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The Loss-Processing Framework

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by

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ABSTRACT

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The circumstances of responding to loss due to human death are among the most stressful experiences encountered in life. Although grief's symptoms are typically considered essential to their gradual diminishment, possible negative impacts of complications related to grief are also well known, and have been associated with detriments to mental and physical health. Grief, however, can also generate transformative positive change. Thus, albeit ineludible, responding to loss is not uniformly experienced, expressed, or understood. It is also culturally-shaped, making attempts to define "normal" grief, as well as to label some grief "abnormal"—and to medicalize it—possibly problematic. Bereavement (the situation surrounding a death) and mourning (the publicly expressed response to loss due to death) are changing. Some of these changes (e.g., the increase in hospice care settings prior to deaths, and alterations in the ritual responses following all deaths—irrespective of their context) may have important implications for avoiding grief's possible complications and for promoting its potential benefits. An improved alignment of grief theory, research, and practice is warranted; but theories of grief are diverse, and historically have not been empirically well-supported. This research articulates a new grief model, the loss-processing framework, featuring three dimensional components (perception, orientation, and direction). As a first step toward validation of the framework, also included is an empirical study examining retrospective descriptive reports of adult loss response relating to the first of these three dimensions (perception). As an interpretive, translational approach to understanding grief, the loss-processing framework may serve to positively impact grieving, health, and life quality.

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Chapter 1. Introduction

Overview

The circumstances of responding to loss due to human death are among the most stressful experiences encountered in life (Holmes & Rahe, 1967; for brief summary see, e.g., Aoun et al., 2019; Layne et al., 2017). Scholars have also noted, however, that the symptoms of loss response are typically essential to their gradual attenuation (e.g., Durkheim, 1915/1965) and have posited the possible import of loss response in relationship to adaptive functioning (e.g., Caplan, 1964; Nesse, 2000; Walsh & McGoldrick, 1991/2004), positive personal growth, and creativity (e.g., Aldwin, 1994/2007; Elliott, 1999; Fahlberg et al., 1992; Finkel, 1974, 1975; Frankl, 1946/1984; Gillies & Neimeyer, 2006; Kessler, 2019; Klein, 1940; Marris, 1974; Nolen-Hoeksema & Davis, 2002; O'Leary & Ickovics, 1995; Pollock, 1981, 1987, 1989a, b; Rochlin, 1965; Schaefer & Moos, 2001; Tedeschi, 1995; Tedeschi & Calhoun, 1996; Tedeschi et al., 1998; Woodward, 1990, 1993; Yalom & Lieberman, 1991; for summary see also Hogan & Schmidt, 2002). Others have noted empirical studies spanning the globe that evince an association between certain complications of loss response and detriments to mental and physical health and well-being (for summary see Stroebe et al., 2007; see also, e.g., Parkes, 1972).

In the U.S., the prevalence of the predominant form of complicated loss response, persistent complex bereavement disorder (PCBD)—a condition for further study in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5; American Psychiatric Association [APA], 2013)—has been estimated to be as high as 20% (Hensley et al., 2009; Middleton et al., 1998; Prigerson & Jacobs, 2001; Silverman et al., 2000). Given the death rate in the U.S. (Kochanek et al., 2016), estimates indicate that as many as 2.6 million people may develop PCBD annually. With baby boomers continuing to age (Ayers et al., 2004; Jemal et

al., 2005), and with the estimated 533,000+ COVID-19-related deaths (through March, 2021; Center for Disease Control and Prevention [CDC], 2021), this number is expected to increase in the future—emphasizing the urgency for an improved alignment of loss response theory, research, and practice going forward (Ayers et al., 2004; Sandler et al., 2005). As Layne et al. (2017) have noted: "This growing recognition of bereavement as a subject of clinical concern and study is further demonstrated by the World Health Organization's (WHO's) inclusion of Prolonged Grief Disorder in its International Classification of Diseases, 11th revision **(**ICD-11; World Health Organization [WHO], 2018**),** which will reach an even wider medical and psychiatric audience worldwide than DSM-5…" (p. 267; see also Maercker et al., 2013; Maercker & Lalor, 2012; Prigerson et al., 2009).

Statement of the Problem

The potential for an increased incidence of complications in loss response in the near future, and the prospect of negative health consequences as a result, are important to consider in relationship to current/recent trends regarding the predominant context of bereavement in the U.S. (palliative/hospice care settings) as well as in relation to possible shifts in the ceremonial collective rites of mourning following on death's occurrence (toward less formalized ritualization—or, in some cases, none at all). The individuality of responses to loss due to human death, which are not uniformly experienced, expressed, or understood (e.g., Neimeyer & Harris, 2011; Shuchter & Zisook, 1993; Stroebe et al., 1994), must also be stressed. Furthermore, loss responses are typically culturally-shaped (e.g., Bonanno, 1999; Rosenblatt, 2001), making attempts to define "normal" grief, as well as to label some manifestations of grief "abnormal"—and to medicalize it—possibly problematic.

Concerns regarding the appropriate labeling of loss response (and the possible pathogenesis of some loss responses) are perhaps being exacerbated by the challenge of discerning how and why certain aspects of responding to loss may be maladaptive for some individuals while for others they are not. Ascertaining what is "normal" grief from what is simply divergent or from what is possibly aberrant can be fraught (see, e.g., Bisconti et al., 2004; Nesse, 2005; Rubin, 1993; Shapiro, 2001; Zisook & Shuchter, 1986). It is difficult to excavate grief's underlying mechanisms and their potential ramifications (positive, negative, and otherwise) with absolute precision. After all, "Grief is a process, not a state" (Parkes, 1970, p. 445); and, as Stroebe et al. (1993) note: "…even one individual's grief varies from moment to moment" (p. 5). It is also important to remember, especially when attempting to avoid possible complications in loss response, that its symptoms are normally considered to be requisite to their gradual diminishment (e.g., Durkheim, 1915/1965), and that grief may enhance adaptivity, foster transformative personal growth, and generate creativity (see previous citations, p. 9; for summary see also Hogan & Schmidt, 2002).

If grieving well can help make one's life better, then explaining the dangers of complex bereavement may serve, however inadvertently, to diminish understanding(s of) grief's restorative, adaptive, and creative potential. Of course, the opposite may also apply: emphasizing grief's transformational and generative features could risk the prospect of missing signs of possible complications related to it. Shapiro (2001) has observed the need to clarify "…paradoxes of grief and growth" via "a comprehensive conceptual approach," noting that "the grief literature lacks agreement in conceptualizing and operationalizing pathological versus successful bereavement" (p. 302).

But conceptual models of grief are diverse, featuring variegated (yet sometimes overlapping) and oft-debated research perspectives (see, e.g., Childress, 2015; Papa et al., 2014), with roots in different disciplines (Rothaupt & Becker, 2007; Stroebe et al., 1993), and professional understandings that are typically based on "alternative discursive frames of reference" (Neimeyer, 2001b, p. 264). Although in recent decades bereavement research has "burgeoned internationally, giving rise to a greatly expanded trove of models and methods which have increasingly been subjected to empirical scrutiny" (Neimeyer, 2014, p. 125), historically evidential support for grief theories has remained shallow (Archer, 2008; Bonanno, 1998, 2009; Bonanno & Field, 2001; Bonanno & Kaltman, 1999; Breen & O'Connor, 2007; Center for the Advancement of Health, 2004; Davis et al., 2000; Lindstrøm, 2002; Stroebe & Schut, 2005; Stroebe et al., 2002; Wortman & Silver, 1989, 2001). As Stroebe et al. (1993) note: "…research on bereavement typically has not been guided by an integrative theory base" (p. 7). Thus, consensus regarding a possible path toward an integrated, unifying, and empirically well-supported approach to loss response remains elusive.

Significance

Multiple factors underscore the need to enhance understanding of human response to loss due to death, or grief. Stroebe et al. (2007) have drawn attention to the adverse effects of certain complications of bereavement on health, including an increased risk of mortality—particularly for certain groups (see also Boyle et al., 2011; Christakis & Iwashyna, 2003; Moon et al., 2011; Prigerson et al., 2009; Raphael, 1993; Rees & Lutkins, 1967; Schultze-Florey et al., 2012; Stroebe & Stroebe, 1993). In the relationship between loss response and health, persistent complex bereavement disorder (PCBD; APA, 2013) is at the negative end of the loss response continuum and has been associated with an increased risk for cardiac disease, hypertension,

cancer, immunological deficiency (Chen et al., 1999; Irwin & Weiner, 1987; Prigerson et al., 1997; Prigerson et al., 1999), and suicide ideation/completion (Hill et al., 2019; Latham & Prigerson, 2004). It is commonly comorbid with major depressive disorder (MDD), posttraumatic stress disorder, and substance use disorders (APA, 2013).

Of these three, PCBD is most frequently comorbid with depression (Maercker & Lalor, 2012; see also Brent et al., 1994; McDermott et al., 1997; Pasternak et al., 1993; Zisook et al., 1997), which is one of the most prevalent, costly, and challenging mental health concerns today (Berto et al., 2000)—and the leading cause of disability worldwide (World Health Organization, 2018a). Both grief complications and MDD are accompanied by an increasing incidence of neuropharmacologic interventions (Horwitz & Wakefield, 2007; Brody & Gu, 2020); possible impacts of these drug-based treatments for complex grief and depressive symptoms on the course and outcome of subsequent response(s) to loss are not yet known (see, e.g., Nesse, 2000).

Other ill effects of complications relating to bereavement may include the disruption of neuroendocrine systems (Fletcher, 1996; Goodkin et al., 1995; Pasternak et al., 1994), a substantial worsening of activity-limiting pain (Bradbeer et al., 2003), insomnia (Marris, 1958/2004; Parkes, 1970), somatic disturbances (Shahane et al., 2018), weight loss (Marris, 1958/2004; Shahar et al., 2001; Shulz et al., 2001), subjective distress (Maciejewski et al., 2007), an increase in rates of surgery and hospitalization (Glick et al., 1974), and elevated rates of chronic inflammatory conditions, such as cardiovascular disease (Carey et al., 2014; Chirinos et al., 2019; Stahl et al., 2016)—which is the leading cause of death both within the U.S. (Kochanek et al., 2019) and globally (Finegold et al., 2013).

Aoun et al. (2019) have noted that adverse outcomes related to complicated grief can span emotional, physical, behavioral, and cognitive domains. Raphael (1993) summates the

possible negative impacts from grief's complications to include "…increased presentations for medical care, increased substance use and abuse, significant mental health problems, [an] increased risk of death for some groups, and, for all, substantial human suffering" (p. xi). As Morris and Block (2015) assert: "these [impacts] are not insignificant and have important implications for how our society as a whole cares for the bereaved" (p. 915).

Historically empirical data regarding both positive *and* negative, or (mal)adaptive, loss responses (including—but not limited to—possible complications, their causes/consequences, and potential preventions/treatments) have been considered insufficient (see, e.g., Kato & Mann, 1999). Studies on which to build effective strategies for caring for all those who are bereaved are sparse, and appropriate tools for the assessment of loss response may be underdeveloped (Agnew et al., 2010).

Varied theoretical understandings of loss response, an historical paucity of robust empirical evidence supporting grief theories, ongoing disagreement regarding bereavement's typical or "normal" course(s), the prospect of labeling (and treating) atypical grief as "abnormal," cross-cultural differences in mourning, and the propensity to medicalize grief are some of the factors that have made loss response research especially challenging. The difficulties of conducting research on populations experiencing loss due to human death have also been well documented (see, e.g., Cassileth & Lusk, 1989; Grande & Todd, 2000; Hudson et al., 2005; Hudson & Hayman-White, 2006).

As noted above, the identification and implementation of comprehensive bereavement measurement instrumentation can also be problematic (see, e.g., Agnew et al., 2010), but is not insurmountable (for review see Hudson & Hayman-White, 2006; Neimeyer, 2015a; see also Burnett et al., 1997; Deeken et al., 2003; Kristjanson et al., 2005). Although advancements in

thanatological research have been a focus for some time, Neimeyer (2001a) has lamented that "fervid developments in research…have not been matched either by a consistent sophistication in our conceptual models of loss or the generation of new insights into clinical practice" (p. 2).

Primary Aim

Assessing loss response is more than looking for possible indicators of a need for prevention and/or treatment for maladaptive grieving; it is the concomitant search for positive indications of adaptive loss response, which includes the possibility that grief can—and often does—effect generative, transformational change. Thus, it is pivotal that research into loss response be approached through an appropriate conceptual framework, one grounded in a full range of possible manifestations rather than, for example, limited only (or primarily) to those considered to be "abnormal"—or to those deemed "normal" when its operationalization has proven fraught (see, e.g., Uren & Wastell 2002 for support of viewing grief typology along a continuum rather than as dichotomized). Relatedly, cultural variations in grief, and the propensity to medicalize it, must also be considered.

The primary aim of this research is to describe a new framework of loss response and to explore the retrospective descriptive reports of bereaved adults relating to it. The loss-processing framework consists of three inter-related elements: 1) perception, 2) orientation, and 3) direction. In contrast to the longstanding, conventional (mis)conception that components of loss response follow one another in a stage- or step-like progression, these dimensional elements intersect, interact, and (may) influence one another (for a brief summary of intersectionality, see Warner & Shields, 2013; for refutations of stage grief theory, see, e.g., Bonanno & Boerner, 2007; Center for Advancement of Health, 2001, 2004; Hall, 2014; Neimeyer, 2014; Osterweis et al., 1984;

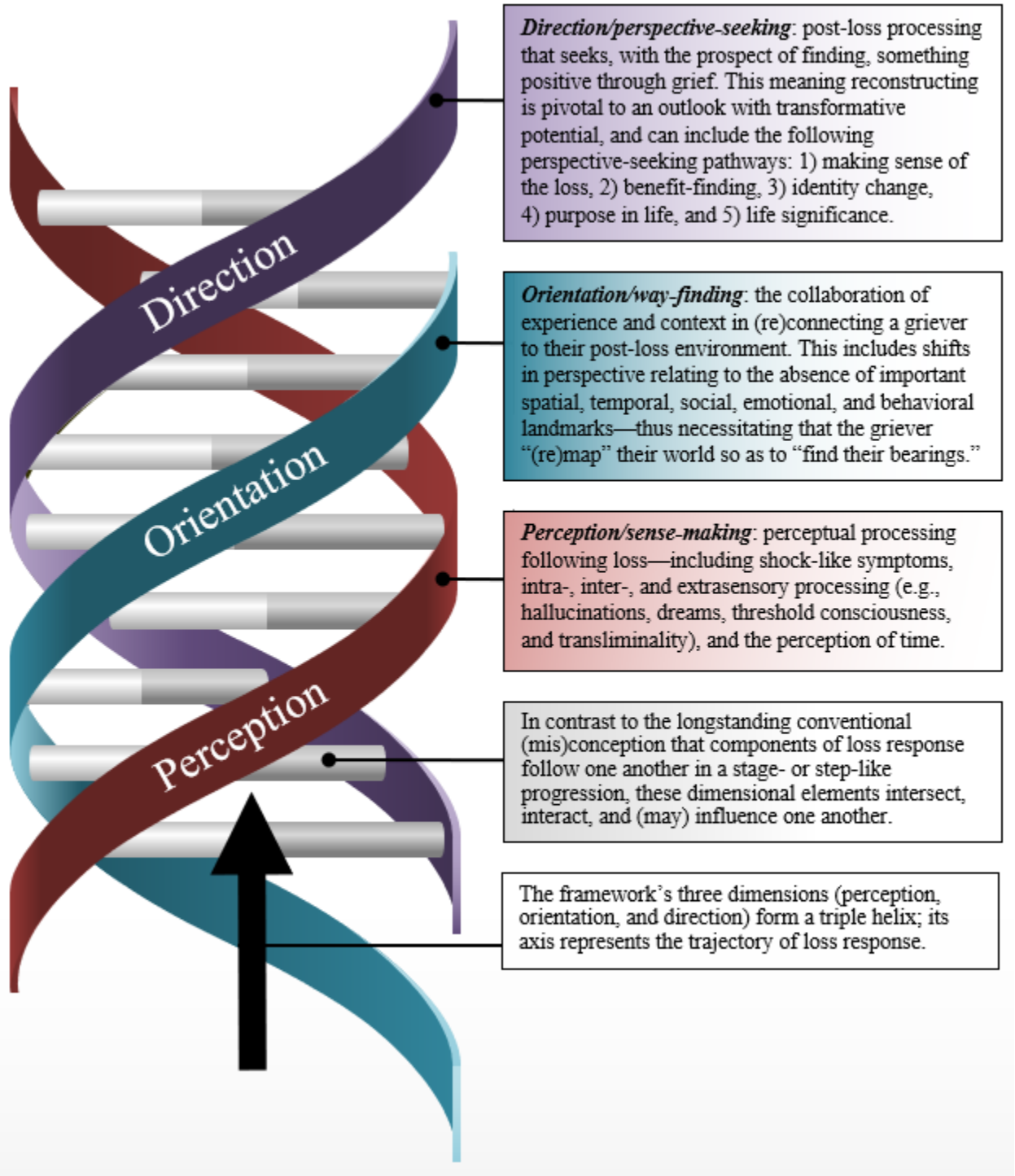
Stroebe et al., 2017; Rothpaut & Becker, 2007; Silver & Wortman, 1980, 2007; Weiner, 2007; Wortman & Silver, 1987, 1989, 1992).

Chapter 1 Summary

The posited loss-processing framework's three components of perception, orientation, and direction (see Figure 1) may be useful in the assessment of numerous indicators of both positive and negative outcomes in the grief-health relationship. From this larger set of possible indicators, a provisional, perception-related subset was examined for this paper; however, future work could also benefit from the proposed modular framework, including with respect to indicators relating to its other two dimensions (orientation and direction). An accessible, interpretive approach with enhanced translational applicability may aid in streamlining grief research, thereby increasing the empirical evidence bases surrounding loss response, its possible interventions, and their efficacy. These include techniques to perhaps help prevent complications due to bereavement as well as methods to possibly reinforce grief's beneficial aspects. As such, improving this empirical knowledge base should have the potential to positively impact grieving, health, and life quality.

Figure 1

The Loss-Processing Framework



Chapter 2. Perception

Perhaps the only way to overcome a traumatic severance of body and mind is to come back to the mind through the body. (Hartman, 2004, p. 541)

The experience of living can change in response to the death of a loved one. Certain expectations regarding how the world does and does not work may no longer be met. Thus, life's reality seems different; it may even feel unreal. As Butler (2003) notes: "…loss fractures representation itself" (p. 467), and as Davis (2001) has posited, responding to loss can often result in "severe threats to how people perceive themselves and how they perceive the world" (p. 137). Similarly, Lindemann (1944/1994) concluded that in grief "the sensorium is generally somewhat altered" (p. 188). Since perceived sensory alterations are potentially a key component of loss response, an assumption of the proposed framework is that perceptual processes can seem to be impaired or are in some way(s) altered by grief. Even so, the precise mechanisms underlying possible changes in perceptual processing in response to loss are understudied. Likewise, and in part because changes in sensory perception in the context of grief are typically (assumed to be) transient, little is known about the possible permanence and/or the longer-term impacts of perceptual alterations in relationship to loss due to human death.

The first dimension of the proposed loss-processing framework, *perception*, therefore primarily refers to the perceptual processing of sensorial information. This dimension (herein also alternately termed *sense-making*) encompasses the core functions of sensation (stimuli detection) and perception (organizing, identifying, and interpreting what has been detected) as well as the liminal space between them (see, e.g., Hochberg, 1956; Kolb, 2009; Schacter et al., 2012). Possible changes to sensory processing in the context of loss may occur in the following related areas: 1) shock-like symptomatology; 2) intrasensory processing; 3) intersensory

processing (a.k.a., multimodal integration or intersensory coordination); 4) extrasensory processing (including hallucinations, illusions, and other post-death experiences of the decedent; dreams; threshold consciousness; and transliminality); and 5) time.

Shock

In summarizing Shontz's (1965, 1975) crisis reaction theory, Silver and Wortman (1980) underscore that shock "…occurs to some degree in virtually every crisis state" (p. 287); Parkes (1970) views this "state of numbness…blunting, or shock" (p. 449) to be the most frequent immediate response to death (see also, e.g., Bowlby & Parkes, 1970; Eliot, 1943; Tyhurst, 1958). Similar to shock—as an acute reaction to (dis)stress (which is often crisis-related)—perceptual processing in the context of loss can also generally feature symptoms of anxiety, agitation, restlessness, fear, helplessness, confusion, dizziness, light-headedness, and/or faintness (for reference, see Summary of Diagnostic Features of Acute Stress Disorder [ASD], Appendix A, APA, 2013; for review see also Bryant et al., 2011). More specifically, clinical symptoms of dissociative acute stress reactions (ASR's) may include a sense of numbing and/or detachment from emotional reactions; a sense of physical detachment, such as seeing oneself from another perspective; decreased awareness of one's surroundings; the perception that one's environment is unreal or dreamlike; and an inability to recall critical aspects of the stressful event (in this case death—or news of its imminence), which is also known as dissociative amnesia (APA, 2013; Bryant et al., 2011; Bryant & Harvey, 2000).

Symptoms of acute dissociative reactions to stressful events are typically transient, beginning within one month following the event and lasting up to one month after onset. Duration may be longer, and/or onset more delayed, in the context of loss (APA, 2013). Additional symptoms include: "constriction of consciousness; depersonalization; derealization;

perceptual disturbances (e.g., time slowing, macropsia); micro-amnesias; transient stupor; and/or alterations in sensory-motor functioning, such as analgesia [and] paralysis" (APA, 2013, pp. 306-307; see also Bryant et al., 2011; Bryant & Harvey, 2000; Kavan et al., 2012). With respect to two of these shock-related symptoms, Lindemann (1944/1994) notes exceptions to macropsia (with other people seeming shadowy and small rather than appearing larger) and analgesia (citing, e.g., evidence of specific somatic complaints, such as constriction of the throat and/or other respiratory problems) in loss contexts (see also, e.g., Goldstein, 2015). Regarding the latter, somatic complaints related to loss response may include symptoms that were experienced by the decedent prior to death (APA, 2013; see also, e.g., Parkes, 1970).

Unlike shock, it should be noted that in some cases perceptual processing can seem to be in some way(s) enriched in response to loss. Although this felt acuity may bear some resemblance to sensitization in non-associative learning, in this context the sensitizing emphasizes awareness of, rather than reaction(s) to, stimuli relative to exposure to a sensory input (in this case one of significant loss). It also bears mentioning that over time certain individuals experiencing losses in this way may come to view perceptual processing as having been honed, intensified, or somehow enhanced by them. For example, following her older brother's sudden death at the age of 40, Elizabeth Feldstein described her sensory perception as follows:

> "It's like all of a sudden a pair of glasses were strapped to my face and I can't take them off. Ever. And these glasses make me see the world differently than I did before. The colors bleed together more vividly. But they are somehow more than they ever were before. More visceral. More vibrant. More present. Simultaneously more awe-inspiring and more aching." (Deerwester, 2019, p.1)

It is also possible that features of sensory perception may alternate during loss response, perhaps tracking an oscillatory pattern similar to the one outlined in Stroebe and Schut's (1999) dual process model (DPM) of coping in grief (see also Stroebe & Schut, 2001, 2010).

Finally, with respect to shock-like symptoms and their relationship to perception in the context of loss, changes are not mutually exclusive; they may be neither discretely dulled nor sharpened, but could be differently altered instead. An example of this—albeit from an extreme circumstance of loss—is evinced in a soldier's recounting of his sensory perception following the realization that his participation in drone warfare may have caused a civilian casualty (taking the life of a child). After making the drone strike, stepping out into the daylight of the desert landscape from the bunker where he was stationed, the soldier reported that "The light was too bright, and the dark places were too dark" (McEvers, 2013). It is therefore possible that in loss certain aspects of sensory perception may be exaggerated while others are simultaneously diminished. In this case the contrast of perceptual visual processing was heightened, while the ability to discern tacit colors and other nuanced visual detail was simultaneously lowered.

Intrasensory Processing

As indicated in some of the shock-like symptoms related to (dis)stress, the perception of each sense (or intrasensory processing) may be impacted by loss. In severe cases (e.g., in the context of brain injury, dementia, or nervous system illness) this has been termed *agnosia* (Greek for "lack of knowledge"), or "a neurological recognition deficit that affects a single [sensory] modality" (Burns, 2004, p.1; Freud, 1891/1953; Lissauer, 1890). First described by Finkelnburg (1870; for translation see Duffy & Liles, 1979) using the term *asymbolia* (the inability to understand previously familiar symbols), and also referred to as *mindblindness* (Munk, 1881/1960), typically agnosia disturbs or disrupts one's ability to understand, recognize, or

appreciate the identity or nature of sensory stimuli (e.g., sights, sounds, or somatosensations), but no specific sense is impaired—only its perception—and there is no significant memory loss (e.g., Joseph, 2018; Puente & Tonkonogy, 2009). Thus, agnosia reflects challenges in accurately *assigning meaning* to detected stimuli (Bauer, 2006); as Burns (2004) posits: those experiencing associative agnosia "perceive the stimuli but [are] unable to attach meaning to [it]" (p. 2).

Here it should also be noted that an inaccurate overvaluing of the meaning of sensations in relationship to one another has been termed *apophenia* (Conrad, 1958; see also, e.g., Mishara, 2010), and that *delusional perceptions* have been defined as instances where normal occurrences are perceived to have special meanings (see, e.g., Martin, 2015). That being said, for the purposes of this discussion, *agnosia* is used to refer to any/all perceptual meaning assignment disparities that possibly relate to or result from grief—including both under- and over-valuations.

In general, grieving individuals have compared agnosia-like perception alterations to experiencing the world as if "in a fog" (e.g., Hodgson, 2016; Shear et al., 2011). This can even feel as though one's sense of gravity has been altered; for example, as one daughter reported following her mother's COVID-19-related death in April, 2020: "[I was] crying so hard that it actually hurt me. I couldn't hold a thought. I was like, what the hell is wrong with me? Why do I feel so heavy?" (Fisher et al., 2020). More specifically, Lindemann (1944/1994) documented gustatory examples of agnosia-like symptoms surrounding loss in an inability to recognize or appreciate the taste of food, which one griever noted "tastes like sand" (p. 188). Or, as a grieving mother stated following the death of her 14-year-old daughter: "[I was] so shattered I could not see my own hand in front of my face" (Starr, 2012, p. 63).

This is not limited to the senses of vestibulation, taste, or sight. For example, Alfred Wilson described his experience when receiving news of the sudden death of his friend and co-

worker, Heather Heyer, as follows: “Everything was so quiet…like somebody had shut the volume control off on the world” (King, 2018). Similar examples may be found across the senses (e.g., sight, hearing, smell, taste, touch. etc.), with variant subtypes categorized within the visual, auditory, and tactile senses (Bauer, 2006; Burns, 2004), as well as with respect to the perception of time. Time-perception-related agnosia in relationship to loss is covered at the end of this chapter.

Agnosia can also be present in social-emotional perception; more broadly, this has been referred to as emotional, social(-emotional), or expressive agnosia (Joseph, 2018), which may be grief-influenced and “has only begun…to be described in a systematic manner” (Puente & Tonkonogy, 2009, p. 21). As related to loss, assessing possible agnosia-like misalignment(s) in emotional meaning assignation (e.g., with respect to anger, sadness, or other emotions) could be particularly salient. This may include with respect to gauging the emotional response(s) of others as well as of oneself (or *alexithymia*; see Sifneos, 1972, 1973). For example, a new type of agnosia, *affective agnosia*, has been described as “an impairment in the ability to mentally represent…what one is feeling” (Lane et al., 2015, p. 594)—which can apply in grief contexts.

Finally, also noteworthy to the discussion of potential intrasensory alterations in grief is *simultanagnosia*, which refers to challenges in appreciating the overall meaning of a complex picture or stimulus—even though the perception of isolated details within the picture or stimulus is maintained (see, e.g., Coslett & Saffran, 1991). Although initially identified in relationship to vision, it could be beneficial to consider possible experiences of simultanagnosia in grief with respect to other sensory modalities (e.g., hearing, smell, taste, and touch); such a consideration hints at grief’s potential impacts on the sensorial assemblage requisite to intersensory processing, which is discussed in the next section.

Intersensory Processing

Perception through intersensory processing is "something else than" (Koffka, 1935, p. 176) the sum of its intrasensory perceptual processing modalities (e.g., vision, audition, olfaction, gustation, somatosensation, etc.). The dimensionality of sensory perception may thus be enhanced when understood in dynamic(al) systems theory (DST) terms. In a DST context, movement itself is considered to be a separate, additional perceptual system that is essential to multimodal integration and intersensory coordination. As Thelen and Smith (1994) assert, "…there is little or no learning or development that is strictly within modality" (p. 194), and "…intersensory coordination is the very *mechanism* of development—not a product, but the process through which intelligent commerce with the world is selected and maintained" (p. 192).

Intersensory selection and maintenance processing may be temporarily affected or in some way(s) altered in relationship to loss. It is therefore possible that grief-related changes to the underlying coordination and integration mechanisms of multimodal perceptual processing point to a source of the "fog" (as noted in the previous section). For example, multisensory integration's import to development is illustrated in the requisite collaboration of the perceptual processing modalities of vision, haptics, and audition (as well as the perception of time, balance, joint position, and muscle memory) in the integrated discernment of the body's movement through (and orientation within) space, or proprioception—also sometimes known as kinesthesia or "movement sense" (see, e.g., Buonomano, 2017). As Wolbers and Hegarty (2010) note: "…spatial navigation is particularly complex because it is a multisensory process in which information needs to be integrated and manipulated over time and space" (p. 138).

But what if one's self-assessment of one's perception of one's own state of conscious awareness is considered to be uncertain, untrustworthy, or inaccurate (i.e., as if one is "in a

fog")? As Freeman (1991) posits, "[Consciousness] enables the brain to plan and prepare for each subsequent action on the basis of past action, sensory input, and perceptual synthesis…. [Thus,] an act of perception…is a step in a trajectory by which brains grow, reorganize themselves, and reach into their environment to change it to their own advantage" (p. 85). When consciousness itself is in question (such as may be the case—even if only episodically, sporadically, or spasmodically—within a context of loss), then how might such an "advantage" be impacted: how might this growth or learning trajectory be altered?

Extrasensory Processing

Hallucinations

In contrast to agnosia, when present stimuli are not fully or accurately perceived, hallucinations involve the perception of absent stimuli. Whereas both are recognition disturbances (Puente & Tonkonogy, 2009), agnosias are present absences and hallucinations are absent presences. Hallucinations of the decedent, when the deceased's presence is (temporarily) sensed, felt, or perceived, have frequently been reported by those experiencing loss (e.g., Baethge, 2002; Sacks, 2012; see also Barbato et al., 1999; Conant, 1992, 1996; Cook & Dworkin, 1992; Grimby, 1993; Jung, 1969; Kalish & Reynolds, 1973; Marris, 1958/2004; Olson et al., 1985; Parkes, 1970, 1971; Rees, 1971a, b; for summary see Berger, 1995; Castelnovo et al., 2015; Cooper, 2017; Krippner, 2006; Kübler-Ross & Kessler, 2005; Nowatzki & Grant Kalischuk, 2009; Shear et al., 2011; Streit-Horn, 2011; Troyer, 2014). Datson and Marwit (1997) have concluded that these occurrences are frequent enough "to be considered a relatively normal correlate of bereavement" (p. 132).

Hallucinations in bereavement and related phenomena have alternately been termed "post-death encounters or events" (PDE's; Nowatzki & Grant Kalischuk, 2009), "after-death

communications" (ADC's; Guggenheim & Guggenheim, 1995; Streit-Horn, 2011); "post-death contacts" (Kalish & Reynolds, 1973, Klugman, 2006; Troyer, 2018), "sensing the presence" or "sense-of-presence" (Conant, 1992, 1996; Marris, 1958/2004; Simon-Buller et al., 1989; Rees 1971a, b; Steffen & Coyle, 2010, 2011, 2012), "post-bereavement hallucinatory experiences" (Castelnovo et al., 2015), "extraordinary experiences or encounters" (LaGrand, 2005; Parker, 2005); "perceived presences of deceased loved ones" (Datson & Marwit, 1997), "hallucinatory wishful psychoses" (Freud, 1917/1957), "hauntings" (Kübler-Ross & Kessler, 2005) and "perceptual 'sets' of the lost person" (Parkes, 1970). Irrespective of terminological differences, these experiences: 1) are not accompanied by psychotic symptoms (e.g., Krippner, 2006; Troyer, 2014); 2) are often considered indicators of the bereaved person's *absence-mindedness*, or preoccupation and strong yearning to be with the person who died (e.g., Conant, 1992, 1996; Gilbert, 2006; Lindemann, 1944/1994; Parkes, 1970; Rando, 1988; Sacks, 2012; Schnell, 2004); and 3) are typically thought to be normal responses in the context of significant loss due to human death (Klass et al., 1996/2014; Worden, 2009; see also, e.g., Parkes, 1970; for summary see Datson & Marwit, 1997).

PDE's can involve auditory, visual, olfactory, tactile, and/or "sense of presence" perceptions of the decedent (Barbato et al., 1999). They may also have kinesthetic features, or "sensations such as falling or floating, sometimes experienced as out-of-body-experiences" (Soffer-Dudek & Shahar, 2009, p. 892).

Baethge (2002) notes that grief (also alternately termed bereavement or post-bereavement) hallucinations: 1) are normally present in only one sensory modality; 2) may persist for years or even decades; 3) are more often seen as comforting, but in rare instances may be viewed as stress-inducing (or even dangerous); and 4) "…probably comprise a heterogeneous

group of disturbances of perception and thought processes" (p. 296). Relatedly, bereavement hallucinations are often "deeply tied to emotional needs and feelings [and] tend to be unforgettable…" (Sacks, 2012, p. 233); for many, they can also be "comforting and [even] transformative" (Krippner, 2006, p. 176).

The healthfulness of hallucinations surrounding loss—as well as their possible link to psychological distress—has been debated (e.g., Castelnovo et al., 2015; Hagman, 2001; Kamp et al., 2019; LaGrand, 2005; Parker, 2005; Pollock, 1987; Volkan, 1974; Volkan & Zintl, 1993/2015; for summary see Datson & Marwit, 1997; Steffen & Coyle, 2012), but most often they are seen as having therapeutic utility (e.g., Cooper, 2017; Krippner, 2006; Nowatzki & Grant Kalischuk, 2009; Steffen & Coyle, 2010, 2011; Streit-Horn, 2011; Troyer, 2014). For example, Jayson Greene recounts experiencing the presence of his 2-year-old daughter, Greta—some months after she died (when a loose brick fell from an 8th-story windowsill above her, striking her in the head)—as follows:

> She stepped out from behind a tree, and I was deeply aware that no one else could see her but me, but yet I ran over to her because it was so overwhelmingly real, and I picked her up, and she told me to go for my run. And so I ran into the park and tears were just coming down my face, and I got to the edge of the park, and that is where I wrote down this sentence: "There will be more light upon this earth for me." (Neary, 2019; see also Greene, 2019, pp. 82-83)

Terminology identifying survivor perceptions of the decedent post-death is often overlapping, with some researchers discriminating bereavement hallucinations from illusions—which include instances where survivors report having sensed the "felt presence" of the decedent "…even in the absence of any visual, auditory, tactile, or olfactory perception" (Castelnovo et

al., 2015, p. 271; see also Baethge, 2002; Conant, 1992, 1996; Rees, 1971a, b). With respect to term differentiation, Conant (1996) notes that although "The vividness of the experience amazed [the widows interviewed]," and "The comparison to hallucinations was voiced spontaneously five times," these widows emphasized that their experiences "were not hallucinations" (p. 186).

Given their reluctance to apply this term, and its relationship to the possible stigmatization of those who report having had hallucinations (see, e.g., Barbato et al., 1999; Stevenson, 1983), Krippner (2006) stresses the importance of classifying these as "'experiences' (subjective verbal reports) [rather] than as 'events' (verifiable outcomes and activities)" (p. 177; for more regarding the discussion of controversial and/or sensitive phenomena, see also Glik, 1992; Grimby, 1993; Streit-Horn, 2011; Zusne, 1985; Zusne & Jones, 1989/2014). As Castelnovo et al. (2015) have asserted, "…the [precise] phenomenological nature of these experiences remains elusive… ranging from hallucinations, pseudo-hallucinations, [and] illusions, [to] felt-presences" (p. 271).

Oliver Sacks (2012) describes an additional type of grief-related illusion, one where bereaved individuals mistake, often fleetingly (perhaps at a distance and/or in a crowd), someone else for the person who died. He suspects his own illusory experiences of this sort were related to a state of "hyper-alertness [and] unconscious searching" (p. 231) for his mother over a period of months following her death, and contrasts these sorts of illusions with bereavement hallucinations—noting the following example, wherein Marion C., a psychoanalyst, recounts a (pseudo-) hallucinatory experience of her husband, Paul, after his death:

> One evening I came home from work as always to our big empty house…. Paul…greeted me in his familiar way: "'Hello! You're back! Hi!' His voice was clear and strong and true; just the way it was when he was well. I 'heard' it…, I 'saw' him, I 'saw' the

expression on his face…, I 'saw' him greet me. That part was like one sees in a dream; as if I were seeing a picture or a movie of an event. But the speech was live and real. (p. 232)

Although her recollection of the aural portion of the experience better meets hallucinatory criteria, Marion's recounting of her visual memory as "like one sees in a dream" is more akin to sleep-related sensory perceptions—including dreams—which are discussed in the next sections.

Dreams

Scientific understandings of why we dream vary considerably (Olsen et al., 2016), and theories regarding their purpose are wide-ranging, from "Jung's…theory of dream function, a dynamic, open-system approach… to Freud's mechanistic, drive-reduction model… sprinkled together with a Darwinian emphasis on adaptation as environmental mastery" (Dallett & Deese, 1973, p. 408). Similarly, perspectives on dreams in the context of loss response are varied, including analyses of their content with respect to loss-related cognitive schemas for complicated grievers (Germain et al., 2013) as well as their (possible) therapeutic utility (see, e.g., Black et al., 2014; Cook & Dworkin, 1992; Garfield, 1996, 1997; Moss, 2005; Nicholson, 2016; Noronha, 2014; Kübler-Ross & Kessler, 2005; Wray & Price, 2005; see also Parkes, 1970 on the role of dreams as part of an ongoing effort to recover a lost "object"—that of the relationship to a deceased loved one).

For many, dream content in grief may focus on the survivor's memories of—and/or their ongoing relationship with—the decedent. An example from Sobol (2017) is as follows:

> I dream that I press the button on the old telephone answering machine and I am surprised to hear my father's voice, saying my name, just the two syllables of my name but in a long, drawn-out, plaintive tone. I feel guilty and apprehensive—is he ok? Why have I forgotten to call him, it feels like an awfully long time—and I try to call him back

but I'm ashamed to realize I've forgotten the number. I go frantically rummaging through every drawer in the bedroom, and as I do I look at the furniture—the old bedroom suite that they got when they were first married, a chair from Pier One, the wall to wall carpet, bits and pieces left over from their lives that I know we will have to somehow dispose of, and somehow the button on the answering machine is pressed again and I hear my father leaving a long slightly surreal and inconsequentially rambling message that sounds something like, "Hello? Everybody? I'm here at this resort, and it's a last resort, and they're taking pretty good care of us, there's plenty to eat and they keep us entertained. It's like a cruise but we aren't going anywhere and it's comfortable enough but I miss our old friends. They keep us busy. Does anyone think about me? There's always things to read, and the weather's pretty good, and I will die some day. I just wanted to say hello. Bye bye for now." And the message machine issues its long conclusive beep, and I suddenly realize, oh yes—he really IS dead. And I wake up, alone in my bed, in Barry, in Wales, in September, 2017. He would have been 95 this month. RIP, Dad.

My personal recollection of a dream about my maternal grandfather (Childress, 1992) features a conspicuous component of emotional expression:

Last night I dreamt that I saw my grandfather for the first time since he died nearly 10 years ago. I was with another man, perhaps not so old as my grandfather. I knew they were friends, and I knew that this man was taking me to see my grandfather. I also knew that my grandfather was dead, even in the dream. We were outside the funeral home where my grandfather used to work. The other man led me around the corner of the building and there he was. My grandfather greeted the other man and shook his hand. Then he turned slowly to me. Smiling, he said “Son.” I ran to him and embraced him. I

> could feel the coarseness of his black wool suit, the chain of his pocket watch draped across his vest. I breathed in, smelling once again the shoe polish and starch, the hard soap and peppermint candy. To me this was the essence of all things old and wise…. I wept uncontrollably, more so than I did the day he died, at his funeral, or any time since. I sobbed into his coat, crying so loudly that I awoke from the dream…. Though he lived 90 years this is all that I have…a glimpse in a dream eclipsed by the sheer joy of experiencing even that much.

Others may perceive dreaming differently when grieving. For example, there are some individuals who report a sort of consciousness inversion surrounding a significant loss; in these cases reality is perceived more as a nightmare, one from which they are certain they will soon awaken. Larry Treadwell reported such an experience following the sudden death of his wife, Amanda: “I was convinced it was just a bad dream, and I argued with people…I was like, there's no way this is real. I'm gonna wake up here in a minute" (McEvers, 2017). Similarly, Parkes (1970) recounted the words of a recently widowed Londoner who stated: “I feel this is a different life…as if there’s another life going on somewhere else and I’ll wake up” (p.457).

Musician Peter Gabriel (1998/2002) captures the interplay between dreaming and awake during grief somewhat differently in the lyric to his song *I Grieve*: “Did I dream this belief / Or did I believe this dream?” (from the album *Up*), and the novelist Donna Tartt (2013) describes a son’s (mostly) asleep experience of his dead mother as a “mysterious dream that felt more like a visitation” (p. 8). Such perceptions of dreams—how realistic they seem and their possible intrusion into waking life (see Solms, 1997/2014; for summary see also Domhoff, 2003)—may relate to threshold consciousness and transliminality (see subsequent sections).

Although interesting to consider in relationship to maladaptive grief (e.g., Germain et al., 2013), for the purposes of the posited framework, dream content is mainly considered from a processing perspective—with particular emphasis on the possibility that "dreams [may] function to balance and complete waking consciousness" (Dallett & Deese, 1973, p. 408) or attempt "to restore through the unconscious what has not been satisfied in waking life" (Rochlin, 1965). This relates to the next category of perception, that of threshold consciousness, which has similarities with the perceptual processing of hallucinations as well (see previous section).

Threshold Consciousness

Often referred to as "half-asleep" (hypnagogia) or "half-awake" (hypnopompia), the transitional states of threshold consciousness can include the related mental phenomena of hallucinations, waking and/or lucid dreaming (see previous sections), and sleep paralysis (see, e.g., Mavromatis, 1987; Ohayon et al., 1996; Schacter & Hernstein, 1976; Sherwood, 2000). Hypnagogia refers to the transitional state of decreased wakefulness (Maury, 1848; Müller, 1826/1967, 1848; see also Vihvelin, 1948), or "the drowsy interval between waking and sleeping" (Schacter & Hernstein, 1976, p. 452). Its mirror image, hypnopompia, is the state of consciousness leading out of sleep (Myers, 1903/1918). Hypnagogic and hypnopompic (H&H) hallucinations have been categorized as visual, auditory, and/or felt-presence (McCarthy-Jones et al., 2011), and primarily differ from hallucinations/PDE's in that they do not occur in a state of (full) wakefulness (Waters et al., 2016).

It should be noted that although the terms hypnagogia and hypnopompia are often conflated, they differ phenomenologically (Warren, 2007). Whereas a hypnagogic state is typically a rational cognition in wakefulness, focused on making sense of non-linear images and associations; hypnopompic states are more emotional and dream-like in nature, focusing on

sense-making in relation to real-world stolidity (Warren, 2007; Waters et al., 2016). Irrespective of their differences, disentangling these twilight states may sometimes be challenging, particularly in instances when sleep is briefly interrupted and subsequently re-instigated. In these situations, differentiation from remnants of dream imagery can also be difficult (see, e.g., Vaitl et al., 2005; Waters et al., 2016).

In the context of loss response, threshold consciousness phenomena are salient in several ways: 1) Response to loss may interfere in hypnagogic states, impairing their utility in enabling the onset of sleep and possibly resulting in sleep deprivation. 2) Similar to the previous section on dreams, the content of hallucinations/PDE's (in this case during hypnagogic and hypnopompic states) may relate to the person who died. 3) The quality and duration of hypnopompic states bears additional scrutiny during loss response. This is evinced by the wave-like realization—on/during awakening—of (remembering) the reality of the loss. As Bowler (2018) recounts after being diagnosed with cancer:

> Ever since the diagnosis, there has been a moment, in the minute between sleeping and waking, when I forget, when I have only a lingering sense that there is something that I am supposed to remember. In the warmth of my bed, I am caught in webs of dreams. And then there is the flood. *I am dying. I am dying. I am dying. I am my son's first goodbye*. (p. 66)

Moving from unconsciousness (during sleep) to consciousness (when awake), the felt magnitude of the impact of (re-)realizing the loss typically attenuates over time, and the duration of the (re)realization process usually contracts. The process can, however, contribute to the possible occurrence(s) of: sleep inertia, or "decreased performance and/or disorientation occurring immediately after awakening from sleep" (Tassi & Muzet, 2000, p. 341); para- and/or

dyssomnias (Waters et al., 2016); and other sleep-related disturbances (see, e.g., Chirinos et al., 2019). It should also be noted that although the precise impacts of grief on dream quality are not precisely known (see previous section), it is possible that dream quantity suffers due to loss response's negative impacts on sleep duration (due to interruption) by influencing the H&H states of threshold consciousness (for an assessment of the possible impacts of auditory/visual intrusive thoughts on H&H modalities, see, e.g., McCarthy-Jones et al., 2011).

Lastly, it must also be mentioned that for some grievers moments of threshold consciousness can be very meaningful. As John Bare (2020) recounted following his wife's death: "During the night and early mornings, in the state between asleep and awake, Betsy and I still talk. In our bed, I reach over and rub her arm. I wake up stroking a pillow. I am grateful for these encounters" (p. 1).

Transliminality

Transliminality refers to "differences in the threshold at which unconscious processes or external stimuli enter into consciousness" (Fleck et al., 2008, p. 1353; see also Thalbourne & Houran, 2000; Thalbourne & Maltby, 2008). Anticipated by James (1902/1982), and for which there is a measurement scale (Lange et al., 2000), transliminality also relates to altered-consciousness tendencies, which may include Watson's (2001) construct *sleep-related experiences* (SRE's). SRE's encompass "…a variety of…altered-consciousness phenomena, such as nightmares, narcoleptic characteristics, recurring dreams, dream recall, vivid dreams, problem-solving dreams, [and] dreams confused with reality or 'waking dreams'" (Soffer-Dudek & Shahar, 2009, p. 891).

Thus, transliminal experiences in the context of loss response refer to a range of possible grief-related changes in the interplay between unconscious and conscious sensory-perceptual

processing. As such, transliminality aptly summarizes both the challenge of discerning states of (un)consciousness in grief (as outlined above; note sections on dreams; hallucinations, PDE's, and illusions; and threshold consciousness) and their possible relationship to an experience of enlightenment—what some have termed "magical thinking" (see, e.g., Krippner, 2006; Zusne, 1985; Zusne & Jones, 1989/2014) or a "mystical state of consciousness" (Teasdale, 2019) surrounding loss (see also Didion, 2005).

Time

Previously noted above (in the section on shock) as a perceptual disturbance symptom of acute dissociative reactions to stressful events (APA, 2013)—as well as in the section on intrasensory processing—the perception of time (sometimes termed *chronoception*, *perceived duration*, or *temporal awareness*; e.g., Brown, 1985; Le Poidevin, 2011; Phillips, 2010; Prieto-González et al., 2014) may feel altered in response to loss. These distortions have been referred to as *temporal illusions* (e.g., Allen & Gibbon, 1994; Nakajima et al., 1991). Although posited in DSM-5 (APA, 2013) as being experienced as slowing in the context of (dis)stress, agnosia-like changes to one's sense of time during grief may also include its perceived acceleration and/or (perhaps more commonly) an inability to accurately gauge time's passage at all, a disengagement from the tracking of it—what Greene (2019) describes as being "…in the time that is no time" (p. 16).

For example, Neimeyer and Anderson (2002) note that "time itself seems to have shrunken" (p. 45) for Helen, 32, following the death of her infant daughter; as Helen states: "I have learned that we can't live in the past, nor in the future…. We must only live in the present" (p. 46). Regarding potential negative impacts of these alterations, consider the known adverse effects of circadian clock misalignment(s), such as jet lag (e.g., McHill, 2020; Sack et al., 2007).

The import of a "time-locked" understanding of development's construal in dynamic(al) systems theory (DST), where it is linked to the exact circumstances of "when" each experience occurs, should also be considered in relationship to loss. In DST, ontogenetic processes are a coordinated relationship between/among past experience(s) and current perceptual context (Thelen & Smith, 1994; Thelen & Ulrich, 1991). Developmental processing is therefore more about "through which" (an integrative and ongoing process) than it is about exactly "where" (a specified location or "seat of sensation" for sensory perception). Thus, within a DST framework one is not looking for a precise place where the developmental mechanism of sensation/perception resides, but more for a process that is "time-locked" to the exact circumstances of each moment of experience. In DST terms, then, every moment reveals the history of past experiences and contributes to the pattern of future ones (Thelen & Ulrich, 1991; see also Clark, 2013; Thelen & Smith, 1994); but what if time itself is perceived as being out of sync (also note previous discussion of intersensory information perception, above)? What are the possible (negative) developmental impacts of grief-related dyssynchrony?

Buonomano (2017) asserts that there is no known, consolidating mechanism in the human brain for sensing/perceiving time: "Unlike vision or hearing, we do not have a sensory organ that detects time" (p. 21). Instead there are multiple "clocks" for different purposes. It is possible, then, that the exact circumstances of a death may exert particular influence on the perception of time vis-à-vis one or more of these clocks, depending on expectancies and other factors—such as when a child dies before a parent (typically a less-expected or "nonnormative" event [Nolen-Hoeksema & Davis, 2002], and one often resulting in an outcome of more complicated bereavement [see, e.g., Craig, 1977; de Vries et al., 1997; Miles & Crandall, 1983; Rubin, 1993; Sanders, 1980]). That being said, little is known regarding the precise impact(s) of

loss response on the perception of time, such as whether or not the mind/body may have any sort of specific, built-in clock that is designated to in some way respond to and/or track time (differently) in relationship to the death of a significant other.

Chapter 2 Summary

For survivors, if the death of a loved one is viewed as the doorway between the experience of life prior to and then after loss, then grief is the threshold of this door. Perception at and around this threshold can seem unfamiliar, or even feel unreal, in multiple ways. For example, Jayson Greene (2019) describes waiting with family and friends at the hospital following his daughter's tragic accident: "We know Greta is going to die…[and] glance around us, realizing this is the last we'll ever see of the world as we've known it. Whatever comes next will raze everything to the ground" (p. 13); later, he describes her death as a "rip in the universe" (p. 77). Similarly, soon after his father died, Freud wrote of feeling "quite uprooted" (Freud et al., 1985, p. 202), and Grossman (2014) has posited that subsequent to a significant loss "…all that is will now echo what is not" (p. 51). Or, as K.T. Nicolaides recounted following the sudden death of her husband, Aaron: "I can feel around me that he's not here, and I know he's not coming back, but it's not quite *real* yet." (McEvers, 2017, emphasis added). And, finally, as described another way by Handler (1999):

> It is a curious thing, the death of a loved one. We all know that our time in this world is limited, and that eventually all of us will end up underneath some sheet, never to wake up. And yet it is always a surprise when it happens to someone we know. It is like walking up the stairs to your bedroom in the dark, and thinking there is one more stair than there is. Your foot falls down, through the air, and there is a sickly moment of dark surprise as you try and readjust the way you thought of things. (pp. 96-97)

In responding to loss, this "moment of dark surprise" can sometimes seem to feel both magnified and protracted. It may be more akin to (but not necessarily exactly like) the queasy, kinesthetic sensation felt when descending rapidly in an elevator, except in this case the floor of destination is not known; thus, the duration of the sense of unease is likewise indeterminate.

Such alterations in perception may relate to what leads many grieving individuals to later report that they thought they were "going crazy" or "losing their minds" (e.g., Cook & Dworkin, 1992; DeFrain, 1991; Rando, 1988; see also Didion, 2005). Although likely operating along a continuum (from less to more severe symptomatology), and/or possibly oscillating in a wave-like pattern (more similar to DPM; see Stroebe & Schut, 1999, 2001, 2010), this feeling of psychosis, of a marked departure from reality or "life circumstance that ruptures one's previous ability to make sense of the world" (Schwartzberg, 1993, p. 489), has in this chapter been addressed at the fundamental level of sensorial interpretation or perception.

As a *thresholding experience* (designating the liminal space between the reality with—and then the reality without—the prospect of again encountering the actual embodied presence of the person who has died), response to loss may involve multiple (re)adjustments to how the world is perceived and experienced. For example, Greene (2019) notes that "…time passes mostly soundlessly. There are days when I am confused, panicked, like I've woken up in a dark room with unfamiliar contours" (p. 73). Sensing what is real and what is not; what is conscious awareness and what is not; what are dreams, hallucinations, or illusions and what are not; what is recognizable and what is not; what is asleep and what is awake; what is present and what is absent; even what is time and knowing how much time has elapsed: all of these processes are potentially impacted in response to loss. There can also be emergent alterations in the gradations of how what "is" is experienced with respect to perceptual processing during grief, with some

perceptions seeming to be more or less valued in terms of the meaning(s) assigned to them than was the case before the loss occurred; these changes, for example, may include agnosia-like grief symptoms in intrasensory and affective perception.

Though of uncertain sufficiency, visuospatial dysgnosia—the loss of a sense of "where-ness" in the relationship between oneself and one's environment "…and in the relation of objects to each other" (Cogan, 1979, p. 367)—is perhaps an apt term to more generally summarize these possible changes in perceptual perspective when grieving. This relates to topographical disorientation, or difficulty finding one's way in the environment (Aguirre & D'Esposito, 1999; Habib & Sirigu, 1987), which is the topic of the next chapter, *orientation*.

Chapter 3. Orientation

In mourning it is the world which has become poor and empty…. (Freud, 1917/1957, p. 245)

The collaboration of experience and context in (re)connecting the grieving individual to their environment, now in the absence rather than in the physical presence of their loved one, is herein referred to as *orientation*. As noted in the previous chapter, the perception of time and space—including the stimuli therein, and the rudimentary navigation thereof—can seem unfamiliar (or even feel permanently altered) following significant loss. Whereas the last chapter on perception emphasized sensory perceptual processing in grief, this chapter emphasizes perspectives developed, at least in part, through those sensory perceptions across space and time. The contextual absence resulting from significant loss is such that survivor perspectives on how to orient themselves within and to navigate previously familiar experiences, as well as new ones, may now seem challenging—or (at a minimum) can feel quite different.

Often linked to visuospatial dysgnosia (or the loss of a sense of "whereness" relative to oneself and one's surroundings, as well as with respect to the relationship of objects to each other; Cogan, 1979), an inability to orient oneself to one's environment has also been termed topographical disorientation (a.k.a., topographical agnosia or topographagnosia). This chapter relates more to the latter, topographical disorientation (Aguirre & D'Esposito, 1999; Habib & Sirigu, 1987), which is normally the result of focal brain injury. For the purposes of this discussion, however, its etiology is traced to the impact(s) of loss, its symptomatological ramifications are usually much less severe, and they typically attenuate over time.

Following the death of a significant other, a new sense of orientation or post-loss worldview is redeveloped. This redevelopment process progressively "emerges from the

cooperative interactions of multiple components within a facilitating context" (Thelen & Ulrich, 1991, p. v); these include: 1) what is perceived; 2) the contextual salience of when, where, and how this perception occurs; and 3) how similar, related, or other relevant perceptions may have been experienced in the past. As Titelman et al. (2011) posit: "Immediate experience is seen as a domain in which [a] fusion of the present and the past as well as the organization of human experience takes place" (p. 296). This fusion, which is continuously updated, is an emergent (re)mapped perspective of the grieving individual's relationship to their environment.

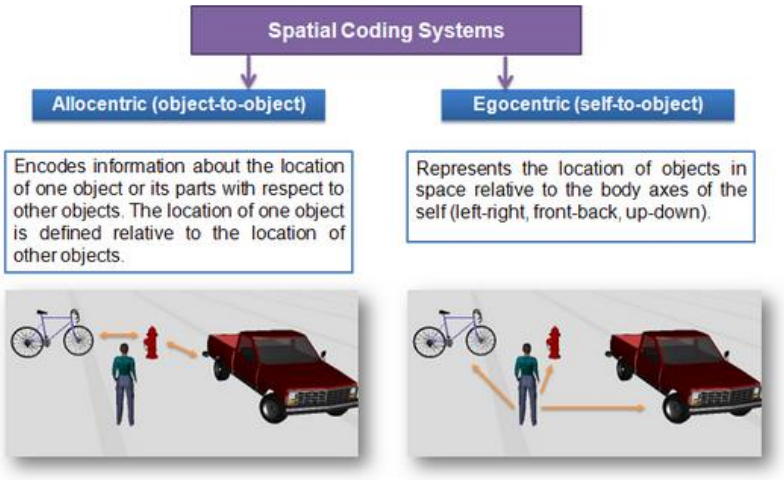
Orientation is perhaps better understood, then, in dynamic(al) systems theory (DST) terms (Thelen, 1992; Thelen & Smith, 1994; Thelen & Ulrich, 1991; for brief summary see also Dixon, 2015): "where" the griever "is" (their situatedness) is redeveloped within the context of significant loss. This process occurs relationally, is collaborative, and "develops from the confluence of many participating elements" (Thelen & Ulrich, 1991, p. vi). Now, in a context that is absent their loved one, a sense of "where" the griever "is" must be reconstrued through the experience of movement through time/space, a *perception-action loop* in DST terms (Thelen & Smith, 1994; Thelen & Ulrich, 1991). For those experiencing significant loss, this loop may need recalibrating. Thus, *the way is in the finding.*

Learning therefore occurs "…by perceptually exploring the world" (Thelen & Smith, 1994, p. 170). As Attig (2001) has asserted: "…grieving involves nothing less than relearning the world of our experience" (p. 33). Just as sensation is typically considered essential to perception, *way-finding* (how individuals find their bearings and begin again to navigate their environments) is integral to orientation. That being said, here it is important to recall the relationship between orientation and perception: in grief, possible changes to the latter (as outlined in Chapter 2, on perception/sense-making) can be challenging to orientation/way-finding—and vice-versa.

Alterations in way-finding during loss response are illustrated in allocentric (object to object) and egocentric (self-to-object) spatial coding systems (see Figure 2). Often the decedent would have been pivotal to each of these coding systems, as well as to their integration.

Figure 2

Allocentric and Egocentric Spatial Coding Systems



Note. See Mental Imagery and Human-Computer Interaction Lab (2021)

The integration of allocentric and egocentric perspectives echoes the prior discussion of macropsia (also known as megalopia) in the previous chapter. Macropsia, one of the shock-like symptoms impacting sensory processing, is a neurological condition influencing visual perception. In general, with macropsia objects in the visual field seem larger than normal. This may cause the perceiver to feel smaller than in actuality. Specifically in the context of loss, however, Lindemann (1944/1994) notes an alternate report of micropsia-like symptoms, wherein objects appear smaller than normal; thus, the person may feel larger than is actually the case.

In and through loss, how these "dualing" or bi-fold perspectives of macro/micropsia are reconciled may relate to the integration of allocentric and egocentric spatial coding systems. Surrounding the loss of a significant other due to death, a previously prominent point of reference or landmark is now absent; in this absence spatial interpretation can be(come) (more)

complicated, particularly with regard to gauging distance—which is also pivotal in order to accurately interpret the size of objects and/or of individuals within the visual field. Grieving individuals may therefore feel orientationally challenged in this unfamiliar environment.

As an illustration, consider the immediate, felt impacts of experiencing a world absent virtually all important, known landmarks, such as is the case in the world's largest salt flat (the Salar de Uyuni, in southwestern Bolivia). A prehistoric lake (now a massive layer of salt crust which sits two miles above sea level and covers approximately 4,000 square miles) the Salar has been described as "one of the most savage and surreal destinations on earth" (Frank, 2014, p. 1). [It is also the location where the final battle sequence in *Star Wars: The Last Jedi* (Johnson, 2017) was filmed.] This vast, void landscape enables what would otherwise be thought of as "trick" photographic methods (e.g., telephoto lenses), but in the Salar no tricks are needed. The absence of access to immediately interpretable visual information (at the horizon and otherwise) makes precise spatial discernment difficult; people and objects can easily seem larger and/or smaller than they actually are (see photographs in Figure 3). Judging the distance between objects is likewise challenging, which also negatively impacts the interpretation of how much time it takes to traverse the landscape from one point to another.

Figure 3

Two "Challenging" Perspectives from the Salar de Uyuni, Bolivia

Typically taken in jest (and generally interpretable with accuracy after a moment's pause), these photographs are obviously not included here as precise representations of what it may or may not exactly be like to experience the world through the lens of loss. However, the surreal nature of such images hints at the challenges that might be involved in (re)calibrating and subsequently navigating one's environment after the loss of a significant other. Orientation and navigation are harder in the absence of important landmarks (Van der Ham et al., 2017), such as may be the case following the loss of a loved one. These situations could be similar to the navigational impairment experienced by those with *landmark agnosia*, or an inability to recognize salient environmental stimuli (Aguirre & D'Esposito, 1999; Van der Ham et al., 2017).

Not only can the sense of "where-ness" seem to be altered in grief (similar to visuospatial dysgnosia), but "when-ness" surrounding loss may also feel changed (similar to dyschronometria—and possibly exacerbating topographical disorientation). Perspectives on motion and speed, on knowing how much time it should/will take to get from one place to another, are difficult to gauge when information regarding the distance between objects is either not clearly evident or is considered to possibly be untrustworthy. Additional data points are needed for more accurate spatial and temporal interpolation. The resulting uncertainness may serve to influence one's sense of the passage of time in general—even in the absence of movement through space, but also with respect to movement through spaces previously considered familiar (see also section on time at the end of the previous chapter on perception).

An additional example is available by way of a tool that is indispensable in the Salar de Uyuni, Global Positioning System (GPS) navigation (see, e.g., Grewal et al., 2007). Given the wide availability of these technological tools today, including in many vehicles and smartphone apps, GPS navigation software is now a familiar and accessible aid to guide drivers/travelers

between and among locations. As was the case with the Salar de Uyuni depiction above, it must be noted that the following GPS illustration is intended to be analogous—but is by no means necessarily equivalent—to how it may feel to orient oneself within and begin to navigate one's world following on loss.

Using satellite-based information to interpolate exact location/direction, GPS navigational guidance is typically interfaced from an egocentric orientation (i.e., from the "driver's" perspective). Landmarks are not always provided, and the "navigator" (or voice thereof) advises the driver through the provision of basic directional instructions (e.g., "in 500 feet turn left onto Smith Boulevard…"). On-screen visuals may be available, but often these may include only rudimentary information, similar to that which is provided audibly.

Thus, albeit enabling, at best navigation with GPS can still feel somewhat constricting. Although landmarks are sometimes absent or missing, with patient persistence it is usually possible to reach one's desired destination. At worst, however, grief can be thought of as potentially altering GPS navigation; it can seem as if the satellite signal (needed for determining position and enabling navigation) is unavailable or intermittent, important landmarks may be missing, and key roads are either permanently closed or are suddenly under construction. In this sense, it can seem as though loss leads to lost.

There may be times, for example, when the driver (in this case the griever) is slow in responding, and is unable to make a turn in time—as directed by the GPS software. This can feel similar to instances when the navigator provides allocentric rather than egocentric information (e.g., "go northwest on Smith Boulevard," rather than "turn left…"), which may be uninterpretable. [Interestingly, most GPS navigation systems technically differ from compasses: with GPS, movement is typically required to accurately determine location/direction.] Or, in the

context of grief, the navigator may seem to be suddenly, inexplicably speaking in a British rather than North American dialect (or vice-versa), or seemingly be speaking in another language altogether. In GPS-terms, these grief-related complicating factors may result in the navigation device's repeated refrain of "recalculating" and/or "make a U-turn as soon as possible." Of course, the recalculating may never resolve and/or the U-turn(s) may in the end be unhelpful, making it sometimes seem as though the griever is "driving in circles."

Estimated arrival times must likewise be recalculated, and—irrespective of actual trip duration—on arrival it can seem like it took longer. The driver/griever may feel weary from what once was an inconsequential journey, or the destination may simply be unreachable (at least for the time being). As Jayson Greene (2019) recounted following on his young daughter Greta's death: "I only have to close my eyes and peer inside to find the repaved roads, the hazard cones and blocked-off exits…" (p. 229). In short, with loss-impacted GPS navigation the griever can sometimes (still) feel lost.

Several caveats are noteworthy here: 1) As mentioned in the previous chapter on perception, in some circumstances (certain aspects of) the grieving individual's sense of orientation may seem to be enhanced following a loss. For example, this can be the case after situations of a protracted and/or painful terminal illness, wherein relief from the (dis)stress(es) of caregiving seems to improve the griever's sense of orientation (i.e., "a weight has been lifted"). 2) It is possible that encountering objects or spaces associated with a deceased loved one may serve to scramble a survivor's perspective of the post-loss environment, often by prompting intense remembering or "flooding." Greene (2019) terms these objects the "physical facts of [the decedent's] life" (p. 36), and the experience of such spaces as being one of "terminal stillness" (p. 50); after his daughter died, he noted: "Everywhere I look, I am blinded by her" (p. 55). And

3) Although it is tempting to make more obvious analogous connections (which can be helpful), viewing the decedent's post-loss navigational role should also be considered in more complex ways. For example, whereas thinking of the loss as "losing satellite signal" (which is essential to orientation and navigation) can be useful, it is not the only way to consider it. It could be more like a previously pivotal landmark is now missing; or, alternately, it may be worthwhile to think of loss as having closed certain routes that were previously available but are now under construction—or are perhaps now permanently closed. This is reflected in the allocentric and egocentric spatial coding systems model: viewing the deceased as having been an integral "object" in the allocentric perspective (which is now missing) is not necessarily complete. The person who died may be a key part of the survivor's sense of identity from an egocentric viewpoint as well. Also, the decedent may or may not still be allocentrically represented as an illusion, hallucination, or other post-death experience (PDE), and may be reflected in memory-laden physical objects and spaces (see, e.g., #2 above).

Furthermore, it must be noted that the use of the GPS navigation analogy for understanding orientation/way-finding surrounding loss should not be limited to spatial and temporal contexts. Just as there are social and emotional understandings of agnosia with respect to perception, these components (as well as behavioral aspects) are potentially important and should be considered with respect to orientation. For example, possible challenges and/or changes following loss may leave survivors feeling socially and emotionally isolated or otherwise unmoored. Navigating interactions at these intersections can be more difficult, and possibly even more important, than physical locational way-finding. Of course, it also bears noting that some social and emotional connections can be, and often are, enhanced following a significant loss due to human death.

Chapter 3 Summary

Returning to the threshold metaphor from the previous chapter summary (viewing the death of a loved one as a doorway between the experience of life before and after loss, with grief as the threshold of this door), not only can perceptions at this threshold seem unfamiliar, or even unreal, but perspectives on the post-loss world from this threshold may also feel disorientingly different. This chapter has therefore focused on orientation, which generally refers to the collaborative way-finding processing of experience that occurs as grieving individuals (re)adjust to and (re)acquire knowledge about the environment just beyond—and then further outside—the range of their more immediate sensory perception.

More specifically, orientation designates possible shifts in perspective that can initially result in an inability to accurately discern size (e.g., macro/micropsia). These shifts (may) relate to ego/allocentric frames of reference, with landmarks being essential to both in order for grieving individuals to appropriately interpolate distance(s) and subsequently "(re)map" or "find their bearings" in a post-loss environment—both spatially and temporally.

The physical absence of their loved one can make the way-finding requisite to this (re)mapping challenging. As Parkes (1970) notes: "Grief…is a complex and time-consuming process in which a person gradually changes their view of the world and the places and habits by means of which they orientate and relate to it" (p. 465). It may be helpful to liken the processing involved to a loss-impacted GPS navigation system, one wherein the user must re-learn routes (from an egocentric perspective) in order to (re)establish important landmarks (part of an allocentric perspective) and subsequently (re)develop an integrated, functional, map-like representation of their environment (what has been termed an exocentric perspective). In exocentric space, "…spatial relations between objects within the environment, *including the*

observer, are emphasized" (Aguirre & D'Esposito, 1999, p. 1614, italics added; see also Taylor & Tversky, 1992).

The construal of this new, post-loss map of the world (or orientation) is not limited to physical dimensionality (O'Keefe & Nadel, 1978; Tolman, 1948), but can include social (Jameson, 1988), emotional (Flatley, 2008), and behavioral (Ittelson et al., 1970) dimensions as well. That being said, having (access to) a map and going somewhere are not the same: it is one thing for someone to have an idea of where one is, and another to have a sense of where one might want to go. Put another way, orientation is more like a frame of reference than a point of view; this leads directly to a discussion of the third and final component of the loss-processing framework, *direction*.

Chapter 4. Direction

When we are no longer able to change a situation…we are challenged to change ourselves. (Frankl, 1946/1984, p. 135)

Similar to meaning (re)construction in existing grief theory (e.g., Gillies & Neimeyer, 2006; Neimeyer, 2001a)—which has also been termed meaning(-)making (e.g., Neimeyer, 2005; Uren & Wastell, 2002)—*direction* herein refers to post-loss processing that seeks, with the prospect of finding, something positive and purposeful through grief. Meaning-making in loss has previously been operationalized to include one or more of the following facets: making sense of the loss, benefit-finding, identity change, purpose in life, and life significance (see, e.g., Hibberd, 2013; Nadeau, 2008; for additional summary, including alternate terminology and other meaning-making mechanisms, see also Park, 2010, 2013).

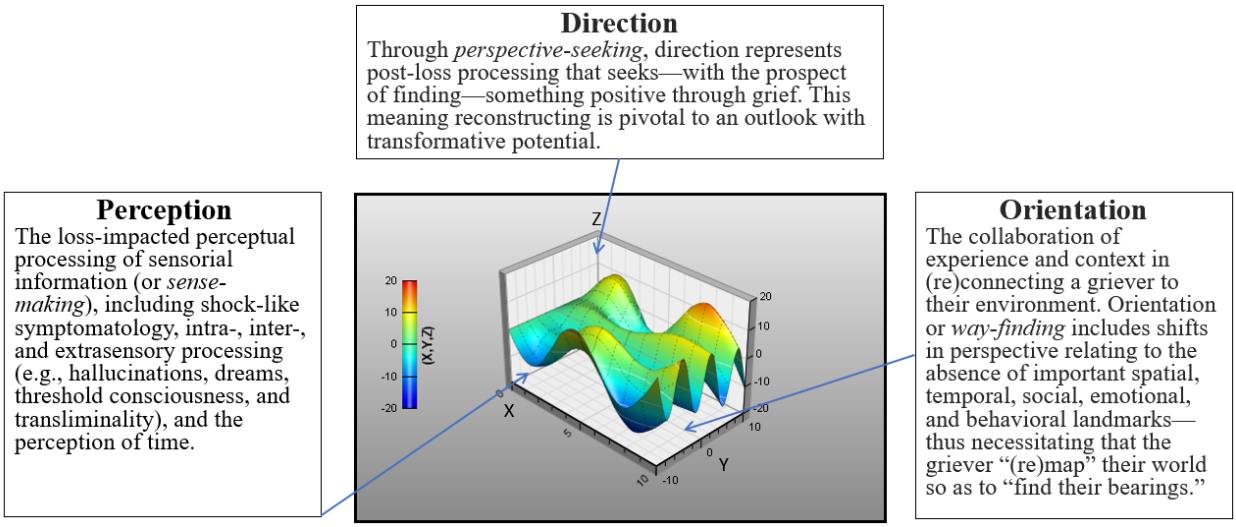
As its operationalization with respect to meaning-making's positive potential implies, here the underlying mechanism of direction is termed *perspective-seeking*, which is analogous to course-charting. Although technically any direction (with a negatively-, benignly-, or positively-interpreted course) may be charted, with perspective-seeking the direction is viewed as being positively-valenced, since "perspective" often connotes an enhanced understanding, and what is "sought" is typically considered desirable. Perspective-seeking therefore denotes the multifaceted ways through which the loss of a loved one (a stressful event known to possibly have adverse effects) may be construed as leading toward—and perhaps even aiding in—the creation of positive meaning and sense of purpose after loss.

In addition, it may be helpful to view the first two components (perception and orientation) as the X and Y axes of the loss-processing framework, with the third or Z axis being that of direction. If perception and orientation represent a two-dimensional or *cartographical*

understanding of grief, then direction adds the third *topographical* (or "depth") dimension (see Figure 4). Whereas perception and orientation are indicative of where the grieving individual is located, direction refers to what it is like there: how the bereaved person is experiencing the environment in that precise location—including their stance/posture within it and their outlook on the world from that vantage point. Do they view being there as having any potential for positive, purposeful, directed movement following the loss or not? Put another way, what is their post-loss sense of direction? Perspective-seeking potentiates this sense of direction.

Figure 4

Topographical Perceptual Space in the Loss-Processing Framework



Understood in this manner, direction with perspective-seeking does not necessarily require a specified destination but indicates more of an attitude toward the (relative) desirability (given the circumstances) of where one is (or how one finds oneself there) and whether or not embarking on any sort of trip (literally or figuratively) might be welcomed—either at present or in the future. Direction with perspective-seeking is therefore more akin to the conative trajectory of a journey than the definitive destination of a quest. As such, it can possibly influence

processing relative to perception and/or orientation, and vice-versa. This renders the three axes, respectively, as being more perceptual, orientational, and motivational in nature.

Through perspective-seeking, then—and as previously operationalized in the meaning (re)construction/meaning-making literature in the context of loss—there are at least 5 possible pathways toward a meaningful, positive trajectory following the death of a significant other: 1) making sense of the loss through (an) explanation(s) of why it happened; 2) benefit-finding: the identification of "silver linings" as a result of the loss; 3) identity change: a new and improved view of oneself following loss; 4) purpose in life: finding reasons to live after losing a loved one; and 5) life significance: assigning value to goals, relationships, and aspects of life in the present and future after a loss (for summary see Hibberd, 2013; Park, 2010, 2013).

Given extant documentation with respect to meaning (re)construction/meaning-making, including empirical support thereof (see, e.g., Davis et al., 1998; Hibberd, 2013; see also Davis, 2001; Gillies & Neimeyer, 2006; Neimeyer, 2001a, 2015b; Nolen-Hoeksema & Davis, 2002; Park, 2010, 2013), this discussion will focus on commonalities among these five pathways and other perhaps-related mechanisms with possible positive potential following loss (e.g., resilience, religiousness, spirituality, sense of coherence, forgiveness, and self-compassion) as well as challenges to them. Key to what is common among them, and to what is commonly challenging to each of them, is the concept of *reconciling*.

Reconciling

When the unimaginable occurs (such as is often the case following the death of a loved one), how does one feel/think/act in response to it, and where does that feeling/thinking/acting lead? Perhaps more important (or at least as much so), does *how* one feels/thinks/acts about the

loss make a difference with respect to where one's feeling/thinking/acting leads (e.g., toward more or less adaptability going forward)?

In the context of grief, *reconciling* is herein defined as the ongoing processing of an encounter with what may seem unencounterable, between what was and what is now no longer, or the moment-to-moment engagement with the reality of significant loss due to human death. As Shwartzberg (1992) notes, with loss "…old beliefs about how the world functions are no longer valid; reality is no longer what it was" (p. 427). Here Worden's (2009) first task of mourning, "accepting the reality of the loss" should be noted—see also Kübler-Ross and Kessler's (2005) "acknowledging the reality of the loss" (adapted from Kübler-Ross, 1969; as summarized in Kessler, 2019), Rando's (1984, 1993) first of six "R" processes of mourning: "recognizing the loss", as well as Freud's (1917/1957) and Klein's (1940) focus on "reality testing." It also bears mentioning that this ongoing relationship to loss may track an oscillatory course toward adaptation (or, put differently, toward adaptiveness; see next paragraph), such as is posited in Stroebe and Schut's (1999) dual process model (DPM) of coping with bereavement, wherein the griever oscillates between loss- and restoration-oriented coping activities—or between one of these and not coping at all (see also Stroebe & Schut, 2001, 2010).

What is perhaps more noteworthy to the current discussion, though, is that in the loss-processing framework *reconciling* is used instead of *resolution*, *restoration*, or even *reconciliation*, terms implying recovery from grief—that there is "closure," i.e., an end-point or specified terminus for the grieving process (e.g., Archer, 2001, 2008; Freud, 1916/1957, 1917/1957; Parkes & Weiss, 1983; Stroebe & Schut, 1999; Volkan & Zintl, 1993/2015; for a less time-delimited elaboration on Freud, see Clewell, 2004; for further discussion, see also Pearce, 2018; Schwartzberg, 1992; Shapiro, 1996, 2001; Wolfelt, 1987; Woodward, 1990, 1993). When

reconciling is perspective-seeking in nature, it is assumed to lead toward more creative and adaptively-patterned feelings, thoughts, and actions over time (i.e., more toward adaptiveness than adaptation—more toward growth than fit; see, e.g., Pike et al., 2010); thus, it is considered to be leading in a positive direction, but does not have to lead toward a precise destination—and it is ongoing (e.g., Attig, 2010/1996; Barthes, 1981; Cook & Dworkin, 1992; Eng & Kazanjian, 2003; Gaines, 1997; Hagman, 2001; McCabe, 2003; Pollock, 1981, 1987, 1989a; Schwartzberg, 1992; White, 2015; Woodward, 1990, 1993). For the purposes of this discussion, any/all reconciling that is not perspective-seeking in nature is not assumed to necessarily lead in a negative direction, or toward any particular diagnostically maladaptive destination (e.g., Persistent Complex Bereavement Disorder or PCBD [APA, 2013] or Prolonged Grief Disorder [World Health Organization, 2018b; see also Maercker et al., 2013; Maercker & Lalor, 2012; Prigerson et al., 2009]).

Regrettably, a discussion of reconciling in relationship to meaning (re)construction vis-à-vis direction/perspective-seeking does not fully address how "meaning" (also alternately termed "meaningfulness," "meaning in life," and "will-to-meaning") is exactly defined (for various perspectives, see, e.g., Davis et al., 1998; Frankl, 1946/1984, 1955/1965; 1969/1988; Gillies & Neimeyer, 2006; Hibberd, 2013; Holland et al., 2006; Klinger, 1977, 1998; Lichtenthal et al., 2010; Nadeau, 2008; Neimeyer, 2000a, 2001a, 2006; Nolen-Hoeksema & Davis, 2002; Park, 2010, 2013; Thompson & Janigian, 1988; Uren & Wastell, 2002). Baumeister (1991) defined meaning as "…shared mental representations of possible relationships among things, events, and relationships," further stating that "…meaning *connects* things" while also noting that defining meaning is perhaps challenging because "…to define meaning is already to use it" (p. 15).

As Hibberd (2013) further elaborates: "the terms *meaning reconstruction* and *meaning-making* [herein jointly termed *perspective-seeking*]… refer to the process of mourners' efforts to find or construct meaning however it may be defined; *meaning* will be used as a shorthand for the sociocultural, cognitive, and/or affective schemas, narratives, experiences, or values so constructed" (p. 672; see also Davis et al., 1998; Neimeyer, 2001a; Nolen-Hoeksema & Davis, 2002; Park, 2010, 2013). In other words, precisely what "meaning" means in the context of loss may be of less import than that it is made—and how (see, e.g., Kessler, 2019). Here I would also add that *perspective-seeking* does not necessarily have to be effortful, or at least it is perhaps best for it not to be framed as such—so as to avoid being (mis)interpreted (exclusively) as "work" (or *trauerarbeit*, Freud, 1917/1957; see also Lindemann, 1944/1994), or as a (set of) specified "task(s)" (see, e.g., Gaines, 1997; Worden, 2009).

For the purposes of this discourse, then, suffice it to say that reconciling may lead in multiple directions—positive, negative, and otherwise (i.e., in no particular direction at all). Through perspective-seeking the direction is considered to be positive (i.e., toward adaptiveness), and the trajectories or mechanisms of perspective-seeking are construed as being similar to those of meaning (re)construction or meaning-making. These include, but are not limited to, the aforementioned five pathways: making sense of the loss, benefit-finding, identity change, purpose in life, and life significance (for summary see, e.g., Hibberd, 2013; see also Park, 2010, 2013). A brief explication of each of these is as follows.

Perspective-Seeking

"The concept of meaning in the social sciences is, of course, a notoriously treacherous one" (Entrikin, 1991, p. 19); as Gipe (2019) has asserted: "…meaning is complex and shifting and difficult to state…" (p. 318). Much research in the field of meaning(-making) has been

conducted more broadly than within the specific context of loss or trauma (for summary see Baumeister, 1991; McDonald et al., 2012; Proulx et al., 2013; Wong, 2012, 2017; Wong & Fry, 1998a, b). For example, Dittmann-Kohli (1991) emphasizes the link between meaning and functioning, stating that meaning "…is a cognitive map that orients the individual in steering through the life course…" (as cited in McDonald et al., 2012, p. 358; Wong & Fry, 1998b, p. 368), and the construct's original proponent, Viktor Frankl (1946/1984, 1955/1965, 1969/1988), has underscored the ubiquity of meaning's motivational dimension. In addition, Zittoun et al., (2008) have noted that in responding to a perceived significant break or rupture in one's ordinary experience, individuals typically "seek to make meaning—engaging in representational labor and in efforts to regulate and integrate emotional and unconscious responses" (p. 164; see also Zittoun et al., 2003).

Specifically with respect to grief, Neimeyer (1998) posits that "…meaning reconstruction in response to a loss is the central process in grieving" (p. 110; 2001a, p. 4; see also, e.g., Gillies & Neimeyer, 2006; Neimeyer, 2000a, 2005, 2015a, 2016), further delineating meaning reconstruction following loss as a dynamic process spanning multiple levels of awareness—from overt, conscious beliefs to the more subtle, deeper mechanisms utilized in construing complex perceptions of the world and self (Neimeyer, 2000b, 2001a). Gillies and Neimeyer (2006) articulate three perspective-seeking pathways (which they term *contexts of meaning*; see also Currier et al., 2008; Neimeyer & Anderson, 2002) through grief: making sense of the loss, benefit-finding, and identity change.

Making Sense of the Loss

Making sense has been more broadly been defined as "a motivated, continuous effort to understand connections (which can be among people, places, [thoughts, feelings,] and events) in

order to anticipate their trajectories and act effectively" (Klein et al., 2006, p. 71). Specifically within the context of grief, *making sense of the loss* designates "both the process of searching for understanding post-loss and the outcome of the searching process at any given moment in time" (Currier et al., 2006, p. 404). As such, making sense of the loss is the ongoing development of interpretations/explanations regarding the comprehensibility of stress-related (and typically stress-inducing) adverse events—in this case due to loss as a result of human death. These explanatory or interpretive construals may rely on existing assumptive schemas (Janoff-Bulman, 1989; Parkes, 1971, 1975)—also known as "senses" or "structures of meaning" (Frankl, 1946/1984; Marris, 1974; Yalom & Lieberman, 1991)—which are "often framed in philosophical or spiritual terms" (Holland et al., 2006, p. 176; see also Wortman et al., 1993). Meaning-making through making sense of the loss typically involves an explanation of why the loss may have occurred in one of two ways: 1) in terms consistent with an individual's pre-existing worldview; or 2) by modifying the survivor's worldview in order to accommodate the reality of the loss (Wortman et al., 1993).

Benefit-Finding

Whereas making sense of the loss relates more to explaining "…how a particular event fits into one's conception of how the world is assumed to work" (Davis et al., 1998, p. 562), *benefit-finding* is construed relative to the valuation or "worth" of the event for one's life—which has also been identified as "positive reappraisal" (Folkman, 2001; Janoff-Bulman, 1992). Davis et al. (1998) note that the derivation of perceived benefits or "silver linings" from loss can be pivotal in assigning positive value in terms of the life of the survivor (i.e., finding something positive through the experience), even though this value originally stems from a negative life event (the death of a loved one). Benefit-finding has alternately been termed "meaning-as-

significance" and making sense of the loss "meaning-as-comprehensibility" (Janoff-Bulman & McPherson-Frantz, 1997; see also Davis et al., 1998; Nolen-Hoeksema & Davis, 2002).

Some empirical evidence suggests improvements in grief's duration (shorter) and acuity (less severe) where benefit-finding was perceived (e.g., Davis et al., 1998; Michael & Snyder, 2005; Neimeyer et al., 2006). Davis (2001) asserted that perceived benefits following loss normally fit into three categories: "that the event led to (1) a growth in character, (2) a gain in perspective, and (3) a strengthening of relationships" (p. 145); relatedly, Tedeschi and Calhoun (1996) posit three broad benefit categorizations: "…changes in self-perception, changes in interpersonal relationships, and a changed philosophy of life" (p. 456).

Identity Change

Gillies and Neimeyer (2006) articulate a third pathway toward meaning reconstruction through grief. When grieving individuals reconstruct meaning in their lives following loss, they are reconstructing themselves—their self-identities (see also Neimeyer & Anderson, 2002; Stroebe & Schut, 2001; Thompson & Janigian, 1988; Zittoun et al., 2008); this reconstructive process has been termed *identity change*. Albeit typically a painful experience, positive changes in identity following loss (or other stressful events) have also been referred to as "posttraumatic growth" (Tedeschi, 1995; Tedeschi & Calhoun, 1996; Tedeschi, Cann, et al., 2017; Tedeschi, Park, et al., 1998), which is "prevalent in those who respond to loss in adaptive ways" (Gillies & Neimeyer, 2006, p. 37) but is not "…the polar opposite of grief distress" (p. 49). The anguish associated with difficult losses may eventually lead to a new view of self as ''sadder but…wiser,'' (Janoff-Bulman, 1992, p. 175), or as being somehow gentler (i.e., more empathetic and emotionally connected) but also simultaneously made stronger (sometimes via religious, spiritual, and/or existential growth) through grief (Gillies & Neimeyer, 2006; Hibberd, 2013;

Tedeschi, 1995; Tedeschi & Calhoun, 1996; Tedeschi, Cann, et al., 2017; Tedeschi, Park, et al., 1998)—what Simon (2021) describes as "…the way personal loss can [both] stretch and strengthen the human heart" (p. 1).

This is illustrated in the words of Greg Gibson, speaking for the first time directly to Wayne Lo, who murdered Gibson's son, Galen, 25 years earlier: "We've all suffered, we've all grown wise from our suffering, and some people do it one way, some people do it another way, I understand that" (Inskeep, 2017). Later, Mr. Gibson added: "Almost since the moment Galen was killed it's been my constant meditation and focus to take this terrible thing and find some good in it, because if we can't and it drags us down, [then] it wins. And that's not—you know—that's [just] not supportable…" (Brooks, 2017).

The above illustration underscores the challenge of etiological discernment with respect to meaning-making—also alternately termed "meaning(s) made" (Gillies et al., 2014, 2015; Lancaster & Carlson, 2015; Park, 2010, 2013)—since the meaning reconstruction mechanism underlying Greg Gibson's words (here intended as an example of identity change) can plausibly be traced back to the other two aforementioned perspective-seeking pathways (making sense of the loss and benefit-finding), particularly the latter. Given their potential fungibility, adding more pathways should serve a useful purpose—but this must be balanced by parsimony. As such, two more are included in this discussion: purpose in life and life significance (see, e.g., Hibberd, 2013).

Purpose in Life

Purpose in life links the import of an ability to articulate reasons to live with positive psychological outcomes following on stressful experiences (see, e.g., Frankl, 1946/1984). For example, bereaved parents who lose only one of their children have reported higher purpose in

life than those losing either an only child or all of their children (Wheeler, 1994), with the clear implication being that these parents' reason to live may relate to their surviving child(ren).

Life Significance

Life significance refers to an "…assignment of value to a goal, relationship, or aspect of life experience that exists or is pursued in the present and future…. [and that] implies a transcendent or ontological importance…" (Hibberd, 2013, p. 679). In this sense, life significance can neither be assigned nor rationally defended and "does not depend entirely on coherent belief systems—it must be 'felt'" (p. 680). This would appear to bring one to the limit of parsimonious utility with respect to possible perspective-seeking pathways, or does it?

First, it bears repeating that additional perspective-seeking pathways have been posited, including several similar to those outlined in this paper—with some using alternate terminology (for summary see, e.g., Park, 2010, 2013; Stroebe & Schut, 2001). As Hibberd (2013) notes: "This explosion of constructs has…increased clarity as researchers develop a common language to describe different aspects of meaning reconstruction, but also increased confusion as to the conceptual relationships among these constructs and the conceptual boundaries of 'meaning' itself" (p. 671; see also Thompson & Janigian, 1988). For example, it is important to remember that for some bereaved individuals, meaning "is" (and may remain) a matter of grieving.

Second, although perspective-seeking, or the ongoing search for something positive and purposeful through the experience of loss, is considered beneficial—and has been empirically supported as such (e.g., with respect to meaning-making, see Davis, 2001; Davis et al., 1998; Gillies & Neimeyer, 2006; Hibberd, 2013; Neimeyer, 2001a, 2016)—more research is needed regarding its possible structural antecedents and/or correlates (for summary see also Park, 2010, 2013). Whereas prior bereavement research has examined possible relationships between/among

religiousness, spirituality, meaning-making, and loss (e.g., Braun & Berg, 1994; Davis et al., 1998; Lichtenthal et al., 2011; McIntosh et al., 1993; Murphy et al., 2003; Pargament & Park, 1997; Park, 2005, 2010, 2013; Uren & Wastell, 2002; for summary see also Wortmann & Park, 2008), as well as considered meaning-making's mediation of dispositional (optimism-pessimism) and situational (age of decedent at death) antecedent factors on adjustment following loss (Davis et al., 1998; Nolen-Hoeksema & Davis, 2002); excavating other mechanisms that may align with or predict perspective-seeking (e.g., resilience, sense of coherence, forgiveness, self-compassion, as well as other meaning-generating well-being-related mechanisms that are typically studied outside the context of loss) merits additional exploration (see also Huta, 2009; for research regarding a resilient grief trajectory, see Bonanno, 2004; Bonanno, Papa, & O'Neill, 2002; Bonanno et al., 2002; Bonanno, Wortman, & Neese, 2004; for research on grief acuity as a function of attachment security [as operationalized by sense of coherence] and meaning, see Uren & Wastell, 2002; for research on grief, forgiveness, and posttraumatic growth, see, e.g., Martinčeková & Klatt, 2017).

Thus, as previously noted, meaning-making constructs are numerous, complex, and challenging to comprehensively identify and concisely define. Considering them too broadly risks empirical imprecision, but construing them otherwise may risk omitting perspective-seeking pathways of potential import for some grievers. Furthermore, the scope of this challenge is not limited to loss-related meaning-making mechanisms; it can also extend to positive psychology constructs (often researched primarily outside the context of loss response) that may be important to (re)consider in relationship to grief, meaning, and well-being. These include not only resilience, religiousness, spirituality, sense of coherence, forgiveness, and self-compassion (as noted above), but could also include awe, communion, Eudaimonia (knowing yourself and

becoming who you are; see, e.g., Ryff, 2014), flourishing, gratitude, (progressive) hope, personal sense of uniqueness, poignancy, surrender, and other possibly-related well-being constructs.

Perhaps it is therefore preferable to consider the complexity in this area of meaning-making research as one of both challenge and opportunity: opportune in the array of possibly-relevant mechanisms available to aid in meaning reconstruction in the context of loss, but challenging to discretely define them. An improved understanding of these types of meaning-enhancing concepts (starting with the five considered here) could serve to better help the bereaved—both in buffering against grief's potential complications and in bolstering its generative possibilities.

Chapter 4 Summary

Having discussed loss's potential impact(s) on one's sense of "what-ness," "where-ness," and "when-ness" in the previous two chapters, this chapter has delved more into the "why-ness" and "how-ness" of responding to significant loss. More generally: why do seemingly meaningless things—such as death—happen, and, more specifically, how can meaningfulness again be sought and discovered once they have?

Returning to the doorway analogy—with the door representing the transition between life before and after the death of a loved one, and grief as its threshold—direction relates to finding purposefulness beyond the threshold, in the post-loss world. Herein termed direction with perspective-seeking, this meaning (re)constructing processing is pivotal to reconciling, or the ongoing engagement with the reality of the loss. Reconciling is important because it represents more of a removal of the door than a closing of it. Perspective-seeking, then, refers to an outlook with meaning-generating potential, one that is progressively less dominated by the pre-loss side

of the door (or what might have been) and more focused on what is possible, positive, and purposeful—even absent (and possibly even because of) what might have been.

This sounds better/easier than it often is, however. Perhaps a more apt term than "better" would be "less worse" regarding reconciling with perspective-seeking, especially initially. Through perception and orientation processing, a sense of direction may (slowly) be (re)developed. Meaning can again seem plausible, whereas previously such a "mending" was viewed as impossible—or seemed unrealistic and ridiculous to even consider. In this way the loss-processing framework represents potentially transforming and generative processes: from "nowhere" (necessitating a focus on perception/sense-making) to "now here" (orientation/way-finding) and then, as outlined in the current chapter, to "know where" (focusing on direction/perspective-seeking).

That being said, there are no guaranteed, fail-safe short-cuts to these processes. Perceiving again, learning how to (better) interpret and trust those perceptions, (re)orienting oneself within and beginning to navigate one's post-loss world, and finding and developing a (re)new(ed) sense of purposeful direction are not check-boxes to be ticked off in a step-wise progression, but how grief is understood may be important to how it is experienced (see, e.g., Granek, 2015), and "…who we are shapes how we grieve" (Neimeyer & Harris, 2011, p. 297). As such, the loss-processing framework is perhaps an accessible, interpretive, translational way to understand grief that can help to avoid grief's possible complications while simultaneously potentiating its life-enhancing impacts toward transformative personal growth.

Figure 5

Salar de Uyuni, Bolivia: Another Point of View (Following a Rainfall)

Chapter 5. Methods

Current Study

This research examines bereaved adults' retrospective self-reports of their grief experiences in relationship to the loss-processing framework. The present study focuses on descriptive evidence relating to the first of the framework's three dimensions, perception/sense-making, and its subcomponents: shock-like symptomatology, intrasensory processing, intersensory processing (a.k.a., multimodal integration or intersensory coordination), extrasensory processing (hallucinations, illusions, and other post-death experiences of the decedent; dreams; threshold consciousness; and transliminality), and time for the purpose of initial validation of the construct.

Participants

Following receipt of Institutional Review Board (IRB) approval at East Tennessee State University (ETSU), all data were collected via online survey. Data collection was managed using Research Electronic Data Capture (REDCap) technology. REDCap is a secure, web-based software platform designed to support data capture for research studies, providing: 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources (Harris et al., 2009, 2019).

Convenience sample recruitment for survey participants was conducted through: 1) purposive sampling outreach using social media and social news aggregation/discussion websites (e.g., Facebook and Reddit), 2) snowball sampling methods via e-mail, and 3) ETSU's Department of Psychology online participant pool (hosted by Sona Systems; SONA).

Advertising for the study targeted bereaved adults (see Appendix B). Ads for participation in the study directly linked individuals to the survey in REDCap via the following URL link (see also Appendix C): https://etsuredcap.etsu.edu/surveys/?s=RLAYYRD3MA.

Participation in the study was not incentivized except for students recruited through ETSU's Department of Psychology online participant pool (SONA) who were enrolled in selected psychology courses. These students were eligible to receive ½ research participation credit for taking part in the survey. For students enrolled in Introduction to Psychology, this ½ credit could be applied toward meeting the research requirement for the course; those students not reaching a pre-specified threshold for study participation credits for the semester were subject to point deductions from their final grade. It should be noted that students could participate in other studies in order to reach the specified threshold, and that there was another way to complete these credits without participating in any research studies. In most—if not all—cases, students exceeding the participation credit threshold were eligible for extra credit in Introduction to Psychology. Participation was also incentivized via extra credit for certain other psychology courses at ETSU; the manner in which this was administered was determined at the discretion of each instructor on a course by course basis (with some not offering extra credit).

Procedures

Eligible bereaved participants—aged 18+, currently physically present in the United States, and who provided informed consent for the study—were given access to a secure, on-line survey in REDCap (the Grief Experiences Survey; Appendix C) that included items assessing socio-demographical; mental and physical health and well-being; as well as bereavement-, mourning-, and grief-related information. Survey participation was anonymous and did not require the completion of any/all items; participants were free to exit the survey at any time, or to

return to it later via the provision of an anonymous link if they so desired. Links to grief resource websites and information regarding how to reach study and/or ETSU IRB staff were provided. Although the survey included extensive instrumentation measuring the grief experiences of participants relating to all three dimensions of the loss-processing framework (perception/sense-making, orientation/way-finding, and direction/perspective-seeking), only items addressing perception/sense-making are examined in this paper.

Measures

A 143-item battery of self-report survey items (Appendix C) was developed and administered in order to gather additional provisional information with respect to the loss-processing framework. Since the framework is in an early stage of development, this preliminary collection of data primarily sought to explore descriptive evidence relating to the framework's first dimension (perception/sense-making); as such, no a priori hypotheses were formally stated before data collection was begun. In addition to perception/sense-making, socio-demographic, self-reported overall mental and physical health and well-being, and information about bereavement, grief, and mourning—as related to a specific death—were collected and are described below.

All survey items were drawn from a combination of existing, psychometrically sound instruments (some in part, others in their entirety); select, adapted individual items taken from these types of instruments; and author-written questions. The rich descriptions of bereaved individuals' grieving experiences as well as qualitative loss response research were also utilized in developing the final battery of measures. A full description of items/instruments—as well as a rationale for their inclusion, follows; the complete survey is included in Appendix C.

Socio-Demographics

Participant socio-demographical information was collected. This included: age, location of residence (by zip code), population density of area of residence (urban, suburban, or rural), gender identity, sexual orientation, race/ethnicity, living situation, employment information, socioeconomic status (SES), relationship status, education, student status, whether or not the participant is a parent, religious or non-religious affiliation, and religious service attendance.

Overall Mental and Physical Health and Well-Being

Items indicating the overall mental and physical health and well-being of participants—which, as previously noted, has been shown to be associated with bereavement responses (see, e.g., Stroebe et al., 2007)—were included in the survey. Overall well-being was assessed using the 5-item World Health Organization Well-being Index (WHO-5; Staehr Johansen, 1998; Appendix D), a short questionnaire consisting of simple, non-invasive questions regarding how the participant has felt during the last two weeks.

The WHO-5 Well-Being Index is a brief, generic, global rating scale measuring subjective well-being. It is based upon the WHO-10, which was derived from a 28-item rating scale originally utilized in WHO research across eight European countries. The WHO-10 was developed by choosing the 10 most valid items from the 28-item rating scale, which was initially created using Zung scales (for depression, distress, and anxiety) as well as the General Health Questionnaire (GHQ) and the Psychological General Well-Being Scale (PGWB). Whereas the 28-item scale and the WHO-10 both include negatively-phrased items to reflect symptoms of distress (e.g., *Feeling downhearted and blue*), the WHO-5 contains only positively worded statements (see Appendix D). In the past, the WHO has considered the terms *positive well-being*

and *mental health* synonymously (Topp et al., 2015); it should also be noted that the WHO-5 "reflects aspects other than just the absence of depressive symptoms" (Bech et al., 2003, p. 85).

As used in the current study, there was a slight change in verb tense (from present perfect to present tense). This adjustment was made because most of the non-WHO-5 questions on the Grief Experiences Survey ask questions about the more distant past, whereas the WHO-5 questions (as originally worded) are only asking specifically about the past two weeks (up to the present). Example wording as used herein: "I feel calm and relaxed" rather than the WHO-5's original wording: "I have felt calm and relaxed." Even in the (rare) instance where a participant had experienced the death of a loved one very recently (e.g., in the past month), re-wording these items from present perfect to present tense still seemed to make sense (see Appendix D).

Topp et al. (2015) conducted a systematic review of the WHO-5 literature, concluding that it "…is a highly useful tool that can be applied in both clinical practice (for instance to screen for depression) as well as in research studies in order to assess well-being over time or to compare well-being between groups," and noting that the WHO-5 "…has been applied successfully as a generic scale for well-being across a wide range of study fields" (p. 174). It has been translated into more than 30 languages and utilized in a variety of settings worldwide, including, for example, with respect to coping strategies (Cole et al., 2013) and in assessing the association between psychosocial conditions and well-being (Schütte et al., 2014). Whereas other measures, such as the World Health Organization (WHO) Brief Quality of Life Scale (WHOQOL-BREF; Bonomi et al., 2000; Skevington et al., 2004) were considered, the WHO-5 was chosen for its brevity and utility.

The following two additional items were included to address the perceived overall self-rated physical and mental health of participants:

1. How would you rate your physical health? (*poor, fair, good, very good, or excellent*)
2. How would you rate your mental health? (*poor, fair, good, very good, or excellent*)

Self-rated health (SRH) is among the most widely used survey measures of subjective health. Numerous studies have shown SRH to be consistently and strongly predictive of mortality (DeSalvo et al., 2006; Idler & Benyamini, 1997; Mossey & Shapiro, 1982), which is considered the most objective measure of individual health (Quesnel-Vallée, 2007).

SRH has also been shown to be a statistically significant predictor of functional health declinations (e.g., Idler & Benyamini, 1997; Idler & Kasl, 1995; Idler, Russell, & Davis, 2000; Lee, 2000; Martinez et al., 2010). More recently, Latham and Peek (2013) examined the relationship between SRH and incident morbidity, expanding the connection between SRH and physical health to include chronic disease—as well as finding evidence suggesting "…that the relationship between SRH and physical health outcomes is evident in midlife as well as at older ages" (p. 107).

According to Idler and Benyamini (1997), SRH's predictive power with respect to health declines (particularly mortality) has four possible interpretations: 1) SRH is more inclusive than other health-rating measures because it captures preclinical/prodromal symptoms, accounts for complex human judgments about the severity of illness, and reflects family history; 2) SRH not only accounts for current health status, it also dynamically estimates health trajectory; 3) SRH influences behaviors, thus subsequently impacting health status; and 4) SRH reflects the availability of personal, economic, and social resources that have been shown to play a role in determining health—irrespective of diagnostic specificity or other mechanisms involved (for additional information about social conditions and health disparities see, e.g., Link & Phelan, 1995; Phelan et al., 2010).

Bereavement-, Mourning-, and Grief-Related

Bereavement-related information was also gathered. This included the participant's relationship to the decedent (e.g., familial or other relation), time since death, approximate age of the person when they died, cause of death, participant involvement in caring for the decedent prior to death's occurrence (if applicable), and whether or not the death followed palliative/ hospice care (i.e., was there foreknowledge of the death prior to its occurrence, and—if so—then for approximately how long). Although all of these bereavement-related factors have been shown to affect grief outcomes, the latter two (and particularly the last one) are often overlooked (for review see Childress, 2016).

Mourning-related information items included those addressing: 1) whether or not the participant viewed the body of their loved one after the death; 2) did a mourning ritual (funeral ceremony or memorial service) take place following the death, and, if so, then did the participant attend, and—if so—then did they find attending the service to be meaningful or not; and 3) was their loved one's body buried, cremated, or donated for scientific/research/medical purposes? Here the paucity of research regarding the relationship between collective mourning rituals and grief must be noted (for summary see Childress, 2015; Hoy, 2013; see also Hayslip et al., 2007); not only are studies specifically addressing funerals sparse (Hoy, 2013), questions relating to funerals are rarely included in grief-related research.

Grief-related information was assessed using a single item: "Did you seek professional help for grief-related issues at any point following the death?" (*yes*, *no*, or *do not recall*; if responding *yes* then from whom [e.g., a therapist, physician, counselor, pastor or spiritual advisor, social worker, grief support group, etc.] and "In general did you find this help-seeking to be beneficial" [*yes, no,* or *do not recall*]). This question emerged during discussions relating to

the author's preliminary project, a literature review investigating possible impacts of foreknowledge of death on grief outcomes for survivors (Childress, 2016). The item was initially suggested by preliminary project committee-member Dr. Peggy Cantrell as a concise way to address possible grief-related complications.

Bereavement-, mourning-, and grief-related items were included to be used individually and descriptively. As such, no scores related to these items have been calculated in this initial analysis.

Perception/Sense-Making

Items assessing mechanisms relating to the perception/sense-making dimension of the loss-processing framework included: 1) shock-like symptomatology; 2) intrasensory processing; 3) intersensory processing (a.k.a., multi-sensory or multimodal integration); 4) extrasensory processing (including hallucinations, dreams, threshold consciousness, and transliminality); and 5) the subjective experience of time. Discretely addressing each of these five assessment areas (and the sub-categorization within some of them) proved to be organizationally unwieldy. There is significant overlap among several of these constructs (e.g., hallucinations, dreams, threshold consciousness, and transliminality); however, all items included in the survey reflected at least one aspect of the perception/sense-making dimension and were identified relative to the construct to which they seemed most closely associated.

Given the retrospective nature of the questions, for most items respondents were asked to address both the frequency of occurrence (*never*, *rarely*, *occasionally*, *a moderate amount*, *a great deal*, or *do not recall*) as well as the possible change in the prevalence of each phenomenon present over time (*occurring less often*, *unchanged*, *occurring more often*, *no longer occurring*, or *unsure*) since the death. For an example item, in this case evaluating shock-like

symptomatology, see Table 1. Note that the last two columns are annotations and do not appear in the survey itself; for identification of the acronyms of sources in the final column, see Appendix E.

Table 1

Sample Item Assessing Perception/Sense-Making

Think about the time following the death of your loved one. Would you say:	Response choices	If selecting "Rarely, Occasionally, A moderate amount" or "A great deal," then how has this changed over time?	Framework dimension(s) and assessed aspect(s)	Item source information
I felt distant from my own emotions	□ Never □ Rarely □ Occasionally □ A moderate amount □ A great deal □ Do not recall	□ Occurring less often □ Unchanged □ Occurring more often □ No longer occurring □ Unsure	Perception Shock-like Symptoms	ASD, ASDS, SASRQ

Many of the items in this section are author-written. Others, as mentioned previously, are based on direct quotations of grieving individuals. Some were drawn verbatim or adapted from previously published instruments. Although source instruments were subject to prior psychometric evaluation, their reliability and validity have not been confirmed for the purposes of this study.

The item development process was iterative. It began with material articulating aspects of the loss-processing framework's first dimension (Chapter 2). Possible items (e.g., those from existing instruments measuring aspects of perception/sense-making and from the narrative self-reports of grieving individuals) were evaluated based on their alignment with each of the

framework's facets. In instances where these item sources were deemed insufficient, the material was either adapted or author-written items were subsequently generated.

Examples of the information and instrumentation utilized in developing survey items assessing the shock-like symptoms of the perception/sense-making dimension of the framework included: 1) the Specific Symptoms of Acute Stress Disorder (ASD; APA, 2013; Appendix A); 2) the Acute Stress Disorder Scale (ASDS; Bryant et al., 2011; Bryant & Harvey, 2000; Bryant et al., 2000; Appendix F); 3) the Stanford Acute Stress Reaction Questionnaire (SASRQ, Cardeña et al., 2000; Appendix G); 4) the Depersonalization-Derealization Inventory (DDI; Cox & Swinson, 2002; Appendix H); 5) the Dissociative Experiences Scale (DES-II; Bernstein & Putnam, 1986; Carlson & Putnam, 1993; Frischholz et al., 1990; Appendix I); and 6) the Cambridge Depersonalization Scale (CDS; Sierra & Berrios, 1996, 2000; Sierra et al., 2005; Appendix J). It should be noted that there were instances of significant overlap in these item-inclusion source materials (i.e., items across measures were worded quite similarly—if not virtually identically).

Some of the intra-, inter-, and extrasensory items were also developed using the above-listed resources; others were taken directly from the personal accounts of grievers, and some were author-written. Troyer's (2005, 2014) qualitative research was used in the development of extrasensory items, particularly with respect to grief hallucinations—alternately termed post death encounters or events (PDE's; Nowatzki & Grant Kalischuk, 2009). The Revised Transliminality Scale (RTS; Houran et al., 2003; Lange et al., 2000; Appendix K) was also considered when developing extrasensory perception items, such as those relating to threshold consciousness and transliminality. With some exceptions, time-perception-related items were mostly author-written. As noted previously, significant overlap was found in the resources used

to develop all items assessing perception/sense-making; for a complete listing of these items, including source cross-referencing information, see Appendix E.

Data Cleaning

Prior to running analyses, data were cleaned to resolve potential problems related to unacceptability, incompleteness, or inaccuracy. For example, 18 surveys were entirely blank and unconsented, and some of the surveys were completed for the death of a pet, which was not the focus of this study; as such, these were deleted. Participants who answered very few or no items, or those who stopped responding to items before beginning the perception/sense-making portion of the survey, were not included. Respondents who answered *do not recall* or *never* to all or to the vast majority of items assessing perception/sense-making were retained—even though those were the only response choices that did not prompt a follow-up item about change over time.

Before data cleaning, the study had an initial sample size of 550 potential survey respondents. There were 103 participants whose data were removed because they did not respond to any of the items or for one of the other reasons outlined above. This left 447 participants who responded to items up to and inclusive of those relating to the primary focus of this study (items assessing socio-demographics; overall mental and physical health and well-being; bereavement, grief, and mourning; and perception/sense-making). Given the descriptive nature of the current research, and considering that participants could skip any items that they did not want to answer, results are reported based upon the number of participants that responded to each individual item; the number or participants not answering an item are reported as "missing".

Planned Data Analyses

All descriptive statistical analyses were conducted using SPSS (version 27.0) and Microsoft Excel (2019) and are reported for: socio-demographical; mental and physical health

and well-being-related; and bereavement-, grief-, and mourning-related data. REDCap's internal reports and stats software was used to confirm all analyses performed in SPSS and Excel. For socio-demographical and bereavement-, grief-, and mourning-related data, frequencies and percentages are reported for nominal variables and means and standard deviations are reported for continuous variables. Scores are reported for the WHO-5 Well-Being Index; percentages and frequencies are provided for self-rated physical and mental health (SRH).

Also reported are descriptive statistical analyses of data collected that relate to the loss-processing framework's perception/sense-making dimension and its subcomponents (shock-like symptoms, intrasensory processing, intersensory processing, extrasensory processing, and time). For this preliminary assessment, perception/sense-making items are reported by frequency and endorsement percentage on an item by item basis. Endorsement was defined as any response choice of: *rarely*, *occasionally*, *a moderate amount*, or *a great deal*. Responses of *never* or *do not recall* were considered not endorsing of the item.

Chapter 6. Results

Sample Characteristics

It must be noted from the onset that these data were collected from August through December of 2020. COVID-19 is therefore a characteristic of this sample.

Also, as previously noted, only one group of participants was recruited with the provision of any sort of incentivization—those students recruited to access the REDCap-managed survey via SONA (ETSU's Department of Psychology online participant pool). Thus, results are reported for three groups: non-SONA, SONA, and those two groups combined.

Socio-Demographics

Diversity characteristics of the study sample and its two subgroups are reported in Table 2. These include: age, population density of area of residence, gender identity, sexual orientation, race/ethnicity, living situation, employment information, socioeconomic status, relationship status, education, student status, parental status, religious or non-religious affiliation, and religious service attendance. Location of residence (by zip code) was collected but is not reported; this item had the lowest response rate of all items included in the study, with 98 responses missing (21.9%, $N = 447$).

The combined sample ($N = 447$) was predominantly female (74.1%, $n = 329$), heterosexual (83.3%, $n = 370$), white (89%, $n = 395$), Christian (70.7%, $n = 316$), and ranged in age from 18 to 87 years ($M = 38.27$, $SD = 21.56$). The Christian affiliation datapoint for this sample aligns with a Pew Research Center (2014) survey estimating that 70.6% of U.S. adults report a Christian religious affiliation. Here it should also be noted that religious service attendance survey responses were probably impacted by COVID-19—although respondents may have reported based upon their pre-COVID-19 church attendance patterns (see Table 2).

Table 2

Diversity Characteristics Across Samples

Characteristic	non-SONA sample (*n*=224)	SONA sample (*n*=223)	Total Sample (*N*=447)
Age			
Mean	56.42	20.11	38.27
Median	59	19	26
SD	16.093	3.198	21.56
Min	23	18	18
Max	87	45	87
Missing	13 (5.8%)	12 (5.4%)	25 (5.6%)
Country of Residence			
US	198 (88.4%)	210 (94.2%)	408 (91.2%)
Non-US	3 (1.3%)	1 (0.4%)	4 (1%)
Missing	23 (10.3%)	12 (5.4%)	35 (7.8%)
Population Density of Area of Residence			
Urban (100,000+ residents)	33 (14.7%)	29 (13%)	62 (13.9%)
Suburban (10,000-100,000 residents)	113 (50.4%)	125 (56.1%)	238 (53.5%)
Rural (less than 10,000 residents)	70 (31.3%)	45 (20.2%)	115 (25.8%)
Unsure	6 (2.7%)	24 (10.8%)	30 (6.7%)
Missing	2 (0.9%)	0	2 (0.4%)
Gender Identity			
Female	188 (83.9%)	141 (63.2%)	329 (74.1%)
Male	32 (14.3%)	78 (35%)	110 (24.8%)
Other Gender Identity	1 (0.4%)	4 (1.8%)	5 (1.1%)
Missing	3 (1.3%)	0	3 (0.7%)
Sexual Orientation			
Asexual	2 (0.9%)	11 (4.9%)	13 (2.9%)
Bisexual	9 (4%)	25 (11.2%)	34 (7.7%)
Gay	3 (1.3%)	4 (1.8%)	7 (1.6%)
Lesbian	2 (0.9%)	4 (1.8%)	6 (1.4%)
Pansexual	3 (1.3%)	7 (3.1%)	10 (2.3%)
Questioning or unsure	0	3 (1.3%)	3 (0.7%)
Straight (heterosexual)	202 (90.2%)	168 (75.3%)	370 (83.3%)
Other Sexual Orientation	0	1 (0.4%)	1 (0.2%)
Missing	3 (1.3%)	0	3 (0.7%)
Race/Ethnicity			
Alaska Native or Native American Indian	2 (0.9%)	1 (0.4%)	3 (0.7%)
Black, Afro-Caribbean, or African American	4 (1.8%)	33 (14.8%)	37 (8.3%)
East Asian or Asian American	1 (0.4%)	6 (2.7%)	7 (1.6%)
Latino/a or Hispanic American	2 (0.9%)	10 (4.5%)	12 (2.7%)
Middle Eastern or Arab American	0	2(0.9%)	2 (0.5%)
Native Hawaiian or other Pacific Islander	0	2(0.9%)	2 (0.5%)
White or Euro-American (Caucasian)	215 (96%)	180 (80.7%)	395 (89.0%)
Multiracial	0	11 (4.9%)	11 (2.5%)
Other Race/Ethnicity	0	0	0
Missing	2 (0.9%)	0	3 (0.7%)

Diversity Characteristics Across Samples (cont'd)

Characteristic	non-SONA sample (*n*=224)	SONA sample (*n*=223)	Total Sample (*N*=447)
Living Situation			
Live alone	56 (25%)	21 (9.4%)	77 (17.2%)
Live with parents/guardian	5 (2.2%)	109 (48.9%)	114 (25.5%)
Live with roommate(s)	6 (2.7%)	59 (26.5%)	65 (14.5%)
Live with spouse/romantic partner	146 (65.2%)	26 (11.7%)	172 (38.5%)
No permanent residence	0	4 (1.8%)	4 (0.9%)
Other	10 (4.5%)	3 (1.3%)	13 (2.9%)
Missing	1 (0.4%)	1 (0.4%)	2 (0.4%)
Employment Status			
Not currently working for pay	17 (7.6%)	72 (32.3%)	89 (19.9%)
Working part-time for pay	28 (12.5%)	110 (49.3%)	138 (30.9%)
Working full-time for pay	84 (37.5%)	34 (15.2%)	118 (26.4%)
Retired	87 (38.8%)	0	87 (19.5%)
Other	6 (2.7%)	6 (2.7%)	12 (2.7%)
Missing	2 (0.9%)	1 (0.4%)	3 (0.7%)
Personal Financial Situation			
Low-income	6 (2.7%)	86 (38.6%)	92 (20.6%)
Lower-middle income	40 (17.9%)	55 (24.7%)	95 (21.3%)
Middle-income	103 (46%)	55 (24.7%)	158 (35.3%)
Upper-middle income	63 (28.1%)	25 (11.2%)	88 (19.7%)
Upper income	10 (4.5%)	1 (0.4%)	11 (2.5%)
Missing	2 (0.9%)	1 (0.4%)	3 (0.7%)
Current Relationship Status			
Single never married	16 (7.1%)	117 (52.5%)	133 (29.8%)
In a relationship; living separately	2 (0.9%)	70 (31.4%)	72 (16.1%)
Cohabitating with a romantic partner	13 (5.8%)	24 (10.8%)	37 (8.3%)
Married	132 (58.9%)	8 (3.6%)	140 (31.3%)
Separated	2 (0.9%)	2(0.9%)	4 (0.9%)
Divorced	22 (9.8%)	0	22 (4.9%)
Domestic Partnership	2 (0.9%)	1 (0.4%)	3 (0.7%)
Widowed	32 (14.3%)	0	32 (7.2%)
Other	1 (0.4%)	1 (0.4%)	2 (0.4%)
Missing	2 (0.9%)	0	2 (0.4%)
Education			
Some high school	0	5 (2.2%)	5 (1.1%)
Technical training	1 (0.4%)	2(0.9%)	3 (0.7%)
High school graduate or equivalent	5 (2.2%)	90 (40.4%)	95 (21.3%)
Some college without receiving diploma	24 (10.7%)	90 (40.4%)	114 (25.5%)
Associate's degree	14 (6.3%)	16 (7.2%)	30 (6.7%)
Bachelor's degree	76 (33.9%)	11 (4.9%)	87 (19.5%)
Advanced degree	99 (44.2%)	1 (0.4%)	100 (22.4%)
Other	4 (1.8%)	7 (3.1%)	11 (2.5%)
Missing	1 (0.4%)	1 (0.4%)	2 (0.4%)

Diversity Characteristics Across Samples (cont'd)

Characteristic	non-SONA sample (*n*=224)	SONA sample (*n*=223)	Total Sample (*N*=447)
Student Status			
No	211 (94.2%)	1 (0.4%)	212 (47.4%)
Yes, part time	5 (2.2%)	8 (3.6%)	13 (2.9%)
Yes, full time	6 (2.7%)	214 (96%)	220 (49.2%)
Missing	2 (0.9%)	0	2 (0.4%)
Parental Status			
Yes	160 (72.3%)	13 (5.8%)	175 (39.1%)
No	60 (26.8%)	209 (93.7%)	269 (60.2%)
Missing	2 (0.9%)	1 (0.4%)	3 (0.7%)
Religious Affiliation			
Buddhist	2 (0.9%)	1 (0.4%)	3 (0.7%)
Christian-Catholic	19 (8.5%)	30 (13.5%)	49 (11%)
Christian-Protestant	128 (57.1%)	127 (57%)	255 (57%)
Episcopalian/Anglican	10 (4.5%)	2(0.9%)	12 (2.7%)
Jehovah's Witness	0	2(0.9%)	2 (0.4%)
Jewish	1 (0.4%)	0	1 (0.2%)
Hindu	0	0	0
Mormon/Latter Day Saints	0	0	0
Muslim	0	1 (0.4%)	1 (0.2%)
Sikh	0	0	0
Unitarian Universalist	6 (2.7%)	0	6 (1.3%)
Wiccan	1 (0.4%)	2(0.9%)	3 (0.7%)
Atheist	13 (5.8%)	10 (4.5%)	23 (5.1%)
Agnostic	12 (5.4%)	22 (9.9%)	34 (7.6%)
Humanist	6 (2.7%)	0	6 (1.3%)
Religious affiliation not specified	13 (5.8%)	16 (7.2%)	29 (6.5%)
Other	10 (4.5%)	9 (4%)	19 (4.3%)
Missing	3 (1.3%)	1 (0.4%)	4 (0.9%)
Religious Service Attendance			
Never	51 (22.8%)	71 (31.8%)	122 (27.3%)
1-2 times per year	47 (21%)	55 (24.7%)	102 (22.8%)
Every month	17 (7.6%)	40 (17.9%)	57 (12.8)
Every week	101 (45.1%)	46 (20.6%)	147 (32.9%)
More than one time per week	6 (2.7%)	9 (4%)	15 (3.4%)
Missing	2 (0.9%)	2(0.9%)	4 (0.9%)

Although virtually identical in size, the non-SONA (n = 224) and SONA (n = 223) samples differ in multiple ways. For example, the SONA sample is more than 36 years younger (M =20.11, SD = 3.2) on average than the non-SONA sample (M = 56.42, SD = 16.09). As expected, the SONA group was predominantly comprised of current full-time students (96%, n =

214), and in the non-SONA sample 94.2% of participants were not students (*n* = 211)—but had been previously (with 78.1% of the non-SONA group reporting having received a Bachelor's or Advanced degree in the past, *n* = 175).

Most of the socio-demographic and diversity characteristics appear to follow the pattern one would anticipate for an older group of adults (38.8% of whom are retired, *n* = 87) as compared to group of young students (of whom 49.3%, *n* = 110) are working part-time and another 15.2% are working full-time (*n* = 34). This includes with respect to relationship status (with the former more likely to be married and be a parent), financial and living situation (with students reporting lower incomes—and almost ½ living with a parent or guardian), and the younger group reporting somewhat greater racial/ethnic and sexual orientation diversity. Where the difference between the two groups is strong, it is striking to see their contrast collapse in the descriptive statistics for the total sample combining the two—albeit the inevitable statistical resolution of their combination (see, e.g., *live with spouse/romantic partner*, *single never married*, or *advanced degree*; Table 2).

Overall Mental and Physical Health and Well-Being

The average score on the WHO-5 Well-being Index for the non-SONA group was 75.15 (*SD* = 15.4, *n* = 221). This was more than five percentage points higher (indicating more positive reported overall well-being) than the average for the SONA sample, which was 69.97 (*SD* = 17.41, *n* = 222). The combined average for both groups was 72.55 (*SD* = 16.63, *N*=443). Records for participants who did not answer all of the WHO-5 items were removed prior to calculating these scores. Please see Appendix D for additional information regarding the scoring of the WHO-5 for this survey. Percentages for self-rated physical and mental health (SRH) across samples are reported in Table 3.

Table 3

Self-rated Physical and Mental Health Across Samples

Characteristic	Non-SONA sample (*n*=224)	SONA sample (*n*=223)	Total Sample (*N*=447)
Physical Health			
poor	4 (1.8%)	7 (3.1%)	11 (2.5%)
fair	25 (11.2%)	47 (21.1%)	72 (16.1%)
good	112 (50%)	79 (35.4%)	191 (42.7%)
very good	68 (30.4%)	69 (30.9%)	137(30.6%)
excellent	13 (5.8%)	21 (9.4%)	34 (7.6%)
missing	2 (0.9%)	0	2 (.4%)
Mental Health			
poor	2 (0.9%)	29 (13%)	31 (6.9%)
fair	31 (13.8%)	70 (31.4%)	101 (22.6%)
good	90 (40.2%)	77 (34.5%)	167 (37.4%)
very good	73 (32.6%)	26 (11.7%)	99 (22.1%)
excellent	27 (12.1%)	20 (9%)	47 (10.5%)
missing	1 (0.4%)	1 (0.4%)	2 (0.4%)

Although caution must be taken when interpreting these data, differences between the two groups are apparent—particularly with respect to self-rated mental health. For example, the percentage of self-rated *poor* or *fair* mental health for the SONA (student) sample is 44.4% (n = 99) as compared to 14.7% (n = 33) for the non-SONA sample; also, student percentages trail those of the older group in each of the other three more positive categorizations (*good*, *very good*, and *excellent*). These data would not appear to be misaligned with the WHO-5 scores across samples.

Bereavement-, Mourning-, and Grief-Related

Bereavement-related characteristics are reported in Table 4. These data may reflect some of the age-difference-based patterning seen in the socio-demographical and diversity characteristics. For example, the three largest percentages for categories of *relationship to the decedent* for the non-SONA sample are *husband* (17.4%, n = 39), *father* (18.3%, n = 41) and

mother (23.2% 52); and for the SONA sample they are *grandfather* (22.1%, *n* = 49), *grandmother* (24.8%, *n* = 55), and *friend* (16.2%, *n* = 36). Here it is possible that the *friend* category may have served to lower the average age of the decedent for the student group (*M* = 56.67, SD = 27.52), which was almost 7 years younger than the age at death for the non-SONA sample (*M* = 63.54, *SD* = 22.11). For the non-SONA group, ⅓ of the deaths were 10+ years ago.

Table 4

Bereavement-Related Characteristics Across Samples

Characteristic	non-SONA sample (*n*=224)	SONA sample (*n*=223)	Total Sample (*N*=447)
Relationship to decedent			
Husband	39 (17.4%)	0	39 (8.7%)
Wife	2 (0.9%)	0	2 (0.4%)
Partner	2 (0.9%)	0	2 (0.4%)
Grandfather	12 (5.4%)	49 (22.1%)	61 (13.6%)
Grandmother	10 (4.5%)	55 (24.8%)	65 (14.5%)
Father	41 (18.3%)	17 (7.7%)	58 (13%)
Mother	52 (23.2%)	2 (0.9%)	54 (12.1%)
Father-in-law	1 (0.4%)	0	1 (0.2%)
Mother-in-law	2 (0.9%)	1 (0.4%)	2 (0.4%)
Brother	13 (5.8%)	3 (1.4%)	16 (3.6%)
Sister	9 (4.0%)	4 (1.8%)	13 (2.9%)
Brother-in-law	0	0	0
Sister-in-law	0	0	0
Son	11 (4.9%)	0	11 (2.5%)
Daughter	4 (1.8%)	1 (0.4%)	5 (1%)
Son-in-law	0 (0.0%)	0	0
Daughter-in-law	1 (0.4%)	0	1 (0.2%)
Uncle	2 (0.9%)	14 (6.1%)	16 (3.6%)
Aunt	4 (1.8%)	12 (5.4%)	16 (3.6%)
Nephew	1 (0.4%)	1 (0.4%)	2 (0.4%)
Niece	2 (0.9%)	2 (0.9%)	4 (0.8%)
Friend	14 (6.3%)	36 (16.2%)	50 (11.2%)
Other	2 (0.9%)	26 (11.7%)	28 (6.3%)
Missing	0	1 (0.4%)	1 (0.2%)
Approx. age of the person when they died			
Mean	63.54	56.67	60.13
Median	68.5	65	67
SD	22.11	27.52	25.15
Min	0.33	0	0
Max	98	105	105
Missing	4 (1.8%)	6 (2.7%)	10 (2.2%)

Bereavement-Related Characteristics Across Samples (cont'd.)

Characteristic	non-SONA sample (*n*=224)	SONA sample (*n*=223)	Total Sample (*N*=447)
How long ago did your loved one die?			
< one month	8 (3.6%)	8 (3.6%)	16 (3.6%)
1-3 months	7 (3.1%)	13 (5.8%)	20 (4.5%)
4-6 months	6 (2.7%)	11 (4.9%)	17 (3.8%)
7-12 months	12 (5.4%)	17 (7.6%)	29 (6.5%)
13-18 months	9 (4%)	7 (3.1%)	16 (3.6%)
19-24 months	6 (2.7%)	11 (4.9%)	17 (3.8%)
2-3 years	25 (11.2%)	55 (24.7%)	80 (17.9%)
4-5 years	31 (13.8%)	36 (16.1%)	67 (15%)
5-10 years	41 (18.3%)	39 (17.5%)	80 (17.9%)
More than 10 years	79 (35.3%)	23 (10.3%)	102 (22.8%)
Missing	0	3 (1.3%)	3 (0.7%)
Cause of death			
Natural causes (anticipated)	117 (52.2%)	97 (43.5%)	214 (47.9%)
Natural causes (sudden)	47 (21%)	51 (22.9%)	98 (21.9%)
Overdose	3 (1.3%)	8 (3.6%)	11 (2.5%)
Accident	20 (8.9%)	23 (10.3%)	43 (9.6%)
Suicide	13 (5.8%)	12 (5.4%)	25 (5.6%)
Homicide	6 (2.7%)	6 (2.7%)	12 (2.7%)
COVID-19	3 (1.3%)	2 (0.9%)	5 (1.1%)
Not known	2 (0.9%)	11 (4.9%)	13 (2.9%)
Other	13 (5.8%)	12 (5.4%)	25 (5.6%)
Missing	0	1 (0.4%)	1 (0.2%)
Were you (one of) the primary caregivers?			
Yes	93 (41.5%)	17 (7.6%)	110 (24.6%)
No	129 (57.6%)	199 (89.2%)	328 (73.4%)
Do not recall	0	6 (2.7%)	6 (1.3%)
Missing	2 (0.9%)	1 (0.4%)	3 (0.7%)
Did the death follow palliative/hospice care?			
Yes	84 (37.5%)	57 (25.6%)	141 (31.5%)
No	138 (61.6%)	131 (58.7%)	269 (60.2%)
Unsure	1 (0.4%)	34 (15.2%0	35 (7.8%)
Missing	1 (0.4%)	1 (0.4%)	2 (0.4%)
If yes, then how long in hospice care?			
n = *Yes* from previous question	*n* = 84	*n* = 57	*n* = 141
Less than one week	23 (27.4%)	13 (22.8%)	36 (25.5%)
1-4 weeks	27 (32.1%)	16 (28.1%)	43 (30.5%)
5-8 weeks	9 (10.7%)	8 (14%)	17 (12.1%)
3-6 months	11 (13.1%)	10 (17.5%)	21 (14.9%)
7-12 months	11 (13.1%)	4 (7%)	15 (10.6%)
13-18 months	0	1 (1.8%)	1 (.1)
19-24 months	2 (2.4%)	0	2 (1.4%)
More than 2 years	1(1.2%)	5 (8.8%)	6 (4.2%)

The cause of death categories track more similarly between the two groups, with natural causes (anticipated or sudden) and accidents being the top three categorizations (accounting for more than ¾ of the causes of death across both groups). The more elderly non-SONA sample reported a higher incidence of having experienced the death of a loved one more than 10 years ago (35.3% [*n* = 79] versus 10.3% [*n* = 23]). Here it should be noted that given the average age of the SONA group (*M* =20.11, *SD* = 3.2), up to 43.9% (*n* = 98) of these respondents may have been younger than the age of 18 when they experienced the death of the loved one for whom they are responding to this survey. The non-SONA sample was much more likely to have been (one of) the primary caregivers for their loved one prior to their death—41.5% (*n* = 93) as compared to only 7.6% (*n* = 17) for the SONA sample. Fifteen percent of SONA respondents (*n* = 34) were unsure if the death of their loved one followed palliative/hospice care.

Results for mourning-related characteristics are reported in Table 5. Data for these characteristics also indicate more similarity between the two groups than for previous measures.

Table 5

Mourning-Related Characteristics Across Samples

Characteristic	non-SONA sample (*n*=224)	SONA sample (*n*=223)	Total Sample (*N*=447)
Did you view the body of your loved one?			
Yes	151 (67.4%)	125 (56.1%)	276 (61.7%)
No	72 (32.1%)	88 (39.5%)	160 (35.8%)
Do not recall	1 (0.4%)	10 (4.5%)	11 (2.5%)
Missing	0	0	0
Was there a funeral or memorial service?			
Yes	211 (94.2%)	207 (92.8%)	418 (93.5%)
No	12 (5.4%)	11 (4.9%)	23 (5.1%)
Do not recall	0	5 (2.2%)	5 (1.1%)
Missing	1 (0.4%)	0	1 (0.2%)
If so, then did you attend?			
n = Yes from previous question	*n* = 211	*n* = 207	*n* = 418
Yes	198 (93.8%)	173 (83.6%)	371 (88.8%)
No	9 (4.3%)	34 (16.4%)	43 (10.3%)

Mourning-Related Characteristics Across Samples (cont'd.)

Characteristic	non-SONA sample (*n*=224)	SONA sample (*n*=223)	Total Sample (*N*=447)
If so, then did you attend? (cont'd.)			
Do not recall	1 (0.5%)	0	1 (0.2%)
Missing	3 (1.4%)	0	3 (0.7%)
If so, then did you find it to be meaningful?			
n = Yes from previous question	*n* = 198	*n* = 173	*n* = 371
Yes	162 (81.8%)	152 (87.9%)	314 (84.6%)
No	15 (7.6%)	8 (4.6%)	23 (62%)
Unsure	20 (10%)	11 (6.4%)	31 (8.4%)
Missing	1 (0.6%)	2 (1.1%)	0.8%)
Was the body of your loved one?			
Buried	91 (40.6%)	156 (70%)	247 (55.3%)
Cremated	123 (54.9%)	48 (21.5%)	171 (38.3%)
Donated for scientific/research	6 (2.7%)	3 (1.3%)	9 (2%)
Other	3 (1.3%)	1 (0.4%)	4 (0.9%)
Unsure	1 (0.4%)	15 (6.7%)	16 (3.6%)

When there was a funeral or memorial service, for those reporting having attended, 84.6% (*n* = 314) responded that it was meaningful to have done so. Also noteworthy among these data is the declination in the of viewing the body of the decedent, which was 11.3 percentage points lower for the younger/student sample even though this group reported a 29.4 percentage point higher incidence of burial. Earth burial has been associated with "traditional" funerals, which historically included a viewing of the body or wake (Childress, 2015)—particularly within the South Central Appalachian region (for geographical area definition, see Appalachian Regional Commission [ARC], 2021). These data may reflect a (continuing) shift away from this particular mourning convention (for summary of possible changes in funeral customs in northeast Tennessee, see Childress, 2015), and/or may also be indicative of the greater geographical diversity of the non-SONA sample (rates of cremation are higher nationally than in the region surrounding ETSU [Cremation Association of North America, 2021]—and the SONA sample is an ETSU-student-based sample).

Grief-related characteristics are reported in Table 6. The student sample was less likely to have sought counsel following the death of their loved one, with 9.9% (*n* = 22) reporting having done so as compared to 31.7% (*n* = 71) for the non-SONA sample. It is interesting to note that although 22 students in the SONA group reported having had some sort of professional grief support after the death of their loved one, five could not recall whether they had sought it or not—and indicated *do not recall* rather than *no*. For the sample combining both groups, 81.7% (*n* = 93) reported that professional grief counseling was helpful to them.

Table 6

Grief-Related Characteristics Across Samples

Characteristic	non-SONA sample (*n*=224)	SONA sample (*n*=223)	Total Sample (*N*=447)
Yes	71 (31.7%)	22 (9.9%)	93 (20.9%)
No	152 (67/9%)	196 (87.9%)	348 (78%)
Do not recall	0	5 (2.2%)	5 (1.1%)
Missing	1 (0.4%)	0	1 (0.2%)
If so, then did you find it to be helpful?			
n = Yes from previous question	*n* = 71	*n* = 22	*n* = 93
Yes	60 (84.5%)	16 (72.7%)	76 (81.7%)
No	10 (14.1%)	6 (27.3%)	16 (17.2%)
Do not recall	0	0	0
Missing	1 (1.4%)	0	1 (1.1%)

Perception/Sense-making

Items assessing perception/sense-making are reported as frequencies with percentage endorsement across samples (see Table 7). As noted previously, item response choices of *rarely*, *occasionally*, *a moderate amount*, or *a great deal* are considered endorsing of the item. Responses of *never* or *do not recall* were calculated as not endorsing; here it should be noted that not remembering is not necessarily the same as not having occurred.

For these self-reports of grief experiences relating to perception/sense-making, the average endorsement percentage among participants in the non-SONA sample (n = 224) was 13.13 points higher (SD = 10.07) than the SONA sample (n = 223). For the non-SONA sample the average endorsement percentage was 43.16% (SD = 24.75) and it was 30.03% for the SONA sample (SD = 21.47). For these two groups combined, the average was 36.59% (SD = 21.47, N = 447).

Table 7

Perception/Sense-Making Items Across Samples

Item		non-SONA sample (n=224)	SONA sample (n=223)	Total Sample (N=447)
1	I had difficulty concentrating/focusing attention	215 (96%)	174 (78%)	389 (87%)
2	I felt restless	186 (83%)	159 (71.3%)	345 (77.2%)
3	I felt numb	174 (77.7%)	144 (64.6%)	318 (71.1%)
4	I felt distant from my own emotions	156 (69.6%)	134 (60.1%)	290 (64.9%)
5	I felt as if I was in a daze	171 (76.3%)	131 (58.7%)	302 (67.6%)
6	I felt like I was watching things happen...outside myself	139 (62.1%)	89 (39.9%)	228 (51%)
7	Memories of the death kept entering my mind	208 (92.9%)	145 (65%)	353 (79%)
8	My surroundings seemed strange or unreal	107 (47.8%)	84 (37.7%)	191 (48.5%)
9	I felt like I was slow to respond to what was happening…	150 (67%)	91 (40.8%)	241 (53.9%)
10	I looked in the mirror and felt...I did not recognize myself	64 (28.6%)	45 (20.2%)	109 (24.4%)
11	I felt as if I might be losing my mind….	78 (34.8%)	65 (29.1%)	143 (32%)
12	Smells seemed weaker or less noticeable than usual	21 (9.4%)	36 (16.1%)	57 (12.8%)
13	Indoor lights seemed so bright...they bothered my eyes	45 (20.1%)	48 (21.5%)	93 (20.8%)
14	Tastes seemed blander or less noticeable than usual	65 (29%)	34 (15.2%)	99 (22.1%)
15	I felt as if the volume control...had been turned down	88 (39.3%)	51 (22.9%)	139 (31.1%)
16	My vision seemed dulled	41 (18.3%)	35 (15.7%)	76 (17%)
17	Things...looked different...than how...they really look	55 (24.6%)	44 (19.7%)	99 (22.1%)
18	People and objects seemed more distant and unclear	61 (27.2%)	37 (16.6%)	98 (21.9%)
19	Smells seemed stronger or more noticeable than usual	32 (14.3%)	19 (8.5%)	51 (11.4%)
20	People and objects seemed closer and clearer	18 (8%)	18 (8.1%)	36 (8.1%)
21	Colors seemed to appear dull or muted	37 (16.5%)	35 (15.7%)	72 (16.1%)
22	Tastes seemed stronger or more noticeable than usual	21 (9.4%)	16 (7.2%)	37 (8.3%)
23	I felt as if the volume control...had been turned up	53 (23.7%)	28 (12.6%)	81 (18.1%)
24	Colors seemed to appear more vivid and vibrant	26 (11.6%)	20 (9%)	46 (10.3%)
25	I felt like I was walking on shifting ground	108 (48.2%)	61 (27.4%)	169 (37.8%)
26	I felt as if I was in a fog	173 (77.2%)	90 (40.4%)	263 (58.8%)
27	I had a sinking feeling in the pit of my stomach	184 (82.1%)	142 (63.7%)	326 (72.9%)
28	I felt like I was descending rapidly in an elevator	40 (17.9%)	39 (17.5%)	79 (17.7%)
29	I had especially vivid memories of my loved one….	211 (94.2%)	168 (75.3%)	379 (84.8%)
30	I sensed or felt the presence of the person who died	161 (71.9%)	93 (41.7%)	254 (56.8%)
31	I saw, heard, smelled, or felt touched by my...loved one	103 (46%)	51 (22.9%)	154 (34.5%)

Perception/Sense-Making Items Across Samples (cont'd.)

Item		non-SONA sample (*n*=224)	SONA sample (*n*=223)	Total Sample (*N*=447)
32	I thought I heard my deceased loved one's voice	85 (37.9%)	47 (21.1%)	132 (29.5%)
33	I thought I saw my deceased loved one	55 (37.9%)	41 (18.4%)	96 (21.5%)
34	I thought I felt my deceased love one beside me	81 (36.2%)	41 (18.4%)	122 (27.3%)
35	I talked to my loved one even though (s)he is not here	171 (76.3%)	84 (37.7%)	255 (57%)
36	Things around me felt unreal or dreamlike	154 (68.8%)	93 (41.7%)	247 (55.3%)
37	It could be hard to tell if I was awake or asleep	28 (12.5%)	34 (15.2%)	62 (13.9%)
38	I had more dreams	110 (49.1%)	68 (30.5%)	178 (39.8%)
39	My dreams about my loved one were comforting	124 (55.4%)	78 (35%)	202 (45.2%)
40	My dreams about my loved one were disturbing	69 (30.8%)	34 (15.2%)	103 (23%)
41	I had fewer dreams	42 (18.8%)	34 (15.2%)	76 (17%)
42	I had difficulty falling and/or staying asleep	172 (76.8%)	102 (45.7%)	274 (61.3%)
43	I felt the presence of my loved one….	104 (46.4%)	48 (21.5%)	152 (34%)
44	Thinking of my loved one made it easier to fall asleep	71 (31.7%)	39 (17.5%)	110 (24.6%)
45	On waking I didn't remember that my loved one had died	115 (51.3%)	93 (41.7%)	208 (46.5%)
46	My thoughts could come so fast I can't write them down	63 (28.1%)	42 (18.8%)	105 (23.5%)
47	Thinking of my loved one made it harder to fall asleep	138 (61.6%)	87 (39%)	225 (50.3%)
48	I experienced an altered state of consciousness….	51 (22.8%)	35 (15.7%)	86 (19.2%)
49	I had...a heightened awareness of sights and sounds….	26 (11.6%)	30 (13.5%)	56 (12.5%)
50	I felt like I had mystical experiences	45 (20.1%)	21 (9.4%)	66 (14.8%)
51	Time seemed to pass very slowly	123 (54.9%	88 (39.5%)	211 (47.2%)
52	Events seemed to happen in slow motion	84 (37.5%)	66 (29.6%)	150 (33.6%)
53	Time seemed to go by quickly	99 (44.2%)	59 (26.5%)	158 (35.3%)
54	Events seemed to speed up	53 (23.7%)	42 (18.8%)	284 (63.5%)
55	Time seemed to stand still	75 (33.5%)	71 (31.8%)	146 (32.7%)
56	I had difficulty keeping track of time	111 (50.2%)	67 (30%)	178 (39.8%)
57	It was challenging for me to...gauge the passage of time	89 (39.7%)	58 (26%)	147 (32.9%)
58	I felt that my sense of time didn't work the way it used to	78 (34.8%)	56 (25.1%)	134 (30%)

Note. Missing records < 5 for all items; the average number of missing records was 1.52 (*SD* = 1.2). Items #38 and #41 (*I had more/fewer dreams*) do not include a follow-up item (*How has this changed over time?*) for those endorsing, as this would not have made sense. All other items do feature this follow-up. As it appears in this table, wording of some items has been altered slightly; see Appendix C for exact wording.

In Chapter 2, the perception/sense-making dimension of the loss-processing framework was described using the following subcomponents: shock-like symptoms, intrasensory processing, intersensory processing, extrasensory processing, and time. Extrasensory processing was further subdivided into hallucinations, dreams, threshold consciousness, and transliminality. Chapter 5 outlined the process used for researching, selecting, and developing items assessing

each of these categorizations. Challenges in separating these constructs and appropriately assigning items to assess each of them has been noted previously; data summarizing their percentage endorsement (by category) across samples is presented in Table 8.

Table 8

Perception/Sense-Making Percentage Endorsement by Category Across Samples

Category (item numbers)	non-SONA sample (*n*=224)	SONA sample (*n*=223)	Total Sample (*N*=447)
Shock-like symptoms (1-11)	66.88%	51.41%	59.14%
Intrasensory processing (12-24)	19.33%	14.52%	16.93%
Intersensory processing (25-28)	56.36%	37.22%	46.79%
Extrasensory processing (29-50)	40.50%	25.68%	33.09%
Hallucinations (29-35)	55.29%	33.63%	44.46%
Dreams (36-41)	39.21%	25.49%	32.35%
Threshold consciousness (42-47)	49.33%	30.72%	40.02%
Transliminality (48-50)	18.16%	12.86%	15.51%
Time (51-58)	39.73%	28.42%	34.08%

Note. See Table 7 for a numbered listing of all Perception/Sense-Making items.

As summarized for the combined sample of both groups (in the third column above), these data indicate lower endorsement for items designated to assess intrasensory processing (16.93%) and the transliminality subcategory of extrasensory processing (15.51%). Higher endorsement percentages were reported for intersensory processing (46.79%), the hallucinations subcomponent of extrasensory processing (44.46%), and shock-like symptoms (59.14%). The latter two categories exhibit the greatest differences between the non-SONA and SONA samples, with the younger/SONA group's percentage being 19.14 points lower for intersensory processing and 21.66 points lower for hallucinations. Findings offer initial support for the validity of the construct of grief-related sensory perceptions (perception/sense-making). Many of the proposed perceptions were endorsed, however there was wide variation among them (e.g., the highest

endorsed category was *Shock-like symptoms* [59.14%] and the lowest was *Intrasensory processing* [16.93%]).

Chapter 7. Discussion

Analysis

Results from this preliminary survey of self-report items assessing aspects of the loss-processing framework's first dimension (perception/sense-making) indicate provisional support across its subcomponents, with participants endorsing some aspects of the dimension more than others. The lower endorsement percentage for intrasensory processing assessment items may relate to the agnosia-like qualities of this particular component of perception/sense-making. With respect to agnosia-like symptoms in bereavement, it is important to recall (as outlined in Chapter 2) that with agnosia no single sense is actually impaired—only its perception—and there is no major memory loss (see, e.g., Joseph, 2018; Puente & Tonkonogy, 2009). This could mean that (mild,) grief-related agnosic symptoms are not recalled because they are not remembered by the person who had them—not necessarily because they did not occur. This feature of agnosia could make recalling them in retrospect difficult. The assessment of agnosia in non-grief contexts can also be challenging (see, e.g., Bauer, 2006; Burns, 2004). For example, diagnosing visual agnosia may require participants to view a photograph and then to draw or describe it—with diagnostic criteria relying on discrepancies between the two. Retrospectively detecting this type of intrasensory disruption using Likert-scale items may not be possible. That being said, agnosia-like symptoms relating to the tracking of time were more endorsed in this survey (34.08%, n = 152). Thus, including time-related items could benefit the assessment of intrasensory processing in relationship to grief.

Another possible factor in the lower endorsement of intrasensory processing is the bidirectionality of several of the items (e.g., see item numbers: 12 & 19, 14 & 22, 15 & 23, 18 & 20, and 21 & 24; Appendix C). Although perhaps consistent with the oft-reported wave-like

patterning of the experience of grief—possibly similar to the oscillation described in Stroebe and Schut's (1999, 2001, 2010) dual process model (DPM) of coping in grief—including items asking respondents to consider endorsing (or not) pairs of "opposites" could have been problematic. For example, including the two items *smells seemed weaker or less noticeable than usual* and *smells seemed stronger or more noticeable than usual* may have served to dampen the endorsement of both (this could have also impacted other portions of the survey, e.g., with respect to dreams). During survey development a disclaimer was considered to address this concern. This would have been a brief statement (provided prior to starting the survey) indicating that discrepant items could both be endorsed (or not), since grief is often experienced in a wave-like manner—with certain of its characteristics seeming to ebb and flow over time. In the end such a statement was not included due to concerns that it could be too confusing for participants.

An over-valuing of the meaning assigned to sensory stimuli (included as an agnosia-like characteristic in the section on intrasensory processing in Chapter 2) could be an alternative way to better assess this duality. For example, these items could be constructed using more nuanced language addressing the potential meaningfulness and/or enhancement of sensory-perceptual experiences through grief, rather than merely confirming whether or not specific senses seemed stronger or weaker (than usual). Such an approach could help with items assessing another of the lesser-endorsed constructs included in the current survey, transliminality. It is important to remember, however, that lower item endorsement does not preclude an item's potential utility—possibly as an indication of grief complications or of a growth/learning opportunity. Exploring alexithymia as well as expressive and affective agnosia as potential sources for items relating to emotional perception could also be beneficial to intrasensory item development.

Thelen and Smith's (1994) assertion that "…there is little or no learning or development that is strictly within modality" (p. 194) also bears mentioning with respect to challenges in measuring intrasensory processing. Experiencing the world multimodally may make it harder to remember those experiences unimodally. This could be (one of) the reason(s) intersensory processing was the second most endorsed component of perception/sense-making (46.79%).

The percentage endorsement for hallucinations (a subcategory of extrasensory processing) was close to that of intersensory processing for the combined sample (44.46%); recall that these two categories also feature the greatest disparity in percentages between the two groups, with the SONA sample being 21.66 points lower for hallucinations and 19.14 points lower for intersensory processing (threshold consciousness was third at 18.61 points lower). The language used for the hallucination-related items could perhaps aid in teasing this apart in the future. For example, item 30 (*I sensed or felt the presence of the person who died*) could be used with either *sensed* or *felt the presence of* (rather than both) along with *my loved one* instead of *of the person who died* to see if this would be more similarly endorsed by both the SONA and non-SONA samples. As noted previously, the stigma associated with reporting having had hallucinatory experiences may have played a role in endorsement levels for these items. It could also be that these are age- or other sample characteristic-related differences that are not language-dependent.

Shock-like symptoms was the most endorsed category for both groups of participants, with the combined sample endorsing these 11 items averaging 59.14%. It is possible that this was influenced by the fact that these were the first non-socio-demographical items to be presented in the survey, and participants were ready to get started (thus perhaps attending to these initial items more than to those that followed). Other possibilities include, but are not

limited to: 1) shock is typically considered a temporary physiological state and is therefore possibly more endorsable than (some of the) other characteristics outlined in the perception/sense-making dimension—which could be viewed as potentially more permanent, psychological in nature, and therefore also more subject to stigmatization. The word *shock* was not, however, used in any of these items, and several of them related to dissociative symptoms of severe (dis)stress (e.g., items 4, 6, 8, and 10). 2) The author's past experiences as a funeral director could have served to somehow aid in the selection of shock-like symptom-related items, since most often a funeral director is with families during the period of time immediately after the death of their loved one (which is known to feature shock-like symptoms). This may have influenced the selection of more authentic or resonant items assessing shock-like symptoms for those remembering their grief. These items were also closely aligned with those from existing scales with items assessing acute (dis)stress, dissociation, depersonalization, and derealization, which were valuable tools in developing assessment items for shock-like symptoms relating to grief (see Appendices A and E – J). 3) Participants possibly endorsed these items more often because they included more general descriptions (e.g., *I had difficulty concentrating/focusing attention*; *I felt restless*; *I felt numb*; *I felt as if I was in a daze*) that were therefore more endorsable. 4) These items resonated more with the grief experiences of participants; thus, they were more endorsed by those participating in the survey. Or, 5) A combination of the aforementioned factors.

Implications

This study articulates a new approach to the understanding of grief, the loss-processing framework. While there is existing support for the framework's three dimensions: perception/sense-making, orientation/way-finding, and direction/perspective-seeking (as

articulated in Chapters 2-4), extant support is strongest for the framework's third dimension, direction/perspective-seeking (or meaning-making). Thus, this preliminary study examined the self-reported retrospective survey responses of bereaved adults containing items selected or developed to assess what is perhaps the least-well studied dimension of the framework, perception/sense-making—and its subcomponents.

The current project added descriptive detail regarding how grief is understood in relationship to sensory-perceptual processing. Results confirmed some support for selected aspects of the perception/sense-making dimension (e.g., shock-like symptoms, intersensory processing, and the extrasensory processing subcomponents of hallucinations and threshold consciousness) but found less support for items assessing other facets of the dimension (e.g., intrasensory processing and the extrasensory processing subcomponent of transliminality).

Challenges regarding the assessment of perception/sense-making may relate to how some aspects of this dimension of the framework have been categorized. For example, including possible agnosia-like impacts on the intrasensory processing of the perception of time and emotions during grief may be helpful in future development of assessment items. Also, altering items to avoid bidirectionality could aid in better assessing intrasensory processing and dreams in perception/sense-making.

The primary aim of collecting and examining these data was to conduct an initial empirical investigation of the first dimension of the loss-processing framework. Doing so underscores the import of the item development process. For example, item 28 (*I felt like I was descending rapidly in an elevator*) was extrapolated from the feeling described by Handler (1999) when: "…thinking there is one more stair than there is. Your foot falls down, through the air, and there is a sickly moment of dark surprise as you try and readjust the way you thought of

things" (p. 97). An item relating to this feeling Handler describes might be endorsed differently than the elevator item that was included in the current survey (which received the fewest endorsements of all items assessing intersensory processing). Similarly, of the eight items relating to the perception of time, two (51 and 56) were endorsed more often; thus, only these could be used in the future to avoid redundancy.

An important implication of the current study, then, is that although it indicates some preliminary support for the loss-processing framework's first dimension, much additional work is needed. Going forward, some of this work will rely upon continued data collection (which is ongoing). A thorough investigation of socio-demographical, bereavement, mourning, grief, and health-related data in association with the perception/sense-making dimension's components is warranted. These analyses will be done in tandem with an assessment of survey data collected regarding the framework's other two dimensions, orientation/way-finding and direction/perspective-seeking, as well as data regarding the trajectory of each item's change over time. Direction/perspective-seeking includes psychometrically validated instrumentation assessing meaning-making, and orientation/way-finding includes items that potentially overlap with those assessing perception/sense-making.

Limitations

Data collection during COVID-19 is a potential limitation of this study. Retrospective self-reports of the experience of loss response during a time of such exceptional loss(es) was possibly problematic. Five participants reported having experienced the loss of a loved one due to the pandemic in their survey responses. It was unfortunate to be assessing grief when attending collective mourning rituals was, for the most part, not possible. Lockdowns, closures, and isolation related to the pandemic may have increased the likelihood of online survey

participation, but trust in (and participation on) the social media platforms used to promote the survey to potential participants was tenuous during this time of upheaval. The reported mental and physical health and well-being of participants was also likely impacted by COVID-19.

Some characteristics of the SONA sample are also limiting, including a lack of geographic and age diversity (constricting the generalizability of these findings), as well as incentivized participation. The SONA studies that were available on-line (and needed in order to achieve the required research credits to avoid grade degradation) were few in number; it is difficult to imagine—but hard to know—how this would not have resulted in participation outside of study guidelines (i.e., students taking the survey who were not bereaved). Opening the survey to SONA in the first place was due to another limitation of the study, finding participants. In this case SONA enabled outreach to and procurement of as many participants in a few weeks as had been previously enlisted in as many months—but their data remains marginally suspect due to the incentivization of their participation.

There were gender identity, race, sexual orientation, and religious affiliation diversity deficiencies for both the SONA and non-SONA samples. The ETSU/SONA sample did exhibit more diversity than the non-SONA sample in terms of race/ethnicity and sexual orientation. The non-SONA group provided greater geographical and age diversity.

Limitations regarding research involving individuals who have experienced loss due to the death of a loved one are well documented (see, e.g., Cassileth & Lusk, 1989; Grande & Todd, 2000; Hudson et al., 2005; Hudson & Hayman-White, 2006). Doing so by anonymous online survey may appear to alleviate some of these concerns, but not altogether. Selecting and wording items for inclusion in the survey was particularly difficult; efforts to “do no harm” in the process of probing for meaningful information regarding the grief experiences of individuals

proved both challenging and limiting. For example, the age of decedent at time of death item did not allow for deaths under the age of 1, which resulted in some participants selecting "0" or using decimal points in response to this item. And for the final mourning-related characteristic, burial and cremation are not mutually exclusive; the former can follow the latter. Also, the ordering of items in the survey was limiting—whereas randomizing them would have been preferred, to avoid possible order effects, doing so could have made the participants' experience potentially more taxing. Item ordering was therefore not randomized.

Future Directions

Having described the loss-processing framework and subsequently designed and implemented a preliminary survey of self-report items assessing aspects of its dimensional components (one of the three of which is reported herein), a future research direction will be to finalize data collection for this assessment and to further analyze it. This includes data regarding the framework's three dimensions, their possible relationship(s) to one another, and the potential associations between/among them and mental and physical health and well-being; specified characteristics of bereavement, grief, and mourning; and socio-demographical factors. Follow-up items regarding the trajectory of change over time (*occurring more often*, *occurring less often*, *unchanged*, or *no longer occurring*) will be important to consider, as these trajectories may aid in possibly predicting other constructs assessed in the survey (e.g., those addressing health and well-being, grief, and/or meaning-making). Further refinement of the items/instruments assessing the framework will be a natural outgrowth of this line of research and will be requisite to further examination of the relationships outlined above.

The framework may have utility as an applied, interpretive model of grief as well. This was the reason for its initial conception, to perhaps serve as a modular tool to help individuals

better apprehend their grief in order to grow both through and with it. For example, might it be possible to create an environment for survivors where awareness of dimensional aspects of the loss-processing framework (perception/sense-making, orientation/way-finding, and direction/perspective-seeking) is cultivated for individuals prior to death's occurrence (in pre-loss bereavement—during palliative/hospice care for their loved one), so as to better leverage the experience of loss (which is inevitable) toward positive personal growth for survivors in its wake? Or might a post-loss intervention more fully articulating and encouraging awareness of the loss-processing framework's dimensions suffice? Or would a combination of both of these approaches be preferred? And, as noted at the end of Chapter 4, more research is needed regarding the possible underlying relationship(s) between and among potential constructs such as resilience, religiousness, spirituality, sense of coherence, forgiveness, and self-compassion (as well as awe, communion, Eudaimonia, flourishing, gratitude, [progressive] hope, personal sense of uniqueness, poignancy, surrender, and other meaning-making-related concepts) and the components of the loss-processing framework.

Conclusion

The current study articulated a novel approach to framing our understanding of response to loss due to human death, the loss-processing framework. Fifty-eight preliminary items assessing the framework's first dimension, perception/sense-making, were developed and administered to a group of 447 participants; initial support for the framework was indicated in the survey responses from this sample.

A better understanding of grief through the loss-processing framework may serve to identify and possibly alleviate (or even prevent) complications due to bereavement, improve

interventions when such complications are indicated, and enhance the adaptive and generative potential for personal growth in response to loss.

Considering the provisional nature of the current study, further inquiry is necessary. First, additional work is warranted regarding the framework's other two dimensions (orientation/way-finding and direction/perspective-seeking). These data have been—and are continuing to be—collected as of the completion of this paper, and their analysis is forthcoming. Future research, perhaps also using qualitative and/or mixed methods approaches, may be needed to provide additional descriptive detail regarding the range of grief experiences relating to the proposed framework. These added empirical techniques could aid in adapting and creating measurement instrumentation (possibly using items included herein) to better leverage the loss-processing framework as a possibly predictive, interpretive, and functional tool for enhancing grief, mental and physical health, and quality of life outcomes.

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APPENDICES

Appendix A: Specific Symptoms of Acute Stress Disorder (ASD: APA, 2013)

Acute stress disorder is most often diagnosed when an individual has been exposed to a traumatic event in which both of the following were present:

- The person experienced, witnessed, or was confronted with (e.g., can include learning of) an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others.
- Though not required, the person's response is likely to involve intense fear, helplessness, or horror.

Either during or following the distressing event, the individual has 3 or more of the following dissociative symptoms:

- A subjective sense of numbing, detachment, or absence of emotional responsiveness
- A reduction in awareness of his or her surroundings (e.g., "being in a daze")
- Derealization
- Depersonalization
- Dissociative amnesia (i.e., inability to recall an important aspect of the trauma)

The traumatic event is persistently re-experienced in at least one of the following ways: recurrent images, thoughts, dreams, illusions, flashback episodes, or a sense of reliving the experience; or distress when exposed to reminders of the traumatic event.

Acute stress disorder is also characterized by significant avoidance of stimuli that arouse recollections of the trauma (e.g., avoiding thoughts, feelings, conversations, activities, places, people). The person experiencing acute stress disorder also has significant symptoms of anxiety or increased arousal (e.g., difficulty sleeping, irritability, poor concentration, hypervigilance, exaggerated startle response, motor restlessness).

For acute stress disorder to be diagnosed, the problems noted above must cause clinically significant distress or impairment in social, occupational, or other important areas of functioning or impairs the individual's ability to pursue some necessary task, such as obtaining necessary assistance or mobilizing personal resources by telling family members about the traumatic experience.

The disturbance in an acute stress disorder must last for a minimum of 3 days and a maximum of 4 weeks, and must occur within 4 weeks of the traumatic event. Symptoms also cannot be the result of substance use or abuse (e.g., alcohol, drugs, medications), caused by or an exacerbation of a general or preexisting medical condition, and cannot be better explained by a brief psychotic disorder.

Appendix B: Advertisements and Other Participant Recruitment Materials

Snowball e-mail template (and Facebook/Reddit ad):

As part of my research to better understand the experience of grief, I am collecting data via an online survey.

If you have experienced grief in response to loss due to human death, then I invite you to take the survey.

Please also forward this e-mail invitation to others and share the ad below through your social media.

The link to the survey is here: Grief Experience Survey (https://etsuredcap.etsu.edu/surveys/?s=RLAYYRD3MA or http://tinyurl.com/griefexperiencesurvey)

Thank you!

Larry

_____

Larry Childress, M.A.
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SONA Ad Description

This study seeks to better understand the experience of grief in response to loss due to human death. Participants will be asked to complete an online survey regarding their personal experience of loss, their overall health/well-being, and meaning in their lives. Although times will vary, it should take approximately 30 minutes to complete the survey, which also includes some questions collecting demographic information. Participation in this research is completely voluntary and may be discontinued at any time; all responses are anonymous.

Appendix C: The Grief Experiences Survey

Age:

Country of residence (US, non-US):

What is your zip code?

If non-US country, what is your country of residence?

Please indicate the type of area you currently live in (urban, suburban, rural):

Gender identity (female, male, other):

Sexual orientation (asexual, bisexual, gay, lesbian, pansexual, questioning or unsure, straight, other):

Race/Ethnicity (please select all that apply; Alaska native, Black, East Asian, Latino/a or Hispanic, Middle Eastern, Native Hawaiian, White, Multiracial, other):

Which of the following best describes your living situation (live alone, with parents, roommate, spouse/romantic partner, no permanent residence, other)?

Please describe your current employment status (not working, working part-time, working full-time, retired, other):

How would you classify your personal financial situation (low-income, lower-middle income, middle-income, upper-middle income, upper income)?

Please describe your current relationship status (single never married, in a relationship living separately, cohabitating with a romantic partner, married, separated, divorced, domestic partnership, widowed, other):

Education (please select one; some high school, technical training, high school grad or equivalent, some college no diploma, associate's degree, bachelor's degree, advanced degree, other):

Are you a student (no, yes part time, yes full time)?

Are you a parent (yes, no)?

Religious or non-religious affiliation (please select one; Buddhist, Christian-Catholic, Christian-Protestant, Episcopalian/Anglican, Jehovah's Witness, Jewish, Hindu, Mormon, Muslim, Sikh, Unitarian, Wiccan, Atheist, Agnostic, Humanist, Religious affiliation not specified, other):

How often do you go to religious services (never, 1-2 time/year, every month, every week?

I feel calm and relaxed (WHO-5 Q1; at no time, some of the time, less than ½ of the time, more than ½ of the time, all of the time—*see Appendix D for additional information re. responses*)

I feel cheerful and in good spirits (WHO-5 Q2)

I feel active and vigorous (WHO-5 Q3)

I wake up feeling fresh and rested (WHO-5 Q4)

My daily life is filled with things that interest me (WHO-5 Q5)

How would you rate your physical health (poor, fair, good, very good, excellent):

How would you rate your mental health? (poor, fair, good, very good, excellent):

Please complete the following statement describing your relationship to the person who died: he or she was my (husband, wife, partner, grandfather, grandmother, father, mother, father-in-law mother-in-law, brother, sister, brother-in-law, son, daughter, uncle, aunt, nephew, niece, friend, other)?

Approximately how long ago did your loved one die (< 1 month, 1-3 months, 4-6, 7-12, 13-18, 19-24 months, 2-3 years, 4-5, 5-10, more than 10 years):

Approximate age of the person when they died

Cause of death (natural causes-anticipated; natural causes-sudden, overdose, accident, homicide, COVID-19, Not known, Do not recall):

Were you (one of) the primary caregiver(s) for your loved one prior to their death (yes, no, do not recall)?

Did the death of your loved one follow palliative/hospice care (yes, no, do not recall)?
If yes then approximately how long was your loved one in palliative/hospice care (1-4 weeks, 5-8 weeks, 3-6 months, 7-12, 13-18, 19-24, more than 2 years)?
Did you view the body of your loved one after the death (yes, no, do not recall)?
Was there any type of funeral ceremony or memorial service for your loved one (yes, no, do not recall)?
If so, then did you attend (yes, no, do not recall)?
If so, then did you find attending the service to be meaningful (yes, no, do not recall)?
Was the body of your loved one (cremated, buried, donated for scientific/medical/research purposes, other):
Did you seek professional help for grief-related issues at any point following this death (yes, no, do not recall)?
If so, then from whom did you seek help (such as, a therapist, physician, counselor, pastor or spiritual advisor, social worker, grief support group, etc.)?
In general, did you find this help-seeking to be beneficial to you (yes, no, do not recall)?
Response options for 1-66: *never*, *rarely*, *occasionally*, *a moderate amount*, *a great deal* or *do not recall*.
If responding *never*, *rarely*, *occasionally*, *a moderate amount*, or *a great deal*, then followed by:
How has this changed over time?: *less often*, *unchanged*, *more often*, *no longer occurring*, or *unsure*.
NOTE: Items #38 and #41 (*I had more/fewer dreams*) do not include a follow-up item (*How has this changed over time?*), as this would not have made sense.

1 I had difficulty concentrating/focusing attention
2 I felt restless
3 I felt numb
4 I felt distant from my own emotions
5 I felt as if I was in a daze
6 I felt like I was watching things happen from outside myself
7 Memories of the death kept entering my mind
8 My surroundings seemed strange or unreal
9 I felt like I was slow to respond to what was happening around me
10 I looked in the mirror and felt as though I did not recognize myself
11 I felt as if I might be losing my mind, but I was reluctant to share this with others
12 Smells seemed weaker or less noticeable than usual
13 Indoor lights seemed so bright that they bothered my eyes
14 Tastes seemed blander or less noticeable than usual
15 I felt as if the volume control on my world had been turned down
16 My vision seemed dulled
17 Things I saw looked different to me than how I know they really look
18 People and objects seemed more distant and unclear
19 Smells seemed stronger or more noticeable than usual
20 People and objects seemed closer and clearer
21 Colors seemed to appear dull or muted
22 Tastes seemed stronger or more noticeable than usual
23 I felt as if the volume control on my world had been turned up
24 Colors seemed to appear more vivid and vibrant
25 I felt like I was walking on shifting ground

26 I felt as if I was in a fog
27 I had a sinking feeling in the pit of my stomach
28 I felt like I was descending rapidly in an elevator
29 I had especially vivid memories of my loved one who died
30 I sensed or felt the presence of the person who died
31 I saw, heard, smelled, or felt touched by my deceased loved one
32 I thought I heard my deceased loved one's voice
33 I thought I saw my deceased loved one
34 I thought I felt my deceased love one beside me
35 I talked to my loved one even though (s)he is no longer living
36 Things around me felt unreal or dreamlike
37 It could be hard to tell if I was awake or asleep
38 I had more dreams
39 My dreams about my loved one were comforting
40 My dreams about my loved one were disturbing
41 I had fewer dreams
42 I had difficulty falling and/or staying asleep
43 I felt the presence of my loved one, but could not see, hear, touch, or smell anyone there
44 Thinking of my loved one made it easier to fall asleep
45 When I first woke up, sometimes initially I didn't remember that my loved one had died
46 My thoughts could come so quickly that I couldn't seem to write them down fast enough
47 Thinking of my loved one made it harder to fall asleep
48 I experienced an altered state of consciousness in which I felt that I became more enlightened
49 I had such a heightened awareness of sights and sounds that I felt I could not shut them out
50 I felt like I had mystical experiences
51 Time seemed to pass very slowly
52 Events seemed to happen in slow motion
53 Time seemed to go by quickly
54 Events seemed to speed up
55 Time seemed to stand still
56 I had difficulty keeping track of time
57 It was challenging for me to accurately gauge the passage of time
58 I felt that my sense of time didn't work the way it used to
59 I felt challenged in navigating the world around me
60 I misplaced things
61 It seemed to take me longer to accomplish tasks-- to get from A to B-- than usual for me
62 I felt as if my internal compass stopped working
63 There have been times when it seemed harder for me to gauge the distance between things
64 I've felt lost
65 I had difficulty remembering things
66 I felt as if I just woke up in an unfamiliar place

Response options for 67-76: *strongly agree, agree, neither agree nor disagree, disagree*, or *strongly disagree.*

67 Since the death, I don't know where to go next in my life

68 I don't understand myself anymore since the death

69 The death has made me feel less purposeful

70 I have difficulty integrating the death into my understanding about the world

71 This death is incomprehensible to me

72 I am perplexed by what happened

73 I'm more creative

74 I've grown as a person

75 I'm better able to adapt to different and changing situations

76 I'm more able to find meaning in life

Response options for 77-85: *Does not describe me at all*, *Does not quite describe me*, *Describes me fairly well*, *Describes me well*, or *Describes me very well*

77 I have learned to cope better with life

78 I feel as though I am a better person

79 I have a better outlook on life

80 I have more compassion for others

81 I am stronger because of the grief I have experienced

82 I am a more forgiving person

83 I am more tolerant of myself

84 I am having more good days than bad

85 I care more deeply for others

Response options for 86-91: *I did not experience this change as a result of the death*, *I experienced this change to a very small degree as a result of the death*, *I experienced this change to a small degree as a result of the death*, *I experienced this change to a moderate degree as a result of the death*, *I experienced this change to a great degree as a result of the death*, or *I experienced this change to a very great degree as a result of the death*

86 I have greater clarity about life's meaning

87 I feel better able to face questions about life and death

88 I feel more connected with all of existence

89 I have a greater sense of harmony with the world

90 I have a better understanding of spiritual matters

91 I have a stronger religious faith

Response options for 92-93: *never true of me*, *occasionally true of me*, *fairly often true of me*, *very often true of me*, *always true of me*, or *not applicable*

When my understanding of a problem conflicts with God's revelation, I will submit to

92 God's definitions

93 Although I may not see results from my labor, I will continue to implement God's plans as long as God directs me to do so.

How much sense would you say you have made of the loss of your loved one?

94 *no sense*, *slight sense*, *some sense*, *a moderate amount of sense*, or *a great deal of sense*

Despite the loss, have you been able to find any benefit from your experience of the loss?

95 *no benefit*, *slight benefit*, *some benefit*, *moderate amount of benefit*, or *a great deal of benefit*

Do you feel that you are different--that your sense of identity has changed--as a result of this loss?

96 *not at all different*, *slightly different*, *somewhat different*, *moderately different*, or *a great deal different*

97 What has been the direction in this difference in your sense of how your identity has changed? *for the better*, *mixed*, or *for the worse*

98 How have you searched for meaning in your loved one's death?
99 How have you searched for meaning in your own life since your loved one's death?
100 What additional support did you need following the death of your loved one that you did not receive?
101 If you could send a message to your deceased loved one, what would it be?

Appendix D: The Who-5 Well-Being Index (Staehr Johansen, 1998; Topp et al., 2015)

The WHO-5 questionnaire

Instructions:
Please indicate for each of the 5 statements which is closest to how you have been feeling over the past 2 weeks.

Over the past 2 weeks...	All of the time	Most of the time	More than half the time	Less than half the time	Some of the time	At no time
1 ... I have felt cheerful and in good spirits	5	4	3	2	1	0
2 ... I have felt calm and relaxed	5	4	3	2	1	0
3 ... I have felt active and vigorous	5	4	3	2	1	0
4 ... I woke up feeling fresh and rested	5	4	3	2	1	0
5 ... my daily life has been filled with things that interest me	5	4	3	2	1	0

Scoring principle: The raw score ranging from 0 to 25 is multiplied by 4 to give the final score from 0 representing the worst imaginable well-being to 100 representing the best imaginable well-being.

The wording was changed from present perfect to present tense for these items in the current study. This was because much of the survey's content asks questions about the more distant past, and these questions are ascertaining participant feelings regarding the past two weeks. The new item wording is as follows:

1. I feel cheerful and in good spirits
2. I feel calm and relaxed
3. I feel active and vigorous
4. I wake up feeling fresh and rested
5. My daily life is filled with things that interest me

Due to an entry error, one of the response choices (*Most of the time*) was not included in the WHO-5 in the Grief Experiences Survey; as such, the possible responses were:

The WHO-5 questionnaire

Instructions:
Please indicate for each of the 5 statements which is closest to how you have been feeling over the past 2 weeks.

Over the past 2 weeks...	All of the time	More than half the time	Less than half the time	Some of the time	At no time
1 ... I have felt cheerful and in good spirits	5	4	3	2	1
2 ... I have felt calm and relaxed	5	4	3	2	1
3 ... I have felt active and vigorous	5	4	3	2	1
4 ... I woke up feeling fresh and rested	5	4	3	2	1
5 ... my daily life has been filled with things that interest me	5	4	3	2	1

The response *At no time* received 0 points, other responses were scored as follows: 2 = 2⅓; 3 = 3⅓; 4 = 4⅓, 5 = 5. The sum of these was multiplied by 4.

Appendix E: Sources Used in Developing Perception/Sense-Making Items

Key:

ASD = Specific Symptoms of Acute Stress Disorder (Appendix A)
ASDS = the Acute Stress Disorder Scale (Appendix F)
SASRQ = Stanford Acute Stress Reaction Questionnaire (Appendix G)
DDI = Depersonalization/Derealization Inventory (Appendix H)
DES-II = Dissociative Experiences Scale (Appendix I)
CDS = Cambridge Depersonalization Scale (Appendix J)
RTS = Revised Transliminality Scale (Appendix K)

Perception/Sense-Making Items included in the Grief Experiences Survey

Item [All items are introduced with: Think about the time following the death of your loved one. Would you say:]	Subcategory of Perception/ Sense-making	Item Source(s)
1) I had difficulty concentrating/focusing attention	Shock	ASD; ASDS: 16; SASRQ: 9 anxiety—62% endorsed, .40 Item-Scale corr.; DDI: 1,3,21,24; DES-II: 2
2) I felt restless	Shock	SASRQ: 2; anxiety—62% endorsed, .40 Item-scale corr.
3) I felt numb	Shock	ASD; DDI: 6; ASDS: 1; DDI: 6
4) I felt distant from my own emotions	Shock	ASD; ASDS, 1; SASRQ: dissoc.—28% endorsed, .54 Item-scale corr.; DDI: 8,13; CDS: 9
5) I felt as if I was in a daze	Shock	ASD; ASDS: 2; DDI: 26,28; DES-II: 20; CDS: 1
6) I felt like I was watching things happen from outside myself	Shock	ASD; ASDS: 4; DDI: 10; DES-II: 7,13; CDS: 3,6,15,23
7) Memories of the death kept entering my mind	Shock	ASD; ASDS: 6; SASRQ: anxiety—26% endorsed, .38 Item-scale correlation
8) My surroundings seemed strange or unreal	Shock	DDI: 1, 7; ASDS: 3; DES-II: 12
9) I felt like I was slow to respond to what was happening around me	Shock	SASRQ: dissoc.—25% endorsed, .53 Item-scale correlation
10) I looked in the mirror and felt as though I did not recognize myself.	Shock	SASRQ: 10 dissoc.—10% endorsed, .57 Item-scale correlation; DES-II: 11
11) I felt as if I might be losing my mind, but I was reluctant to share this with others	Shock	Larry Childress
12) Smells seemed weaker or less noticeable than usual	Intrasensory Processing	CDS: 25
13) Indoor lights seemed so bright that they bothered my eyes	Intrasensory Processing	RTS: 13
14) Tastes seemed blander or less noticeable than usual	Intrasensory Processing	CDS: 7

Item [All items are introduced with: Think about the time following the death of your loved one. Would you say:]	Subcategory of Perception/ Sense-making	Item Source(s)
15) I felt as if the volume control on my world had been turned down	Intrasensory Processing	Alfred Wilson (see King, 2018)
16) My vision seemed dulled	Intrasensory Processing	DDI: 18
17) Things I saw looked different to me than how I know they really look	Intrasensory Processing	SASRQ: 11% endorsed; .51 Item-Scale Correlation; DDI: 11; DES-II: 12
18) People and objects seemed more distant and unclear	Intrasensory Processing	DDI: 9; DES-II: 28; CDS: 19
19) Smells seemed stronger or more noticeable than usual	Intrasensory Processing	Andrea Clements; RTS: 19
20) People and objects seemed closer and clearer	Intrasensory Processing	Opposite of #18 (above)
21) Colors seemed to appear less dull or muted	Intrasensory Processing	Opposite of #24 (below)
22) Tastes seemed stronger or more noticeable than usual	Intrasensory Processing	Opposite of #14 (above)
23) I felt as if the volume control on my world had been turned up	Intrasensory Processing	Opposite of #15 (above)
24) Colors seemed to appear more vivid and vibrant	Intrasensory Processing	Elizabeth Feldstein (see Deerwester, 2019)
25) I felt like I was walking on shifting ground	Intersensory Processing	DDI: 19
26) I felt as if I was in a fog	Intersensory Processing	DDI: 26,28; DES-II: 28; CDS: 1
27) I had a sinking feeling in the pit of my stomach	Intersensory Processing	DDI: 3
28) I felt like I was descending rapidly in an elevator.	Intersensory Processing	adapted from Handler, 1999
29) I had especially vivid memories of my loved one who died	Extrasensory Processing Hallucinations	Common across multiple sources
30) I sensed or felt the presence of the person who died	Extrasensory Processing Hallucinations	see e.g., Castelnovo et al., 2015
31) I saw, heard, smelled, or felt touched by my deceased loved one	Extrasensory Processing Hallucinations	see, e.g., Troyer, 2005, 2014; see also Durham Hypnagogic and Hypnopompic Questionnaire: 1, 14 (Jones et al., 2009)
32) I thought I heard my deceased loved one's voice.	Extrasensory Processing Hallucinations	see e.g., Sacks, 2012

Item [All items are introduced with: Think about the time following the death of your loved one. Would you say:]	Subcategory of Perception/ Sense-making	Item Source(s)
33) I thought I saw my deceased loved one.	Extrasensory Processing Hallucinations	Sacks, 2012; Durham Hypnagogic and Hypnopompic Questionnaire: 7
34) I thought I felt my deceased loved one beside me	Extrasensory Processing Hallucinations	Bare, 2020
35) I talked to my loved one even though (s)he is no longer living	Extrasensory Processing Hallucinations	see e.g., Troyer, 2005, 2014
36) Things around me felt unreal or dreamlike	Extrasensory Processing Dreaming	ASDS: 3; DDI: 5; DES-II: 12,16; CDS: 13
37) It could be hard to tell if I was awake or asleep	Extrasensory Processing Dreaming	DES-II: 15
38) I had more dreams	Extrasensory Processing Dreaming	Opposite of 41 (below)
39) My dreams about my loved one were comforting	Extrasensory Processing Dreaming	Opposite of #40 (below)
40) My dreams about my loved one were disturbing	Extrasensory Processing Dreaming	ASD; ASDS: 7; SASRQ: 6
41) I had fewer dreams	Extrasensory Processing Dreaming	Opposite of 38 (above)
42) I had difficulty falling and/or staying asleep	Extra-sensory Processing Threshold Consciousness	ASDS: 14; SASRQ: 1; anxiety—39%, .43 Item-scale correlation
43) I felt the presence of my loved one, but could not see, hear, touch, or smell anyone there	Extrasensory Processing Threshold Consciousness	Durham Hypnagogic and Hypnopompic Questionnaire: 1 (Jones et al., 2009); Note similarity to items 28-33 assessing hallucinations
44) Thinking of my loved one made it easier to fall asleep	Extrasensory Processing Threshold Consciousness	Opposite of 47 (below)
45) When I first woke up, sometimes initially I didn't remember that my loved one had died	Extrasensory Processing Threshold Consciousness	see e.g., Bare, 2020; Bowler, 2018

Item [All items are introduced with: Think about the time following the death of your loved one. Would you say:]	Subcategory of Perception/ Sense-making	Item Source(s)
46) My thoughts could come so quickly that I couldn't seem to write them down fast enough	Extrasensory Processing Threshold Consciousness	DDI: 11; RTS: 9
47) Thinking of my loved one made it harder to fall asleep	Extrasensory Processing Threshold Consciousness	Opposite of 44 (above)
48) I experienced an altered state of awareness which I believe utterly transformed the way I looked at myself	Extrasensory Processing Transliminality	RTS: 16
49) I had such a heightened awareness of sights and sounds that I felt I could not shut them out	Extrasensory Processing Transliminality	RTS: 25
50) I felt like I had mystical experiences	Extrasensory Processing Transliminality	RTS: 18
51) Time seemed to pass very slowly	Time	DDI: 2
52) Events seemed to happen in slow motion	Time	DDI: 12
53) Time seemed to go by quickly	Time	Opposite of #'s 51 & 52 (above)
54) Events seemed to speed up	Time	Opposite of #'s 51 & 52 (above)
55) Time seemed to stand still	Time	e.g., Neimeyer & Anderson, 2002
56) I could not keep track of time	Time	Greene, 2019
57) It was challenging for me to accurately gauge the passage of time	Time	Greene, 2019
58) I felt that my sense of time didn't work the way it used to	Time	Larry Childress

Perception/Sense-Making Items considered but not included in the Grief Experiences Survey

Item (considered but **NOT** included)	Subcategory of Perception/ Sense-making	Item Source(s)
I've felt irritable and/or had outbursts of anger	Shock	ASD; ASDS: 15; SASRQ: 10 anxiety—21% endorsed, .49 Item-scale correlation
I've felt distant from my "normal" self [OR I've not had the usual sense of who I am]	Shock	ASDS: 4; SASRQ: dissoc.—16% endorsed, .55 Item-scale correlation
I've felt isolated from the world	Shock	DDI; 10; SASRQ: dissoc.—21% endorsed, .53 Item-Scale corr.
My thoughts have seemed blurred	Shock	DDI: 11

Item (considered but **NOT** included)	Subcategory of Perception/ Sense-making	Item Source(s)
I've been unable to recall important aspects of the death	Shock	ASDS: 5; SASRQ: dissoc.—2% endorsed, .37 Item-scale correlation
I've tried not to think about the death	Shock	ASDS: 10
The distance between close and distant has seemed blurred	Intra-sensory Processing	DDI: 23
My vision seemed sharpened	Intra-sensory Processing	Opposite of #16 (above)
My sensations were more overwhelming than usual	Intra-sensory Processing	Exact source(es) not recalled
I've experienced things as if they were doubly real	Intra-sensory Processing	Exact source(es) not recalled
My surroundings appeared as if covered with a haze	Inter-sensory Processing	DDI: 17
I've felt off balance	Inter-sensory Processing	Similar to #28 (above)
I've found myself acting as if my loved one was still alive	Extra-sensory Processing Hallucinations	see e.g., Didion, 2005
I've been unsure if things really happened to me or if I just dreamed that they did	Extra-sensory Processing Dreaming	DES-II: 15
I've felt like I was waking up in a room unfamiliar to me	Extra-sensory Processing Threshold Consciousness	Greene, 2019
I've had the sense of the invisible presence of my loved one watching me while I sleep	Extra-sensory Processing Threshold Consciousness	Durham Hypnagogic and Hypnopompic Questionnaire: 4 (Jones et al., 2009)
I've seen the blurry figure of my loved one in my room	Extra-sensory Processing Threshold Consciousness	Durham Hypnagogic and Hypnopompic Questionnaire: 3 (Jones et al., 2009)
I've experienced an altered state of consciousness in which I felt that I became cosmically enlightened	Extra-sensory Processing Transliminality	RTS: 3, 16
I've behaved in a much more impulsive or uninhibited way than is usual for me	Extra-sensory Processing Transliminality	RTS: 6
I thought I really knew what some people mean when they talk about mystical experiences	Extra-sensory Processing Transliminality	RTS: 18
I've felt unaware of the passage of time	Time	DES-II: 20
I felt a sense of timelessness	Time	SASRQ: 3; 48% endorsed, .43 Item-Scale Correlation

Appendix F: Acute Stress Disorder Scale (ASDS)

Name: Date:

Briefly describe your recent traumatic experience:

Did the experience frighten you? Yes or No

Please answer each of these questions about how you have felt since the event. Circle one number next to each question to indicate how you have felt.

1 *Not at all*

2 *Mildly*

3 *Medium*

4 Quite a bit

5 Very much

1. During or after the trauma, did you ever feel numb or distant from your emotions?
2. During or after the trauma, did you ever feel in a daze?
3. During or after the trauma, did things around you ever feel unreal or dreamlike?
4. During or after the trauma, did you ever feel distant from your normal self or like you were watching it happen from outside?
5. Have you been unable to recall important aspects of the trauma?
6. Have memories of the trauma kept entering your mind?
7. Have you had bad dreams or nightmares about the trauma?
8. Have you felt as if the trauma was about to happen again?
9. Do you feel very upset when you are reminded of the trauma?
10. Have you tried not to think about the trauma?
11. Have you tried not to talk about the trauma?
12. Have you tried to avoid situations or people that remind you of the trauma?
13. Have you tried not to feel upset or distressed about the trauma?
14. Have you had trouble sleeping since the trauma?
15. Have you felt more irritable since the trauma?
16. Have you had difficulty concentrating since the trauma?
17. Have you become more alert to danger since the trauma?
18. Have you become jumpy since the trauma?
19. When you are reminded of the trauma, do you sweat or tremble or does your heart beat fast?

(Bryant et al., 2000)

Appendix G: Stanford Acute Stress Reaction Questionnaire (SASRQ) (Cardeña et al., 2000)

Stanford Acute Stress Reaction Questionnaire

DIRECTIONS:
Recall the stressful events that occurred in your life during the PAST MONTH.

Briefly describe the one event that was the most disturbing on the lines below:

_____
_____
_____
_____

How disturbing was this event to you? (Please mark one):

Not at all disturbing ____
Somewhat disturbing ____
Moderately disturbing ____
Very disturbing ____
Extremely disturbing ____

DIRECTIONS: Below is a list of experiences people sometimes have during and after a stressful event. Please read each item carefully and decide how well it describes *your* experience since the stressful event described above. Refer to this event in answering the items that mention "the stressful event." Use the 0-5 point scale shown below and circle the number that best describes your experience.

0	1	2	3	4	5
not experienced	very rarely experienced	rarely experienced	sometimes experienced	often experienced	very often experienced

1.	I had difficulty falling or staying asleep.	0	1	2	3	4	5
2.	I felt restless.	0	1	2	3	4	5
3.	I felt a sense of timelessness.	0	1	2	3	4	5
4.	I was slow to respond.	0	1	2	3	4	5
5.	I tried to avoid feelings about the stressful event.	0	1	2	3	4	5
6.	I had repeated distressing dreams of the stressful event.	0	1	2	3	4	5
7.	I felt extremely upset if exposed to events that reminded me of an aspect of the stressful event.	0	1	2	3	4	5
8.	I would jump in surprise at the least thing.	0	1	2	3	4	5
9.	The stressful event made it difficult for me to perform work or other things I needed to do.	0	1	2	3	4	5
10.	I did not have the usual sense of who I am.	0	1	2	3	4	5

Appendix H: Depersonalization-Derealization Inventory (DDI)
(Cox & Swinson, 2002)

1. Surroundings seem strange or unreal
2. Time seems to pass very slowly
3. Body feels strange or different in some way
4. Feel like you've been here before (deja vu)
5. Feel as though in a dream
6. Body feels numb
7. Feeling of detachment or separation from surroundings
8. Numbing of emotions
9. People and objects seem far away
10. Feeling detached or separated from your body
11. Thoughts seem blurred
12. Events seem to happen in slow motion
13. Your emotions seem disconnected from yourself
14. Feeling of not being in control of self
15. People appear strange or unreal
16. Dizziness
17. Surroundings appear covered with a haze
18. Vision is dulled
19. Feel as if walking on shifting ground
20. Difficulty understanding what others say to you
21. Difficulty focusing attention
22. Feel as though in a trance
23. The distinction between close and distant is blurred
24. Difficulty concentrating
25. Feel as though your personality is different
26. Feel confused or bewildered
27. Feel isolated from the world
28. Feel "spacy" or "spaced out"

Appendix I: Dissociative Experiences Scale (DES-II)
(Bernstein & Putnam, 1986; Carlson & Putnam, 1993)

Directions: This questionnaire consists of twenty-eight questions about experiences that you may have in your daily life. We are interested in how often you have these experiences. It is important, however, that your answers show how often these experiences happen to you when you are not under the influence of alcohol or drugs. To answer the questions, please determine to what degree the experience described in the question applies to you, and circle the number to show what percentage of the time you have the experience.

For example: 0% 10 20 30 40 50 60 70 80 90 100%
(Never) (Always)

1. Some people have the experience of driving or riding in a car or bus or subway and suddenly realizing that they don't remember what has happened during all or part of the trip. Circle a number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

2. Some people find that sometimes they are listening to someone talk and they suddenly realize that they did not hear part or all of what was said. Circle the number to show what percentage of the time this happens to you. 0% 10 20 30 40 50 60 70 80 90 100%

3. Some people have the experience of finding themselves in a place and have no idea how they got there. Circle a number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

4. Some people have the experience of finding themselves dressed in clothes that they don't remember putting on. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

5. Some people have the experience of finding new things among their belongings that they do not remember buying. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

6. Some people sometimes find that they are approached by people that they do not know, who call them by another name or insist that they have met them before. Circle the number to show what percentage of the time this happens to you 0% 10 20 30 40 50 60 70 80 90 100%

7. Some people sometimes have the experience of feeling as though they are standing next to themselves or watching themselves do something and they actually see themselves as if they were looking at another person. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

8. Some people are told that they sometimes do not recognize friends of family members. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

9. Some people find that they have no memory for some important events in their lives (for example, a wedding or graduation). Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

10. Some people have the experience of being accused of lying when they do not think that they have lied. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

11. Some people have the experience of looking in a mirror and not recognizing themselves. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

12. Some people have the experience of feeling that other people, objects, and the world around them are not real. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

13. Some people have the experience of feeling that their body does not seem to belong to them. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

14. Some people have the experience of sometimes remembering a past event so vividly that they feel as if they were reliving that event. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

15. Some people have the experience of not being sure whether things that they remember happening really did happen or whether they just dreamed them. Circle the number to show what percentage of the time this happens to you. 0% 10 20 30 40 50 60 70 80 90 100%

16. Some people have the experience of being in a familiar place but finding it strange and unfamiliar. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

17. Some people find that when they are watching television or a movie they become so absorbed in the story that they are unaware of other events happening around them. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

18. Some people find that they become so involved in a fantasy or daydream that it feels as though it were really happening to them. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

19. Some people find that they sometimes are able to ignore pain. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

20. Some people find that they sometimes sit staring off into space, thinking of nothing, and are not aware of the passage of time. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

21. Some people sometimes find that when they are alone they talk out loud to themselves. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

22. Some people find that in one situation they may act so differently compared with another situation that they feel almost as if they were two different people. Circle the number to show what percentage of the time this happens to you. 0% 10 20 30 40 50 60 70 80 90 100%

23. Some people sometimes find that in certain situations they are able to do things with amazing ease and spontaneity that would usually be difficult for them (for example, sports, work, social situations, etc.). Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

24. Some people sometimes find that they cannot remember whether they have done something or have just thought about doing that thing (for example, not knowing whether they have just mailed a letter or have just thought about mailing it). Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

25. Some people find evidence that they have done things that they do not remember doing. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

26. Some people sometimes find writings, drawings, or notes among their belongings that they must have done but cannot remember doing. Circle the number to show what percentage of the time this happens to you. 0% 10 20 30 40 50 60 70 80 90 100%

27. Some people sometimes find that they hear voices inside their head that tell them to do things or comment on things that they are doing. Circle the number to show what percentage of the time this happens to you. 0% 10 20 30 40 50 60 70 80 90 100%

28. Some people sometimes feel as if they are looking at the world through a fog, so that people and objects appear far away or unclear. Circle the number to show what percentage of the time this happens to you.
0% 10 20 30 40 50 60 70 80 90 100%

(Bernstein & Putnam, 1986; Carlson & Putnam, 1993)

Appendix J: Cambridge Depersonalization Scale (CDS)
(Sierra & Berrios, 1996, 2000; see also Sierra et al., 2005)

Responses are for Frequency: 0 = *never*, 1 = *rarely*, 2 = *often*, 3 = *very often*, 4 = *all the time* and for Duration: 1 = *a few seconds*, 2 = *few minutes*, 3 = *few hours*, 4 = *about a day*, 5 = *more than a day*, 6 = *more than a week*

1. Out of the blue, I feel strange, as if I were not real or as if I were cut off from this world.
2. What I see looks 'flat' or 'lifeless', as if I were looking at a picture.
3. Parts of my body feel as if they didn't belong to me.
4. I have found myself *not being frightened at all* in situations normally I would find frightening or distressing
5. My favourite activities are no longer enjoyable.
6. Whilst doing something I have the feeling of being a 'detached observer' from myself.
7. The flavour of meals no longer gives me a feeling of pleasure or distaste.
8. My body feels very light, as if it were floating on air.
9. When I weep or laugh, I do not seem *to feel* any emotions at all.
10. I have the feeling of *not having any thoughts at all*, so that when I speak it feels as if my words were being uttered by an 'automaton'.
11. Familiar voices (including my own) sound remote and unreal.
12. I have the feeling that my hands or my feet have become larger or smaller.
13. My surroundings feel detached or unreal, as if there were a veil between me and the outside world.
14. It seems as if things that I have recently done had taken place a long time ago. For example, anything which I have done this morning feels as if it were done weeks ago.
15. Whilst fully awake, I have 'visions' in which I can *see* myself outside, as if I were looking at my image in a mirror.
16. I feel detached from memories of things that have happened to me—as if I had not been involved in them.
17. When in a new situation, it feels as if I have been through it before.
18. Out of the blue, I find myself not feeling any affection towards my family and close friends.
19. Objects around me seem to look smaller and further away.
20. I cannot feel properly the objects that I touch with my hands for it feels *as if it were not me* who were touching it.

Cambridge Depersonalization Scale (continued)

21. I am unable to picture things in mind.
22. I feel detached from pain.
23. I have the feeling of being outside my body
24. When I move it doesn't feel as if I were in charge of the movements, so that I feel 'automatic' and mechanical as if I were a 'robot'.
25. The smell of things no longer gives me a feeling of pleasure or dislike.
26. I feel so detached from my thoughts that they seem to have a 'life' of their own.
27. I have to touch myself to make sure that I have a body or a real existence.
28. *I seem to have lost* some bodily sensations (e.g., of hunger and thirst) so that when I eat or drink, it feels an automatic routine.
29. Previously familiar places look unfamiliar, as if I had never seen them before.

(Sierra & Berrios, 1996, 2000; see also Sierra et al. 2005)

Appendix K: Revised Transliminality Scale (RTS)
(Houran et al., 2003; Lange et al., 2000)

Your Date of Birth: —/—/— Your Age: — Your Sex: M/F

1. Horoscopes are right too often for it to be a coincidence.

2. At times I perform certain little rituals to ward off negative influences.

3. I have experienced an altered state of consciousness in which I felt that I became cosmically enlightened.

4. At the present time, I am very good at make-believe and imagining.

5. I have felt that I had received special wisdom, to be communicated to the rest of humanity.

6. I have sometimes behaved in a much more impulsive or uninhibited way than is usual for me.

7. I am fascinated by new ideas, whether or not they have practical value.

8. I have sometimes sensed an evil presence around me, although I could not see it.

9. My thoughts have sometimes come so quickly that I couldn't write them all down fast enough.

10. If I could not pretend or make-believe anymore, I wouldn't be me I wouldn't be the same person.

11. Sometimes I experience things as if they were doubly real.

12. It is sometimes possible for me to be completely immersed in nature or in art and to feel as if my whole state of consciousness has somehow been temporarily altered.

13. Often I have a day when indoor lights seem so bright that they bother my eyes.

14. I am convinced that I have had at least one experience of telepathy between myself and another person.

15. I am convinced that I am psychic.

16. I have experienced an altered state of awareness which I believe utterly transformed (in a positive manner) the way I looked at myself.

17. I am convinced that I have had a premonition about the future that came true and which (I believe) was not just a coincidence.

18. I think I really know what some people mean when they talk about mystical experiences.

19. I have gone through times when smells seemed stronger and more overwhelming than usual.
20. I can clearly feel again in my imagination such things as: the feeling of a gentle breeze, warm sand under bare feet, the softness of fur, cool grass, the warmth of the sun and the smell of freshly cut grass.
21. A person should try to understand their dreams and be guided by or take warnings from them.
22. While listening to my favorite music, in addition to feeling calm, relaxed, happy, etc., I often have a feeling of oneness with the music, or of being in another place or time, or vividly remembering the past.
23. At times I somehow feel the presence of someone who is not physically there.
24. I am convinced that it is possible to gain information about the thoughts, feelings or circumstances of another person in a way that does not depend on rational prediction or normal sensory channels.
25. For several days at a time I have had such a heightened awareness of sights and sounds that I cannot shut them out.
26. I sometimes have a feeling of gaining or losing energy when certain people look at me or touch me.
27. Now that I am grown up, I still in some ways believe in such beings as elves, witches, leprechauns, fairies, etc.
28. Sometime people think Im a bit weird because my ideas are so novel.
29. When listening to organ music or other powerful music, I sometimes feel as if I am being lifted up into the air.

(Houran et al., 2003; Lange et al., 2000)

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