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Encountering Disenfranchised Grief: A Pilot Investigation of the Clinical Lived Experiences in Dance/Movement Therapy

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ENCOUNTERING DISENFRANCHISED GRIEF: A PILOT INVESTIGATION OF THE CLINICAL LIVED EXPERIENCES IN DANCE/MOVEMENT THERAPY

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Abstract

This study employed a transcendental phenomenological methodology to understand how clients' lived experiences of disenfranchised grief are present within the clinical therapeutic relationship in dance/movement therapy. Data was collected through individual semi-structured interviews from four dance/movement therapists who have worked with clients experiencing disenfranchised grief. Moustakas' (1994) adaptation of the Stevick-Colaizzi-Keen method of data analysis was used concurrently with data collection. Data analysis resulted in four textural themes: a) Disenfranchised grief can be described as disconnecting, overwhelming, complex, unrecognized, and pervasive; b) It is distinguished by exacerbated grief; c) It is recognized as a distinct form of grief; and d) It involved consistencies in treatment goals and focus. Structural themes describe how disenfranchised was experienced: a) social/cultural factors, b) dance/movement therapy, c) heightened kinesthetic empathy and somatic countertransference, and d) the therapeutic movement relationship. These themes support the current literature and suggest that the experience of disenfranchised grief includes embodied effects. Furthermore, dance/movement therapy may assist with addressing these effects, restoring their right to grieve, and supporting them in their grieving process.

Acknowledgements

Mom & Family: I would like to honor your unyielding support and encouragement that I have relied upon over these three difficult years. Thank you for continuously understanding my absence. **Infinity**: Thank you for continuously understanding my absence. I admire and thank you for bearing the pain of distance and continuing to support me in unimaginable ways. AND for being the home I return to as though I never left.

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J. R. R. Tolkien: I will forever treasure the metaphor the One Ring provided me with to illustrate the immense burden I have bared these years.

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Introduction

Grief is widely recognized as one of the most painful universal experiences that profoundly impacts us (Gross, 2016; Howarth, 2011; Worden, 2009). Its uniqueness lies in the vast range in presentation, with grief manifesting through emotional, cognitive, behavioral, spiritual, as well as physical symptomatology (Doka, 2002; Gross, 2016; Lindemann,1944; Worden, 2009). The grieving process that follows is regarded as a "'relational process'" (Neimeyer & Jordan, 2002, p. 95), during which we redefine the bonds held with the deceased or source of loss while drawing consolation and encouragement from our existing social network (Worden, 2009). While these relationships can be a strong source of support during bereavement, they can also be detrimental to those grieving when their social support denies them the right to enter grieving (Doka, 1989). Disenfranchised grief is defined as "…grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported" (Doka, 1989, p. 4). According to Doka (1989; 2002), social support and validation is withheld from the grieving individual, because their loss is not viewed as warranting grief.

The ongoing discussion preceding the proposal of grief-related disorders, such as prolonged grief disorder and persistent complex bereavement disorder, has stimulated continued debate on the boundaries between normative and nonnormative grief (Maciejewski, Maercker, Boelen, & Prigerson, 2016). These are attempts at specifying the circumstances or related reactions in situations where complications in functioning and adapting to life post-loss are present (Gross, 2016; Worden, 2009). Physical symptomatology has been regarded as a particular facet of the grieving process that is "often overlooked" (Worden, 2009, p. 23). While most individuals are able to adjust after experiencing loss, there are those that require additional

guidance through this process (Parkes, 2011). Disenfranchised grief has been identified as a form of grief that possesses such complications, including potential physical manifestations that may go unnoticed or excluded from consideration (Doka, 1989; Doka, 2002).

During the past three years of my academic endeavors, I have lost five family members, including my father. Grief became a familiar presence in my life, and I found it most unbearable during instances my grief was invalidated and silenced. Unbeknownst to me, in these moments I was experiencing disenfranchised grief. As an emerging dance/movement therapist, enduring this has deeply informed how I approach supporting others in their experiences of loss, and has led me to question how doing so may be different when addressing disenfranchised grief.

The purpose of this pilot study was to gain an understanding of how clients' lived experiences of disenfranchised grief are perceived by dance/movement therapists during the therapeutic process in dance/movement therapy (DMT). As body-based clinicians, dance/movement therapists have unique training that allows them to be acutely aware of how life experiences, such as grief, are present within the body and are illustrated through movement (Callahan, 2011). This study was guided by the research question: How is the lived experience of disenfranchised grief experienced by dance/movement therapists who work with clients experiencing disenfranchised grief?

The current body of literature outlines and describes what qualifies as disenfranchised grief, in addition to identifying the societal and cultural underpinnings of this problem (Doka, 1989; Doka, 2002). The literature largely consists of examples and narrative accounts of specific forms, circumstances, or situations in which disenfranchised grief is present, which contextualizes the phenomenon (Aloi, 2011; Doka, 1989; Doka, 2002; Dwyer & Miller, 1996; Jones & Beck, 2006; Packman et al., 2014; Spidell et al., 2011; Wlodarczyk, 2010). However,

the existing literature lacks detailed information on the subjective experience of this phenomenon, specifically the embodied or physical effects of experiencing disenfranchised grief and its clinical presentation. The following literature review opens with a discussion contextualizing disenfranchised grief in addition to the role of culture inherent within the phenomenon. The concept of disenfranchised grief is elucidated, accompanied by an examination of factors fueling the phenomenon, in addition to the resulting impact of disenfranchisement identified within the literature. Lastly, the literature on DMT as an approach to grief work is reviewed.

Literature Review

Cultural Context of Grief

A basic tenet of normative bereavement is the involvement of integrating the reality of the loss, regardless of the vast variation through which this occurs (Howarth, 2011; Worden, 2009). The expression of grief is essential within this process; factors interfering with individuals' abilities to honor their unique grieving process may increase the likelihood of developing atypical grief reactions possessing negative consequences (Worden, 2009). The high intensity and extended duration of grief reactions are factors indicative of complicated grief when the degree of negative impact on individuals' functioning inhibits their ability to process and adapt to their loss (Neimeyer & Sands, 2011; Shear, Boelen, & Neimeyer, 2011; Worden, 2009). Disenfranchised grief has been recognized as a contributing factor (McNutt & Yakushko, 2013) and risk factor for complicated grief (Gross, 2016). Although sharing a cultural foundation (Gross, 2016), complicated grief is an umbrella term encompassing the impairing maladaptive reactions and behaviors that result from hindered grief (Neimeyer & Sands, 2011; Shear, Boelen, & Neimeyer, 2011), whereas disenfranchised grief is specifically concerned with grief that is actively denounced, rejected, or unacknowledged by others (Corr, 2002; Doka, 1989; Doka, 2002).

Among the many factors that influence the experience of grief and bereavement, culture is the most central in shaping how we process and respond to loss (Neimeyer & Harris, 2011). While grief is frequently emphasized within the literature as highly individualized (Doka, 2016; Gross, 2016; Neimeyer & Harris, 2011; Worden, 2009), society still provides a "uniform set of instructions" that dictate both the internal and external expressions of grief (Konigsberg, 2011, p. 15). Grief is viewed as appropriate and acceptable as long as the process of adapting to loss

adheres to the social parameters, or "grieving rules" (Doka & Martin, 2002, p. 338), dictated by each respective culture (Neimeyer & Harris, 2011). From this understanding, culture serves as the governing body that "polices grief" (Neimeyer & Harris, 2011, p. 344). When grieving deviates from these norms and expectations, an individual may encounter disapproval or loss of validation and support from others; disenfranchised grief is a potential consequence of this deviation (Doka, 1989; Doka, 2002; Doka & Martin, 2002; Neimeyer & Harris, 2011). Therefore, it is important to bear in mind that disenfranchised grief is a social phenomenon and cannot be examined outside of the cultural context. This literature review utilizes the framework pioneered by Doka (1989; 2002) to understand the scope of disenfranchised grief, while briefly acknowledging subsequent research that has expanded upon this topic.

Disenfranchised Grief

Doka's (1989) comparison of heterosexual and homosexual grief experiences during the 1980s drew attention and ensuing discussion within the field of grief and bereavement on grieving situations lacking social recognition. Rising concern and stigma surrounding homosexual relationships during the subsequent AIDS epidemic only further illuminated the lack of social support for affected grieving individuals (Doka, 1989). As this phenomenon crystallized, it was formally distinguished as 'disenfranchised grief' and recognized as grief that is not socially acknowledged, supported, or viewed as acceptable (Doka, 1989; Doka, 2002). Disenfranchised grief was initially conceptualized as occurring within three categories: unrecognized relationships, losses, and grievers (Doka, 1989). Doka (2002) later identified two additional categories: circumstances of the death and ways of grieving. Disenfranchisement of unrecognized relationships can occur when the presence of grief or the intensity of grief for non-kin based relationships, nontraditional relationships, or past relationships are not socially

expected or viewed as acceptable (Doka, 1989; Doka, 2002). Losses can be disenfranchised when the loss is not "socially defined as significant" and thus, not warranting a grief response (Doka, 1989, p. 5). Grievers can be disenfranchised when individuals are seen as incapable of grieving or not viewed as needing to grieve (Doka, 2002). The circumstances of death can render grieving individuals susceptible to disenfranchisement if their loss involves stigmatized death or if a stigmatized lifestyle contributed to the death (Doka, 2002). Lastly, the way in which individuals express their grief can be disenfranchised, particularly if their style of grieving deviates from social expectations of what it looks like, as well as where and when it is expressed (Doka, 2002).

The conceptualization of disenfranchised grief has since been expanded upon in several ways that further distinguish its characteristics and illustrate other manners in which it may occur. Corr (2002) highlighted an important distinction in discerning the phenomenon of disenfranchised grief: It is the act of "disavowal, renunciation, and rejection" that renders grief disenfranchised, which distinguishes it from grief that is merely not communicated with others or grief that goes "unnoticed, or forgotten" (p. 40). Additionally, Corr (2002) sought to enhance the concept of disenfranchised grief by contributing three different areas in which disenfranchisement can occur, including grief reactions and expressions, mourning practices, and the outcome of mourning. Kauffman (2002) recognized the self as a possible source of disenfranchisement or as complicit in the experience of disenfranchisement from others, both of which Kauffman classified as driven by shame. This experience was deemed as self-disenfranchisement (Kauffman, 2002). Researchers Neimeyer and Harris (2011) proposed the empathic failure of others in understanding and empathizing with the bereaved as a compelling distinction of the underlying mechanism inherent within disenfranchisement. This phenomenon

was later recognized as a political failure from the viewpoint that the perpetrators of disenfranchisement inflict a sense of authority over another's grief (Attig, 2004). Additionally, this phenomenon is also recognized as an ethical failure insomuch as it involves a lack of respect for the bereaved (Attig, 2004).

Disenfranchised grief is regarded as an experience that complicates otherwise normative bereavement (Rando, 1993). Doka's (1989; 2002) appraisal of its impact asserts disenfranchisement as inherently problematic due to the removed or minimized social support for the bereaved. Thus, the existing grief and associated emotions can be exacerbated with disenfranchisement, and even more so if additional crises or ambivalent relationships and feelings are involved (Doka, 1989; Doka, 2002). Resulting effects may be evident through intensified emotional reactions, the inability to access or engage in mourning practices, the inability to utilize sources of comfort (Doka, 1989; Doka, 2002), and increased isolation (Kauffman, 2002). Self-blame or self-destructive tendencies may emerge if individuals become conflicted with their grief and internalize their disenfranchisement (Kauffman, 2002). These factors are suggested as having the potential to interfere with individuals' abilities to fully process and resolve their grief (Doka, 1989; Doka, 2002).

Social/Cultural Factors. Specific actions have been associated with causing disenfranchised grief. A consistent theme across experiences of disenfranchisement within the literature shows a lack of validation and support from the individual's social support system (Baum & Negbi, 2013; Jones & Beck, 2006; Lang et al., 2011; Mulvihill & Walsh, 2014; Packman et al., 2014). In some instances, the significance of the loss was not recognized (Jones & Beck, 2006; Lang et al., 2011; Mulvihill & Walsh, 2014; Packman et al., 2014). The availability of outlets for grief expression felt limited for affected individuals (Packman et al.,

2014), with some experiencing complete unavailability of support in extreme cases (Jones & Beck, 2006). Mulvihill and Walsh (2014) presented an example of this with participants experiencing pregnancy loss who "felt denied opportunities to publicly mourn the loss of their baby" (p. 2300). There was consistency among researchers referring to this lack of social support as an empathic failure (Packman et al., 2014; Piazza-Bonin, Neimeyer, Burke, McDevitt-Murphy, & Young, 2015). Researchers Sobel and Cowan (2003) and Piazza-Bonin et al. (2015) provided unique insight on the perpetrating end of disenfranchisement by identifying the presence of others' uncertainty in how to support bereaved individuals, in addition to a lack of willingness to continue supporting the bereaved. A lack of understanding may contribute to the overall avoidance of attempting to provide support for these bereaved individuals (Jones & Beck, 2006; Lang et al., 2011; Mulvihill & Walsh, 2014; Packman, 2014).

Differing expectations regarding the grieving process, including appropriate reactions, behaviors, and length of time, appeared to be strong motivators behind the social disapproval of grief (Lang et al., 2011). Piazza-Bonin et al. (2015) noted the gradual withdrawal of social support for individuals who were homicidally bereaved. This withdrawal occurred in passive ways such as people avoiding or abruptly ceasing communication, in addition to more active ways including verbal communication of disapproval of the individual's continued grief or comments regarding the length of grief "'You're not better *yet*?!'" (Piazza-Bonin et al., 2015, p. 415). Piazza-Bonin et al.'s (2015) case study also illustrated the continued social expectation for bereaved individuals to resume their previous roles along with the resulting disenfranchisement when the bereaved were unable to fulfill that expectation.

Health care professionals were indicated as a source of disenfranchisement, often through verbal exchanges with word choices or terminology that minimized or questioned the

individual's grief (Lang et al., 2011; Mulvihill & Walsh, 2014). A dissertation on disenfranchised grief revealed kidney transplant donors experienced lack of empathy, lack of acknowledgement of emotional needs, and the desire for stronger communication throughout the donating process amongst health care professionals (Young, 2008).

Minimization of grief also comes from community members as demonstrated in the case of losing a family member to execution (Jones & Beck, 2006). In this particular situation, the individuals experienced isolation from their community (Jones & Beck, 2006). Their grief was greeted with contempt by others, along with extreme social backlash in the form of outward displays of aggression directed towards them, including "vehicles being shot up, jobs lost, human feces left on doorsteps, and children being asked to leave their middle school" (Jones & Beck, 2006, p. 293). Compared with other instances of disenfranchised grief not involving such violent acts, the motivation for refraining from grief also served a protective purpose (Jones & Beck, 2006). Specific cases involving stigmatized loss, such as the court-ordered removal of children from the home, were accompanied by blaming and shaming from people within their social support system and larger community (Baum & Negbi, 2013).

Subjective Experience. The subjective experience of disenfranchised grief is described within the literature as "manifold" (Jones & Beck, 2006, p. 296) with its impact permeating "emotional, spiritual, physical, psychological, and practical" dimensions (Packman et al., 2014, p. 345). Disenfranchised grief was found to be accompanied by strong physical and emotional reactions (Lang et al., 2011), with an intensity described as debilitating (Packman et al., 2014). Emotions vary between shock, devastation, depression, anger, and high levels of distress (Mulvihill & Walsh, 2014). Additionally, disenfranchised grievers reported feeling a sense of isolation (Baum & Negbi, 2013; Lang et al., 2011), loneliness (Doughty Horn, Crews, Guryan, &

Katsilometes, 2016), and even abandonment (Packman et al., 2014; Piazza-Bonin et al., 2015). There was consistency in the desire to be understood (Baum & Negbi, 2013; Doughy Horn et al., 2016), and many individuals were left frustrated with the inability to be understood by others (Baum & Negbi, 2013). For some, the intensity of grief reached clinically significant levels for depression and suicidality (Packman et al., 2014). The depth of their grief was reflected in the vivid descriptions often used to describe their experiences such as "'gaping hole in my heart'" (Packman et al., 2014, p. 346). In circumstances in which a death was involved, the closeness of the relationship has been suggested as influencing the degree to which the disenfranchisement negatively affected the individual (St. Clair, 2013), including the relationship with that of a pet (Cordaro, 2012; Packman et al., 2014). Researchers Baum and Negbi (2013) in addition to Lang et al. (2011) identified disenfranchised grief as interfering with psychological wellbeing and grief resolution.

Generalized pain was also reported and varied between emotional and physical manifestations (Packman et al., 2014). Disenfranchised grievers experienced a strong sense of guilt and regret, particularly when feeling a sense of responsibility in the loss (Baum & Negbi, 2013; Packman et al., 2014; Sobel & Cowan, 2003). Self-blame was also present (Baum & Negbi, 2013; Mulvihill & Walsh, 2014) and accompanied by self-loathing (Sobel & Cowan, 2003). In one instance, this internalized guilt and shame led to withdrawal and isolation from others (Piazza-Bonin et al., 2015). Some individuals that experienced social blaming as a result of their loss identified these accusations as directly causing their intense emotional reactions (Baum & Negbi, 2013). In one instance, feeling unrecognized by others led to questioning one's existence (Doughty Horn et al., 2016).

Experiencing disenfranchised grief negatively impacts individuals' subsequent approach towards seeking support, as disenfranchisement encourages the privatization of grief (Lang et al., 2011; Packman et al., 2014) and elicits hesitation or refraining from sharing their grief entirely (Jones & Beck, 2006; Packman et al., 2014). Differing views regarding the experience and process of grieving within interpersonal relationships may prompt relational complications and marital tensions, including growing frustrated with one another or becoming emotionally distant from one another (Lang et al., 2011). One means of support for those experiencing these difficult emotions and hurtful responses by others is dance/movement therapy.

Dance/Movement Therapy and Grief

Dance/movement therapy is grounded in the understanding that the body is not only a receiver and processor, but a physical embodiment of the experiences we endure (Levy, 2005), including that of grief (Philpott, 2013). Early research has provided evidence for grief manifesting somatic symptomatology. Lindemann (1944) entitled this experience as "somatic distress" that presents intermittently in wave-like occurrences (p. 141). Physical sensations involved may range from muscle tension or weakness, headaches, depersonalization, lack of energy, "respiratory disturbance" characterized by breathlessness, in addition to tightness in specific areas of the body such as the chest and throat (Lindemann, 1944, p. 141; Worden, 2009).

Research on DMT and grief has concentrated on the use of DMT as a therapeutic approach (Baum, 2013; Callahan, 2011; Philpott, 2013). Interventions harnessing creative nonverbal expression of grief and related emotions via movement remain the predominant focus of discourse regarding DMT and bereavement (Akunna, 2015; Callahan, 2011; Callahan, 2014; Larsen, 2014; Larsen & Young, 2014; Smith, 2014). Although disenfranchised grief remains an uninvestigated area within the DMT literature, neighboring forms of grief have been examined.

Callahan (2011) investigated how DMT could serve as an active facilitator of the grieving process for bereaved parents experiencing complicated grief. This study unveiled the temporary body-mind disconnect and increased body tension that can occur for bereaved parents (Callahan, 2011). Baum's (2013) work further uncovered the complexity of grief and its presentation with developmentally delayed children and their caregivers, leading to her proposal of grief as palpable and not always visible. The somatic symptoms of grief appear to house a wealth of information that may greatly inform the subjective experience of grief and what may be needed within the therapeutic process (Philpott, 2013). Philpott (2013) attempted to capture this through interviewing dance/movement therapists regarding their clinical work with grieving children. Results revealed that the subjective experiences of dance/movement therapists, specifically their own emotional and somatic responses, are important in contextualizing the therapeutic process and informing clinical interventions. Music therapy is one branch of creative arts therapies that has conducted research on the treatment of disenfranchised grief with results suggesting music therapy as an effective intervention for increasing awareness of grief and facilitating grief expression for disenfranchised hospice workers (Wlodarczyk, 2010).

Summary

Much of the current literature on disenfranchised grief has focused on expanding the breadth of the phenomenon by directing attention to specific forms of loss that may fit the criteria of disenfranchised grief (Thornton & Zanich, 2002). The predominantly theoretical examination of this concept has assisted with crystallizing the experience (Thornton & Zanich, 2002). However, much of the literature is limited in the capacity that it does not seek to identify the overarching experience of disenfranchised grief. The identified effects are suggested within the context of particular forms of disenfranchised grief as opposed to identifying consistent

themes and qualities across experiences of disenfranchised grief. The principal investigator argues that the body-based approach ingrained within DMT provides a specialized framework for examining how disenfranchised grief affects grieving individuals. This study attempts to utilize the body-based experiences of dance/movement therapists to capture the lived experiences of clients' disenfranchised grief, including the embodied presentation and therapeutic process of working with clients experiencing this form of grief.

Methods

Methodology

This pilot study employs a transcendental phenomenological methodology to understand how clients' lived experiences of disenfranchised grief are present during the therapeutic process in dance/movement therapy. The purpose of transcendental phenomenology lies in capturing the lived experience or essence of a phenomenon through subjective accounts of the experience in question (Creswell, 2013). An *epoché* precedes the investigative process and involves bracketing the researcher's personal experience of the phenomenon to identify any preconceived notions or biases (Creswell, 2013; Moustakas, 1994). Doing so supports transcendental phenomenology's fundamental objective of removing the researcher as the informing source of the phenomenon so that it can be investigated "freshly" with only the participants' information illustrating the experience of the phenomenon (Moustakas, 1994; p. 33). This was consistent with the intention to focus on the participants' subjective experiences as opposed to the principal investigator's perspective playing the central role in conceptualizing the phenomenon, as is prescribed in hermeneutical phenomenology (Creswell, 2013).

Participants

The participants in this study included four R-DMT or BC-DMT dance/movement therapists who self-identified as having current or previous professional experience working with clients experiencing disenfranchised grief. Further inclusion criteria required that they understand the phenomenon, as operationally defined in this study, and were willing to be video recorded during the data collection process. Participants were recruited through two online avenues: the American Dance Therapy Association Member's Forum on the association website and email invitations to dance/movement therapists within the principal investigator's

professional network (see Appendices A and B). The latter was the only successful recruitment method to produce participants. Additional demographic information to consider is that participants identified themselves as women, within the 20-50s age bracket, and were sampled from the Midwest region of the U.S. Each participant was assigned a pseudonym identified by the principal investigator as a protective measure against identification. Due to the small community of dance/movement therapists and the related risk of identifying those involved, further demographic information has been withheld in order to preserve the confidentiality of the participants' identities. For this reason, there is little reference throughout this study to the client populations with which the participants work. However, the clinical experiences referenced in each interview were based on DMT with child, adolescent, and adult clients, and each qualified as a vulnerable population (Aday, 2001).

Procedure

Prior to beginning the interview process, the principal investigator engaged in the *epoché* process by conducting a self-interview utilizing the same interview questions employed within the data collection process for participants (Moustakas, 1994; see Appendix C). These responses were analyzed and then referenced throughout data analysis for the purpose of monitoring bias. Informed consent was obtained from each participant prior to beginning data collection (see Appendix B). Data was collected from each participant individually through semi-structured interviews that were one-two hours in duration (see Appendix C). Interviews were held in a private location that was mutually agreed upon by the participant and principal investigator. Each interview was video recorded using a camcorder, and then transcribed by the principal investigator. A continued relationship with the participants was maintained for the purpose of

asking additional questions for clarification or further elaboration and member checking (Mertens, 2005).

Data Analysis and Validation Strategies

Each transcript was analyzed individually using Moustakas' (1994) modification of the Stevick-Colaizzi-Keen interview analysis method. The first step included obtaining the breadth of each participants' clinical experience working with disenfranchised grief via the semi-structured interviews (see Appendix C). Meaningful and descriptive statements related to their clients' experience of disenfranchised grief were drawn out of each transcript and clustered together to form themes (Creswell, 2013; Moustakas, 1994). These themes were organized into a textural description highlighting the "what" of their experience or a structural description highlighting the "how" of the experience (Moustakas, 1994, pp. 120-121). The textural and structural descriptions were then synthesized into a textural-structural description capturing the essence of the participant's experience. This process was repeated for each participant, and culminated in a "composite textural-structural description" that produced a comprehensive understanding of the clinical experience of working with clients experiencing disenfranchised grief (Moustakas, 1994, p. 122). Prior to compiling the composite textural-structural description, member checking was utilized as a validation strategy to gain insight into the accuracy and significance of the themes that emerged in each textural-structural description (Creswell, 2013). The primary investigator's *epoché* was also utilized in this stage as a means of returning to any biases to assess how they were informing final interpretations.

Results

Several textural and structural themes were identified across all four participants' descriptions as illustrating the phenomenon of disenfranchised grief throughout the therapeutic process. The textures and structures are strongly interrelated in the way that they influence and inform one another; Figure 1 provides a diagram that visually elucidates this connection. The diagram consists of several layers with the outermost layer consisting of the structure that underlies all themes involved. The subsequent layer includes textural qualities describing the global experience of disenfranchised grief, which is followed by textural and structural themes involved in the therapeutic process located within the innermost layer.

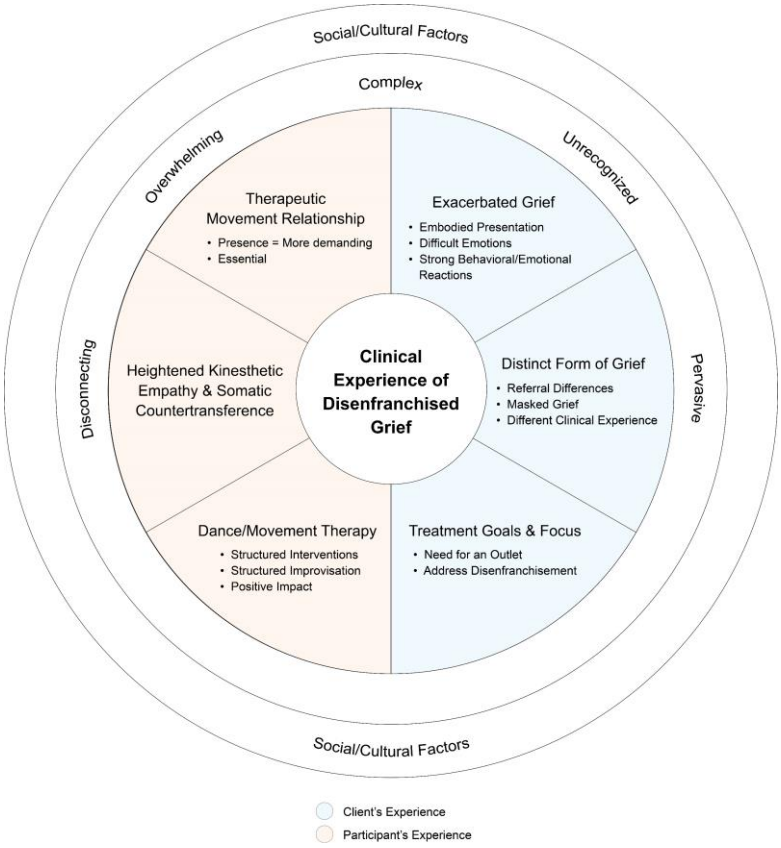

Figure 1. Composite textural and structural themes that emerged as well as their interrelatedness.

Social/Cultural Factors

Social and cultural factors held the most fundamental role in fueling the phenomenon of disenfranchised grief and shaping how it was experienced by each client and dance/movement therapist. Data analysis revealed three subthemes that collectively delineate the components and complications found to be characteristic of this form of grief; these include the lack of social support, restrictive social perceptions, and social grieving parameters. Participants reported a lack of social support within their clients' social network. Aside from verbal statements of disapproval, nonverbal forms of relational distancing occurred, "they isolated him; they didn't want to connect with him anymore." Restrictive social perceptions magnified the lack of support and also negatively impacted how their clients' loss and subsequent coping was viewed and treated by others. Lastly, the imposition of parameters around grief was evident across client experiences. One participant described these cultural factors in the following way: "If you express your grief in an angry way and you're black, then you're written off as the angry black woman. Your grief is not even acknowledged, especially if the way that you deal with it is through anger."

Overarching Characteristics

Five textures were identified as describing the overarching qualities inherent in the experience of disenfranchised grief: complex, pervasive, unrecognized, disconnecting, and overwhelming. Disenfranchised grief is a complex phenomenon with many interrelated factors at play. It is pervasive in the way that it extends throughout the clients' lives and grieving experiences, and in how it has the potential to be experienced by the dance/movement therapist. One participant described it as "this domino effect of silence and shaming." Disenfranchised grief is unrecognized in that it is unsupported or invalidated by others; — "They feel it but

they've been told it doesn't matter." Disconnecting is the texture that highlights the isolating nature of disenfranchised grief resulting from the severed relationships within the clients' social support system as well as from themselves. The phenomenon of disenfranchised grief was also identified as overwhelming due to the intense nature of the experience. This was reflected in statements such as, "It kind of takes over their soul" and "It just consumes."

Exacerbated Grief

A consistent texture across participants' experiences with clients was the presence of exacerbated grief as a result of their disenfranchisement. Exacerbated grief was characterized by an embodied presentation, difficult emotions, and strong behavioral/emotional reactions. Each client's physical presentation appeared to embody their experience of disenfranchisement, specifically through distinct holding patterns within their body. Holding patterns were evident through bound flow, muscle tension, and rigidity in the spine and body posture. Breathing was very shallow and appeared "stuck" inside the body. One participant recounted her client's experience as, "He would take big gasps of breath and it wasn't really flowing." Exacerbated grief elicited the presence of difficult emotions, including anger, shame, guilt, fear, and hopelessness. A pattern of strong behavioral/emotional reactions stemmed from the exacerbated grief which took two forms: imploding (internal) or exploding (external). Behavioral reactions include "…increase in aggression, isolation, depression; more reactive." External reactions were characterized as impulsive and out of control, while internal reactions involved severe withdrawal, appearing through "stillness" and/or detachment from self and environment. Both reactions were reported as observed with accompanying maladaptive attempts at coping through self-destructive behaviors such as cutting, suicide attempts, and overdose.

Therapist Response to Disenfranchised Grief

The dance/movement therapists' responses to working with clients experiencing disenfranchised grief are illustrated through the structure of heightened kinesthetic empathy and somatic countertransference. For this study, kinesthetic empathy is defined as embodied empathy involving the process of dance/movement therapists attending to and with the body, whereas somatic countertransference refers to the body-felt somatic responses or reactions to clients that can be used in the therapeutic process (Downey, 2016). Disenfranchised grief was described as having a contagious quality: "It's hard not to take on; It's hard to get rid of." Participants strongly empathized with their clients and reported feeling highly receptive to their emotional and somatic experiences as evidenced by the vivid somatic "sensations that were quite palpable of the sadness", "…like my body was crying for him", "it felt like it really enveloped my whole body". Other times, the participants experienced emotional and somatic responses resembling their clients' experiences that lingered in the body. As a result, participants felt overwhelmed and depleted. One participant described her experience as resulting in extreme immobilizing fatigue: "I've come home sometimes and fallen over on my couch and then not been able to get up until the next day because I just can't really move my limbs." Three of the dance/movement therapists reported feeling burnout symptoms and desensitized to disenfranchised grief. This was accompanied by experiences of disconnection within the body similar to that of their clients.

Therapeutic Movement Relationship

The therapeutic movement relationship is a structure that is considered integral throughout the therapeutic process (Young, 2017). It provides the container for the expression and validation of disenfranchised grief. The body in relationship serves as the primary tool of connection. This experience was highly demanding on each participant's ability to be present

during sessions. Participants' report that the therapeutic movement relationship may be more challenging to establish with clients experiencing disenfranchised grief, yet invaluable to clients once established. The participants' role served as a source of stability, organization, and support for their clients to ground themselves, as reflected in one participant's statement: "My first instinct is to try to anchor."

Distinct Form of Grief

Disenfranchised grief was defined as texturally distinct for several reasons. First, the clients were referred for secondary symptoms as opposed to grief. Often these secondary symptoms were behaviors or forms of emotional expression, or lack thereof, that were considered problematic. Secondly, the therapeutic process was identified as more clinically challenging in that it was harder to access, express, and explore. Clients often maintained an external focus on the disenfranchisement or its source instead of focusing on the grief from their original loss, which impacted their ability to process and adapt to their loss. Thus, the grieving process was described as hindered, "You're not going to be able to grieve in that fluid way." Participants also attributed the distinctiveness to the intensity and heightened emotionally taxing nature involved: "I mean there's despair with the grieving process anyway but I feel like it's more torturous." Thirdly, the lingering quality and physical pain sometimes accompanying the participants' somatic countertransference was identified as unique to this form of grief, in addition to the lack of clarity in their body sensations. Lastly, the presence of masked grief also characterized this phenomenon as distinct. Clients' grief reactions impaired their normal functioning, and they lacked awareness of the connection between their grief and their symptoms and behaviors, as evidenced through client statements such as, "'I just know that I'm angry all

the time, I can't control it'" and participant reports: "They're so disconnected from what's going on within them[selves], they won't label or express it as what it is…they won't connect it."

Treatment Goals and Focus

Treatment goals addressing the clients' presenting symptoms and behaviors took precedence before processing their loss and related grief. The focus of therapy was predominantly centered on increasing self-awareness and strengthening the client's ability to self-regulate. Participants identified psychoeducation as a main component of therapy which included topics such as coping skills, emotion identification, impulse control, anger management, and relationship building, as well as healthy and effective modes of expression. In addition to processing the grief from the original loss, processing and coping with the disenfranchisement was also a focus in therapy (Kauffman, 2002). The focus of therapy also included providing a platform for the expression of grief through avenues such as telling one's story, engaging in cultural mourning practices, and increasing positive connection and social support. Furthermore, strengthening self-esteem, self-efficacy, and resiliency was incorporated to combat the negative impact of internalizing the disenfranchisement and reinstating a sense of agency over their grief. Corresponding movement goals of increasing body awareness and connection with the body were aligned with the aforementioned goals. This was emphasized through increasing stability and grounding within the body in order to establish a greater sense of control and management of their somatic reactions.

Dance/Movement Therapy

Results showed consistencies in the use of structured interventions and structured improvisation among participants' approaches in dance/movement therapy. Guided facilitation coupled with intention and flexibility, provided clients with choice during movement

experientials. This structure cultivated encouragement and fostered creative expression and exploration. Dance/movement therapy interventions were often "tangible" and stabilizing in order to foster a greater sense of connection and agency over the body. Participants utilized attunement with the senses, breath work, and props to assist in grounding the clients in the present moment. Interventions were presented in a manner that was inviting, safe, and trauma informed: "I never say 'okay now we're going to recreate the person's funeral. It's never that direct." However, interventions to support memorializing, such as rituals, were utilized when they organically emerged. Clients were provided the option to utilize symbolic movement to represent their messages or pain during moments when feeling unsafe to verbally discuss their disenfranchised grief in groups.

Positive Impact

Participants regarded dance/movement therapy as beneficial for their clients through the provided outlet to express and explore their grief and disenfranchisement. This resulted in increased awareness of the connection between their symptoms and disenfranchised grief — "When we started to get into his narrative he realized it's like…I have all of these deaths that I wasn't able to process." Clients demonstrated stronger body awareness and connection in the body with an increased sense of stability also reflected in their temperament: "There was more of a grounded sense to feeling his personality than what had been there before." The emphasis on acknowledging individuality and recognizing self-worth, "when they're able to talk about things that interest them or their genuine self," elicited increased engagement and investment in participation during groups. One participant shared how a client stated that DMT helped him the most in reassembling his life. Dance/movement therapy was effectively utilized to address the

negative impacts of disenfranchisement by positively contributing to each client's life in a variety of ways that were otherwise absent.

Discussion

This study set out to identify how dance/movement therapists perceive their clients' lived experiences of disenfranchised grief within the context of dance/movement therapy. Results elicited qualitative information that provided an essence of the dance/movement therapists' understanding of their clients' disenfranchised grief. All textural and structural themes were found to be strongly interrelated; thus, individual consideration is impossible without undermining the breadth of each theme.

Results support what is recognized in the literature, specifically regarding the recognition of the socio-cultural context as the most defining factor in how grief and bereavement are experienced, in addition to being the platform through which the disenfranchisement of grief occurs (Doka, 1989; Doka, 2002; Doka & Martin, 2002; Gross, 2016). The overarching textural themes—complex, pervasive, unrecognized, disconnecting, and overwhelming—illustrate the nature of these factors while simultaneously describing the qualitative manner in which the social and cultural factors influence the experience of disenfranchised grief.

The cultural contexts consisted of the clients' social network as well as the facility or system where treatment took place. The impact was two-fold. For clients without social support and the opportunity to express themselves, the grief became confined within them and prevented engagement in their authentic grieving process or ability to utilize "sources of solace" (Doka, 2002, p. 18), —a characteristic of disenfranchised grief (Corr & Corr, 2013; Doka, 2002). One participant described the parameters placed around the clients' grief as resulting in being "forced to deal with loss and grief based on how the system tells them to move on." The grief would remain inside the client until triggered by some negative event or thought process that roused the disenfranchised grief and the overwhelming nature of it would take over. Unable to contain it

any longer, it would pour out in destructive ways that were difficult to mitigate. This finding reinforces the literature's support that disenfranchisement may exacerbate grief and can be demonstrated through intensified emotional reactions (Doka, 1989; Doka, 2002).

The clients' strong behavioral and emotional reactions appear to stem from the heightened complexity of the situation, as demonstrated by some clients who were unable to engage in mourning practices or mourn with their community (Doka, 1989; Doka, 2002). This study deepens the scope of the observable impact of disenfranchisement on clients to include nonverbal behavior and/or body posturing that is congruent with their experiences of censorship, such as holding patterns and a disconnection within the body/mind experience (Callahan, 2011). Participants observed this confined grief as tangible and observable within the body, which corroborated the texture of the necessity of an outlet for grief: — "I could see that there was something that wanted to come out, it was almost as if it was waiting, like for some sort of release."

For the participants, social and cultural factors contributed to the increased sense of responsibility and effort required throughout the therapeutic process: "Who else is going to create space for this disenfranchised grief if I don't do it." This negatively impacted the participants' ability and process of engaging in the therapeutic movement relationship: "It held me back from being present with her." For some participants, the increased sense of responsibility added pressure to their role which participants regarded as distinct from their clinical experiences with other forms of grief: "When it's grief that's more accepted I feel more relieved that I know other people will support. It feels more shared."

The active process of engaging in this more demanding presence elicited somatic sensations in response to attempting to remain grounded. The dance/movement therapists were

very attuned with the gravity of the grief as they reported feeling like they were "holding a lot" while supporting their clients. Thus, some participants reported a need to be more deliberate in maintaining their own sense of stability and grounding while working with their clients or they risked taking on too much of the clients' energy. Finding this was a necessary part of the process to create, hold, and protect space for disenfranchised grief in session. As a result, the clinical experience was regarded as much more taxing and described by participants as exhausting and effortful.

Structurally, the therapeutic movement relationship acted as a surrogate for the absent social support and validation throughout the grieving process during therapy, allowing clients who were disconnected to be connected, those silenced to be heard, those unrecognized to be recognized, and those invisible to be seen. Thus, participants identified the therapeutic movement relationship as paramount in supporting their clients and addressing the textural themes of unrecognized, overwhelming, and disconnecting, as illustrated in the following participant statement: "The therapeutic relationship is what provides the opportunity for the grief to no longer be disenfranchised." The participants' emphasis on this structure parallels Neimeyer and Jordan's (2002) suggestion for therapists to utilize their assessment on the intersectionality of grief to inform how the therapeutic relationship can be harnessed as a corrective experience for those disenfranchised. The participants' experience of strong kinesthetic empathy and somatic countertransference provided a wealth of insight into the clients' embodied experience of disenfranchised grief, which offers a unique contribution to the understanding of how disenfranchised grief is experienced. Participants suggested that this experience produces an increased risk for secondary or vicarious trauma. A similar connection has been drawn between

health professionals' experiences of disenfranchised grief and the increased risk for compassion fatigue and burnout (Romesberg, 2004).

Both the participants and their clients received judgment and shaming within the structure of social and cultural factors, as opposed to the validation, attention, and support generally expected after experiencing a loss, or as a clinician, support in the process of working with their clients. This is consistent with what has been regarded as an empathic failure (Neimeyer & Jordan, 2002). For two participants, their place of work illustrated how systems operated as a source of disenfranchisement. Certain clients received more attention according to whether their losses were ranked as worthier of care amongst staff, as illustrated by one participant's statement: "The 'who deserves my attention, my care, and my honoring' also happens all the time." Attig (2004) pointed out the political implications involved in the misuse of authority and power to influence how an individual's grief is treated and shaped according to another's assumptions of what this should consist of and how it should look. This appears to demonstrate what occurred on a systematic level in the participants' experiences. Similarly, Lamers' (2002) warned of institutions as potential sources of disenfranchised grief, and emphasized the importance of considering the role in which systems contribute to disenfranchisement. This finding sheds light on the potential risk for systems oppressing the individuals they seek to serve. An important connection can be drawn between oppression and disconnection from the self and body in the clients' presentations. Reynolds (2002) distinctly articulated this association by drawing on theory from the psychology of oppression to underline the result of interpersonal and intrapersonal disconnect elicited in the alienation process inherent within disenfranchised grief.

Stein (2012) drew attention to our culture's "attitude towards time" that demands grieving individuals return to their former functioning and fulfillment of previously held social

roles prior to the loss (p. 177). Grief is seen as appropriate only as long as grief does not interrupt this expectation. This was evident through the motivation behind some of the clients' referrals due to their behavior or forms of emotion expression, or lack thereof, deemed as problematic by those in authority. One participant went as far as to "wonder if disenfranchised grief increases as we become less tolerable of our own vulnerability." The presence of referrals for secondary symptoms may be indicative of the referring individuals' lack of consideration for the relationship between the clients' behavior, physical symptoms, and their grief (Doka, 2002; Worden, 2009). This supports the understanding within the literature of the presentation of masked grief as well as the increased likelihood of physical symptoms being overlooked or regarded as unrelated (Worden, 2009). The structure of a stronger presence and openness strengthened the therapeutic movement relationship and effectively invited the clients into vulnerability and acknowledging their grief, addressing the textural themes of unrecognized and exacerbated grief. Reconnecting clients with their emotions and authentic experience was necessary to process their grief and disenfranchisement.

The focus of treatment was centered on the grief from the original loss in addition to the supplemental grief stemming from disenfranchisement (Kauffman, 2002). The explorative yet structured approach used in DMT provided a safe, inviting, and encouraging environment necessary to address the multiple experiences of grief that some clients were not afforded elsewhere. The participants facilitated the process of reconnecting the clients with their grief and emotional self through a physically engaging approach that parallels the active framework presented by Worden (2009). Worden's (2009) four tasks of mourning outline a fluid process in which the griever is regarded as an empowered agent with the freedom to engage in the individuality of their process of adapting to the loss (Worden, 2009). Understanding and

processing the connection between symptoms and their grief allowed for increased adaptation in their post-loss life to occur, and in some cases, provided the clients with a sense of closure or resolution. Utilizing structured interventions provided supportive containment and permission for their clients to explore their grief. This was complemented by the improvisational nature of dance/movement therapy that allowed for processing to unfold in a manner that was congruent to the clients' grieving process.

The relationship between the structure of social and cultural factors and the overarching textural themes lay the groundwork for how disenfranchised grief was experienced as distinct from other forms of grief. The clients' masked grief, specifically the lack of awareness and insight into the connection between their grief and their symptoms, combined with the texture of strong behavioral and emotional reactions impacted their ability to fully engage in the therapeutic process and their ability to effectively release their emotions. The external focus, prompted by the social and cultural factors at play, even further diverted the clients' attention and energy away from their grief. This distinctiveness was also reported as evident through the decrease in professional support available to the participants. This texture emphasized the pervasiveness of the clients' disenfranchised grief as it blended into the participants' experience and was described as "This disenfranchised grief that this person isn't able to talk about and then you're not able to talk about it [with colleagues]."

In conclusion, the dance/movement therapists' appraisal of their clients' disenfranchised grief reveals a complex phenomenon with its intricacies experienced as overwhelming, unrecognized, disconnecting, and pervasive. Social and cultural factors lie at the root of the phenomenon and are embedded throughout all facets of the experience. The clinical process of working with clients experiencing disenfranchised grief was distinctive in the secondary

symptoms prompting referral for therapy, presentation of masked grief, and the therapeutic process and relationship feeling more challenging and complicated, yet invaluable in supporting clients. Disenfranchised grief was evident in the clients' physical embodiment of their grief, strong behavioral and emotional reactions, and difficult emotions that were all rendered stuck within themselves. Participants experienced heightened kinesthetic empathy and somatic countertransference while working with clients. The complex nature of disenfranchised grief and the clients' distinct experience of it determined the goals of treatment which sought to mitigate the intense need for an outlet that was otherwise absent while addressing the disenfranchisement and the resulting symptoms. Dance/movement therapy was utilized in a structured manner to provide support and guide the clients through their grieving process, with participants' reports of a positive impact increasing clients' interpersonal and intrapersonal connection.

Limitations and Future Implications

This pilot study contained several key limitations. First was the lack of utilization of movement data that was video recorded during the interview process. Although this data informed the principal investigator's understanding of the participants' experience, this data may have served a more prominent role within this study than the current design allowed. Secondly, the use of a convenience sample always runs the risk of skewing the results and may have been the case in this study. Thirdly, the presence of researcher bias inevitably guided the interview via the questions generated by the principal investigator. The data analysis process was oriented in the principal investigator's personal interpretation of the data, which may also have influenced the results, even when considering the validation strategies. Lastly, the participants' reports of positive benefits of utilizing DMT in their clinical work may stem from their bias as practitioners of dance/movement therapy.

This study was the first attempt to examine the phenomenon of disenfranchised grief from a DMT standpoint. Future research can enrich the understanding of disenfranchised grief by addressing several questions: How do kinesthetic empathy and somatic countertransference inform interventions for disenfranchised grief; How can DMT uniquely address the effects of disenfranchised grief? The present study initiated discussion on how DMT was utilized as a treatment modality, and a closer examination of assessment and choice of interventions would explicate the treatment process more thoroughly.

Research involving a pretest and posttest of the clients' subjective experience of disenfranchised grief may provide deeper insight into their perspective on receiving therapeutic support. Additionally, research involving a pre and post movement assessment would allow for cross reference to determine the degree to which the clients' grief is reflected in their movement patterns, and if the movement shifts that occur reflect the shifts in their grieving process. This could also reveal the effectiveness of using a body-based treatment approach, such as DMT, with clients experiencing disenfranchised grief. Finally, investigation of the individual experience of disenfranchised grief has the potential to inform research on a macro level, specifically with how disenfranchised grief may live in communities.

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Appendix A

Recruitment Procedure: Email Script

Encountering disenfranchised grief: A pilot investigation of the clinical lived experiences in dance/movement therapy

Katie Dominguez

Hello,

My name is Katie Dominguez and I am a graduate student in the Dance/Movement Therapy and Counseling program at Columbia College Chicago. I write to extend a warm invitation to participate in my research study exploring the phenomenon of disenfranchised grief. You are being invited to participate if you are a dance/movement therapist (credentialed as an R-DMT or BC-DMT) who either currently works or has worked with individuals who have experienced trauma and/or grief, and are likely to have experienced this phenomenon.

The purpose of this study is to gather clinical accounts and narratives from dance/movement therapists, like you, who work with or have worked with clients experiencing disenfranchised grief. The study further intends to identify how a client's lived experience of disenfranchised grief presents itself within the therapeutic relationship, along with addressing the role of the body and impacts on nonverbal communication during the experience of disenfranchised grief.

In order to participate in this study, you must have an R-DMT or BC-DMT credential. Secondly, you must self-identify as having worked or currently working with clients experiencing disenfranchised grief. Disenfranchised grief is operationally defined for this study:

> "Disenfranchised grief is grief that persons experience when they incur a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported" (Doka, 1989, p. 4).

There are five areas in which a person can experience disenfranchisement of grief and they are as follows:

1. **Relationships** –relationships that are not deemed appropriate or legitimate by society or relationships outside of the immediate family.

   (E.g. friends, homosexual relationships, neighbor, ex-spouse, etc.)

2. **Loss –**death related losses that are not socially defined as significant, a loss that does not involve a death, and non-human death/loss.

   (E.g. abortion, peri/still/neonatal deaths, animal/pet, religious conversions, career, foreclosure, adolescent romantic relationship, Alzheimer's disease, infertility, etc.)

3. **Grievers –**the person is not seen as capable of grief, or is not recognized as having a need to grieve.

   (E.g. children, those with intellectual/developmental disabilities, the elderly, etc.)

4. **Circumstances of the Death –**stigmatized death may inhibit those grieving from receiving social support

   (E.g. suicide, autoerotic deaths, drunk driver deaths, homicide, etc.)

5. **Ways Individuals Grieve –**certain ways of expressing grief are not socially acceptable

   (E.g. length of grieving, excessive or very little expressions of emotion, etc.)

*The experience of loss and grief in any circumstance, whether listed above or not, does not necessarily mean disenfranchisement has occurred. It is the act of being denied the social support, acknowledgment of feelings, or the right to openly express these feelings (mourn), is when disenfranchisement of grief occurs.

If you self-identify as having identified disenfranchised grief in your current or past clients, and remain interested in participating in this study, please refer to the attached informed consent form for further details. Please feel free to contact me via phone or email with further questions about the study or the informed consent form. Thank you for your consideration and for the meaningful work you do.

With appreciation,

Katie Dominguez
2016 M.A. Candidate, Dance/Movement Therapy and Counseling
Department of Creative Arts Therapies
Columbia College Chicago
katie.dominguez@loop.colum.edu
805.889.8159

Doka, K. J. (1989). Disenfranchised grief. In K. J. Doka (Ed.), *Disenfranchised grief: Recognizing hidden sorrow* (pp. 3-11). Lexington, MA: Lexington Books.

Appendix B

Columbia
COLLEGE CHICAGO

Approved
IRB STAMP REQUIRED

Informed Consent Form

Consent Form for Participation in a Research Study

Title of Research Project: Encountering disenfranchised grief: A pilot investigation of the clinical lived experiences in dance/movement therapy
Principal Investigator: Katie Dominguez, M.A. Candidate, katie.dominguez@loop.colum.edu, 805.889.8159
Faculty Advisor: Laura Allen, MA, LCPC, BC-DMT, GL-CMA, lallen@colum.edu, 312.369.7963
Chair of Thesis Committee: Laura Downey, BC-DMT, LPC, GL-CMA, ldowney@colum.edu, 312.369.8617

INTRODUCTION
You are invited to participate in a research study to explore the phenomenon of disenfranchised grief through the perspective of dance/movement therapists who currently work with or have in the past worked with clients experiencing disenfranchised grief. This consent form will give you the information you will need to understand why this study is being done and why you are being invited to participate. It will also describe what you will need to do to participate and any known risks, inconveniences or discomforts that you may have while participating. You are encouraged to ask questions now and at any time. If you decide to participate, you will be asked to sign this form and it will be a record of your agreement to participate. This process is called 'informed consent.' You will receive a copy of this form for your records. Please review the informed consent form provided to you and return with a response.

You are being asked to participate because you are a dance/movement therapist of R-DMT or BC-DMT standing, who either currently works or has worked with clients experiencing trauma and/or grief, and may also be experiencing disenfranchised grief.

PURPOSE OF THE STUDY

The purpose of this research study is to gain an understanding of how a client's lived experience of disenfranchised grief presents itself within the clinical therapeutic relationship in dance/movement therapy. This investigation hopes to utilize the body knowledge, diverse movement repertoire, and training of dance/movement therapists to identify how disenfranchised grief is experienced within the body and how it may affect nonverbal communication and the body-mind experience in their clients.

PROCEDURES

Potential participants must meet the following inclusion criteria:

- Have an R-DMT or BC-DMT standing under the American Dance Therapy Association. If potential participant does not possess this standing, they will not be considered for role of participant.
- Self identify as having worked or currently working with clients experiencing disenfranchised grief.
- Must be willing to be recorded during data collection process.
- Must understand the concept of disenfranchised grief as operationally defined in this study. (Available on the recruitment letter).

Steps of Procedure:

- The information necessary for this study will be collected through a 1-2 hour individual interview. This interview will include questions and/or statements that invite you to give clinical accounts of your working with a client(s) experiencing disenfranchised grief. The questions will be worded in such a way that will invite you to give specific examples, as well as personal responses, professional opinions, and the opportunity for movement responses through embodying a client's movement patterns.
- The interviews for this study will be conducted in person or via Skype at a time that is convenient for both participant and researcher. If the interview is conducted in person, it will take place in a reserved, private space located at Columbia College Chicago or at another private location based on the convenience of both the participant and researcher. If the interview is conducted via Skype, the participant and researcher will together determine a private location to engage in the interview process.
- The interviews that will be conducted will last no more than two hours. If for some reason more information is required, you will be contacted in order to schedule a second interview session. This might be necessary in instances where important information was not collected during the initial interview or the first interview is interrupted or shortened due to unforeseen circumstances. If necessary, the second interview session will last not more than one hour.
- In order to most accurately and effectively capture the research interview, it will be recorded via video recording. If the interview is conducted over Skype, the video recording will begin at the start of the conversation. If the interview is conducted in person, you will be told prior to entering the interview space when the video recording will be turned on and off, indicating the beginning and ending of the interview process.
- After the interview, you will be contacted again at a later stage of the study to review the written interview narrative, which will be provided to you by the researcher. You will be

invited to provide feedback, clarifications and/or additional information you feel is relevant to your research data.

If you agree to participant in this study, you will be asked to do the following:

- Read through and sign informed consent.
- Respond to any communication from myself (principal investigator) prior to and after the interview process.
- Schedule a date and time for the interview to take place with researcher.
- Set aside at least two hours for the interview process.
- Grant permission for portions of your interview to be included and possibly quoted in the final presentation of the research study.
- Commit to the possibility of a second, 1 hour interview if necessary.
- Be willing to review and provide feedback, clarifications and/or additional information, upon reviewing the written interview narrative following the interview during the data analysis process.

POSSIBLE RISKS OR DISCOMFORTS

The risk(s) in this study is(are):

- The potential risks in this study mainly include emotional or psychological responses due to re-counting past or current clinical experiences of working with clients experiencing disenfranchised grief. While asking you to share your clinical experiences of working with clients experiencing disenfranchised grief, positive or negative memories, feelings, sensations, and/or thoughts, might be recalled and as a result this could lead to re-living those experiences in the moment. The emotional or psychological responses to reliving the memories could emerge during the interview process or after the interview process. If these responses arise, you will be invited to openly acknowledge any feelings or thoughts that emerge. During the interview, I will have the opportunity to acknowledge your responses and appropriately respond to your experience by offering breaks and allowing you to proceed when ready. The role of the principal investigator is not intended to provide clinical and therapeutic support, and thus, it is ultimately your responsibility to maintain individual safety. You may discontinue the interview and further participation in the study at any time. It is recommended and encouraged that you seek professional supervision or personal therapy is assistance if needed.
- The shared details of the interview transcriptions, narratives, and/or quotations in the written findings may unintentionally reveal your identity in your interview. To minimize this risk, you will be assigned a pseudonym to protect your anonymity. The use of direct quotations will also be approved through your verbal consent.
- If chosen and willing to participate in this study, possible inconveniences that may be encountered as a result of this study include finding and funding your own transportation to and from the interview location if participating in an in-person interview.
- Another potential inconvenience is the additional required time it will take to review and validate the written description of your experience.

POSSIBLE BENEFITS

The possible benefits of being in this study include:

- Further develop personal knowledge and insight on disenfranchised grief.
- Increased clinical awareness of disenfranchised grief

- The opportunity to contribute to growing a clinical understanding of disenfranchised grief within grief literature.
- Contribution to the increased clinical awareness of the role of the body in the experience of grief and disenfranchisement, particularly the embodied component and impacts on nonverbal communication.
- Contribution to future research and clinical implications for dance/movement therapy methods as uniquely beneficial for those experiencing disenfranchised grief.

CONFIDENTIALITY

Confidentiality means that the investigator will keep the names and other identifying information of the research participants private. The investigator will change the names and identifying information of research participants when writing about them or when talking about them with others, such as the investigator's supervisors.

The following procedures will be used to protect the confidentiality of your information:

1. The researcher will keep all study records locked in a secure location with access only to researcher.
2. No one else besides the researcher will have access to the original data.
3. Any personal communication between you (research participant) and I (researcher) will be retrieved in a private location, on my private computer. My private computer and e-mail will be protected through the use of a firewall, as well as encrypted password. Personal communication through e-mail will be exchanged through my private, academic email account.
4. All interviews whether in-person or online Skype communication will take place in a secure, safe, and private location.
5. Any videotape recordings will be viewed and transcribed only by researcher. Any videotape recordings will be destroyed after transcription in December 2016.
6. Personal study notes that I create may be kept indefinitely with any and all personal identifying information stripped from the data.
7. All electronic files containing personal information will be password protected.
8. You will be assigned a pseudonym to protect your privacy and confidentiality and minimize the chances of you being identified.
9. You (research participant) are responsible and ethically obligated for upholding client-therapist confidentiality; however, if something is mistakenly said that reveals the identity of another person I will redact this information from the interview and subsequent transcription.
10. Information about you that will be shared with others will be unnamed or utilize assigned pseudonym to help protect your identity.
11. At the end of this study, the researcher may publish their findings. If so, you will not be personally identified in any publications or presentations.

If incidents of child or elderly abuse or neglect, or harm to self or others, are revealed during the interview process, your confidentiality may be compromised due to my role as a mandated reporter.

RIGHTS
Being a research participant in this study is voluntary. You may choose to withdraw from the study at any time without penalty. You may also refuse to participate at any time without penalty.

Thoughtfully consider your decision to participate in this research study. We will be happy to answer any question(s) you have about this study. If you have further questions about this project or if you have a research-related problem, you may contact the principal investigator, Katie Dominguez at 805.889.8159, katie.dominguez@loop.colum.edu, or the faculty advisor, Laura Allen, MA, LCPC, BC-DMT, GL-CMA, at 312.369.7963, lallen@colum.edu. If you have any questions concerning your rights as a research subject, you may contact the Columbia College Chicago Institutional Review Board (IRB) staff at 312-369-8795 or IRB@colum.edu.

COST OR COMMITMENT

- As a participant in this study, you are required to supply your own transportation to and from the interview location. As a result you may incur minimal fees from your involvement in this research study, such as mileage, parking fees, or public transportation costs.
- Your potential time commitment includes:
    - Responding to personal communication with researcher (e.g. emails, phone calls, reading and signing informed consent).
    - Any personal preparation needed on your part to prepare for the interview(s).
    - Travel time to and from the interview location, if applicable.
    - 1-2 hours for the research interview, not including additional time needed for bathroom, snack, or other personal needs breaks
    - Approximately one hour for a secondary interview, if necessary.
    - Additional time for future narrative data review.

COMPENSATION FOR ILLNESS AND INJURY
If you agree to participate in this study, your consent in this document does not waive any of your legal rights. However, in the event of harm arising from this study, neither Columbia College Chicago nor the researchers are able to give you money, insurance, coverage, free medical care or any other compensation injury that occurs as a result of the study. For this reason, please consider the stated risks of the study carefully.

PARTICIPANT STATEMENT
This study has been explained to me. I volunteer to take part in this research. I have had opportunity to ask questions. If I have questions later about the research or my rights as a research participant, I can ask one of the contacts listed above. I understand that I may withdraw from the study or refuse to participate at any time without penalty. I will receive a copy of this consent form.

_____	_____	_____
Participant's Signature:	Print Name:	Date:
_____	_____	_____
Principal Investigator's Signature:	Print Name:	Date

Appendix C: Interview Questions

Date:_____Interview location/mode: _____
_____
Participant name/pseudonym: _____

Client Information
Client pseudonym: _____
_____
City:_____ Age: _____Gender:_____

Ethnicity: _____ ____Race: _____
_____
Nationality: _____ Sexual Orientation: _____ _____

Tell me about how you knew your client(s) was experiencing disenfranchised grief.

Was disenfranchised grief the primary reason for attending therapy initially? Or was it for something else?

If not, what did client and/or therapist identify it as?

If you did identify it as disenfranchised grief, how did you know it was that?

Based on your client(s) experience:

How have you observed disenfranchised grief manifest within the body?

How have you observed disenfranchised grief embodied?

How did your body feel in relationship with disenfranchised grief?

Did it affect your client(s) movement and nonverbal communication?

How do you think disenfranchised grief influenced your client(s) body/mind experience?

What social and/or cultural factors, if any, did you notice influencing disenfranchised grief?

Does it look different from other forms of grief?

How did you experience the client's disenfranchised grief in your own body or sensory experience?

Was that different than how you experience other forms of grief when working with clients?

How did you use dance/movement therapy with your client(s) experiencing disenfranchised grief?