A Critical Analysis of the *Pandemic Grief Scale:* Screening People for "Dysfunctional Grief" after a COVID-19 Death

On December 21, 2020, *Death Studies* journal published an article titled "Pandemic Grief Scale: A screening tool for dysfunctional grief due to a COVID-19 loss" (Lee & Neimeyer, 2020). To read the article, here is a reference link: https://doi.org/10.1080/07481187.2020.1853885.

My analysis of the article centers in three areas of concern: some of the language used; the methodology utilized to develop the scale, limiting its generalizability; and the scale's validity and reliability as a construct.

Concerns About Language

The language we choose to define any group of people shapes and determines how we respond to them and their needs. The ABSTRACT of this article states that the objective was "to develop and evaluate the properties of the Pandemic Grief Scale (PGS)…a brief mental health screener to identify probable cases of dysfunctional grief associated with a COVID-19 death." I have concerns with three terms used: "pandemic grief," "probable cases," and "dysfunctional grief."

What is "pandemic grief"? Will we have "tornado grief" and "hurricane grief" and "earthquake grief" and (insert catastrophe here) grief? There is no universal response to a death from COVID-19 which warrants the term "pandemic grief." While recognizing many complicating factors facing people who are grieving the death of someone from COVID-19, as well as from any other cause during the restrictions of the pandemic, I suggest it is better stated as *Grieving during the pandemic*.

Next, the term "probable cases," from the ABSTRACT, summarizing the screening instrument's goal as "to identify probable cases of dysfunctional grief." We are talking about people here. People who are grieving a death or deaths are not *cases,* defined as "an instance of a disease or problem" (Oxford Dictionary, n.d.). I suggest it is better stated as *Identifying people at high risk after a COVID-19 death.*

Then, the unfortunate term, "dysfunctional grief." This term seemed to be fading from much of our more recent thanatological discourse, along with "pathological grief," "absent grief," "distorted grief," and others, replaced with terms like "complicated grief" and "prolonged grief disorder." Other than the 5 questions on their scale, the authors do not offer a definition of "dysfunctional grief." We know, however, that "dysfunction" means "an abnormality or impairment in the function of a specified bodily organ or system; deviation from the norms of social behavior in a way regarded as bad" (Oxford Dictionary, n.d.). Under this terminology, people who screen positive for "dysfunctional grief" on the Pandemic Grief Scale have abnormal or impaired functioning in their grief responses and are deviating from the norms of social behavior in way that is regarded as bad. I would assert that the norms of social behavior have been impaired due to pandemic restrictions, adding complications to how a person grieving a death may function in their grief responses, and that the dysfunction is in the situation and not in the individual who is grieving during extremely abnormal circumstances.

I believe that a tool to help health professionals and researchers identify those who may be supported in their grieving after someone in their lives has died from COVID-19 (or any other mode of death during the time of pandemic restrictions) has potential benefit. I don't, however, believe this is the correct tool to achieve this outcome. And its unfortunate labeling of people who are suffering after the death, branding them with "dysfunctional grief" adds to my concern. Why couldn't it be "a brief screening instrument to help identify people who may be at high risk for negative outcomes after someone in their lives has died of COVID-19"?

Making the scale a "mental health screener" implies there is a problem *within the person*, that is, they have this "dysfunctional grief." The mental disorder approach takes it out of the social and cultural environment, focusing on what is (presumably) wrong with the person, and not *what happened to the person*, a differentiation clearly articulated by trauma-informed principles of holistic, human-centered, strength-based, contextual approaches. (For more information, see Schuurman & Mitchell, 2020). Rather, this symptom-based, problem-centered, individual pathology-focused approach is reductionistic.

To be clear, I believe anyone grieving the death of someone from COVID-19, or any other cause of death during this time of pandemic restrictions, may have additional complicating factors which make grieving even more complex. Among them: not being able to be present during a loved one's illness, or at their bedside at their death; the inability to honor the person through traditional or usual funerals, life celebrations, or other rituals; being even more socially isolated because of the physical restrictions; coping with one's own grief in a world where nearly everyone is grieving non-death losses; the additional strains of the loss of a job or income; the tense and divided political climate; potential relational strains due to imposed togetherness; social turmoil, and the list goes on. With all these additional complicating factors and conditions, to imply that a person mourning a death from COVID-19 or another cause during the pandemic has "dysfunctional grief" is unhelpful, and potentially harmful.

In addition to problems with the language being used, there are significant limitations in the methodology used to develop this scale.

Concerns About Methodology

The authors acknowledge two limitations of the study, 1) the exclusive use of an online survey using convenience sampling, and 2) the use of single-item scales for suicidal ideation and substance use coping. There are other limitations they did not address, but first, let's look at the two limitations they did acknowledge.

The Limitation of Convenience Sampling through an Online Survey

The first limitation is the exclusive use of an online survey using convenience sampling. Convenience sampling means accessing people who are readily available, therefore "convenient," where data can typically be collected quickly and at a low cost (Crossman, 2020).

In this study, the online survey recruited participants through Amazon MTurk, for which they were paid fifty cents upon completion of the survey. What is Amazon MTurk, and why were respondents paid such a curious amount? MTurk is short for Mechanical Turk, an Amazon crowdsourcing marketplace where people looking for tasks to be completed ("Requesters") post work as Human Intelligence Tasks (HITs) in exchange for a reward, in this case, a small amount of money (MTurk.com). Some of the people who perform the HITs do so to supplement their income; others to have an income at all. The site was referred to in *The Atlantic* as "a new kind of poorly paid hell", noting that the only work available for some Americans is on-line tasks paying sub-minimum wage (Semuels, 2018), and that was before at least 33 million Americans lost their jobs or had their hours and pay cut due to the impact of the coronavirus, according to the Economic Policy Institute (Shierholz, 2020).

MTurk is used by businesses and increasingly by academics for research purposes, as an alternative to conducting samples representative of the American public, though there is active debate in the research community around the validity of surveys posted on the site (Pew Research Center, 2016). One must ask the question about the validity of the surveys completed by these 831 individuals, as well as the generalizability of these results to other populations. Disadvantages of convenience sampling include limits to generalizability, in that the persons in the sample may not be representative of the population the researchers are attempting to study, and that the results may be biased (Crossman, 2020).

Once these types of scales or inventories get disseminated, they may be used in situations with populations for which they are not appropriate. Here's just one example: The Inventory of Complicated Grief. The data was originally "derived from 97 conjugally bereaved elders" (Prigerson et al, 1995). In 1999 a National Institute of Mental Health (NIMH)-funded study, the Yale Bereavement Study, convened a panel of leading experts to formulate criteria symptoms for what was then referred to as "disordered grief" or "traumatic grief." The population studied, 350 people, was primarily white (95%), older (mean age of 61), females (70%) who had spouses die from natural causes after an average 32 years of marriage (Maciejewski et al, 2016). The validity of the proposed complicated grief criteria was critiqued and found wanting (Hogan, Worden & Schmidt, 2003), yet the tool has been widely used over the past 25 years as if it is generalizable to other populations. In more recent years, the terminology shifted to debates among proponents of "Complicated Grief," "Prolonged Grief Disorder" and "Persistent Complex Bereavement Disorder," the latter proposed as a compromise term in the American Psychiatric Association's DSM-5 "Conditions for Further Study" section (APA, 2013). Some of the original panelists from the 1999 Yale Bereavement Study reflected in 2016 that "future studies ought to examine whether and the extent to which CG and PGBD tests and items differ with respect to the bereaved individual's age, gender, race, ethnicity, relationship to the deceased, and geographic or cultural setting, as well as with respect to circumstances of the lost loved-one's death" (Maciejewski, et al, 2016, 274). Yet here we are in 2021, with a screening instrument developed from data derived from a specific population that does not represent the larger population for which the instrument has been proposed.

The MTurk respondents, in addition to people being technologically savvy enough to know about the site, were predominately white (76%) males (60%), who, on average, were 38 years old, and who reported that they had an extended or immediate family member die of COVID-19 (60%) an average of three months prior to completing the survey. Another critical piece to keep in mind is that 37% of the sample reported that not only did someone in their lives die of

COVID-19, they had also been diagnosed with the disease caused by this virus (full demographic statistics are outlined in the article).

Participants completed the survey between November 3, 2020, which, notably, was Election Day in the U.S., and November 5, 2020, a period filled with contention and uncertainty, while election results still hung in the balance. Could this social event and its uncertain outcome have had a bearing on how people responded to this survey, particularly related to anxiety and/or depression? All these concerns threaten the external validity of this study, that is, the generalizability of the results from this particular sample to the larger population.

The Limitation of Single-item Scales for Suicidal Ideation and Substance Use Coping

Another limitation Lee and Neimeyer noted in the article was the use of single-item scales for suicidal ideation and substance use coping. The "suicidal ideation" item used was "I wished I was already dead so I did not have to deal with this loss." Whether or not this statement actually reflects "suicidal ideation" is debatable, especially since it was the only question asked to deduce whether a person is thinking about suicide or wanting to take their life. The substance use coping item was, "I have used alcohol or other drugs to help me get through this loss." Coping through substance use turned out not to be included in the 5-item screening tool, which shouldn't be a big surprise, as adult alcohol and marijuana use have soared to new heights during the pandemic. The Nielsen Company reported a whopping 54% increase in national sales of alcohol in March 2020 compared to the prior year, with online sales increasing 262%, and that was in the early days of the pandemic (The Nielsen Company, 2020). In my state of Oregon, recreational cannabis sales jumped from $795 million in 2019 to over $1 billion in 2020, about a 40% increase (Associated Press, 2021). These record-breaking highs clearly set a social context that needs to be considered when asking people who are grieving about their "substance use coping." It seems those who are grieving a death are not the only ones increasing their substance use during the pandemic.

Additional Methodological Limitations to Consider

There are questions about the measures used to determine who had "dysfunctional grief" that one should consider.

Patient Health Questionnaire-4

Lee and Neimeyer state that in their MTurk sample, "73.3% and 74.4% of the sample were classified as having clinical levels of depressive…and generalized anxiety symptoms, respectively." Clinical symptoms of depression and generalized anxiety were measured through the Patient Health Questionnaire-4, which asks respondents how often they have been bothered by 4 problems over the past two weeks (PHQ-4; Kroenke et al., 2009). The 4 problems are:

1. Feeling nervous, anxious or on edge
2. Not being able to stop or control worrying
3. Little interest or pleasure in doing things
4. Feeling down, depressed, or hopeless

For each of these problems, one is instructed to circle "Not at all," (0 points); "Several days" (1 point); "More than half the days" (2 points); or "Nearly every day" (3 points). The lowest score possible is 0, meaning one has not experienced these problems at all. The highest score is 12, should one be bothered by the four problems "nearly every day." In this scenario, a person would be labeled with clinical levels of depression by being bothered by "little interest or pleasure in doing things" and/or "feeling down, depressed, or hopeless" several days or more than half the days of the previous two weeks. A person would be labeled with clinical levels of anxiety by being bothered by "feeling nervous, anxious or on edge" and/or "not being able to stop or control worrying" several days or more than half the days of the previous two weeks. None of these problems would be unusual for someone who experienced the death of a spouse, relative, or friend in 2020 from COVID-19. (For literalists, one could conceivably experience all four of these problems nearly every day over the last two weeks but not be bothered by them, in which case they would show no psychological distress according to this scale.)

Adaptation of the Work and Social Adjustment Scale (WSAS)

The authors state that 64.7% of their sample was "functionally impaired" due to a COVID-19 death. Let's look at how they got to that conclusion. They adapted the Work and Social Adjustment Scale (WSAS) by Mundt et al (2002), which is a five-item scale of functional impairment related to an identified problem, in this case, grieving the death of someone from COVID-19. The WSAS statement begins, "Because of my disorder…" and was adapted on the Pandemic Grief Scale to "Because of this loss…" Participants were asked to respond to five statements on a 9-point severity scale, with 0 meaning "not at all," and 8 indicating "very severely to the point I can't work." A rating of 4 would be a middle ground between "not at all" and "very severely." In the article, the sample question the authors shared was this one: "Because of this loss, my ability to work is impaired."

The four statements the authors did not share were these:

1. Because of this loss, my home management (cleaning, tidying, shopping, cooking, looking after home or children, paying bills) is impaired.
2. Because of this loss, my social leisure activities (with other people, such as parties, bars, clubs, outings, visits, dating, home entertainment) are impaired.
3. Because of this loss, my private leisure activities (done alone, such as reading, gardening, collecting, sewing, walking alone) are impaired.
4. Because of this loss, my ability to form and maintain close relationships with others, including those I live with, is impaired.

Statement #2 is moot since all our social leisure activities are impaired by quarantine restrictions, so it is not relevant. Statement #4 may also be challenged by the pandemic restrictions and render that statement irrelevant. I also can't help but comment on the terminology in both renditions: *functional impairment*? Aren't we all "functionally impaired" to some degree during these months of the pandemic restrictions?

Additional questions on the survey were generated but the article does not include them. From inference, it does not appear Neimeyer and Lee (2020) asked questions related to the context around the death or the respondent's social or economic conditions. They did not ask if they had lost a job or suffered economically, whether they were able to be with their loved one during their illness, how and whether they were able to honor their loved one after their death, and other factors relevant to how they might be coping with this death.

Concerns About the Scale's Validity, Reliability, and Usefulness as a Construct

Ultimately, after a series of factor analytic methods, a "reliable subset of five items that best represent the latent construct of COVID-19 grief" were identified. Let's unpack this statement.

"Reliability" refers to the consistency of a measure, in essence, whether the results can be reproduced. It doesn't address whether or not what is being measured matters, or whether the questions being asked actually represent or address the issue being discussed.

One of the methods they used was "bias-corrected bootstrap Maximum Likelihood estimations." Basically, bootstrapping takes sample data from a population and resamples the sample data to make inferences. However, the results depend on the representative sample itself, which leads to the question of validity. Validity refers to the accuracy of a measure, that is, whether the results represent what they're supposed to measure, in this case, "the latent construct of COVID-19 grief" and by extension, pandemic dysfunctional grief. What is a "latent construct"?

Latent refers to "a quality or state existing but not yet developed or manifest; hidden or concealed" and a construct is "an idea or theory containing various conceptual elements, typically one considered to be subjective and not based on empirical evidence" (Oxford Dictionary, nd). To me, this is the biggest flaw in the construction of the "latent construct of COVID-19 grief." More specifically, to screen people for "dysfunctional grief" based on a set of five statements that are solely internal feelings without a larger contextual understanding, and to label them with this disorder is seriously problematic. The five statements each have four possible responses, ranging from "Not at all" (a score of 0), "Several days" (a score of 1), "More than half the days" (a score of 2), to "Nearly every day" (a score of 3). Here they are, with some of my concerns and questions below each one:

Over the last 2 weeks, how often have you experienced the following thoughts, feelings, or behaviors related to your loss?

1. I wished to die in order to be with the deceased.

While this is presented as passive suicidal ideation, wanting to die, and/or join the deceased is not an uncommon wish for people who are newly bereaved, let alone who had someone die of a potentially preventable disease during a time when they might not have been able to be with the person during their illness and suffering. The statement does not say "I wish to end my life" or "I wish to take my life." Additionally, the strong bias of this statement implies that all respondents believe they will be reunited with the deceased when they die, a concept that is not universally shared. One could conceivably be actively suicidal, but not wishing to (or believing one could) be with the deceased.

2. I experienced confusion over my role in life or felt like my identity was diminished because of the loss.

Why would experiencing confusion over one's role in life (something a lot of us are wondering in these pandemic times, even absent a death) be dysfunctional? And…some people's identities **are** diminished after the death of a spouse, romantic partner, parent, child, etc. That seems…normal…

3. Nothing seemed to matter much to me because of this loss.

Suffering the death of someone stretches us to think about meaning, and what really matters in life. Many of us already know that what matters is the people in our lives. So when a person we love dies, it certainly and understandably makes a lot of other things not seem to matter much. Because they don't.

4. I found it difficult to have positive memories about the deceased.

Could that have anything to do with you not being able to be with them as they died a horrible death alone without family members, which you believe could have been prevented with better national attention to the pandemic? Or that you picture the person gasping for air in their final moments? Or that you couldn't honor them in the way they deserved due to pandemic restrictions? Or any of the other social conditions surrounding their death?

5. I believed that without the deceased, life was either meaningless, empty, or could not go on.

It can feel that way when a loved one dies a meaningless death and you couldn't do anything to prevent it, or even to comfort them in their dying days.

Two final observations:

1. The authors found that 43% of participants stated they had received professional help for their COVID-19 loss and that they had higher Pandemic Grief Scores than those who did not receive professional help for their COVID-19 loss. They used this finding to support the external validity of the scale "by demonstrating that mourners whose scores reflect greater clinical elevations are in fact more likely to seek professional intervention." That's one possible interpretation. But I would ask, shouldn't those who received professional help be doing better than their peers who did not seek professional help? This finding could also be interpreted that the professional intervention wasn't helping them. We don't know.

2. It alarms me that this scale has now been "placed in the public domain to encourage its use in clinical assessment and research." It concerns me that a person could be diagnosed with "dysfunctional grief" when this scale is devoid of the social conditions and context in which the person who is grieving is living.

While the authors mention social, socioeconomic, educational, and institutional factors that impact grief during a pandemic, they have chosen to focus on symptoms indicating dysfunction which are solely within the individual. They discuss how many people may "suffer from pathological levels of grief" and state that research indicates that "grief due to a COVID-19 death is indeed more severe than that resulting from other forms of loss."

It reminds me of a family at Dougy Center who had three relatives die in a small plane crash the same week as the 9/11 plane crashes. They described how people asked if their loved ones died in one of the 9/11 plane crashes, and when they explained it was another, private, plane crash, some people responded, "wow, thank God!" As if their loss was somehow better since it was not so…so *what*? So public? The result of a crime? To them, their loss was as "severe" as the losses others experienced; it just happened under different circumstances.

I can't say whether grief due to a COVID-19 death is more severe than other deaths during this pandemic time period, as I don't believe in viewing grieving as a competition, contest, or hierarchy from worst to best death. I don't see where saying "your grief is worse than this other person's grief" can be helpful, because their loved one didn't die of COVID-19. What I can say is that paying attention to all of the internal and external complicating factors those who are grieving a death are facing is what matters. I believe we have, and will continue to have, many people with pent-up issues related to deaths during the pandemic, and that we will experience what's been referred to as a tsunami of grief when we can gather again, hold in-person gatherings, delayed funerals, services of remembrance, and death rituals. Let's not call our struggles before that time comes "dysfunctional" ~ deviating from the norms of social behavior in a way regarded as bad.

And finally, for those who would assert that I "shouldn't get hung up on the language" or that "dysfunctional" is "only a word," I reassert that the language we use shapes how we think, talk, and respond to each other. Labeling people who are struggling after someone in their life died of COVID-19 during the pandemic restrictions as "functionally impaired" with "dysfunctional grief" and "pandemic grief" is, in my view, a grave mistake.

Donna Schuurman, EdD, FT
Sr. Director of Advocacy & Training
Dougy Center: The National Grief Center for Children & Families
donna@dougy.org

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders*. (5th ed.). https://doi.org/10.1176/appi.books.9780890425596

Associated Press (January 7, 2021). Oregon marijuana sales soared in 2020, topping $1B. https://www.usnews.com/news/best-states/oregon/articles/2021=-01-07/oregon-marijuana-sales-soared-in-2-020-topping-1b.

Crossman, Ashley. (2020). Convenience samples for research. ThoughtCo, thoughtco.com/convenience-sampling-3026726.

Hogan, N., Worden, J., & Schmidt, L. (2003-2004). An empirical study of the proposed complicated grief disorder criteria. *OMEGA*, *48*(3), 263-277.

Kroenke, K., Spitzer, R., Williams, J., Lowe, B. (2009). An ultra-brief screening scale for anxiety and depression: the PHQ-4. *Psychosomatics*, 50, 613-621.

Lee., S.A. & Neimeyer, R.A. (2020). Pandemic Grief Scale: A screening tool for dysfunctional grief due to a COVID-19 loss, *Death Studies*, DOI: 10.1080/07481187.2020.1853885.

Lundorff, M., Holmgren, H., Zachariae, R., Farver-Vestergaard, Il, & O'Connor, M. (2017). Prevalence of prolonged grief disorder in adult bereavement: A systematic review and meta-analysis. *Journal of Affective Disorders*, *212*, 138-149. https://doi.org/10.1016/j.jad.2017.01.030.

Maciejewski, P., Maercker, A., Boelen, P., & Prigerson, H. (2016). "Prolonged Grief Disorder" and "Persistent Complex Bereavement Disorder", but not "Complicated Grief", are one and the same diagnostic entity: An analysis of data from the Yale Bereavement Study. *World Psychiatry*, 15(3), 266-275.

Mundt, J.C., Marks, I.M., Shear, M.K., & Greist, J.H. (2002). The work and social adjustment scale: a simple measure of impairment in functioning. *British Journal of Psychiatry*, *180*, 461-464.

Pew Research Center (2016). Research in the Crowdsourcing Age, a Case Study. https://www.pewresearch.org/internet/2016/07/11/turkers-in-this-canvassing-young-well-educated-and-frequent-users/

Prigerson, H.G., Maciejewski, P.K. Reynolds, C.F., Bierhals, A.J., Newsom, J.T., Fasiczka, A., Frank, E., Doman, J. & Miller, M. (1995). Inventory of complicated grief: A scale to measure maladaptive symptoms of loss. *Psychiatry Research*, 59, 65-79. https://doi.org/10.1016/0165-1781(95)02757-2.

Schuurman, D. & Mitchell, M. (2020). *Becoming grief-informed: A call to action*. Dougy Center. https://www.dougy.org/articles/becoming-grief-informed-a-call-to-action.

Semuels, A. (2018). The internet is enabling a new kind of poorly paid hell. *The Atlantic.* https://www.theatlantic.com/business/archive/2018/01/amazon-mechanical-turk/551192/

Shierholz, H. (2020). At least 33 million workers are being hurt by the coronavirus recession. https://www.epi.org/blog/at-least-33-million-workers-are-being-hurt-by-the-coronavirus-recession., *Economic Policy Institute*, downloaded 1/25/21.

The Nielsen Company. (2020). Rebalancing the ‘COVID-19 Effect’ on alcohol sales. https://www.nielsen.com/us/en/insights/article/2020/rebalancing-the-covid-19-effect-on-alcohol-sales/