Mindfulness-Based Group Therapy for the Caregivers of Those with ID

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MINDFULNESS-BASED GROUP THERAPY FOR THE CAREGIVERS OF THOSE WITH ID

By Krista Kirk

It has been well documented that parents of children with developmental delays consistently report higher levels of parenting stress than compared to parents of children without such additional difficulties (Baker et. al, 2003; Cummins & Yiolitis, 2000; Emerson, 2003; Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001; Majnemer, Platt, & Shevell, 2008; Neece, Green, & Baker, 2012). Studies have found that internalizing and externalizing behavior problems are relative to children without developmental deficiencies, showing 26.1% of children with developmental delays exhibiting behavior problems at a clinical level, while 8.3% of typically developing children showed the same (Baker, Blacher, Crnic, & Edelbrock, 2002). Furthermore, the stress associated with the additional components to parenting a child with an intellectual disability can decrease parenting effectiveness (Jones & Prinz, 2005) and, in turn, result in poor child outcomes (Webster, Majnemer, Platt, & Shevell, 2008) such as increased behavioral problems and lower social competence (Neece & Baker, 2008). Evidence suggests these childhood problems and parental stress represent a bidirectional effect; as parenting stress increases, greater childhood problems increase, thereby heightening parental stress even more (Neece & Baker, 2008; Neece et al., 2012).

Mindfulness-based stress reduction (MBSR), founded by Jon Kabat-Zinn, MD in 1979, has been empirically supported and practiced for three decades to reduce the negative means of stress while enhancing the participant’s intentional awareness and unfolding experience moment by moment (Kabat-Zinn, 2003). The use of MBSR has been implemented in both clinical populations and community based samples to decrease distress characterized by elements such as depression, anger, fatigue, and confusion by implementing techniques such as intensive training in mindfulness mediation (body scan mediation, sitting meditation, and yoga) (Evans, Ferrando, Carr, & Haglin, 2010). Mindfulness-based cognitive behavioral therapy (CBT) has taken on new ground as CBT adherents have recently begun incorporating mindfulness interventions with cognitive behavioral techniques to treat depressive symptoms, addiction dependencies, binge eating symptoms, emotional regulation skills, and other maladaptive behaviors (Imani et al., 2015; Leahey, Crowther, & Irwin, 2007). Although MBSR and mindfulness-based cognitive behavioral therapy have begun to make their way into empirically based treatment, there is little knowledge or research investigating the effects of group incorporation of the mindfulness techniques versus individual treatment-as-usual. This article outlines the dispositional accompaniment of symptomatic behaviors within a population of those who care for intellectual disabilities. In addition, it displays the benefits of mindfulness-based stress reduction and cognitive therapy for those caregivers, and ways the mediating effects of the cost effective group-based mindfulness techniques, versus only individual psychotherapy, may enhance psychological well-being for those caring and those being cared for.
LITERATURE

Intellectual Disabilities

Intellectual disabilities as defined in the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2013), are deficits in intellectual functioning (reasoning, problem solving, planning, experiential learning, etc.) and adaptive functioning (communication, social skills, personal independence, school/work functioning, etc.), both of which originate before the age of 18. The diagnosis is split into four categories: mild, moderate, severe, and profound. Most people who are diagnosed fall onto the mild category, while the percentage considerably drops throughout the spectrum. Every level has deficits in fine or gross motor and adaptive behavior, expressive language, receptive language, and cognitive/visual reception (Boyle, et al., 2011).

Children with intellectual disabilities also have a greater risk for developing psychopathology and behavioral issues in comparison than those without an intellectual disability (Dekker & Koot, 2003). Behavioral problems are generally revealed in diagnoses of disruptive behavior, oppositional defiant disorder and conduct disorders (Wallander, Dekker, & Koot, 2003). The parent-child relationship is associated with parenting behavior (Schuiringa, van Nieuwenhuijzen, Castro, & Matthys, 2015); therefore, parenting skills and mindfulness practices can potentially moderating the effects of the behavioral issues. Behavior problems occur with internalizing and social problems which minimize societal opportunities, thereby perpetuating adult outcomes (Embregts, Drimbel du Bois, Graef, 2010). As these problems are perpetuated throughout adulthood, caregivers are then given a heavier burden of caring for their adult children with minimal societal supports.

Symptomology of Caregivers

Parents of children with intellectual disabilities (ID) have shown to have high depression and anxiety scores, meeting clinical criteria for both, suggesting that strongest predictor of morbidity is caregiver burden (Gallagher, Phillips, Oliver, & Carroll, 2008). The task of caring for a child with disabilities for a long-term dependency presents a bleak outlook for the future and may be detrimental for the psychological well-being of the caregiver (Raina et al., 2005). Literature has supported the evidence of poor social support and the persistence of problematic child behaviors which are key factors associated with this psychological distress in parents who have children with intellectual disabilities (Gallagher, Phillips, Oliver, & Carroll, 2008; White & Hastings, 2004; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Caregiver burden encompasses negative social and personal consequences, psychological burden, and guilt (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005), and, as a consequence, leads to isolation, lack of fulfillment, and low self-esteem (Shearn & Todd, 2000).

It has been argued that the caregiver burden experienced by those who care for people with intellectual disabilities is similar to the burden of those who care for individuals with dementia (Paradise et al., 2015), with 65% exhibiting depressive symptoms (Papastravrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007). There is a reciprocal effect with the caregiver when the one who is being cared for has either a hopeful or a detrimental outlook. If the cared-for person has difficulty coping with daily living activities, the burden of the caregiver then rises, and physical dependency even becomes second to behavioral problems (Pinquart &
Sorensen, 2003). With the need to accommodate physical dependency and behavioral problems, the caregiver is definitively more susceptible to burnout and clinical depression.

Psychotherapy Cost

The World Health Organization (2008) identified mental illness as the leading cause of global disability. The associated costs for chronic mental health illnesses pose a crisis in the United States as 50% of the population will suffer from at least one psychiatric disorder (Kessler, Berglund, Demler, Jin, Merikangas, Walters, 2005), 30% of the adult population has a diagnosable psychiatric disorder, and only 41%, in a given year, receive treatment (Lazar, 2010). The annual cost of anxiety disorders are $42.3 billion and of depression, $43.7 billion.

In context of costs, family caregivers of individuals with ID are offered long-term services through Medicaid supports and are given access to care coordination through their state of residence; however, a recent qualitative study showed that some caregivers experience little flexibility in the provision of services and heavy advocacy involvement is needed for implementation of the services in almost every state researched (Williamson et al., 2016). If caregivers are looking for face-to-face support, most must turn to support-groups offered either through the state or through insurance carriers. It should be noted various organizations can offer emotional support and connections with others who are experiencing the same difficulties. Some organizations such as The Alzheimer’s Association (2017), The National Family Caregiver Program (2017), and the National Cancer Institute (2017) offer support groups for both the chronically ill and the caregivers of the chronically ill. Additionally, within organizations such as YAI Institute (2016) and The ARC (2017), services are provided for parents and caregivers of ID as these long-term effects can carry heavy burn-out rates. Although these organizations offer these supports, no research has been done on their effects for this specific population. Furthermore, minimal research has been seen in the group-based, cost effective support for these caregivers of ID, as seen through the mindfulness techniques.

With the rising of medical costs and mental health treatments, there is a need for substantiated group formatted treatments to support the under-resourced. Caring for those with intellectual disabilities is a life-long need and therefore urges adaptive, affordable treatments. Empirically based treatment which addresses such life long distress, teaching individuals to practice and utilize treatments at home, are under-researched in the affordable group formats.

Mindfulness-Based Stress Reduction (MBSR)

A literature review by Kirk (2015), shows that MBSR is highly correlated with the reduction of depressive symptoms. MBSR is an 8-week stress reduction program that teaches participants how to pay attention purposefully, presently, and non-judgmentally, and then implement such practices into daily living for ongoing positive coping. As this awareness is cultivated, participants then become more mindful in their thoughts, emotions, sensations, and self-preservation (Kerr, Josyula, & Littenberg, 2010). Furthermore, MBSR also has been extensively researched to treat in both mental and physically-ill clinical samples while using various approaches such as dialectical behavior therapy (Linehan, 1993), acceptance and behavior therapy (Cox & Hayes, 1999), and mindfulness-based cognitive therapy (Segal, Williams, & Teasdale, 2002). Its techniques appear to reduce stress symptoms and improve mood, and have been associated with enhanced quality of life in serious physical illnesses.
including cancer (Carlson, Specia, Faris, & Patel, 2007) and HIV-AIDS (Creswell, Myer, Cole, & Irwin, 2009). These clinical samples showed differences in physiological levels of altered cortisol, immune patterns, and in the HIV-AIDS study, CD4+T lymphocyte declines.

Mindfulness-based stress reduction has also been empirically supported for the efficacy of lessening perceived stress in relation to caring or parenting illnesses (Darbyshire, 2008), and more recently, lowering parental stress for those with children who have developmental disabilities (Bazzano et al., 2015). Additionally, MBSR has also lessened healthcare utilization in inner-city populations, significantly decreasing total medical and chronic care visits (Roth, 2002). These positive results continued to a follow up of a 2-month post treatment examination, indicating that consistent use of the techniques, as they were integrated into the participants’ daily lives, continued to show effectiveness (Bazzano, et. al., 2015). This research suggests that community-based MBSR programs can be an effective intervention to reduce stress and strengthen inner psychological resources and resilience for parents and caregivers of those with intellectual disabilities. While previous studies seek to provide parents with only skillsets for mindful parenting techniques, Neece (2013) was the first to use MBSR to target parent stress without any focus on parenting skills or parent-child interactions and how MBSR might lead to improved child behavior problems. In addition to MBSR efficaciousness in reducing overall parenting stress and depression, the purpose was to show a positive “spillover effect” on the child in other developmental areas (Neece, 2013). One of these “spillover effects” was expounded upon as the child’s development was shown to not only improve social skills but also improved the parent-child relationship, which may then imply long-term improvements within a child’s social development (Lewallen & Neece, 2015). This particular study revealed enhancements in the child’s social skills after the parents participated in an MBSR training group, showing results of gain in self-control, assertion, empathy, and engagement. Delivering MBSR to parents of children with intellectual disabilities can also enhance the efficiency of child-directed interventions as it promotes parental consistency and parental closeness (Lewallen & Neece, 2015). Although these implications appear to be significant, the lack of empirical data to support long-term implications of healthy psychosocial functioning development has yet to be examined. Just as social competence is an integral proponent of an individual’s development (Fenning, Baker, & Juvonen, 2011), early intervention with highly stressed parents may contribute to an enhanced efficacy for integration of classrooms, as “spillover” components such as emotion regulation and behavior regulation assist in the possibility of successful integration. Specifically, the examination of the reciprocal effects of MBSR within emotional and behavioral regulation of children have yet to be explored. Research needs to continue in the quest of examining the ongoing emotional regulation and behavior regulation in children with intellectual disabilities who have been under the parenting of those who have participated in MBSR, as early intervention may lessen further maladaptations and increase adaptive functioning. Implications of such research can continue to build a firm grounding for the promotion of MBSR techniques for parents to optimize a child’s overall positive adaptive development and most relevantly, potential successful integration within both the community and schools.

MBSR has been shown to effectively treat the dispositional distress in which caregivers are exposed; however, the cost for such treatment can be out of reach for those in need. The University of Massachusetts’ Medical School has a Center for Mindfulness in which practitioners can come and be trained in mindfulness techniques and clients can participate in treatment. The cost for treatment at this university begins at $575 for an 8-week session, and other treatment centers are generally around the same cost (Valley Mindfulness, 2015; UC San
Mindfulness Group Therapy for Caregivers

There are group therapy studies that reveal that caregivers are able to reframe meaning, problem solve stressors, and cope with emotions efficiently (Kanas, 2006). Data suggests that groups support the educational factors of caregiving while also growing in peer support processes. Group therapy has been associated with many advantages that individual therapy lacks. There is typically a shorter wait time, per cost savings, and the effects of group cohesion, interpersonal learning, and mutual support (Morrison, 2001). The work within this realm supports group methods in being useful for caregivers of those with intellectual disabilities; however, much more work needs to be further identified to solidify such a premise.

Mindfulness-based group cognitive therapy (MBCT)

Mindfulness based stress reduction has shown to be effective for caregivers of people with intellectual disabilities; however, it is also a costly option that is generally not available for these caregivers. The combination of group therapy with the mindfulness techniques may propose a more efficient, cost-effective tool that enhances the additional benefits of group therapy such as mutual support, group cohesion, etc. As mentioned, caregivers are susceptible to depression and are often predisposed to factors that illuminate symptomology (Gallagher, Phillips, Oliver, & Carroll, 2008; White & Hastings, 2004; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Treatment for such depression includes coping skills, engagement in pleasurable activities, and interpersonal effectiveness (Beck, 2011); however, little research has been done for group mindfulness, as seen in mindfulness-based cognitive therapy. This format is a psycho-educational and group-skills training program that integrates elements of mindfulness with this treatment of depression (Lenz, Hall, & Smith, 2015). The group format is specifically utilized to prevent major depressive relapses, as this population may be susceptible to the dispositional depressive factors. MBCT recognizes thoughts and emotions as preeminent to making positive changes and accomplishes this through psycho-education and skills training through four domains: metacognitive awareness, decentering, explanatory style and flexibility, and extreme responding (Herbert & Forman, 2011). Practitioners help the group respond to thoughts after identifying those feelings and bodily sensations, which then promotes functioning. After the beginning stage of the group with a formal mindfulness practice, the participants and therapist investigate these experiences through participatory dialogue. The interactive aspect of the group modality in MBCT helps facilitate a personal translation of the experience while emphasizing collaboration through feedback (Lenz, Hall, & Smith, 2015). Segal, Williams, and Teasdale (2002) explain that the collaboration and sharing of personal experiences with feedback supports the developmental process and helps exemplify a sense of individuality and collective meaningfulness. MBCT also provides accountability and empowerment for the daily home activities that may elucidate symptoms of depression (Lenz, Hall, & Smith, 2015).
REFLECTION

As the research suggests, caregivers of those with an intellectual disability are susceptible to burnout, which in turn, affects the developmental growth of the child, both emotionally and physically. These cyclic effects will continue to hinder both the caregivers, and those they care for, unless continued research searches for more efficacious and cost-effective ways to both treat and train these caregivers. As Christian counselors, a responsibility as researchers goes a bit further than sole scientific progression.

Genesis 1:27 discusses how God created man in the image of himself. The placement of this text is interesting because it comes toward the end of the chapter, suggesting that the creation of man is the pinnacle of creation. McMinn & Campbell (2007) discuss how the imago dei interconnects with the three domains of man: the functional, structural, and relational. The authors detail how these three domains mimic Freud’s id, ego and superego in their function. The functional view, is seen in the emphasis of Freud’s ego, where the humans attempt to manage themselves, therefore reflecting God’s character within humans’ behavior. The structural view reflects the superego, where rationality and morality reflect God’s character within humanity. Relational views reflect God’s desire and character, which is then revealed in humanity. When able to recognize the interconnectedness of these three domains, we can begin to see the intricacy of God’s character awakened in treatment. The functional behavior in thoughts, behaviors, and feelings can be engaged because of the core structural view in beliefs. Simultaneously, relational longings influence the individual’s functional behavior and core beliefs.

This insight allows the Christian counselor to look beyond scientific progression to the purpose behind the progression. Just as man’s creation came during the pinnacle of creation, clients long for a deep relationship because they are made in the imago dei, and reflect the relational component which God encompasses. Moreover, those whom clients might care for are also created in the imago dei, and developmental deficits can cause potential barriers to meeting their relational needs. Future research to support this population could not only combat the effects of burnout, but also serve foundational human needs.

The Christian faith challenges the immediate and innate posture of the counselor’s heart. Sinfully, we are prone to wander and seek our own glory in our work (Romans 7:15; Matthew 16:26; I Corinthian 9:25; Ecclesiastes 1). Serving the “least of these” (Matthew 25:40) with those who are unable to serve themselves, it causes the Christian counselor to look beyond the glory of self, to seek scientific progress for the good of those who are unable to help themselves. This research for those with intellectual disabilities softens and catalyzes the servant’s heart (Matthew 20:28). As a lover of research, it has challenge me to look beyond the publication, beyond the letters after my name, and forward to the ultimate Kingdom of God and His plan on this side of glory. This concept spills over into the function of the church and the body in which believers function. Historically, the church and science have found conflict, where both argue that the other side does not accurately reflect reality. It is here where the church has the responsibility to embrace the concept of common grace (Hebrews 1:2-3; John 1:1-4), and accept the knowledge that God is revealing through research.
FUTURE RESEARCH

With the Christian perspective in view, future research is a necessity as we progress toward serving this population more fully. Mindfulness-based techniques have shown significant improvements in alleviating stress symptoms while heightening the psychological well-being of the both caregiver and the child or adult with intellectual disabilities. There have been significant strides in identifying the dispositional psychosocial stressors that caregivers of those with intellectual disabilities inevitably face, yet there is little empirical evidence suggesting that collaboration and accountability support the longevity of such positive strides.

Mindfulness-based stress reduction and mindfulness-based cognitive therapy are both costly treatments that many caregivers are unable to afford. MBCT has been minimally studied with additions of group formatting, yet pilot evidence suggests the addition of accountability empowers the caregiver, while feedback provides significant enhancement in the developmental process. Psycho-educational groups with skills training are immersed in the mindful-based treatment, targeting the intrapersonal needs of the client while promoting a self-soothing training which the individual is able to continue at home. The longevity of the treatment is promising for caregivers of people with intellectual disabilities and urges further research to identify more cost-effective ways of supporting such a population. Mindfulness-based group techniques can uphold the empirical evidence of MBSR and MCBT while providing a space for clients to collaboratively engage in participatory dialogue.

As mental health costs rise and medical treatments become less accessible for under-resourced clients, further evidence to substantiate these group formats in addition to treatment-as-usual can open opportunities for more effective treatments with lower costs. Ethical questions arise as clinicians seek to further the counseling field, adapt treatments according to population needs, and ensure accessibility for those who need it most. Group formatting immersed within mindful-based techniques is a pertinent area to start such adaptive treatments. This article explores the efficacy of these techniques, arguing for their foundation for healthy and sustainable caregiving, and subsequently, higher competency in their children.
References


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