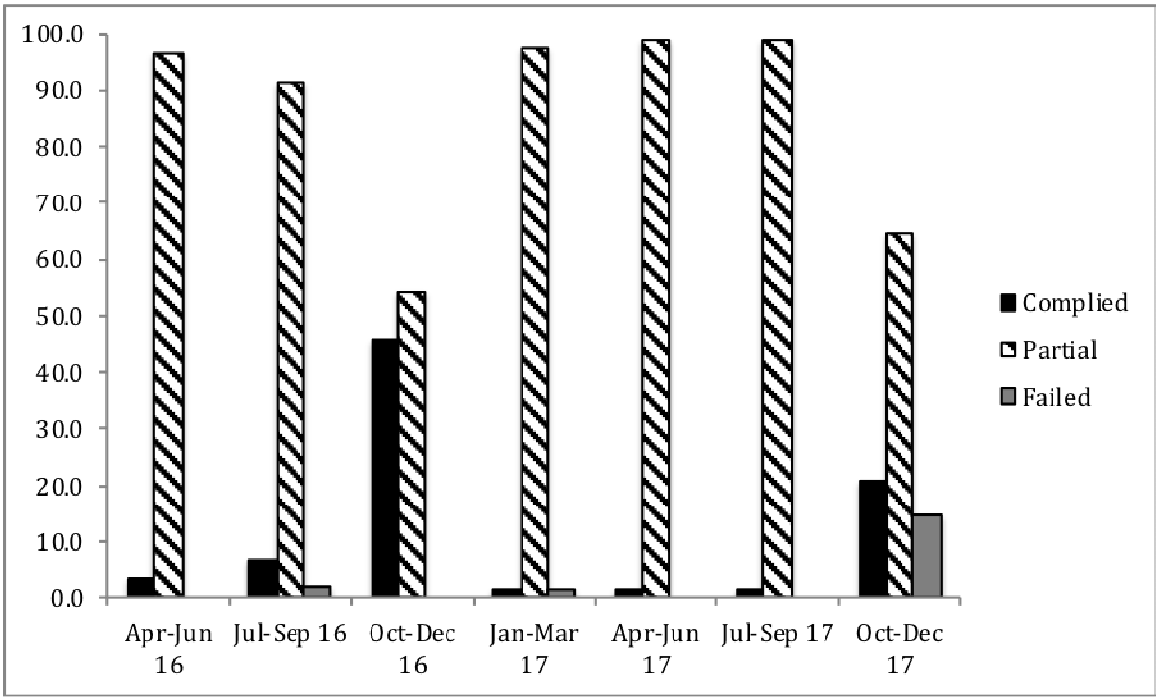

Figure 9. Percentages for Task 3: Patient is offered informal rewards for attending scheduled activities including subway rides, treats, and special attention to his daily recliner repairs. Apr = April; Jun = June; Jul = July; Sep = September; Oct = October; Dec = December; Jan = January; Mar = March.

Overall, the recording period for S's goal behaviors was limited, and for the most part remained steady at partial compliance for all behaviors. There was some variation in the behaviors, but it was not consistent as the variation observed in M's data. Changes in S's behaviors appeared to be independent of each other. It would have been optimal to obtain data spanning a longer time period, similar to what was available for M; however, with the limited data that are available it is clear that S needs support and assistance to accomplish his goals. Without more information, it is impossible to tell if the goals set for S are reasonable ones given his lack of ability to complete them independently.

As discussed above, the nature of the data that were collected made hypothesis testing for the quantitative component of this mixed method study impossible; I could not test RQs 1 and 2. I was only able to visually inspect the data for change, as previously discussed. Quantitative data can also be examined in conjunction with the qualitative data in order to assess the degree of clinical significance of symptom change rather than statistical significance of symptom change. Statistically significant findings are based on probability that an event or set of events would reflect certain qualities assuming that the sample of events is taken from the known population (the null hypothesis) while clinically significant findings are based on the ability to observe findings in a given setting. This means that though statistically significant results may be obtained, because the effect size is very small the ability to use the findings in a clinical setting would not produce observable outcomes. It also means that statistical findings may not be significant, but the effect size is so large that practical decisions can be made from the findings.

Qualitative Component

I asked one qualitative RQ in this study: What are the experiences and perceptions of the family members and caretakers of twins with IDDs who were each treated with different approaches (conventional vs. aversion therapy) of those treatments in terms of outcome and ethical implications? Each of the themes and their accompanying subthemes addressed this question. The qualitative RQ was written to capture the experiences and perspectives of family and caretakers of the twins from early adulthood until the present. Table 3 presents the themes and subthemes that arose from the qualitative data analysis. There were six themes: behaviors in young adulthood, behaviors targeted for treatment, types of treatment, efficacy of treatment, ethics of treatment, and current state of patients. Each theme had a minimum of two discernible subthemes.

Table 3

Thematic Structure

Theme	Subtheme
1. Behaviors in young adulthood	Outwardly-directed aggressive behaviors Self-injurious behaviors
2. Behaviors targeted for treatment	(a) aggressive behaviors toward objects, (b) aggressive behaviors toward others, (c) self-harm behaviors or antisocial behaviors
3. Types of treatment	(a) behavioral modification, including reward and punishment; (b) GED skin shock treatment; (c) psychotherapy; (d) psychotropic drugs
4. Efficacy of treatment	(a) disapproval of, or concerns about, use of psychotropic drugs; (b) positive relationship of GED skin shock therapy and positive behaviors; (c) level of intellectual functioning interferes with alternative treatment success; (d) positive reinforcement systems have helped or are currently helping negative behaviors; (e) treatment consistency and structure have been effective; (f) treatment seems to be related to the patient's quality of life
5. Ethics of treatment	(a) the treatment was ethical because the benefits outweighed the risks, (b) the treatment was ethical because the patient showed improvement, (c) the treatment was unethical because only the drug industry benefitted, (d) the treatment was unethical because it resulted in reduced functioning and quality of life
6. Current state of patients	(a) patient has not exhibited self-harm or outwardly directly aggressive behaviors to caregiver or family member in recent years, (b) patient's frequency of negative behaviors has decreased, (c) patient exhibits positive or prosocial behaviors, (d) patient has not required a GED treatment in 5 years

Note. GED = graduated electronic decelerator.

Theme 1: Behaviors in Young Adulthood. The theme Behaviors in Young Adulthood was composed of two subthemes: (a) outwardly-directed aggressive behaviors and (b) SIBs. Each highlights the early behaviors of the twins prior to any behavioral interventions or entering any treatment facilities. This theme emerged from the two

relatives of the brothers, and the clinician of M, who has worked long term with him and is familiar with his behaviors and medical care history.

Behaviors directed toward others or toward property. This first subtheme provided some of the context needed to fully address the qualitative RQ, which was to understand the early adulthood behaviors of the twins based on the perspectives of their caretakers and family members. While both twins exhibited harmful behaviors, these manifested themselves in different ways when the brothers were teenagers and young men. S's aggressive behaviors were directed more toward inanimate objects rather than people. M's aggressive behaviors, on the other hand, were directed toward other people. According to the care provider of M (Participant 1) and one family member (Participant 3), both twins began harming others and destroying property early in life. In his teenage years, M's "aggression towards his parents and family [also] accelerated" and "he caused frequent injuries to his parents" (Participant 1). This was confirmed by another family member of the twins (Participant 4), who stated that each time she would try to stop M's aggressive behaviors he would attack her.

Little information was provided about S's early outwardly-directed aggressive behaviors prior to his 20s. Participant 3 stated that he "has [sic] property destruction and did not get physically aggressive to others until his 20s." His other family member, Participant 4, confirmed this by stating that S's aggressive behaviors toward others appeared to escalate around the age of 25, concomitant with his moving into a treatment facility. At this time, according to Participant 3, he also tried to "place his and a peer's hand over a fire on the stove" in an attempt to burn both his and his peer's hand.

***Self-injurious behaviors*.** SIBs are the second subtheme of Behaviors in Young Adulthood. The information contained within this subtheme provides further context for the qualitative RQ, and a deeper understanding of the SIBs that the twins exhibited in adolescence and young adulthood. M apparently exhibited SIBs from an early age. Participant 4 recalled that as a toddler, M exhibited self-abuse, like head banging, which was confirmed by his other family member. These behaviors became more severe as he got older, and eventually he required hospitalization for some of his self-inflicted injuries.

S's SIBs began at his adult residence, according to Participant 3. There is some indication based on the statement from Participant 3 that S was exhibiting SIB as a toddler, but no further details were provided about this aspect of his behavioral history. In addition, because S's care provider (Participant 2) has not been working with him throughout his life, this participant was unable to comment on S's early behaviors. From the way that the brothers' care providers and family members spoke about their early behavior, M appeared to exhibit more harmful behavior toward himself at an early age, whereas S's outwardly harmful behavior did not begin until later, in his early 20s.

Theme 2: Behaviors Targeted for Treatment. The second theme that emerged from this research and that relates directly to the qualitative RQ was that of Behaviors Targeted for Treatment. Three subthemes emerged within this theme and were broken down by the type of behavior. These subthemes were aggressive behaviors toward objects, aggressive behaviors toward others, and self-harm behaviors or antisocial behaviors. M exhibited "physical aggression towards others (e.g. bite others, hit others, kick others, push others, grab others, head butt others, including all attempts to hurt others" (Participant 1).

M's care provider broke these behaviors into three categories: Health Dangerous Behaviors 1 and 2, and aggressive behaviors. "Health Dangerous Behavior 1 consists of hit self, bite self forcefully to cause injury"; whereas, Health Dangerous Behavior 2 was "pick skin to cause damage, pick inside of nose to cause bleeding, forcefully scratch self to cause redness or bleeding" (Participant 1). The reports of Participants 3 and 4 were consistent with this description and added that property destruction was targeted for treatment for both brothers (per the reports of Participants 2, 3, and 4).

Participant 3 also noted antisocial behavior in S. These behaviors have not been and are not currently targeted for treatment, but she would like to see them included into treatment goals in the future. There is no indication that M exhibited these behaviors at any point, but S has. These antisocial behaviors have included neglect of personal hygiene and appearance. "Wearing old clothes and refusing new ones" has been a concern for Participant 3, as she believes that this leads to stigma based on S's outwardly "disheveled appearance." Prosocial behaviors were not specifically mentioned as being targeted for improvement by any of the research participants.

Theme 3: Types of Treatment. The range in behaviors that the twins exhibited lent themselves to several different treatment types, and each twin has been through a variety of treatments. These treatments are the focus of this theme, Types of Treatment. Each treatment type became its own subtheme: (a) behavioral modification, including reward and punishment; (b) GED skin shock treatment; (c) psychotherapy; and (d) psychotropic drugs. Clinicians have tried to address, or treat, M's behaviors in the following ways: immediate primary reinforcement, verbal redirection, verbal reprimands,

planned to ignore, environmental modifications, antecedent interventions, activity modifications, escape extinction, response-cost, and setting manipulations (Participant 1). There have also been "decelerative consequences, including non-preferred clothing, time out, contingent physical exercise, positive practices, and restitution overcorrection" (Participant 1). Two other treatment types have been used with M in the past: psychotropic drugs and GED shock therapy (Participants 1, 3, and 4).

Some of these same types of treatment have been used for S, including the consistent implementation of "positive behavior supports that include food as reinforcement" (Participant 2), and the use of psychotropic drugs (Participants 2, 3, and 4). GED was never tried for S, and according to the participants, clinicians and caregivers have relied much more heavily on the use psychotropic drugs for S over the years. When asked what treatments have been tried to address his problem behaviors, S's mother said, "Medications, over 2000 [pills] a month," as well as calling the police and calling for hospitalization if needed.

Theme 4: Efficacy of Treatment. In this theme, Efficacy of Treatment, the beliefs about the efficacy of each brother's treatment regiment are discussed. Each participant provided valuable input about the treatment approaches (aversion therapy or behavioral therapy) that were provided to the brothers. From the participants' responses, six subthemes emerged: (a) disapproval of, or concerns about, use of psychotropic drugs; (b) efficacy of GED skin shock therapy on behaviors; (c) level of intellectual functioning interferes with alternative treatment success; (d) positive reinforcement systems have

helped or are currently helping negative behaviors; (e) treatment consistency and structure have been effective; and (f) patient's quality of life was improved.

Both brothers have been exposed, over their lives, to a suite of behavioral treatment types, but M was exposed to GED aversion therapy, whereas S was only exposed to conventional PBT and pharmacological treatments such as psychotropic drugs. The underlying theme of this research addresses the way different treatments are perceived by many in the field of mental health and the outcomes of giving these treatments, using the brothers as examples. Three of the research participants, excluding S's care provider, expressed great concern over the use of psychotropic drugs for the treatment of both brothers' behaviors. As Participant 3 put it, "I disapprove of [S] taking psychiatric medication." The other family member felt the same way, and included that "the med did not change their behaviors, but had serious side effects" (Participant 4). Participant 1 offered their professional opinion about this, stating that M's diagnoses "are not diagnoses which support use of psychoactive medication" (Participant 1).

Of the GED aversion therapy, to which only M was exposed, Participant 1 stated that

> when the GED was introduced . . . it served as an effective punisher for M's most clinically significant behaviors. A behavioral program, rich in positive reinforcers, together with a punishment component to be available, if necessary, to rapidly decelerate unwanted behaviors, has proven to be the most beneficial, least restrictive, treatment alternative for M.

Both of M's family members shared his clinician's belief that the GED skin shock therapy has been beneficial overall for treating M's aggressive behaviors. For example, one of them spoke about M's condition now. She said that "the behaviors have improved, he has been safe, [and] taken all his psychotropic medications" (Participant 3). Further, M is now able to hold a paid job and can access the community regularly without any aggressive behaviors toward others or himself. Perhaps most significantly, this family member stated that she feels comfortable with M around her children, and that he has proven that he can be safe around them, although she did not specifically attribute this to the change in his GED treatment. Unfortunately, she does not feel the same way about S, whom she prefers to visit with one of his care providers to ensure safety.

S was not exposed to GED skin shock therapy. Instead, his aggressive behaviors have been treated through a combination of psychotropic drugs and positive behavioral approaches. S's caregiver stated that the "positive behavior approach is the right way to go about it," when asked about their general opinion of that treatment approach. His caregiver believed that there is nothing wrong with the positive behavioral approach combined with psychotropic medications. Further, his caregiver stated that S finds it difficult to "control his actions using positive reinforcement because he has his own way of thinking." His sister reported that the frequency of his behaviors, which she did not further specify, had decreased, but did not talk about these specifically in terms of the positive behavioral approach.

Theme 5: Ethics of Treatment. When asked about the ethical considerations involved in types of treatment to which the brothers were exposed, the participants had

mixed feelings. There were four subthemes: (a) the treatment was ethical because the benefits outweighed the risks, (b) the treatment was ethical because the patient showed improvement, (c) the treatment was unethical because only the drug industry benefitted, and (d) the treatment was unethical because it resulted in reduced functioning and quality of life.

M's care provider believed that because the benefits of the treatment outweighed the possible risks, the GED treatment was ethical. He took a long-term approach when assessing these benefits and risks. At M's treatment facility, GED treatment was employed as part of aversive therapy, according to Participant 1. Participant 3 did not directly address the ethical concerns related to GED treatment, but stated that this aversive therapy as well as other positive behavior contracts have really increased the quality of M's life.

Restriction was also an important component of the risk/benefit analysis and played a role when assessing the ethical implications of S's treatment. S's care provider (Participant 2) believed that there was nothing ethically wrong with the combination of psychotropic drugs and positive behavioral approaches to treat S because of the perception that the treatments worked. Participant 3 offered a different perspective on this, however. She stated that he "continues to be on multiple psychotropic medications which make him sleepy, which is really chemical restraint." For her, the lethargy resulting from the psychotropic drugs should be considered a form of restraint, and this has really restricted and impeded his quality of life. When asked about the ethical concerns of the treatment, she wrote on her questionnaire that "medications instead of

using ABA caused multiple medical problems, have been less effective, and have resulted in lower functioning and quality of life."

The other family member (Participant 4) had negative things to say about the use of psychotropic drugs as well. She stated that the use of psychotropic drugs was unethical because the only person or people to benefit from S's drug treatment regime was the pharmaceutical industry. She believed that instead of focusing on S's quality of life, the drugs were pushed for the benefit of those making money from their sales.

Theme 6: Current State of Patients. The sixth theme, Current State of Patients, describes the brothers today. There were four distinguishable subthemes that arose from Theme 6: patient has not exhibited self-harm or outwardly directly aggressive behaviors to caregiver or family member in recent years, patient's frequency of negative behaviors has decreased, patient exhibits positive or prosocial behaviors, patient has not required a GED treatment in 5 years.

M's care provider and both family members agreed that the incidence of his negative behaviors has decreased based on his current treatment plan and the prior use of aversive GED skin shock therapy. Participant 3 wrote that he has a job and accesses the community without worry of any negative incidents. She said that he "is happy, almost always in a good mood, enjoying himself." She feels comfortable with him around her children, and that their safety is not compromised in his presence.

Similarly, S's care provider reported that they have not witnessed any negative or inappropriate behaviors in a long time. Participant 3 also stated that the frequency of his negative behaviors "has decreased, although he is often sleeping due to his medications."

Despite this overall lack of inappropriate behaviors, this participant noted other behavioral changes that she believed were significant. She described his mood as generally irritable and annoyed, and often very tired. There are many things that S enjoys doing, like watching videos and visiting family, but he is often so tired from his medication regimen that he sleeps often. Participant 3 believes that while the instances of S's negative behaviors has decreased, the medications make him sleepy and have, overall, decreased his quality of life.

Each twin is currently on one or more treatment plans. M has not received a GED skin shock treatment in over five years. His care provider stated that "although the GED was profoundly influential in [M's] overall improvement, he reached a point where he no longer needed it, and it was dropped entirely from his program in 2016." For M, these treatments, over time, were no longer needed to redirect his negative behaviors, so they are no longer a part of his treatment protocol. Instead, as Participant 3 reported, M is on six behavioral contracts to promote positive behaviors through incentives and rewards. He also no longer takes any psychotropic medications for negative behaviors.

S, in contrast, currently takes a large quantity of psychotropic medications to control his negative behaviors in addition to conventional PBT programs. Participant 2, the care provider for S, believes that his current treatment regimen is working. Participant 2 reported not seeing S exhibit any negative aggressive behaviors in the last 3 years. They added that the behavioral programs designed to reward S for his good behavior work only when they are consistently implemented. This can be a challenge because, as Participant 2 stated, "once in a while he listens, he requires lots of encouragement." This sentiment

was echoed by Participant 4, who wrote that S "tells me that he's in charge" when asked to do something. Participant 4's responses did not correspond with Participant 2's statement that treatment was effective.

Synthesis of the Findings

When comparing data to determine the effectiveness between the two approaches, it is important to look at the nature of the data that were provided. In the case of M, I examined 10 years of data compared to S's 19 months of data. For the first 6 years of data, M displayed high frequencies of all six negative behaviors. At Month 80, all behaviors decreased, and some of them spiked again at the end of the period of record keeping.

The quantitative findings for M were consistent with the qualitative findings that noted how M successfully completed the aversion therapy routine and no longer required the therapy. I could not examine the quantitative data for statistically significant change over time; however, visual inspection of the data revealed a decrease in negative behaviors over time that was clearly clinically significant, and this was confirmed by M's family members. One participant talked about how M now had a job and can access the community without other fearing negative incidents. She noted M had a cheerful disposition in life and that she felt comfortable with him around her children because he was not a safety concern. According to Participants 1, 3, and 4, M experienced a significant transformation regarding his behavior. Because of his transformation and what they described as his current mindset, they believed aversion therapy was an ethical

choice to make for their family. Participant 3 believed their choice increased the quality of M's life because of he no longer needed aversion therapy and was working.

Compared to M, S had not demonstrated success using conventional PBT in terms of self-managing behaviors and family members' perceived efficacy. Although the data were limited, it demonstrated that S predominately performed only part of the tasks successfully, with few exceptions, across all 19 months of data. Connecting these performances with the qualitative findings, 3 out of 4 (75%) participants believed that use of psychotropic drugs in the treatment of S were not ethical in managing negative behavior because they did not feel it adequately addressed the behaviors themselves.

Both the quantitative and qualitative data revealed that S's positive behaviors demonstrated no clinically significant change over time. Instead, the psychotropic drugs increased lethargy and made the patient drowsy. Although Participant 2 reported a decrease in S's negative behaviors over time, Participants 3 and 4 did not feel it was an accurate representation of changed behavior. They felt it reflected a lack of ability, created by the "chemical restraint" of psychotropic drugs, which negatively affected the perceived quality of life for *S* (Participant 3).

Quantitatively, the twin who had been provided GED aversion therapy displayed consistent decreases in negative behaviors, albeit with a sudden increase in these behaviors at the end of the recording period. This was supported by the reports from Participants 1, 3, and 4 who all noted that M no longer required aversion therapy after nearly eight years of receiving therapy, compared to S who continued to struggle to meet behavioral goals. This was further supported when Participant 3 shared that she felt

comfortable having M alone with her children but did not feel the same way about S. Additionally, at the time of data collection, M was employed and able to interact in the community, whereas S had not yet reached these milestones. The quantitative and qualitative data were consistent and corresponded in demonstrating clinically significant change in M's behavior, but not in S's behavior.

Evidence of Trustworthiness

Credibility is considered the most important aspect in establishing trustworthiness. I established credibility in this research study in two ways. First, the archival data that I used is considered accurate and was validated through internal review. Second, the mixed-methods research design and multiple sources of data allowed me to triangulate these data to ensure credibility. Each of the participants wrote their responses, so there was clear communication regarding what they intended to communicate.

Thomas and Maglivy (2011, p 153) wrote that transferability in qualitative research refers to the ability to take the findings from one research study, or its methods, and to apply them to other contexts or studies. I established transferability in this research study by providing a rich, detailed description of the methods used to collect and analyze the data generated by this study.

A research study is considered dependable when other researchers can follow the steps that the researcher took throughout a study. I ensured dependability in this research study by describing all decisions that I made throughout data collection and analyses. This is referred to as an audit trail, whereby another researcher could review this trail and understand why I made the decisions that I made to collect data and analyze them.

Confirmability, then, was something that I established through ensuring that this research study was credible, transferable, and dependable.

Summary

This chapter presented the findings of the quantitative and qualitative data analysis, as well as a consideration of the synthesis of the data. One purpose of this study was to investigate the comparative effectiveness of conventional PBT and aversion therapy in the treatment of SIB in a pair of intellectually disabled twins. A second purpose was to explore the lived experiences of caregivers and family members regarding their understanding of the ethics and effectiveness of treatment using essay-type questionnaires. Overall, M's negative behaviors decreased over time, while S's positive behaviors showed little-to-no change over the course of a significantly shorter time frame. Caretaker and family reports were consistent with the quantitative data, with the exception of S's caretaker reporting significant improvement that was not consistent with the quantitative data and the family member's report. Ethically, shock therapy seemed to be considered more ethical than medication in the view of family members and caretakers.

In the next chapter, I will continue to explore the findings of the data analysis. Connections will be made to the literature and theoretical framework selected for the study. I will also explore implications of the findings and suggestions for future research.

Chapter 5: Discussion, Conclusions, and Recommendations

The problem I addressed in this study regarded the treatment options of aversion therapy versus conventional ABA treatment to address chronic SIBs. Also addressed was the need to reassess ethical issues relevant to the use of aversion therapy. SIBs are devastating and potentially life-threatening chronic behavioral problems that are sometimes exhibited by people with developmental disabilities. The use of aversion therapy has long been controversial and frowned upon in the treatment of SIBs and other behaviors. However, research focused on the potential for aversion therapy to effectively treat SIBs, especially in cases where other therapies have failed, has recently resurfaced (e.g., Staiger et al., 2013; Verendeev & Riley, 2012). Historically, there has been a lack of attention given to this topic. In conducting this study, I attempted to add to the discussion about the efficacy of aversion therapy in comparison to therapy that focuses on positive behavior reinforcement, as well as the ethical controversy concerning its use.

The purpose of this mixed-methods study was to investigate the effectiveness of aversion therapy in comparison to traditional ABA treatment modalities focused on positive behavior support in the treatment of SIBs in a pair of intellectually disabled twins. I also wanted to explore the subjective lived experience of the relatives and caretakers regarding the efficacy and ethics of those therapies. I used archival data in a single-case design in the quantitative component to determine treatment effectiveness, examining one case that used aversion therapy and another that used conventional behavior modification methods. The quantitative data were obtained from two U.S.-based clinical psychiatric and psychological treatment centers. The qualitative component was

prospective, in the form of essay-type questionnaires administered to the family members and caretakers of the twins; however, the data could not be used in a quantitative study because the data collected were not comparable. The participants in the qualitative component were two people who were related to twins and two additional individuals who were each responsible for the caretaking of one of the twins, but the data collected for the first twin reflected only 2 months of responses in positive terms while data collected on the other twin concerned negative behaviors. This affected the planned study, in that the approach needed to change from a quantitative study to a qualitative study.

Interpretation of Findings

The treatment administered to M and S was delivered over the same period, but M started an ABA behavior therapy approach in another state 29 years ago because of unmanageable behavior including head banging and accelerated aggression. M's subsequent placement out-of-state and the application of GED aversion treatment occurred after exhausting all in-state placement possibilities, as his home state did not offer a therapeutic approach that was tailored to his specific SIBs. The quantitative RQs could not be addressed given the incompatible nature of the data obtained from the facilities; however, the findings of qualitative analysis indicated that the quality of life for M was perceived as better than for S. The frequency of the targeted behaviors for M decreased to the point that he now has the ability to hold a job and access the community worry free, according to Participant 3. The same is not true for S, who, according to

family members, continues to display inappropriate verbal behaviors and learning interference.

It is important to acknowledge M's sudden increase of SIB followed by a decrease at the end of the recording period. This may be due to an anomaly but could also be related to the discontinuation of aversion therapy. M's highest frequency undesired behavior was inappropriate vocalizations followed by learning interference. Since M's admission, the number of GED shocks decreased so that the majority of his current therapy incorporates a consistent ABA behavioral approach offering the most effective, least restrictive, treatment alternative. The findings suggest that ABA is a form of treatment that appears to be associated with quality of life improvement, which is consistent with the assertions of Addison &Lerman, 2009). The addition of aversion therapy for M appeared to be associated with the decrease of his problematic behaviors according to the quantitative data. The improvement in functioning and quality of life was clearly the impression of his family members and caretaker.

One of the things that distinguishes positive treatment from aversion therapy is that positive treatment focuses on positive reinforcement for desired behaviors, and undesired behaviors are ignored. ABA also consists of several defining characteristics or dimensions, including a focus on problems of social or psychological importance (applied), direct measurement of behaviors (behavior), and the use of analytical procedures and methods to document evidence of behavior change (analysis; Lerman et al., 2009). ABA is a positive reinforcement primary focus for intervention. In contrast, aversion therapies focus on aversive consequences to discourage undesired behavior.

GED, the aversive therapy used with M, is a brief electrical stimulus or skin shock that is applied as a consequence as soon as a specified undesirable behavior is recognized. The purpose of the skin shock is to decrease the likelihood of the undesired behavior reoccurring as predicted by the theory of operant conditioning.

For M, aggressive behavior spiked at the beginning of the treatment period but leveled off over the span of treatment with another spike at the end but with a frequency of incidents that was less than 1% of that pretreatment. The quantitative RQs could not be addressed, but, in integrating the quantitative data and qualitative data, it appeared that M's behavior was associated with change over time, while S's did not. The qualitative data adds an element of the perception of quality of life for the twins. According to family members, the changes in M's behavior were accompanied by increased ability to function, while S not only did not exhibit change but appeared to be managed by drugs rather than behavior management.

It is important to point out that this study focused on only two individuals, their family members, and their caretakers; therefore, the results are not generalizable. The findings do, however, provide at least case study evidence that aversion therapy may be both effective and ethical. In this case, the individual who received it appeared to have substantially increased quality of life by the end of treatment. Cause and effect conclusions cannot be made for M's data. Given the probable biases of the twin's family members, cause and effect conclusions are also not possible from those sources.

Another issue that complicated the study was that the data collected from M were not comparable to the data collected from S. M's data focused on the frequencies of

negative behaviors with a goal of reduction, while the data collected from S were of positive behaviors that were encouraged. One set of data were more complete and organized while the other was limited and had missing data. This difference indicates that the treatment received may not have been only different in type, but also possibly different in quality.

For S, only part of his tasks were performed successfully, and, nearing the end of the recording period, only 2 of 3 of his tasks were performed. There did not appear to be a significant difference in S's performance of tasks over time. The contrast in the twins' behavioral data was remarkable in that M appeared to improve substantially over time as his undesired and SIBs decreased along with the need for medication while S's desired behaviors did not appear to change over time, and his family members remarked on how his behavior appeared to be controlled by the sedative effects of his medications. Even though the behaviors that were tracked in the quantitative data were not comparable, it does appear that M is functioning better than S.

Statistical analysis could not be completed on the quantitative data that were gathered, as the data could not be used to test the hypotheses for the first two RQs. Visual analysis and the qualitative data from both M and S's family seemed to support clinical improvement in M's behavior and no clinical improvement in S's behavior. The qualitative data from S's caretaker, Participant 2, contrasted with the family members' viewpoints, however, and was in support of the positive behavior treatment. Participant 3 stated that S spends some entire days alternating between the bed and the recliner. In addition, the staff has advised the family not to take him on vacation due to his behaviors.

The participants who were relatives of the brothers reported that both of them displayed aggressive and destructive behavior before treatment. Their observations reflected that, while the brothers were young, S's destructive behaviors were directed towards things, while M's destructive behaviors were directed toward people, at times causing injury to his parents. Given the descriptions of M's pretreatment behavior, his case was clearly more severe, even to the point of needing to be sent out of state for treatment. Aversion therapy was not the family's first choice of treatment, yet the treatment results that he obtained were desired by the family members. Again, this cannot be attributed only to aversion therapy, as the treatment facility itself appeared to be highly organized in comparison to S's treatment facility, and ABA treatment was administered, including supplemental GED treatment. M's treatment care providers may have been more vigilant, attentive, and consistent in comparison to S's providers. Much more information would be needed in order to determine if the quality of care differed between the twins over several years of treatment.

From the reports of family members, it is clear that M was severely hurting himself before aversion therapy was administered, and over the course of treatment this behavior decreased. According to his family members and his caretaker, he is living a much better life. His family and caretaker also believed that the use of GED treatment was ethical, especially considering the outcome of treatment. S's destructive behavior towards others escalated around the age of 25. In contrast, M has not exhibited outward destructive behavior in recent years and has not required a GED treatment in 5 years. There have been no improvements in behavior for the officially recorded outcomes for S

and the members of his family and caretakers have noted that his responsiveness has been general decreasing as he has remained on high levels of medication and his response to these are that he refuses to take part in program. He developed generalized seizures, obesity, constipation, gastrointestinal obstruction, and tardive dyskinesia. He is often asleep and some days, instead of attending his day program, he lies in bed or sits in a rocking chair all day. According to his family members, his quality of and participation in life is considerably less than that of M.

The CDC method for visual inspection, which was originally planned as the data analysis method, was not used because the data recorded for M was only for negative behaviors and data recorded for S was only for positive behaviors. The time frame of the data also differed in the data sets that were provided. Therefore, trends were examined using visual reports. Because the necessary data were not available to answer the quantitative RQs, the findings were limited, and the quantitative data needed to be considered in the context of the qualitative interviews.

The qualitative data combined with the limited quantitative data suggested that the family members and caretaker of M believed that aversion therapy was related to improvement and that it was ethical given the outcome of treatment. The emerging theme that came from the interviews consisted of comments suggesting success of the GED shock therapy for M's negative behaviors and that he seems happy, is almost always in a good mood, and enjoys himself. M's care provider indicated that, although the GED played an important role in M's change, it had been dropped from his treatment program 5 years earlier. He remains on a treatment plan based on positive reinforcement, as he no

longer needed GED as part of his treatment protocol. Incentives and rewards are now exclusively used to promote positive behaviors. He also does not take any medication. Thus, although aversion therapy appeared to be useful in the beginning of the treatment period, it was discontinued, and at the time of the study M was receiving the same treatment as S.

In contrast to M, S continues to need medication as part of his treatment in order to control his negative behaviors. His caretaker stated that his current program is working to control his negative behaviors and added he has seen no negative behaviors for 3 years. He also added that S's positive behaviors require lots of encouragement, and that therapeutic interventions need to be consistent in order to get results. The mother of M and S did not agree that the treatment was effective and gave examples of irrational behavior when S was asked to perform a task. Perceptions that he has improved may be due to inactivity, which in turn may be because of his medication.

Ethical Issues

The theory that was employed as a basis for the qualitative component of this mixed methods study is the consequentialist theory, which states that, to determine morality, consequences and/or outcomes of the behavior rather than motivation must be taken into account (Gandjour & Lauterbach, 2003; Knapp, 1999). The findings of this research in the context of consequentialist theory indicate that GED treatment is ethically sound, and it would be ethically questionable to remove this therapeutic approach from the options caregivers have to treat sufferers of SIBs. In comparison, the family members who participated in this research indicated that S's behavior may be primarily managed

with medication, and although his treatment program focuses on positive reinforcement, overall treatment seems to have caused harm, as S is now sedated much of every day. Although he is not engaged in SIB, he does not have functioning or a quality of life anywhere near that of M.

Consequentialist theory focuses on outcomes, and utilitarianism is a branch of this thinking that posits that decisions about actions to take should be made to maximize human well-being (Knapp, 1999). Through the lens of this theoretical framework, it can be argued that aversion therapy appeared to be related to maximizing the well-being of M, and therefore is a beneficial treatment. One difficulty with the use of this theory as a framework for aversion treatments is that one must know the outcome of treatment in order to evaluate whether it is ethical; and at this point in time, access to case study research, such as the present study, is all that is available in order to make that judgment. The research that has been published on the outcome of cases using GED for SIBs has been, overall, positive (Kix, 2008); however, it is not universally successful. Determining which individuals may benefit from such treatment and which would not is an important part of assessing the overall ethics of aversion therapy, and unfortunately, there is not enough information available for all conditions to make such a determination.

Looking at the benefits and risks of the two treatment approaches used with the twins, and evaluating the findings in the context of consequentialist theory, indicates that the GED treatment as part of applied behavioral analysis, in these cases, was more ethical than the medication with positive treatment. In the population of those suffering from autism, SIBs and aggressive behavior are common. There is a great deal of controversy

surrounding the use of aversion therapy for these behaviors, and the arguments against the use of devices such as the GED appear to be fueled by emotion rather than facts about the treatment.

Nipper (2016) indicated in an article published in the *National Register* that people who are treated for SIB or aggressive behavior using GED exhibit pain and suffering as a result of the shock administered and suggested that each patient has a difficult time dealing with that pain and suffering. She appears to misrepresent the involvement of the patient in the decision-making process regarding GEDs, stating that unreasonable deception is used and that the use of the device causes harm to the point that the patient may be in peril. Nipper also listed potential negative effects of aversion treatment, including depression, fear, and panic and physical reactions like escape and avoidance behaviors, aggression towards others, and the replacement of undesirable behaviors with behaviors that are just as undesirable such as catatonia. The author advocated for banning the device, and while negative anecdotal evidence needs to be taken into account and ethics should be considered in all cases, there is no objective empirical data to support such a ban.

When considering the ethical use of GEDs as behavioral aversion therapy, which is based on the behaviorist theory that reinforcement and punishment will increase or decrease the probability of a behavior being repeated, operant conditioning, it is important to address the potential for benefit to the client and whether the therapist is willing to adhere to proper rules of conduct concerning when and how to use GEDs. A cost benefit analysis would require investigation of the degree of discomfort to the client

when undergoing treatment by GEDs in comparison to the degree of discomfort both emotionally and physically that the client would undergo without the use of GEDs in behavioral aversion therapy. The proper rules of conduct concerning the when and how to use GEDs can be established with guidelines determined by therapists who are properly trained in the use of GEDs.

It is important to have an ethical framework in place to evaluate the pros and cons of application in each individual case. According to *Rewire News* (2018), there are a number of antiaversion activists who continue to apply pressure to the U.S. Food and Drug Administration to ban the use of GEDs, suggesting that these devices are not ethical without having experienced the degree of discomfort or seen the results that benefit the client. Ethical use of any device should include the understanding of what a client undergoes, with and without the treatment.

Limitations

The most obvious limitation of this study is that I compared only two individuals, and although they are identical twins and therefore carry the same genome, they are still two individuals with their own experiences and reactions. The lack of availability of data also decreased my ability to conduct analyses, compare the two cases, and generalize the findings. The data were limited in terms of the range of behaviors that could have been tracked, the quality and time duration of S's data, and the fact that the data were not collected prospectively. Therefore, the quantitative component of this mixed methods study was weakened by an inability to compare the twins change in behavior over time.

Another important limitation in this study was that the treatment programs administered to the twins differed in a number of ways other than the use of GED. There are a number of factors that may have been related to treatment results such as staff, consistency of treatment, functional communications tokens used, the community the facility is in. Also, the qualitative component was limited by two of the participants' lack of knowledge of the plans of treatment (the caregiver for S and the mother of both patients). Except for the data on the frequencies of M's problem behaviors, the study mainly relied on the recollections of the twins' sister, M's clinician, and S's caretaker concerning their behaviors. As a result, the responses may not be as accurate as behaviors documented at the time would have been. If a one-on-one interview could be carried out instead of essay-type questions, the answers may have been more detailed and informative.

Recommendations

Future research should include more research studies with large sample sizes, ideally made up of not only autistic individuals receiving similar therapy for SIBs with the use of the GED device in one group, but also populations. A limitation to this recommendation is that for a life threatening behavior it is unethical to withhold treatment for a life-threatening behavior. Randomization to groups in an experimental study of this population would provide the best control over extraneous factors; however, the ethical issues that were discussed earlier in this chapter as well as in Chapter 2 need to be resolved before such a study can take place. Such an approach would also need to follow ethical guidelines and, given the controversy that has surrounded the use of the

GED device, it is unlikely that this type of research could take place on any large scale. Given the ongoing ethical dilemma regarding the use of aversion treatment, the data needed to establish aversive therapy as an ethical and effective treatment for SIBs will likely not be collected anytime soon, if at all. In the meantime, public opinion and perhaps even the opinion of those in charge of decision-making at the U.S. Food and Drug Administration may be fueled by negative emotional impressions of treatment rather than objective information weighing the pros and cons of treatment for each individual.

Data collection for any proposed study in this regard should be planned and carried out according to that plan so that both positive and negative challenging behaviors would be documented with the intent to analyze appropriately. It is important to use an ethical framework when conducting such research. Observations should also be recorded for analysis. This would enable some degree of generalizability of the findings. The methods used to obtain reactions of family and treating professionals should allow probing to obtain further information where needed. Individuals who are a part of the treatment or family members should be interviewed concurrently with treatment.

Therapists are trained to “do no harm” and have translated that into a belief that only PBT is acceptable (Jacob-Timm, 1996; Maurer, 1983; Pickering et al., 1988). They have been taught that it is not ethical to treat an autistic self-injurious person using physical and mechanical restraints or shock therapy without going through a human rights committee (APA, 2010; Maurer, 1983; Sherman, 1991). However, aversion therapy has been viewed as a reliable and effective behavioral treatment modality for a

range of clinically defined disorders, despite the fact that it has fallen from favor. This change is possibly because of the media coverage of overuse of aversion treatment (Eikeseth et al., 2006; Furniss & Biswas, 2012; Holden, 1990; Nord et al., 1991). Social changes affecting the classification of some behaviors led to the decline in public acceptance of punitive techniques (Dickinson et al., 2012). As a result, aversion therapy has been largely discredited.

Aversion therapy is likely to remain underutilized unless contemporary researchers provide evidence of its effectiveness and ethical appropriateness. If aversion therapy is supported by evidence to reduce dangerous and physically harmful behaviors in individuals who do not respond to other treatments, its abandonment as a treatment option could be considered unethical. In order to be perceived as ethical, the benefits need to be seen as outweighing the risks and costs of such treatment. There has been little attention paid to aversion therapy for SIBs in developmentally disabled populations, and it is recommended that further research in the use of aversion therapy may be suitable for use in the treatment of SIB in persons with intellectual and/or developmental disabilities.

Implications

The importance of the findings of this study within the context of the larger body of knowledge about treatment for autism and SIBs is to set precedence for further research to determine whether or not GED shock therapy is an effective and ethical treatment. Given the findings of this study, it may be the case that this approach, in combination with other approaches and used ethically, can lead to improved quality of life in individuals with developmental disabilities and SIBs. Looking at the two different

treatment modalities, it can be said that medication treatment combined with PBT did not improve quality of life for S and that side effects developed after continued use of the medication treatment. However, M was started on medication and ABA with GED but now is able to maintain a job and is no longer on medication, nor is he a threat to himself or others. The family participant who is the guardian of both brothers and a respected psychiatrist in the field of autism therapy indicated that she feels safer with M than with S. Ethically, the family members believed that M had experienced enough of an improvement of quality of life to more than compensate for the discomfort of the GED treatments. Given the findings of the current study, further research investigating outcomes of these approaches on a larger scale should be made. Ethical guidelines need to be followed carefully to ensure that the likelihood of benefit outweighs the discomfort experienced by the individuals in treatment.

Conclusion

I found that a strong, consistent behavioral approach (ABA) paired with aversion therapy appeared to be associated with the treatment of M in that it appeared to reduce SIBs. M did receive conventional interventions initially; however, his behaviors were severe enough that the family sought the alternative of aversion therapy to reduce the frequency of SIBs. In contrast, S did not experience progress in that he is still on medication and his compliance to requests has remained unchanged. Because the ultimate measure of success of a behavior plan is not to be found in the effect of a plan on the frequency of a single individual behavior, it is important to establish whether functioning and quality of life overall has been improved before a behavior plan can be endorsed. For

a controversial topic like this one, it is very important to approach the research by obtaining data from multiple sources, and a mixed-method approach such as the current research may be the most effective way to assess both effectiveness and ethics of any treatment. Findings will then be less affected by method or by the views of those from whom the data is collected, therefore increasing validity of the research (Onwegbuzi & Johnson, 2006). Aversive therapy and ABA therapy has benefited M, according to his family, vindicating their feeling that this would be a worthwhile approach. His quality of life has improved based on the data collected, which is evidenced by the reduction in his inappropriate behavior frequencies enabling him to successfully maintain a job and his ability to function and live normally without medication.

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Appendix A: Qualitative Questionnaire—Family

Participant code#: _____
Study Individual: Aversion or Positive Approach (circle one)

Please answer the following questions as honestly as possible, providing complete answers to the best of your ability:

A. Background

1. What is your relation to the individual?
2. How often do you see or make contact with him (e.g., daily, weekly, monthly, occasionally, etc.)?
3. Do you participate in the direct care of this individual, and if so, in what ways?
4. What is the nature of your decision-making authority or input into the treatment and care for this individual?

B. **Questions Concerning Condition and Treatment**

1. What are the specific self-harm, behaviors that have been targeted for treatment in this individual?

   a. How long has the individual been exhibiting these behaviors?

2. What are the specific aggressive behaviors that have been targeted for treatment in this individual?

   a. How long has the individual been exhibiting these behaviors?

3. What are the specific destructive/disruptive behaviors that have been targeted for treatment in this individual?

   a. How long has the individual been exhibiting these behaviors?

4. What different treatments have been tried to address problem behaviors and/or promote positive and prosocial behaviors?

   a. Why do you think these treatments have worked?

   b. Why do you think the treatments have failed to work?

5. Describe positive behaviors you have observed when the individual is not exhibiting the negative behaviors.

6. Describe any behavioral changes you have observed.
   a. What do you believe caused these changes?

7. How has the treatment affected the person's quality of life (positively and/or negatively)?

8. What do you think are the ethical issues or concerns in the clinical treatment implemented?

Thank you very much for your responses to this questionnaire. Your identity, as well as the identity of the two study individuals, will remain confidential. Please indicate if you would like a copy of the final dissertation sent to you upon completion of the study:

____ Yes, I would like a copy ____ No, I do not want a copy.

Appendix B: Qualitative Questionnaire—Caregiver

Participant code#: _____
Study Individual: Aversion or Positive Approach (circle one)

Please answer the following questions as honestly as possible, providing complete answers to the best of your ability:

A. Background

5. What is your relation to the individual?
6. How often do you see or make contact with him (e.g., daily, weekly, monthly, occasionally, etc.)?
7. Do you participate in the direct care of this individual, and if so, in what ways?
8. What is the nature of your decision-making authority or input into the treatment and care for this individual?

B. **Questions Concerning Condition and Treatment**

1. What are the specific self-harm, behaviors that have been targeted for treatment in this individual?

   a. How long has the individual been exhibiting these behaviors?

2. What are the specific aggressive behaviors that have been targeted for treatment in this individual?

   a. How long has the individual been exhibiting these behaviors?

3. What are the specific destructive/disruptive behaviors that have been targeted for treatment in this individual?

   a. How long has the individual been exhibiting these behaviors?

4. What different treatments have been tried to address problem behaviors and/or promote positive and prosocial behaviors?

    a. Why do you think these treatments have worked?

    b. Why do you think the treatments have failed to work?

5. Describe positive behaviors you have observed when the individual is not exhibiting the negative behaviors.

6. Describe any behavioral changes you have observed.

    a. What do you believe caused these changes?

7. How has the treatment affected the person's quality of life (positively and/or negatively)?

8. Why do you think the treatment has affected the person's quality of life?

9. What is your general opinion of the treatment approach?

10. What is your view of the ethics of the treatment approach?

Thank you very much for your responses to this questionnaire. Your identity, as well as the identity of the two study individuals, will remain confidential. Please indicate if you would like a copy of the final dissertation sent to you upon completion of the study:

____ Yes, I would like a copy ____ No, I do not want a copy.