School of Population Health

Explaining public stigma of grieving persons during COVID-19

Tamara Zammit

ORCID 0000-0001-8633-3989

This thesis is presented for the Degree of

Master of Research (Psychology)

of

Curtin University

May 2023

Declaration

Originality

To the best of my knowledge and belief, this thesis contains no material previously published by any other person except where due acknowledgment has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Human Ethics

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2014). The studies presented received human research ethics approval from the Curtin University Human Research Ethics Committee (HRE2021-079).

Name: Tamara Zammit

Signature:

Date: 10 May 2023

Acknowledgements

I want to thank my principal supervisor, Professor Lauren Breen, and my associate supervisors, Dr Vincent Mancini, Dr Carly Reid, and Dr Lexy Staniland. I feel very grateful to have been supervised by such a knowledgeable and supportive team.

Thank you, Lauren, for helping me conceptualise my project, for sharing your extensive knowledge regarding grief and bereavement, and for your endless enthusiasm, encouragement, and support.

Thank you, Vincent, for your continual support, patience, and advice regarding statistics.

Thank you, Carly, for sharing your clinical knowledge of trauma, ongoing care, and support.

Thank you, Lexy, for your support, advice regarding stigma, and great feedback on my drafts.

Thank you to all the participants who took part in this study; your time and effort were appreciated.

Personal acknowledgements

Thank you so much to my dearest husband, daughters, family, and friends,
Mark, Maya, Anika, Fiona, Adrian, Xavier, Essaia, Barbara, Peter, Kylie, Jodie, Paul, Dom, Anne, Alan, Leticia, Lara, Tania, Luisa, Teresa, Amy, Jenny, Billy, and Poppy.
You have each made a significant and positive difference by providing me with ongoing care, encouragement, and support throughout my study journey. You frequently reached out to me, encouraged me, and provided thoughtful assistance when I needed it most; this helped me to persevere during many stressful periods toward achieving my study goal.

To my husband and daughters,
Thank you for always being by my side to support me and for believing in me while I travelled through my study journey.

Dedication

I dedicate this thesis to my mum Carmel and my grandmother Kate. Thank you for always providing me with unconditional love and kindness. You are my inspiration and role models; your humility and kindness made a significant and positive difference in my life and the lives of many others, and for this, I am eternally grateful.

Acknowledgement of Country

We acknowledge that Curtin University works across hundreds of traditional lands and custodial groups in Australia, and with First Nations people around the globe. We wish to pay our deepest respects to their ancestors and members of their communities, past, present, and to their emerging leaders. Our passion and commitment to work with all Australians and peoples from across the world, including our First Nations peoples are at the core of the work we do, reflective of our institutions' values and commitment to our role as leaders in the Reconciliation space in Australia

Journal Articles

Published

1. **Zammit**, T., Mancini, V. O., Reid, C., Singer, J., Staniland, L., & Breen, L. J. (2023). Public stigma toward prolonged grief and COVID-19 bereavement: A vignette-based experiment. *Death Studies*, 1-11. https://doi.org/10.1080/07481187.2023.2192010

Conference Presentations

1. **Zammit**, T., Mancini, V. O., Reid, C., Singer, J., Staniland, L., & Breen, L. J. (2023). Public stigma toward prolonged grief and COVID-19 bereavement: A vignette-based experiment. *Death Studies*, 1-11. https://doi.org/10.1080/07481187.2023.2192010

Copyright Statement

I have obtained permission from the copyright owners to use any third-party copyright material reproduced in the thesis and to use any of my own published work in which the copyright is held by another party.

Statements of Contributors

Zammit, T., Mancini, V. O., Reid, C., Singer, J., Staniland, L., & Breen, L. J. (2023). Public stigma toward prolonged grief and COVID-19 bereavement: A vignette-based experiment. *Death Studies*, 1-11. https://doi.org/10.1080/07481187.2023.2192010

The purpose of this statement is to detail the nature and extent of the intellectual contribution by the Master of Research (Psychology) Candidate, Tamara Zammit, and all other co-authors of this study publication. Professor Lauren Breen, Dr Vincent Mancini, Dr Carly Reid, Dr Jonathan Singer, and Dr Lexy Staniland were involved in the overall supervision of the project, supporting the conception and design of the study, interpretation of results, and writing of the manuscript. Tamara Zammit led the data collection, analysis, and interpretation, and manuscript writing. I affirm the details stated in the Statement of Contribution are true and correct.

_____   _____

Tamara Zammit   Professor Lauren Breen

_____   _____

Dr Vincent Mancini   Dr Carly Reid

_____   _____

Dr Jonathan Singer   Dr Lexy Staniland

Table of Contents

Author's Note

This thesis is presented in a "hybrid" format, with both studies presented in manuscript form. Study 1 (Chapter 2) has been published in *Death Studies*, the premier journal devoted to bereavement issues. Chapter 2 is a typescript version of the publication; only the spelling has been changed for overall coherence with the thesis. Study 2 (Chapter 3) is presented in manuscript form and a version of it was accepted for publication during the thesis examination period. Due to the hybrid nature of this thesis, there is some unavoidable repetition of context setting and operationalism of concepts. The thesis ends with a master reference list and supplementary materials relevant to all chapters.

List of Tables

List of Supplementary Materials

Abstract

Prolonged Grief Disorder (PGD) is a recent addition to diagnostic manuals. There have been concerns from researchers and clinicians that establishing PGD as a disorder may pathologise grief and result in public stigma toward bereaved individuals. In the context of the COVID-19 pandemic, the stigma reported toward bereaved individuals may be complicated by the stigma of infectious disease. The overall aim of this thesis is to investigate public stigma towards individuals diagnosed with PGD, who were bereaved by a COVID-19 death. I achieved this aim through two experimental studies, both adopting a two-by-two experimental vignette design. Study 1 examines the differences in public stigma reported toward a bereaved individual depending on whether they were bereaved by COVID-19 or a brain haemorrhage, and whether they did or did not have PGD. Study 2 further investigates the potential effect of COVID-19 death and PGD on stigma by expanding on Study 1 to compare COVID-19 to underlying medical conditions. Both studies showed participants reported significantly more public stigma towards bereaved individuals with PGD than those without PGD. However, no significant difference was reported between stigma reported towards individuals bereaved by COVID-19 than brain haemorrhage death and no interaction between cause of death and PGD diagnosis. Further, there was no significant difference between stigma reported towards individuals bereaved by COVID-19 with underlying medical conditions than without and no interaction between cause of death and PGD diagnosis. The results show a robust finding that the general public will likely stigmatise individuals with PGD. Clinical implications and avenues for future research are discussed.

Chapter 1 General Introduction

Grief and the COVID-19 Context

In 2019 the Coronavirus disease (COVID-19), caused by the SARS-CoV-2 virus, was discovered, leading to a worldwide pandemic (WHO, 2023). An infectious disease, the virus causes mild to moderate respiratory illness for most people who are infected. However, some people are more likely to develop serious illness, including those with underlying medical conditions (UMC) such as diabetes, cardiovascular disease, cancer, chronic respiratory disease, and those who are older (WHO, 2023). The COVID-19 pandemic has caused over seven million deaths worldwide, leaving many millions of people bereaved. The pandemic has changed how we live and die, by complicating the dying processes for those who have died from COVID-19 or other causes during the pandemic and the grieving processes for those who are bereaved (Bauld et al., 2021). Some of these disruptions include being separated from loved ones during the dying process and disrupted mourning rituals (Stroebe & Schut, 2021).

Grief is the experience of many emotions related to the behavioural, psychological, physical, and social reactions following the death of a close person (Boerner et al., 2016). Acute grief is a combination of thoughts, images, and memories of the person who died and their death, combined with sadness, yearning, and a tendency to be more internally focused (Shear, 2012). The manifestations of grief are unique, variable, and wide-ranging, influenced by many factors including the circumstances of the death and the relationship to the bereaved person (Shear, 2012). The grief journey is usually unpredictable in its intensity and presentation; however, most bereaved people will progress through the difficult journey that finally leads to accepting the loss, integrating the loss into their life, and considering a future that includes satisfaction and happiness (Shear, 2012). The acute grief, which is dominant and intensely painful, eventually becomes integrated and recedes into the background. Grief can become complicated for some individuals; this is when the grief experience deviates from cultural and societal norms regarding the intensity of reactions, duration of grieving, or presentation of grief symptoms (Boerner et al., 2016). When intense grief symptoms endure for a long time, an individual may be at risk of developing prolonged grief disorder.

Prolonged grief disorder (PGD) includes symptoms of significant functional impairment and an invasive, persistent preoccupation and longing for the person who died. A diagnosis of PGD can be made when these symptoms persist for six (WHO, 2019) or 12 months (American Psychiatric Association, 2022) after bereavement. Approximately 10% of individuals bereaved by a natural death were at risk for meeting PGD criteria before the

pandemic (Boelen & Smid, 2017; Lundorff et al., 2017). However, an increased risk of PGD associated with COVID-19 bereavement was suggested by researchers during the early stages of the pandemic, due to the circumstances and characteristics of COVID-19 deaths (see Eisma & Boelen, 2023; Stroebe & Schut, 2021). This is concerning, given the associations between PGD and the negative impacts of functional impairment.

PGD is associated with decreased quality of life, self-injury, and suicidality, along with the disorder's distress and functional impairment symptoms (Lichtenthal et al., 2011; Prigerson et al., 2021). Therefore, it is crucial that individuals experiencing complex grief can access social support and therapeutic treatment if needed. However, most people needing bereavement support do not access it (Harrop et al., 2021). Stigma is one such barrier to seeking and receiving support.

Stigma and Grief

Stigma is described as the co-occurrence of stereotyping, labelling, separation, discrimination, and status loss within a setting of power inequity (Link & Phelan, 2001). To efficiently categorise information about social groups, people rely on socially constructed stereotypes and simplistic representations of groups endorsed by a collective (i.e., society, cultural group; Corrigan, 2005). Incompetent, dangerous, and being of weak character are common stereotypes associated with mental illness (Corrigan, 2005). Endorsing a negative stereotype can generate prejudice in the form of negative thoughts and emotional reactions directed at the stigmatised person/group (Corrigan, 2005). Discrimination occurs after prejudice and includes reduced work and housing opportunities, social exclusion, and withdrawal or exclusion from help and support (Corrigan, 2005).

There are two interacting levels of stigma in the context of mental illness: public stigma and self-stigma. Public stigma occurs when large social groups of people endorse stereotypes about a stigmatised group and then act against this group (Corrigan, 2005). Self-stigma occurs when individuals internalise public stigma and perceive themselves as less worthy due to accepting the stereotypes are true and deserve the subsequent prejudice and discrimination (Corrigan, 2005). People who have mental illness and are stigmatised face twice the number of challenges, firstly from the symptoms of their mental illness, and secondly from the stigma that results in reduced opportunities for quality of life such as secure housing, adequate health care, and meaningful employment (Corrigan & Watson 2002).

Therefore, there were concerns from researchers and clinicians that establishing PGD as a disorder may pathologise grief and result in public stigma toward bereaved individuals

(Dietl et al., 2018; Lichtenthal et al., 2011). An association has been shown between individuals experiencing severe grief symptoms and their family and friends reporting negative reactions toward them (Johnson et al., 2009). Research conducted with Australian, Dutch, and German participants also showed more negative attributions, stronger desired social distance, and increased emotional reactions toward bereaved individuals who met PGD criteria (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020). These reactions represent public stigma towards individuals who are bereaved.

In the context of the pandemic, the stigma toward bereaved individuals may be complicated by the stigma of infectious disease. The pandemic has created fear and anxiety around COVID-19, where individuals with the disease and their families have an elevated risk of being stigmatised due to their association with the disease (WHO, 2020). A common association between stigma and infectious viruses has been reported in previous pandemics (Demirtas-Madran, 2020). Family members who were bereaved by the Ebola virus, during the Ebola epidemic, reported being stigmatised within their own community (Kamara et al., 2017). This also appears to be a similar theme regarding the COVID-19 disease. UK based research shows that people diagnosed with long COVID-19 reported higher levels of stigma than those without a with long COVID-19 diagnosis (Pantelic et al., 2022). Additionally, bereaved people in the United Kingdom reported concerns about potential stigma from having COVID-19 recorded on the death certificates (Pearce et al., 2021). Beyond the stigma of contracting COVID-19 or being associated with someone with the illness, bereavement due to COVID-19 may strengthen/worsen the stigma.

Previous research has investigated public stigma that is associated with cause of death and shown mixed results. According to a systematic review of bereavement studies, more interaction difficulties with the bereaved, guilt, shame, and blame were reported towards individuals who were bereaved by suicide than natural causes, accidents, and illness (Logan et al., 2018a). More recently, experimental research with Dutch participants showed equal levels of stigma reported towards individuals bereaved by suicide, natural causes, and homicide (Eisma et al., 2019). Similarly, experimental research with participants from the United States and Australia showed equal stigma levels reported towards individuals bereaved by voluntary assisted dying/medically assisted dying and long-term illness (Philippkowski et al., 2021; Singer et al., 2022).

Bereaved individuals are coping with profound loss. The experience of grief is painful and challenging and can become complex for some individuals, leading to prolonged grief responses. In addition to this painful experience, bereaved individuals can be stigmatised

for their grief, particularly when they experience prolonged grief responses, which adds to their burden and reduces their potential for recovery and support seeking. In the context of the pandemic, this is further complicated by disease stigma and cause of death stigma that may make the grief experience for individuals bereaved by COVID-19 extraordinarily difficult. To ensure that bereaved people seek and receive the appropriate support they need, we need to understand more about the role of public stigma towards individuals bereaved by COVID-19. Therefore, it is important to investigate whether stigmatising responses are reported towards individuals bereaved by COVID-19 deaths as this is currently unknown.

Thesis Objectives and Outline

The overall aim of this thesis is to investigate public stigma reported towards individuals bereaved by COVID-19 with PGD. I achieved this aim through two experimental studies, both adopting a two-by-two experimental vignette design to examine the effect of COVID-19 death and PGD on stigma. Vignette-based experimental designs have been used in many studies investigating public stigma and predictions of grief symptoms, and have also been validated in multiple studies (e.g., Penman et al., 2014; Eisma, 2018; Logan et al., 2018; Eisma et al., 2019, Philippkowski et al., 2021, Singer et al., 2022) Singer et al 2022.

In Chapter 2, I present Study 1, *Public stigma toward prolonged grief and COVID-19 bereavement: A vignette-based experiment*, which examines the differences in public stigma reported toward a bereaved individual depending on whether they were bereaved by COVID-19 or a brain hemorrhage, and whether they did or did not have PGD. This study showed participants reported significantly more public stigma towards bereaved individuals with PGD than those without PGD. At the same time, there was no significant difference reported between stigma reported towards individuals bereaved by COVID-19 than brain haemorrhage death and no interaction effect between cause of death and PGD diagnosis.

In Chapter 3, I present Study 2, *Prolonged grief disorder, but not death from COVID-19, elicits public stigma: A vignette-based experiment*, which further investigates the potential effect of COVID-19 death and PGD on stigma by expanding on Study 1 to compare COVID-19 to underlying medical conditions (UMC). This study showed participants reported significantly more public stigma towards bereaved individuals with PGD than those without PGD. However, there was no significant difference between stigma reported towards individuals bereaved by COVID-19 with UMC than those without UMC and no interaction effect between cause of death and PGD diagnosis.

      In Chapter 4, I provide a general discussion of results from the two studies, including strengths, limitations, future directions, and conclusions. The thesis ends with a master reference list and supplementary materials relevant to all chapters.

Chapter 2 Public stigma toward prolonged grief and COVID-19 bereavement: A vignette-based experiment

In the first study, I sought to examine the role of COVID-19 as cause of death and the role of PGD diagnosis in public stigma toward bereaved individuals. Using an experimental design, I showed participants one of four vignettes and then measured their level of stigma toward each person in the vignette. This study has been published open-access in *Death Studies*, the premier journal devoted to bereavement issues with an impact factor of 4.34 (2021).

Zammit, T., Mancini, V. O., Reid, C., Singer, J., Staniland, L., & Breen, L. J. (2023). Public stigma toward prolonged grief and COVID-19 bereavement: A vignette-based experiment. *Death Studies*, 1-11. https://doi.org/10.1080/07481187.2023.2192010

The publishing agreement can be found in Supplementary W.

Abstract

We investigated the effects of cause of death and the presence of prolonged grief disorder (PGD) on eliciting public stigma towards the bereaved. Participants ($N = 328$, 76% female; $M_{age} = 27.55$ years) were randomly assigned to read one of four vignettes describing a bereaved man. Each vignette differed by his PGD status (PGD diagnosis or no PGD diagnosis) and his wife's cause of death (COVID-19 or brain hemorrhage). Participants completed public stigma measures assessing negative attributions, desired social distance, and emotional reactions. Bereavement with PGD (versus without PGD) elicited large and significantly stronger responses across all stigma measures. Both causes of death elicited public stigma. There was no interaction between cause of death and PGD on stigma. With increased PGD rates expected during the pandemic, the potential for public stigma and reduced social support for people bereaved via traumatic deaths and people with PGD requires mitigation.

Introduction

The COVID-19 pandemic is a public health crisis that has caused over six million deaths worldwide (World Health Organization [WHO], 2022). Each death leaves approximately nine family members bereaved, resulting in over 54 million bereaved individuals to date (Verdery et al., 2020). The nature of COVID-19 deaths has created unique bereavement conditions and new potential risk factors. Some of these circumstantial risk factors associated with loss include forced separation during the dying process and disrupted mourning rituals. These factors are associated with an increased risk of impaired social and work functioning, psychological distress, and poor mental health for the bereaved (Breen et al., 2022a; Lee & Neimeyer, 2022; Neimeyer & Lee, 2022; Schneider et al., in press). Therefore, early into the pandemic, the individual, community, and global experience of death, dying, and bereavement was predicted to be negatively impacted by adverse bereavement outcomes such as increased grief intensity or prolonged grief responses (Eisma et al., 2021; Mayland et al., 2020).

Prolonged grief disorder (PGD) is characterized by a pervasive, enduring preoccupation with and longing for the deceased, substantial functional impairment, and intense grief symptoms, persisting for six (WHO, 2019) or 12 months (American Psychiatric Association, 2022; Prigerson et al., 2021) beyond bereavement. People who meet PGD criteria before 12 months of bereavement are at increased risk of receiving a PGD diagnosis (Boelen & Lenferink, 2022). Before the pandemic, approximately 10% of people bereaved by natural deaths met the criteria for PGD (Boelen & Smid, 2017; Lundorff et al., 2017); however, evidence from early in the pandemic suggested an association between bereavement due to COVID-19 and an increased risk of PGD (see Eisma & Boelen, 2023; Stroebe & Shut, 2021). Given the negative impacts of PGD on functioning etc., this association warrants further investigation.

A pioneering study by Eisma et al. (2021) compared acute grief symptoms using the Traumatic Grief Inventory Self Report (TGI-SR; Boelen & Smid, 2017) between people bereaved by natural deaths ($n = 1182$), unnatural deaths ($n = 210$), and COVID-19 ($n = 49$) and found that the latter group reported higher levels of acute grief than the natural death group. Multiple studies of COVID-19 bereaved participants in the United States assessed grief symptoms using the Pandemic Grief Scale (PGS; Lee & Neimeyer, 2022) and have shown high proportions of dysfunctional grief, depression, anxiety, and functional impairment (Breen et al., 2021; Lee & Neimeyer, 2022; Lee et al., 2021; Lee et al., 2022; Neimeyer & Lee, 2022; Schneider et al., in press). A recent study with COVID-19 bereaved participants

from the United Kingdom assessed grief symptoms using the PGS and also showed high levels of dysfunctional grief (Breen et al., 2022b). A study with Chinese participants bereaved by COVID-19 assessed grief symptoms using the International ICD-11 Prolonged Grief Disorder Scale (WHO, 2019) and showed that 38% met the criteria for PGD (Tang & Xiang, 2021). A comparative study from the Netherlands (Eisma & Tamminga, 2022) showed that COVID-19 deaths yielded higher grief levels than natural deaths (but not unnatural deaths), as measured by the Traumatic Grief Inventory Self Report Plus (TGI-SR+; Lenferink et al., 2022). A study of American participants assessed grief symptoms using the PGS and showed no significant difference between bereavement by COVID-19, natural death, and violent death (Breen et al., 2022a). Similarly, Gang et al. (2022) reported a substantially elevated frequency of probable PGD (67%) in a sample from the United States; with the potential risk of PGD for COVID-19 death being higher than some natural death, such as dementia, but lower than unnatural deaths.

The recognition of PGD as a psychiatric diagnosis, as it has been added to the ICD-11 and DSM-5-TR, has elicited concerns that the diagnosis will lead to stigmatization (e.g., Breen et al., 2015; Dietl et al., 2018; Ogden & Simmonds, 2014). Stigma is the co-occurrence of labelling, separation, stereotyping, discrimination, and status loss, within a context of power inequity (Link & Phelan, 2001) and has two linked components: public stigma and self-stigma (Eisma et al., 2019; Livingston & Boyd, 2010). Public stigma occurs when members of the general population support stereotypical beliefs, endorse prejudicial reactions, and discriminate against a stigmatized group (Corrigan & Watson, 2002). Self-stigma occurs when individuals internalize public stigma (Corrigan & Watson, 2002). From a mental health perspective, public stigma is associated with diminished help-seeking (Bracke et al., 2019). Stigma related to PGD may lead to less social support being received by the bereaved, which is essential for coping with bereavement (Gonschor et al., 2020).

Indicators of public stigma in relation to the bereaved include negative attributions about them, increased desired social distance, and negative emotional reactions towards them (Eisma et al., 2019). These negative effects of stigma associated with PGD can be substantial and might explain why bereaved people who experience more severe grief symptoms also report experiencing increased negative reactions from their loved ones (Johnson et al., 2009). Recent vignette-based studies with Dutch, German, and Australian participants demonstrated a robust finding that a bereaved individual who meets PGD criteria elicits public stigma, with more negative attributions, stronger desired social distance, and increased emotional reactions elicited for people with PGD (vs. without PGD; Dennis et al., 2022; Eisma, 2018; Eisma et

al., 2019; Gonschor et al., 2020). Further, in determining whether the diagnostic label of PGD itself increases stigma, one study showed that public stigma did not differ for people with both PGD symptoms and diagnosis compared to people only experiencing PGD symptoms (Gonschor et al., 2020).

An understudied potential source of public stigma is whether bereaved people are stigmatized due to COVID-19 as the cause of death (Somse & Eba, 2020; WHO, 2020). Previous viral pandemics have shown that viruses and prejudice spread simultaneously (Demirtaş-Madran, 2020). This was documented in the Ebola virus epidemic, where bereaved family members were stigmatized and discriminated against (Kamara et al., 2017). A recent survey investigated the COVID-19 pandemic's impact on bereavement care in the United Kingdom and showed that some families reported concerns about being stigmatized from having COVID-19 recorded on the deceased person's death certificate (Pearce et al., 2021). Therefore, understanding the risks of public stigma being elicited towards people bereaved by COVID-19 is a current and important concern.

Studies of public stigma according to the cause of death reveal mixed findings. A systematic review of bereavement studies showed more guilt attributions, blame, shame, and difficulty interacting with the bereaved individual were elicited for bereavement from suicide than an accident, natural causes, and illness (Logan et al., 2018a). In contrast, a recent experimental study with Dutch participants showed no difference in public stigma elicited for bereavement from suicide than natural causes or homicide (Eisma et al., 2019). Further experimental studies with participants from Australia and the United States also showed no difference in public stigma elicited for bereavement from voluntary assisted dying/medical assisted dying than long-term illness but found more public stigma elicited when the deceased was younger than older (Philippkowski et al., 2021; Singer et al., 2022). Although previous studies show mixed findings for public stigma according to the cause of death, it is unknown whether COVID-19 is a source of stigma for the bereaved and is therefore important to investigate.

The Current Study

Given that previous research has not investigated public stigma related to COVID-19 bereavement and PGD, and the significant potential for adverse outcomes, a better understanding of stigma being implicated in COVID-19 bereavement is important. We hypothesized an interaction effect between cause of death and PGD on eliciting public stigma, in that public stigma would be intensified for people bereaved by COVID-19 with PGD. We predicted that people bereaved by COVID-19 death would elicit more stigmatizing responses

than brain hemorrhage bereavement. We further predicted that bereaved people with PGD would elicit more stigmatizing responses than people without PGD.

Method

Research Design

A randomized factorial 2x2 (COVID-19 death vs. brain hemorrhage; PGD vs. without PGD) between groups, vignette-based experimental design was used to investigate the impact of cause of death and PGD diagnosis on levels of public stigma. Nine dimensions of public stigma were examined: attributions (competent, warm, emotionally stable, dependent, and sensitive), desired social distance, and emotional reactions (anger, prosocial, and fear).

Participants

Participant inclusion criteria included being aged 18 years and over, and literate in the English language. Participants were unpaid and recruited using convenience and snowball sampling via social media (e.g., Facebook). The information included a weblink to access the study online. An a priori power analysis (Faul et al., 2007) determined that 343 participants were needed to detect a small-to-moderate ($f^2 = 0.03$) 2-way interaction at an alpha level of 0.05, based on the effect size for PGD/no PGD reported by Dennis et al. (2022). Our final sample included 328 participants, falling shy of the a priori sample size, but sufficient to detect moderate-to-large effects. The sample was predominantly female (76%), ranging from 18 to 82 years old ($M = 27.55$, $SD = 14.55$), and most were university-educated (71%), and mainly living in Australia (75%) and the United States (22%) as shown in Table 2.1. Participants who were significantly impacted by grief were mainly residents of Australia (74%) and the United States (24%); had received COVID-19 diagnosis lived mostly in the United States (83%) and Australia (17%); and had knowledge of others with COVID-19 lived in Australia (52%) and the United States (47%).

Measures

Demographic questions

Demographics included participants' gender, age, highest education level, main employment, country of residence, personal bereavement experience, personal diagnosis with COVID-19, and knowing someone diagnosed with COVID-19.

Vignettes

Four fictional vignettes were adapted from Eisma et al. (2019), describing a fictional character *Robert* who was bereaved by his wife, Margaret (see Table 2.2). Vignette conditions differed by Robert's PGD diagnosis (with PGD vs. without PGD) and Margaret's cause of

death (COVID-19 vs. brain hemorrhage). As per Eisma et al. (2019), the vignettes containing a PGD diagnosis included two PGD criteria (grief continuing longer than the six months minimum and daily functioning impairment) and four PGD symptoms (struggling to accept the death, longing for the deceased, struggling to engage in activities, and guilt; Eisma et al., 2019; WHO, 2019). Spousal bereavement was selected due to its regular occurrence, social acceptance of strong grief reactions (Logan et al., 2018a), and use in other grief and stigma research (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020). The vignette's time since death was ten months to create distance from the six months minimum grief period required for PGD diagnosis in the ICD-11 (WHO, 2019). Although some other studies have used two years, this period could be considered an anniversary reaction by participants (see Eisma, 2018).

Stigma

Participants completed measures of three stigma components: attributions (competent, warm, emotionally stable, dependent, sensitive), desired social distance, and emotional reactions (anger, prosocial emotion, fear).

Attributions. The attribution items were previously used by Eisma (2018) and Eisma et al. (2021) based on research of depression stigma (Angermeyer & Matschinger, 2003). Participants were asked to assess the characteristics associated with Robert. Using a 4-point Likert scale ranging from 1 (completely disagree) to 4 (completely agree), participants indicated the extent to which each attribute (competent, warm, emotionally stable, dependent, sensitive) represents Robert (e.g., "Robert is competent"), with higher scores indicating a higher level of the attribute.

Social Distance Scale. The 7-item Social Distance Scale (SDS; Link et al., 1987) measures participants' desired social distance from an individual by asking participants how willing they are to interact with them. In the present study, items referred to Robert, and were adapted to reflect more practical scenarios (e.g., "having your children marry someone like the person in the story" was changed to "having Robert marry a family member"). A 4-point Likert scale, ranging from 1 (definitely willing) to 4 (definitely unwilling) was used with higher scores indicating a larger desired social distance from Robert. The SDS is internally consistent, with a Cronbach's alpha of 0.85 in previous research (Eisma et al., 2019) and 0.84 in this study.

Emotional Reactions Scale. Emotional reactions toward Robert were measured using an adaptation of von dem Knesebeck et al.'s (2017) 9-item scale, which assesses common reactions to individuals with mental illness (anger, fear, and prosocial emotions; Angermeyer

& Matschinger, 2003). Eisma et al.'s (2019) adaptation involved adding five items and removing one to improve construct validity. This 13-item version comprises three sub-scales: anger (four items, e.g., "I feel irritated"), prosocial emotion (four items, e.g., "I take pity"), and fear (five items, e.g., "I feel tense"). Each item is rated on a 4-point Likert scale, from completely agree (4) to completely disagree (1), with higher scores indicating stronger reactions. Internal consistency was demonstrated by Eisma et al. (2019) for each subscale (anger, $\alpha = 0.82$; pro-social emotion, $\alpha = 0.75$; and fear, $\alpha = 0.85$). Cronbach's alpha was also good for each subscale in the current study (anger, $\alpha = 0.80$; prosocial emotion, $\alpha = 0.81$; and fear, $\alpha = 0.88$).

Manipulation check

A post-manipulation check was used to assess participants care with reading the questions and included "What was the cause of death for Robert's wife?" and "Was Robert diagnosed with a mental health disorder?".

Procedure

We obtained ethics approval from the Curtin University Human Research Ethics Committee [HRE2021-079]. Interested participants were directed to the Qualtrics survey, which first displayed the participant information sheet before asking participants to provide informed consent via a check box. Participants were randomly assigned to read one of four fictional vignettes before being asked to complete three measures in relation to the vignette character (Robert). Finally, participants were asked to complete the demographic questionnaire and manipulation check questions. Participation took approximately 10 minutes to complete the survey.

Data Analyses

The Statistical Packages for the Social Science (SPSS; Version 27) was used for all analyses. We collected 425 participant responses from 17 July to 19 September 2021 (9 weeks). The overall missing data was 23% and missing completely at random, χ^2 (df, $N = 213) = 210.54$, $p = .535$ (Little, 1988). Consequently, listwise case deletions ($N = 97$) were conducted where we could not perform imputation methods (Tabachnick & Fidell, 2013) for cases: without any data ($n = 71$); missing significant single-item questionnaires and/or whole missing constructs ($n = 24$); and, although gender is not binary, there were too few participants indicating that they were not women and men to include in comparisons ($n = 2$).

Table 2.1

Sociodemographic Characteristics of Participants (N = 328) by Groups

Characteristic	COVID/PGD *n* = 89	Brain/PGD *n* = 78	COVID/NoPGD *n* = 77	Brain/NoPGD *n* = 84	Total *n* (%)
Age (years), *M* (*SD*)	28.02 (14.36)	29.19 (15.66)	26.0 (14.38)	26.95 (13.89)	27.55 (14.55)
Gender, *n* (%)					
Women	70 (79)	60 (77)	54 (70)	65 (77)	249 (76)
Men	19 (21)	18 (23)	23 (30)	19 (23)	79 (24)
Education, *n* (%)					
Primary	0 (0)	1 (1)	1 (1)	1 (1)	3 (1)
Secondary	15 (17)	17 (22)	16 (21)	10 (12)	58 (18)
Vocational	9 (10)	12 (16)	5 (6)	9 (11)	35 (10)
Undergraduate	30 (34)	29 (37)	26 (34)	39 (46)	124 (38)
Postgraduate	35 (39)	19 (24)	29 (38)	25 (30)	108 (33)
Employment, *n* (%)					
Home duties	5 (6)	3 (4)	3 (4)	3 (4)	14 (4)
Full-time	36 (40)	36 (46)	47 (61)	38 (45)	157 (48)
Part-time	25 (28)	21 (27)	14 (18)	20 (24)	80 (24)
Retired/volunteer	11 (12)	11 (14)	3 (4)	7 (8)	32 (10)
Student	8 (9)	4 (5)	8 (10)	9 (11)	29 (9)
Unemployed/disability	4 (5)	0 (0)	0 (0)	1 (1)	5 (2)
Unemployed	0 (0)	1 (1)	2 (3)	2 (2)	5 (1)
Other	0 (0)	2 (3)	0 (0)	4 (5)	6 (2)
Country, *n* (%)					
Australia	67 (75)	56 (72)	61 (79)	63 (75)	247 (75)
United States	21 (24)	19 (24)	15 (20)	18 (21)	73 (22)
Other	1 (1)	3 (4)	1 (1)	3 (4)	8 (3)
COVID diagnosis, *n* (%)					
No, myself	88 (99)	74 (95)	77 (100)	83 (99)	322 (98)
Yes, myself	1 (1)	4 (5)	0 (0)	1 (1)	6 (2)
No, do not know others	46 (52)	45 (58)	45 (58)	56 (67)	192 (58)
Yes, know others	43 (48)	33 (42)	32 (42)	28 (33)	136 (42)
Bereavement status, *n* (%)					
Not bereaved	18 (20)	15 (19)	15 (19)	16 (19)	64 (19)
Bereaved, not impacted	33 (37)	29 (37)	27 (35)	31 (37)	120 (37)
Bereaved, impacted	38 (43)	34 (44)	35 (46)	37 (44)	144 (44)

Note. COVID= COVID-19 death; PGD = Prolonged Grief Disorder present; NoPGD = Prolonged Grief Disorder absent; Brain = brain hemorrhage death.

Table 2.2

Content of Vignettes Varying Conditions of Cause of Death and PGD

Vignette condition	Vignette Description
PGD diagnosis/COVID-19 death	Robert is aged seventy years old, and his wife Margaret died ten months ago due to COVID-19. Robert is not functioning well at work or at home, and is finding being bereaved extremely difficult. Since Margaret's death, he has been yearning strongly for her. Robert has difficulty accepting her death, and has been experiencing strong feelings of guilt. Robert has withdrawn socially and is not engaging in many activities. He has been diagnosed with Prolonged Grief Disorder from a mental health professional, due to this behavior.
PGD diagnosis/brain hemorrhage death	Robert is aged seventy years old, and his wife Margaret died ten months ago due to a brain hemorrhage. Robert is not functioning well at work or at home, and is finding being bereaved extremely difficult. Since Margaret's death, he has been yearning strongly for her. Robert has difficulty accepting her death, and has been experiencing strong feelings of guilt. Robert has withdrawn socially and is not engaging in many activities. He has been diagnosed with Prolonged Grief Disorder from a mental health professional, due to this behavior.
No PGD/COVID-19 death	Robert is aged seventy years old, and his wife Margaret died ten months ago due to COVID-19. Although Robert was extremely sad after Margaret's death and strongly yearned for her, he has learnt to live with her death. Robert is now able to function well at home and work. He has further accepted Margaret's death, is able to participate in meaningful activities and is experiencing less feelings of guilt.
No PGD/brain hemorrhage death	Robert is aged seventy years old, and his wife Margaret died ten months ago due to a brain hemorrhage. Although Robert was extremely sad after Margaret's death and strongly yearned for her, he has learnt to live with her death. Robert is now able to function well at home and work. He has further accepted Margaret's death, is able to participate in meaningful activities and is experiencing less feelings of guilt.

Normality was assessed by visually inspecting the histograms and boxplots, and using Shapiro-Wilk tests. The histograms and boxplots indicated univariate outliers present for some of the variables, though none were extreme (> 3 SDs) and were within the possible range of scores and therefore retained. As anticipated, the Shapiro-Wilk results indicated that the data distribution differed significantly from a perfect normal distribution (as $p < .05$). However, visual inspection of the histograms and boxplots, in conjunction with mostly

acceptable skewness and kurtosis statistics (z scores between -1.96 and + 1.96), and the large sample size suggested that the results of the MANOVA could be interpreted meaningfully (Pituch & Stevens, 2016). Also, as a measure of best practice, separate non-parametric tests (i.e., the Kruskall-Wallis ANOVA) were performed on those variables that were the most skewed and/or kurtosis, with these results revealing a similar pattern of findings and statistical significance, further supporting the interpretability of the MANOVA. The presence of multivariate outliers were indicated using the maximum Mahalanobis Distance; however, Cook's Distance was less than 1, indicating a low influence. Multicollinearity was found to be appropriate by examining the dependent variables (DVs) correlations. The scatterplots indicated the DVs relationships were roughly linear. Box's M was significant at $\alpha = <.001$; however, a MANOVA analysis is robust against this violation with larger participant group samples. Levene's Test of Equality of Error Variances was based on the median due to having a reduced bias from outliers (Field, 2018) and was non-significant for all DVs except pro-social, indicating equality of variance (Field, 2018).

A two-way multivariate analysis of variance (MANOVA) was used to test the hypotheses with a two-tailed significance test ($\alpha = 0.05$). Cause of death (COVID-19, brain hemorrhage) and PGD (with PGD, without PGD) were included as independent variables, and attributions (competent, warm, emotionally stable, dependent, and sensitive), desired social distance, and emotional reactions (anger, fear, and prosocial) were the DVs. Significant MANOVA results were followed up with ANOVAs. Partial eta squared (n_p^2) was used to determine the effect sizes, with 0.01 considered a small effect, 0.06 a medium effect, and 0.14 a large effect (Cohen, 2013). Confidence Intervals (95%) were used to assist with interpreting results.

Results

Preliminary Findings

Analysis of variance (ANOVAs) and chi-square tests of independence (χ^2) were used to assess successful participant randomization. Between the four vignette groups, no significant differences were found based on: gender, χ^2 (3, $N = 328$) = 1.92, $p = .590$; age, $F(3, 324) = 0.70$, $p = .553$; education level, χ^2 (12, $N = 328$) = 12.83, $p = .382$; employment, χ^2 (21, $N = 328$) = 30.39, $p = .085$; country of residence, χ^2 (9, $N = 328$) = 8.02, $p = .532$; bereavement experience, χ^2 (6, $N = 328$) = 0.17, $p = 1.000$; COVID-19 diagnosis (self), χ^2 (3, $N = 328$) = 6.60, $p = .086$; COVID-19 diagnosis (know others), χ^2 (3, $N = 328$) = 4.03, $p = .258$. These results indicate successful randomization. The manipulation check showed most

participants correctly identified cause of death (88%) and PGD diagnoses (74%). As per convention (Dennis et al., 2022; Eisma, 2018), we reported the full sample's findings as there were no differences in the full and partial samples' resulting patterns. Normality assumptions were assessed for the nine DVs and were found to be appropriate. Statistical assumptions relevant to the MANOVA were assessed and appropriately met (Tabachnick & Fidell, 2013).

Main Findings

The MANOVA identified a non-significant interaction between cause of death and PGD diagnosis, indicating the effect of cause of death did not differ depending on PGD diagnosis. The means and standard errors for the four conditions are listed in Table 2.3. A non-significant main effect for cause of death was found, $F(9, 321) = 1.61$, $p = .319$, $n_p^2 = .03$, $\lambda = 0.97$, indicating COVID-19 death did not elicit more public stigma than brain hemorrhage death.

A significant main effect for PGD diagnosis was found, indicating more public stigma is elicited for those with PGD than without PGD, $F(9, 321) = 44.83$, $p = < .001$, $n_p^2 = .56$, $\lambda = .44$, indicating that the vignette with the person with PGD elicited more stigma than the person without PGD. Follow-up univariate ANOVAs indicated that Robert was perceived to be: less competent, $F(1, 329) = 17.94$, $p = < .001$, $n_p^2 = .05$; less emotionally stable, $F(1, 329) = 172.97$, $p = < .001$, $n_p^2 = .35$; more dependent, $F(1,329) = 10.36$, $p = .001$, $n_p^2 = .03$; and more sensitive, $F(1,329) = 36.91$, $p = < .001$, $n_p^2 = .10$ in the vignettes with PGD compared to without PGD. Likewise, the vignette describing Robert with PGD elicited more social distance, $F(1, 329) = 28.23$, $p = < .001$, $n_p^2 = .08$; more prosocial emotions, $F(1, 329) = 175.41$, $p = < .001$, $n_p^2 = .35$; and more fear, $F(1, 329) = 14.80$, $p = < .001$, $n_p^2 = .04$ than the vignette without PGD. No differences were observed for warm, $F(1, 329) = .02$, $p = .893$, $n_p^2 = .00$; or anger, $F(1, 329) = .29$, $p = .589$, $n_p^2 = .00$.

Post Hoc Analyses

Half of the sample (44%) reported having experienced a significantly impacting bereavement experience, which might have affected warm ratings. We tested differences between the reported warm mean scores according to bereavement status (bereaved vs. non-bereaved) with a two-tailed t-test ($\alpha = 0.05$). The results of the *t* test comparing the difference in warm scores reported by participants who were bereaved ($n = 264$; $M = 2.95$, $SD = .54$) to those who were not bereaved ($n = 64$; $M = 2.92$, $SD = .51$) was not significant, $t(326) = .388$, $p =. 698$, two-tailed, 95% CI of the mean difference [-.175, .117]. As a measure of best

practice, we conducted a separate non-parametric test (i.e., the Mann-Whitney U) due to violated normality assumptions and kurtosis; both analyses revealed the same result, supporting the interpretability of the *t* test.

Discussion

Our overall study aim was to investigate the effects of cause of death and PGD on eliciting public stigma for the bereaved. Consistent with our expectations, participants reported more stigma towards a bereaved person with PGD than without. The significant main effect detected for PGD diagnosis on public stigma supports previous research findings (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020). Specifically, participants assessed the bereaved person with PGD as being less competent and emotionally stable, but more dependent and sensitive than the bereaved person without PGD. Participants also expressed increased desired social distance, more prosocial emotions, and more fear towards the person with PGD than without PGD. These results indicate the public may experience mixed feelings of wanting to help the bereaved while also feeling fearful of them and wanting to avoid them (Dennis et al., 2022).

However, our PGD findings contrast with previous research in two ways. First, previous research showed bereaved people with PGD elicited significantly more anger than people without PGD (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020). Our sample size was adequate and similar to previous research that detected a moderate effect (Eisma, 2018; Eisma et al., 2019). In our sample, anger towards the bereaved was elicited equally irrespective of PGD, which aligns with previous research showing that bereaved people elicited anger without PGD present (Philippkowski et al., 2021). Second, unlike previous studies (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020), bereaved people with PGD were not perceived by our sample as significantly less warm. Given that our sample size was adequate and similar to or larger than previous research that achieved a moderate effect (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019), the contrasting results could have been because almost half of our sample reported experiencing a significantly impacting bereavement experience. Other studies (e.g., Dennis et al., 2022) reported a smaller proportion of the sample as significantly impacted by bereavement (28%) or did not report whether participants' bereavement experience was significantly impacting (Eisma, 2018; Gonschor et al., 2020). Previous research has shown that personal experience with bereavement and interacting with bereaved individuals can promote an understanding of bereavement (Costa et al., 2007; Jorm & Oh, 2009), but has no effect on intentions to provide support to bereaved people (Logan et al., 2018b). However, our analysis showed no

difference between warm mean scores according to bereavement status (bereaved experience vs. nonbereaved experience), indicating the limited impact that personal bereavement history has on social support following bereavement (Logan et al., 2018b).

Overall, our findings suggest that bereaved people with PGD are significantly more likely to be stigmatized than people without PGD. A major consequence of this stigmatization relates to support and treatment; stigma may prevent potential supporters from helping bereaved individuals and limit support seeking (Corrigan, 2005). The latter is particularly noteworthy in that people with PGD symptoms are less likely to seek counseling or mental health services than other grieving persons (Lichtenthal et al., 2011). This finding contributes to a growing body of research across countries and languages that the role of PGD in eliciting stigma is a robust effect that is generalizable across Western cultures (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020).

In contrast to our expectations, we found no significant interaction between cause of death and PGD diagnosis, and stigma did not differ based on cause of death (COVID-19 and brain hemorrhage). However, the mean stigma scores in our sample showed high levels of stigma for both death causes (COVID-19 and brain hemorrhage). Although COVID-19 deaths are potentially stigmatizing (Pearce et al., 2021) and traumatic in nature (Doka, 2021), brain hemorrhage deaths may also be experienced as traumatic due to being unpredicted and sudden (Penman et al., 2014). COVID-19 and brain hemorrhage deaths may have been perceived as similarly traumatic causes of deaths.

Interestingly, a comparison of our COVID-19 stigma results with those reported in a previous study (Eisma et al., 2019) shows that participants in this study reported the strongest stigma mean scores. Specifically, our stigma means were higher than those reported by Eisma et al. (2019), using the same stigma measures, such that, compared to people bereaved by suicide, stroke, or homicide, those bereaved by COVID-19 were perceived as less warm, and emotionally stable, but more dependent, and elicited more anger and fear; there were no differences in attributions of sensitivity or prosocial emotions. Together, these comparisons suggest that, although people bereaved by COVID-19 did not elicit significantly stronger stigma than brain hemorrhage deaths in our sample, both causes elicited higher stigma levels than other causes of death studied previously (i.e., suicide, stroke, homicide; Eisma et al., 2019). It is possible that the unique pandemic conditions contribute to public stigma of the bereaved, irrespective of whether COVID-19 is the cause of death. Currently, however, no other COVID-19 bereavement and public stigma research exists for comparison.

Strengths, Limitations, and Future Directions

Strengths of this research include experimentally investigating COVID-19 bereavement and PGD eliciting public stigma and contributing to the body of research. Our study used a robust experimental design, participant randomization to vignettes, participant manipulation checks, and multiple comprehensive stigma measures. Limitations of the study included participants being mainly female, highly educated, and young, potentially limiting the generalizability of the findings. However, previous research conducted in different cultures with varying sexes/genders, education, and ages showed similar results (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020; Singer et al., 2022). Future research could use other recruitment methods to recruit a broader participant range and extend the generalizability of the findings, including non-Western samples. For example, one study from mainland China showed that nearly one-quarter were concerned that labelling grief as a disorder will subject bereaved persons to public stigma (Tang et al., 2020). Despite previous evidence that public stigma does not differ for people with both PGD symptoms and diagnosis compared to people only experiencing PGD symptoms (Gonschor et al., 2020), it is possible that the PGD label itself was stigmatizing, and future research could address the impact of the diagnosis from the widower's struggle, whether diagnosed or not. There is evidence that emphasizing underlying health conditions of the deceased could elicit stigma (Gronholm et al., 2021), and future studies could investigate if such conditions elicit stigma. Although using vignette-based experiments for stigma approximates real-life responding, it is not well established how generalizable the results are to public stigma in real situations (Dennis et al., 2022).

Conclusions

Results indicate COVID-19 deaths do not elicit significantly more public stigma for the bereaved than brain hemorrhage deaths, but both elicit high levels of stigma. Further, this study supports the robust finding that PGD elicits public stigma. With an increased risk of elevated PGD rates expected during the pandemic, further research is needed to understand factors that elicit PGD stigma and enable timely support for the bereaved in need.

Table 2.3

Means, Standard Errors, and Confidence Intervals for Stigma Variables (N = 328)

Measure	COVID/PGD		Brain/PGD		PGD TOTAL	COVID/NoPGD		Brain/NoPGD		NoPGD TOTAL
	M	*(SE)*	*M*	*(SE)*	*M* (SE) [95% CI]	*M*	*(SE)*	*M*	*(SE)*	*M* (SE) [95% CI]
Attributions										
Competent	2.87	(0.051)	2.81	(0.056)	2.84 (0.038) [2.76,2.92]	2.99	(0.056)	3.16	(0.054)	3.07 (0.039) [2.99,3.15]
Warm	2.96	(0.056)	2.91	(0.060)	2.93 (0.041) [2.85,3.02]	2.90	(0.061)	2.99	(0.058)	2.94 (0.042) [2.86,3.03]
Emotionally stable	2.23	(0.057)	2.18	(0.061)	2.20 (0.042) [2.12,2.28]	2.94	(0.062)	3.05	(0.060)	2.99 (0.043) [2.91,3.08]
Dependent	2.54	(0.062)	2.48	(0.068)	2.51 (0.046) [2.42,2.60]	2.27	(0.068)	2.32	(0.065)	2.30 (0.047) [2.20,2.39]
Sensitive	3.10	(0.058)	3.20	(0.063)	3.15 (0.043) [3.07,3.23]	2.71	(0.064)	2.83	(0.061)	2.77 (0.044) [2.69,2.86]
Social distance scale	14.85	(0.314)	14.52	(0.340)	14.68 (0.231) [14.23,15.14]	13.34	(0.345)	12.50	(0.330)	12.92 (0.239) [12.45,13.39]
Emotional reactions										
Anger	5.58	(0.199)	5.68	(0.216)	5.63 (0.147) [5.34,5.92]	5.91	(0.219)	5.58	(0.210)	5.75 (0.152) [5.45,6.04]
Prosocial	12.33	(0.231)	12.20	(0.251)	12.27 (0.170) [11.93,12.60]	9.47	(0.254)	8.58	(0.243)	9.03 (0.176) [8.68,9.37]
Fear	8.76	(0.272)	8.73	(0.295)	8.75 (0.200) [8.36,9.14]	7.83	(0.298)	7.45	(0.286)	7.64 (0.207) [7.24,8.05]

Note. 95% Confidence intervals within square brackets. COVID = COVID-19 death; PGD = with Prolonged Grief Disorder; NoPGD = without Prolonged Grief Disorder; Brain = brain hemorrhage death.

Chapter 3

Prolonged grief disorder, but not death from COVID-19, elicits public stigma: A vignette-based experiment

As the project in Chapter 2 showed that high stigma levels were reported towards those bereaved by COVID-19 and brain haemorrhage death, it appeared appropriate, due to the media's specific reporting of COVID-19 deaths with an underlying medical condition (UMC), to investigate whether more stigma was reported toward those bereaved by COVID-19 death with an UMC than without UMC.

Abstract

We investigated the effects of cause of death (COVID-19 with an underlying medical condition vs without) and prolonged grief disorder status (PGD present or absent) on participants' reported public stigma towards the bereaved. Participants (N=304, 66% women; M_{age} = 39.39 years) were randomly assigned to read one of four vignettes describing a bereaved man. Participants completed stigma measures assessing negative attributions, desired social distance, and emotional reactions. Participants reported significantly stronger stigmatizing responses towards an individual with PGD (versus without PGD) across all stigma measures. There was no significant difference in stigma based on cause of death; however, stigma was reported regardless of cause of death. There was no significant interaction between cause of death and PGD on stigma. This study supports the robust finding of public stigma being reported toward an individual with PGD, suggesting these individuals are at risk of public stigma and not receiving adequate bereavement support.

Introduction

The COVID-19 pandemic, which has caused more than seven million deaths worldwide (WHO, 2024), is an immense bereavement event that has severely disturbed the experience of grief and bereavement (Harrop et al., 2021). COVID-19 deaths are associated with new bereavement conditions and potential risk factors including mandated separation during the dying process and disrupted mourning rituals, which are associated with an increased risk of psychological distress, poor mental health, and impaired functioning for the bereaved (Breen et al., 2023; Lee & Neimeyer, 2022; Neimeyer & Lee, 2022). These findings provide support for early pandemic predictions, that death, dying, and bereavement experiences would be negatively impacted for bereaved individuals and their communities through intense and prolonged grief responses (Eisma et al., 2021; Mayland et al., 2020). When grief responses are intense and prolonged, a bereaved individual may be more likely to develop prolonged grief disorder (PGD).

Characterized by significant functional impairment and an invasive and persistent preoccupation with and longing for the person who died, PGD is diagnosed when intense grief symptoms endure for six (WHO, 2019) or 12 months (American Psychiatric Association, 2022) after bereavement. In addition to the distress and functional impairment of the disorder itself, PGD is associated with a decreased quality of life, suicidality, and self-injury (Lichtenthal et al., 2011; Prigerson et al., 2021). Bereaved individuals are most likely to be diagnosed with PGD when the diagnostic criteria are met within 12 months of bereavement (Boelen & Lenferink, 2022). Before the COVID-19 pandemic, approximately 10% of individuals who experienced bereavement from a natural death were at risk for meeting PGD criteria (Boelen & Smid, 2017; Lundorff et al., 2017). However, research conducted during the pandemic's early stages suggests that bereavement from COVID-19 is associated with an increased risk of PGD (see Eisma & Boelen, 2023; Stroebe & Schut, 2021).

Research performed with COVID-19 bereaved participants from China, the United Kingdom, and the United States showed high levels of anxiety, depression, functional impairment, and dysfunctional grief (Breen et al., 2021; Breen et al., 2022; Lee & Neimeyer, 2022; Neimeyer & Lee, 2022; Tang & Xiang, 2021). Further research conducted with COVID-19 bereaved participants from the United Kingdom showed they experienced restrictions in interacting with loved ones, loneliness, and social isolation (Selman et al., 2022a), and those bereaved by a close relationship who reported loneliness and social isolation also experienced increased grief and support needs (Selman et al., 2022b).

Experimental studies conducted with Dutch participants showed higher grief levels were experienced by those bereaved by COVID-19 than natural, but not unnatural death (Eisma & Tamminga, 2022; Eisma et al., 2021). Other similar COVID-19 studies showed cause of death was not associated with higher grief levels, suggesting increased grief symptoms may be associated with the experience of being bereaved and the unique pandemic bereavement conditions rather than COVID-19 bereavement itself (Breen et al., 2023; Gang et al., 2022).

The establishment of PGD as a mental disorder in DSM-5- and ICD-11 has raised concerns from researchers and clinicians that a diagnosis might pathologize grief and contribute to the stigmatization of bereaved individuals (Breen et al., 2015; Dietl et al., 2018; Lichtenthal et al., 2011). Stigma occurs when stereotyping, separation, discrimination, and status loss arise in an environment of power imbalance (Link & Phelan, 2001). Two interacting forms of stigma are public stigma and self-stigma (Eisma et al., 2019; Livingston & Boyd, 2010). Public stigma occurs when stereotypical beliefs, prejudicial reactions, and discriminatory behaviors are endorsed by the general public towards a stigmatized group, and self-stigma occurs when an individual within a stigmatized group internalizes this stigma (Corrigan & Watson, 2002). In the context of mental illness, stigma results in poor self-esteem, low self-efficacy, and reduced motivation to seek mental health support (Corrigan, 2005; Vogel et al., 2007). In the context of bereavement, public stigma results in negative attributions of the bereaved, increased desired social distance from them, and negative emotional reactions towards them (Eisma et al., 2019).

Early research indicated an association between severe grief symptoms and negative reactions towards bereaved individuals without a PGD diagnosis, including family and friends telling the bereaved they were exaggerating their grief (Johnson et al., 2009). More recently, a vignette study with German participants showed there was no difference in stigma reported towards individuals with PGD symptoms who were diagnosed with PGD, than individuals who had PGD symptoms who did not have a diagnosis of PGD (Gonschor et al., 2020). Further experimental research with Australian, Dutch, and German participants showed more stigmatizing responses through negative attributions, stronger desired social distance, and increased emotional reactions towards individuals with PGD (vs without PGD; Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020; Zammit et al., 2023).

Previous pandemics have shown a common association between infectious viruses and stigma (Demirtas-Madran, 2020), including during the Ebola epidemic where family members bereaved by the Ebola virus reported being stigmatized within their community (Kamara et al., 2017). This appears to be the case for the COVID-19 disease as well. Studies

conducted with participants from the United Kingdom showed people diagnosed with long COVID-19 reported higher levels of stigma than those without a diagnosis (Pantelic et al., 2022). This may possibly be due to people diagnosed with long COVID-19 experiencing more severe symptoms, additional impact upon their daily living, further dismissal of their condition, and added stereotyping, throughout the process of obtaining their diagnosis, than people who did not obtain a long COVID-19 diagnosis (Pantelic et al., 2022). Whereas an investigation into bereavement care showed some bereaved family members reported concerns about stigma from having COVID-19 listed as the cause of death (Pearce et al., 2021). Although previous research has investigated the effect of cause of death on public stigma (Eisma et al., 2019) the results have been mixed. A systematic review of bereavement experiences showed individuals bereaved by suicide experienced more stigmatizing responses than those bereaved by natural causes, accidents, and illness (Logan et al., 2018a). Recent experimental studies showed no significant difference between stigma reported toward individuals bereaved by suicide, homicide and natural causes, or voluntary assisted dying/medical assisted dying and long-term illness (Eisma et al., 2021; Philippkowski et al., 2021; Singer et al., 2022). A recent Australian study showed that deaths from COVID-19 elicited comparable stigma to deaths from brain hemorrhage; however, both causes elicited high levels of stigma (Zammit et al., 2023).

In the context of cause of death and stigma, an additional consideration may be the role of an underlying medical condition (UMC), including diabetes, heart failure, obesity, chronic kidney disease, and liver cirrhosis with COVID-19, due to the increased risk of negative outcomes such as intensive care admission, hospitalization, and death (Venkatakrishnan et al., 2021). However, over-emphasizing COVID-19 deaths with UMC assigns blame, devalues those affected, creates a false sense of security for the remaining population, and corrodes epidemic control measures (Gronholm et al., 2021). For those bereaved by COVID-19, the grief experience may be complicated by layers of stigma regarding bereavement, the virus, UMC, and mental illness. Therefore, with new bereavement conditions and potential risk factors negatively affecting bereavement experiences during the pandemic, including COVID-19 death with UMC and increased prolonged grief responses, it is critical that stigma be mitigated to reduce negative experiences and community division (Gronholm et al., 2021). Consequently, more research is required to understand the facets of bereavement stigma, especially in the context of the current pandemic, to ensure stigma-reduction efforts are implemented to target critical factors that will reduce the stigma barriers and enable the bereaved to seek and receive adequate support.

The aim of this research was to investigate the effects of cause of death by COVID-19 with UMC (versus without UMC) and PGD diagnosis (with PGD vs. without PGD), on participants' reported public stigma towards the bereaved using an experimental vignette design. We hypothesized an interaction effect between UMC and PGD, such that stigma would be intensified for an individual with PGD who was bereaved by COVID-19 with an UMC. We also hypothesized participants would report greater public stigma toward an individual bereaved by COVID-19 with UMC than without UMC and greater public stigma toward a bereaved individual with PGD than without PGD.

Method

Research Design

The design was a fully randomized factorial 2x2 (COVID-19 death with UMC vs. without UMC; with PGD vs without PGD), between groups, vignette-based experiment, investigating group differences in reported public stigma according to cause of death and prolonged grief. Multiple dependent variables of stigma were used: attributes of the bereaved (competent, warm, emotionally stable, dependent, sensitive), desired social distance from the bereaved, and emotional responses towards the bereaved (anger, fear, prosocial).

Participants

The criteria for inclusion required participants to be aged 18 years or over, and literate in the English language. It was determined using an a priori power analysis (Faul et al., 2007) that 343 participants were required to detect a small-to-moderate ($f^2 = 0.03$) two-way interaction with 80% power at an alpha level of 0.05, based on the effect size for PGD/no PGD reported by Dennis et al. (2022). Our final sample included 304 participants, slightly less than the a priori sample size, but sufficient to detect moderate-to-large effects. Participants were paid (GBP 0.70) and recruited using convenience sampling via the Prolific platform. Participants were mostly women (66%), university educated (60%), aged from 19 to 75 years old ($M = 39.39$, $SD = 12.64$), and were residents from the United Kingdom (81%) and the United States (19%) as shown in Table 3.1. A cross-sectional comparison of the United Kingdom, the United States, Australia, and Japan highlighted the role that structural regulatory and policy environments concerning issues such as job protection, sick leave provisions, medical coverage, and so on had on the experience of the pandemic in those countries (Qureshi et al., 2023). Many participants had personal bereavement experience (78%), were significantly impacted by grief (44%), knew someone who died from COVID

(21%), knew people who died during the pandemic from other causes (47%), and had experienced a COVID-19 diagnosis themselves (46%).

Measures

Demographic Questions

Participants reported their gender, age, highest education level, main employment, country of residence, personal bereavement experience and whether bereavement had a significant impact on them, their personal experience with COVID-19 bereavement, personal experience with pandemic bereavement, and personal experience with a COVID-19 diagnosis.

Vignettes

Vignettes are a commonly used approach to examining stigma (Link et al., 2004) and were used in this study to investigate public stigma towards cause of death and PGD. We adapted four fictional vignettes from Eisma et al. (2019), depicting a character named Robert who was bereaved by the death of his wife Margaret (see Table 3.2). Each vignette differed by whether Robert did or did not have PGD (diagnosis and symptoms) and by his wife's cause of death (COVID-19 with UMC vs COVID-19 without UMC). The vignettes that showed Robert diagnosed with PGD included four PGD symptoms (struggling to accept the death, longing for the deceased, struggling to engage in activities, and guilt) and two PGD criteria (grief continuing for more than the six months minimum and daily functioning impairment; Eisma et al., 2019; WHO, 2019). The vignettes described Margaret's death as ten months ago to establish the minimum time of six months since bereavement required for a PGD diagnosis (WHO, 2019).

Public Stigma

Participants completed three self-report measures that assess three components of public stigma: attributions, desired social distance, and emotional reactions.

Attributions. The five Attributions items used were developed by Eisma (2018) and Eisma et al. (2021) based on Angermeyer and Matschinger's (2003) research into public stigma and depression. Participants indicated their level of agreement with each attribute (competent, warm, emotionally stable, dependent, sensitive) assigned to Robert (e.g., "Robert is competent.") using a 4-point Likert scale ranging from completely disagree (1) to completely agree (4) with higher scores indicating a higher level of the attribute. More stigmatizing attitudes are reported through higher scores on dependent and sensitive, and lower scores on competent, warm, and emotionally stable.

Table 3.1

Sociodemographic Characteristics of Participants (N = 304) by Groups

Characteristic	UMC/PGD *n = 74*	NoUMC/PGD *n = 76*	UMC/NoPGD *n = 77*	NoUMC/NoPGD *n = 77*	Total *n (%)*
Age (years), *M* (*SD*)	39.18 (12.82)	38.75 (12.66)	40.01 (12.35)	39.60 (12.95)	39.39 (12.64)
Gender, *n* (%)					
Women	46 (62)	53 (70)	55 (71)	46 (60)	200 (66)
Men	28 (38)	23 (30)	22 (29)	31 (40)	104 (34)
Education, *n* (%)					
Primary	1 (1)	1 (1)	2 (2)	0 (0)	4 (1)
Secondary	9 (12)	16 (21)	18 (23)	19 (25)	62 (20)
Vocational	19 (26)	13 (17)	9 (12)	14 (18)	55 (18)
Undergraduate	33 (45)	32 (43)	33 (43)	31 (40)	129 (43)
Postgraduate	12 (16)	14 (18)	15 (20)	13 (17)	54 (18)
Employment, *n* (%)					
Home duties	0 (0)	10 (13)	7 (9)	3 (4)	20 (7)
Full-time	42 (57)	42 (56)	35 (45)	43 (56)	162 (53)
Part-time	17 (23)	12 (16)	19 (24)	19 (24)	67 (22)
Retired	5 (6)	3 (4)	6 (8)	5 (6)	19 (7)
Self-employed	3 (4)	0 ()	2 (3)	2 (3)	7 (2)
Student	3 (4)	2 (3)	2 (3)	3 (4)	10 (3)
Unemployed/disability	2 (3)	1 (1)	1 (1)	0 (0)	4 (1)
Unemployed	2 (3)	5 (6)	3 (4)	2 (3)	12 (4)
Volunteer	0 (0)	1 (1)	2 (3)	0 (0)	3 (1)
Country, *n* (%)					
UK	63 (85)	56 (74)	67 (87)	61 (79)	247 (81)
USA	11 (15)	20 (26)	10 (13)	16 (21)	57 (19)
COVID diagnosis, *n* (%)					
No, myself	39 (53)	42 (55)	37 (48)	45 (58)	163 (54)
Yes, myself	35 (47)	34 (45)	40 (52)	32 (42)	141 (46)
COVID death, *n* (%)					
No, do not know others	55 (74)	63 (83)	61 (79)	64 (83)	243 (80)
Yes, know others	19 (26)	13 (17)	16 (21)	13 (17)	61 (20)
Pandemic death, *n* (%)					
No, do not know others	35 (47)	37 (49)	31 (40)	41 (53)	144 (47)
Yes, know others	39 (53)	39 (51)	46 (60)	36 (47)	160 (53)
Bereavement status, *n* (%)					
Not bereaved	23 (31)	19 (25)	10 (13)	15 (19)	67 (22)
Bereaved, not impacted	28 (38)	25 (33)	28 (36)	23 (30)	104 (34)
Bereaved, impacted	23 (31)	32 (42)	39 (51)	39 (51)	133 (44)
Underlying medical condition					
Asthma	0 (0)	0 (0)	0 (0)	1 (1)	1 (0)
Cancer	7 (9.5)	10 (13)	13 (17)	11 (14)	41 (14)
Combination	0 (0)	0 (0)	1 (1)	0 (0)	1 (0)
Diabetes	3 (4)	6 (8)	9 (12)	5 (6)	23 (8)
General fitness	0 (0)	0 (0)	1 (1)	0 (0)	1 (0)
Heart disease	4 (5.4)	8 (10.5)	17 (22)	5 (6)	34 (11)
High blood pressure	3 (4)	3 (4)	5 (6)	3 (4)	14 (5)
Immune compromised	0 (0)	1 (1)	0 (0)	0 (0)	1 (0)
Kidney disease	0 (0)	1 (1)	0 (0)	0 (0)	1 (0)
Lung disease	56 (76)	10 (13)	11 (14)	16 (21)	93 (31)
Obesity	0 (0)	6 (8)	9 (12)	2 (3)	17 (6)
Stroke	0 (0)	0 (0)	1 (1)	0 (0)	1 (0)
None	1 (1)	31 (41)	10 (13)	34 (45)	76 (25)

Note. UMC = Underlying medical condition present; NoUMC = Underlying medical condition absent; PGD = Prolonged Grief Disorder present; NoPGD = Prolonged Grief Disorder absent

Table 3.2

Content of Vignettes Varying Conditions of Cause of Death and PGD

Vignette condition	Vignette Description
PGD diagnosis/ COVID-19 death and UMC	Robert's wife Margaret died ten months ago due to COVID-19. Margaret also had an underlying medical condition that affected her lungs. Robert is finding being bereaved extremely difficult and is not functioning well at work or at home. Since Margaret's death, he has been yearning strongly for her. Robert has difficulties accepting her death, and has been experiencing strong feelings of guilt. Robert has withdrawn socially and is not engaging in many activities. He has been diagnosed with Prolonged Grief Disorder from a mental health professional, due to this behavior.
PGD diagnosis/ COVID-19 death and No UMC	Robert's wife Margaret died ten months ago due to COVID-19. Margaret did not have an underlying medical condition and was in good health. Robert is finding being bereaved extremely difficult and is not functioning well at work or at home. Since Margaret's death, he has been yearning strongly for her. Robert has difficulties accepting her death, and has been experiencing strong feelings of guilt. Robert has withdrawn socially and is not engaging in many activities. He has been diagnosed with Prolonged Grief Disorder from a mental health professional, due to this behavior.
No PGD/COVID-19 death and UMC	Robert's wife Margaret died ten months ago due to COVID-19. Margaret also had an underlying medical condition that affected her lungs. Although Robert was extremely sad after Margaret's death and strongly yearned for her, he has learnt to live with her death. Robert is now able to function well at home and work. He has further accepted Margaret's death, is able to participate in meaningful activities and is experiencing less feelings of guilt. According to Robert's mental health professional, he is coping well with his grief.
No PGD/ COVID-19 death and no UMC	Robert's wife Margaret died ten months ago due to COVID-19. Margaret did not have an underlying medical condition and was in good health. Although Robert was extremely sad after Margaret's death and strongly yearned for her, he has learnt to live with her death. Robert is now able to function well at home and work. He has further accepted Margaret's death, is able to participate in meaningful activities and is experiencing less feelings of guilt. According to Robert's mental health professional, he is coping well with his grief.

Social Distance Scale. To measure participants' desired social distance from Robert and willingness to interact with him, the Social Distance Scale (SDS; Link et al., 1987) was used. The scale contains seven items (e.g., "how would you feel about working with someone like Robert") and uses a 4-point Likert scale, ranging from definitely willing (1) to definitely unwilling (4), with higher scores indicating a larger desired social distance from Robert. In the current study, we adapted the measure to reflect more specific scenarios to the vignette by changing the word children to family member (e.g., "having your children marry someone like the person in the story" to "having a family member marry someone like the person in the story") and using scoring of 1-4 rather than the original 0-3 (Penman et al., 2014). The SDS's internal consistency was good in previous research ($\alpha = 0.85$; Eisma et al., 2019), and in this study $\alpha = 0.92$.

Emotional Reactions Scale. Emotional reactions toward Robert were measured using an adapted version of von dem Knesebeck et al.'s (2017) scale, with nine items assessing participants' responses towards individuals with mental illness (Angermeyer & Matschinger, 2003). Eisma et al. (2019) developed an adapted scale by adding five items and removing one item to improve construct validity. This comprises 13 items across three subscales: anger (4 items, "I feel irritated"); prosocial emotions (4 items, "I take pity"); and fear (5 items, "I feel tense"). Participants rate each item on a 4-point Likert scale, from completely agree (4) to completely disagree (1), with higher scores indicating stronger emotional responses. The internal consistency for each subscale was demonstrated by Eisma et al. (2019; anger $\alpha = 0.82$; pro-social emotion $\alpha = 0.75$; and fear $\alpha = 0.85$). In the current study, Cronbach's alpha was good for each subscale (anger $\alpha = 0.91$, prosocial emotion $\alpha = 0.83$; and fear $\alpha = 0.84$).

Manipulation check. The manipulation check was used to assess participants' care with reading the questions and comprised two questions ("Did Margaret have an underlying medical condition?"; "Was Robert diagnosed with a mental health disorder?").

Procedure

Ethics approval was obtained from the Human Research Ethics Office at Curtin University [HRE2021-0279]. Participants were recruited via the online Prolific platform which directed them to the Qualtrics survey where they were asked to provide consent via a check box. Each participant was randomly assigned to read one of four vignettes and asked to complete three measures to assess their response toward Robert. To conclude, participants completed the demographic questionnaire and manipulation check questions.

Data Analyses

All analyses were conducted using the Statistical Packages for the Social Science (SPSS; Version 27). The participant responses were collected from 21st June to 20th July, 2022 for 304 participants. There was no missing data. Listwise case deletions were conducted where there were not enough participants indicating gender other than woman or man to include in comparisons ($n = 1$).

Normality was assessed using histograms, boxplots, skewness, kurtosis, and Shapiro-Wilk tests. The histograms and boxplots indicated some univariate outliers, but none were extreme (> 3 SDs) and all were retained because they were within the acceptable score range. The Shapiro-Wilk results indicated the data was not normally distributed; however, with the skewness and kurtosis statistics being mostly acceptable (z scores within ±1.96) and the large participant groups (> 30), the MANOVA results could be meaningfully interpreted (Pituch & Stevens, 2016). Separate non-parametric tests (i.e., the Kruskall-Wallis ANOVA) were conducted as a measure of best practice, on variables with the most skewness and/or kurtosis Results showed statistical significance that supported the MANOVA's interpretability. The maximum Mahalanobis Distance indicated multivariate outliers; however, Cook's Distance indicated these were appropriate and were retained. Multicollinearity was assessed, with the correlations between dependent variables found to be appropriate. Scatterplots indicated the relationships between DVs were approximately linear. Box's M was found to be significant at $p < .001$; however, with large sample sizes a MANOVA analysis is robust against this violation, and Levene's Test of Equality of Error Variances was non-significant for all DVs except warm and sensitive, indicating equality of variance was met (Field, 2018).

To test the hypotheses, a two-way multivariate analysis of variance (MANOVA) was performed with a two-tailed significance test ($\alpha = .05$). The independent variables included cause of death (COVID-19 death with UMC, COVID-19 death without UMC) and PGD diagnosis (with PGD, without PGD). The nine dependent variables were attributions (competent, warm, emotionally stable, dependent, sensitive), desired social distance, and emotional reactions (anger, fear, and pro-social). Significant MANOVA results were followed up with ANOVAs. Partial eta squared (n_p^2) was used to determine the effect size (small = 0.01, medium = 0.06, and large = 0.14; Cohen, 2013). To assist with interpreting results Confidence Intervals (95%) were used.

Results

Preliminary Findings

Prior to hypothesis testing, analyses of variance (ANOVAs) and Chi-Square tests were conducted to check participant randomization to vignettes and manipulation checks according to demographics. No significant differences were found between the four vignette groups based on: gender, χ^2 (3, $N = 304$) = 3.30, $p = .348$; age, F (3, 300) = 0.14, $p = .936$; education level, χ^2 (12, $N = 304$) = 10.07, $p = .610$; employment, χ^2 (24, $N = 304$) = 24.46, $p = .330$; country of residence, χ^2 (3, $N = 304$) = 5.48, $p = .140$; bereavement experience, χ^2 (6, $N = 304$) = 11.43, $p = .076$; COVID-19 diagnosis (self), χ^2 (3, $N = 304$) = 1.79, $p = .618$; COVID-19 death, χ^2 (3, $N = 304$) = 2.38, $p = .498$, pandemic death, χ^2 (3, $N = 304$) = 2.68, $p = .443$. These results indicate randomization was successful. For the manipulation check questions most participants correctly identified whether Margaret had an UMC (94%) and Robert's PGD diagnosis (88%). As there was no difference in the resulting pattern between the full and partial samples, the findings from the full sample were reported. The nine DVs' normality assumptions were assessed and found to be appropriate. The MANOVA's statistical assumptions were assessed and showed they were met appropriately.

Main Findings

A two-way MANOVA was performed to assess differences in stigma reported by participants toward an individual bereaved by COVID-19 death with UMC (vs. without UMC), and PGD (with vs. without PGD), and their interaction effects. The results for the four conditions (means and standard deviations) are listed in Table 3.3.

Contrary to our prediction, there was a non-significant interaction between cause of death (COVID-19 death with UMC/without UMC) and PGD diagnosis (with PGD/without PGD). There was a non-significant main effect for cause of death, F (9, 292) = 1.35, p= .213, $n_p^2 = 0.04$, indicating that UMC did not increase public stigma for the bereaved individual.

A large and significant main effect was found for PGD diagnosis, indicating that participants assigned more stigma to an individual with PGD than without PGD, F (9, 292) = 50.72, $p < .001$, $n_p^2 = 0.61$, Wilks' Lambda = 0.39. Follow-up univariate ANOVAs were performed using a Bonferroni adjusted alpha level of .006, and indicated participants perceived a bereaved individual with PGD to be less competent, F (1, 303) 45.50, $p < .001$, $n_p^2 = 0.13$, a large effect; less emotionally stable, F (1, 303) = 351.40, $p < .001$, $n_p^2 = 0.54$, a large effect; more dependent, F (1, 303) = 14.14, $p < .001$, $n_p^2 = 0.05$, a small to medium effect; more sensitive, F (1, 303) = 53.94, $p < .001$, $n_p^2 = 0.15$, a large effect; and participants reported: desiring more social distance, F (1, 303) = 40.94, $p < .001$, $n_p^2 = 0.12$, a medium to large effect; more prosocial emotions, F (1, 303) = 103.71, $p < .001$, $n_p^2 = 0.26$, a large effect;

and more fear, F (1, 303) = 18.07, $p < .001$, $n_p^2 = 0.06$, a medium effect, than an individual without PGD. Although the participants did not perceive a bereaved individual with PGD to be less warm, F (1, 303) = .007, $p = .931$, $n_p^2 = .000$; or more angry, F (1, 303) = 3.69, $p = .056$, $n_p^2 = 0.01$.

Discussion

This study investigated the role of UMC and PGD on public stigma toward an individual bereaved by COVID-19, using a sample of 304 English-speaking participants from the United Kingdom and the United States. Consistent with our hypothesis, participants reported significantly more public stigma towards a bereaved individual with PGD than without PGD. However, no significant interaction was found between cause of death and PGD diagnosis, and participants reported similar levels of public stigma towards individuals bereaved by COVID-19 regardless of UMC status.

Participants perceived the vignette individual with PGD as less competent and less emotionally stable than the vignette individual without PGD. Participants also reported greater desired social distance, more pro-social emotions (e.g., I am concerned about this person), and more fear toward the individual with PGD than without. This corroborates other research finding a significant main effect for PGD diagnosis on public stigma (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020), and indicates the general public may simultaneously experience feelings of desiring increased social distance, fear, and wanting to help the bereaved. This stigma finding may also indicate the general public sees the prolonged grief response as being the bereaved person's responsibility, which aligns with mental illness stigma research showing that attributing personal responsibility for a mental illness was the most significant predictor of stigma and desired social distance (Feldman & Crandall, 2007).

In contrast to previous research (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020), participants reported similar levels of anger towards the vignettes' individual regardless of PGD, with high mean anger scores for both groups. This suggests that it may be bereavement status that is associated with participants reporting high levels of anger toward the bereaved rather than PGD status. Indeed, research shows bereavement status alone (without a PGD diagnosis) generates high anger scores (Philippkowski et al., 2021). Also contrasting with previous research (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020), participants attributed similar levels of warmth towards bereaved

Table 3.3

Means, Standard Errors, and Confidence Intervals for Stigma Variables (*N* = 304)

Measure	UMC/PGD		NoUMC/PGD		PGD TOTAL	UMC/NoPGD		NoUMC/NoPGD		NoPGD TOTAL
	M	*(SE)*	*M*	*(SE)*	*M (SE)* [95%CI]	*M*	*(SE)*	*M*	*(SE)*	*M (SE)* [95%CI]
Attributions										
Competent	2.87	0.06	2.80	0.06	2.83 (0.043) [2.75,2.92]	3.23	0.06	3.25	0.06	3.24 (0.042) [3.16,3.32]
Warm	3.05	0.06	3.01	0.06	3.03 (0.044) [2.95,3.12]	3.08	0.06	3.0	0.06	3.04 (0.044) [2.95,3.13]
Emotional stable	1.92	0.07	1.91	0.07	1.91 (0.048) [1.82,2.01]	3.23	0.07	3.13	0.07	3.18 (0.048) [3.09,3.28]
Dependent	2.61	0.08	2.51	0.08	2.56 (0.057) [2.45,2.67]	2.30	0.08	2.22	0.08	2.26 (0.056) [2.15,2.37]
Sensitive	3.37	0.07	3.33	0.07	3.35 (0.046) [3.26,3.44]	2.78	0.06	2.96	0.06	2.87 (0.046) [2.78,2.96]
Social distance scale	15.28	0.40	15.03	0.39	15.16 (0.278) [14.61,15.70]	12.94	0.39	12.38	0.39	12.66 (0.274) [12.12,13.20]
Emotional reactions										
Anger	5.45	0.23	5.68	0.23	5.57 (0.161) [5.25,5.88]	5.00	0.23	5.26	0.23	5.13 (0.159) [4.82,5.44]
Prosocial	12.60	0.27	12.62	0.27	12.61 (0.189) [12.23,12.98]	9.56	0.26	10.23	0.26	9.90 (0.187) [9.53,10.26]
Fear	8.45	0.28	8.59	0.28	8.52 (0.196) [8.13,8.90]	7.05	0.27	7.65	0.27	7.35 (0.193) [6.97,7.73]

Note. UMC= Underlying medical condition present; NoUMC= Underlying medical condition absent; PGD = Prolonged Grief Disorder present; NoPGD = Prolonged Grief Disorder absent

individuals regardless of PGD status. This may be explained by the samples' experience with bereavement. Almost half of our participants (44%) reported bereavement experiences rated as significantly impacting. While most comparative studies did not measure bereavement experiences, 24% of Dennis et al.'s (2022) sample reported significantly impacting bereavement, which may account for the differences in reported warmth between studies. Personal experience with grief and contact with bereaved individuals can provide individuals a better understanding of bereavement (Costa et al., 2007; Jorm & Oh, 2009), which may increase reported warmth. However, personal bereavement experience does not appear to be associated with intentions to offer bereavement support (Logan et al., 2018b) and therefore does not mean it will prevent stigmatizing responses.

Overall, participants reported more public stigma towards a bereaved individual with PGD than those without PGD. They assigned more negative attributes, desired greater social distance, and were more fearful of the individual with PGD, while simultaneously reporting a desire to help them. This implies that although people experience a desire to help the bereaved their feelings of fear may be stronger. This could potentially be due to an individual's bereavement experience being too confronting for people to bear witness to and causing fear, therefore, the increased desired social distance may assist in reducing fear. For the bereaved individual, experiencing others as being fearful of them and socially distancing from them may create increased feelings of distress and isolation during their grief. This may leave a bereaved individual with PGD at risk of not receiving appropriate support due to stigma effects preventing them from seeking support, blocking potential supporters from offering help (Corrigan, 2005), and believing they do not require mental health support (Lichtenthal et al., 2011). The findings show greater social distance, more pro-social emotions, and more fear towards the person described in the vignette with PGD, but the individual and cumulative impact of these factors on stigma could be explored in future studies.

The non-significant cause of death results contrasted with our prediction, as the mean stigma scores were high for both groups, suggesting stigma was reported towards all people bereaved by COVID-19 regardless of UMC. It is possible that participants perceived a death with UMC as more similar to a natural death than a death by COVID-19 alone (Australian Institute of Health and Welfare, 2022). As previous research has shown less stigma reported towards those bereaved by natural deaths than COVID-19 and unnatural deaths (Eisma et al., 2021), this suggests participants may have perceived death

by COVID-19 with UMC as a more natural death and therefore, not more stigmatizing than COVID-19 without UMC. It is also possible that no stigma differences were found as participants may hold only the deceased person responsible for their underlying medical condition rather than the bereaved, as previous research has shown that attributing personal responsibility for a mental illness was a significant predictor of stigma and lead towards desiring social distance (Feldman & Crandall, 2007), but without a comparison group who are bereaved by non-disease causes, this cannot be confirmed.

Strengths, Limitations, and Future Directions

The strengths of this research include its robust experimental design using manipulation checks, randomization of participants to vignettes, and multiple stigma measures to optimize the reliability and validity of findings. Although this study is experimental, it is also cross-sectional, and therefore inferences can only be made about the factors that cause bereavement stigma based on the experimental conditions of this study and not about the progression of stigma over time. Therefore, longitudinal research is needed to assess how participants' perceptions of bereaved individuals develop and change over time, and what social, experiential, and psychological factors are implicated in the development, maintenance, and alteration of these perceptions.

The findings must also be considered alongside limitations to the sample, which comprised mainly highly educated women. While this demographic composition is typical across bereavement research, generalizability of the findings may be potentially limited to this population. The participants were from multiple countries which may affect bereavement stigma due to social and cultural factors; however, similar results were shown when compared to previous studies with varying western cultures, genders, and education levels (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020; Singer et al., 2022). The stigma measures were developed for mental illness and not bereavement stigma. Although PGD is a mental illness and these measures have been used in several PGD studies, they may not comprehensively measure bereavement stigma, therefore, developing a new measure should be considered to potentially assess bereavement stigma more comprehensively. Although we used measures used in previous similar studies to enable comparison of results with these studies, it is worth noting that the PGD vignettes describe the person with PGD as not functioning well at work or at home, which might have influenced participants' ratings concerning the attributes of the bereaved, desired social distance from the bereaved, and emotional responses towards the bereaved).

Additionally, cause of death (e.g., violent killings) is associated with a greater likelihood of PGD than non-violent causes (Djelantik et al., 2020), yet studies disclosing grief severity (Eisma et al., 2019) do not find such a pattern with regards to suicide. It could be that cause of death may be used by participants to infer grief levels, which may result in stigma.

There are also several factors not assessed in this study that may provide further insight into bereavement stigma. For example, more stigma is reported towards individuals who are bereaved in early adulthood than late adulthood (Philippkowski et al., 2021) and a greater social distance is desired from bereaved men than women (Gonschor et al., 2020); as such, examining these factors will be important for future work. Future vignette research could manipulate additional variables to examine the role of other factors in bereavement stigma. The UMC could also be manipulated to examine how different conditions affect stigma. Some medical conditions (e.g., obesity) are more stigmatized than others and may therefore generate greater bereavement stigma if they are implicated in the cause of death (Pearl & Schulte, 2021). Furthermore, manipulating whether the deceased had been diagnosed with long COVID-19 could be insightful, as individuals diagnosed with long COVID-19 experience more stigma than those without a diagnosis (Pantelic et al., 2022). A key future direction will be to investigate the mental health impacts of public stigma upon individuals bereaved by COVID-19 and whether it leads to self-stigma; so that the negative effects of self-stigma can also be mitigated.

Implications

The results of this study may be used to inform the development and provision of targeted support for COVID-19 bereaved individuals. Stigma towards bereaved individuals, particularly those experiencing PGD, may prevent the bereaved from seeking support and deter potential supporters from helping them. With the growing number of people bereaved during the pandemic, the number of people experiencing grief and potentially developing PGD is growing. Given that bereaved individuals who are most at risk of PGD may also be at an increased risk of stigma, active outreach intervention is required to ensure they are adequately supported. While at the same time implementing stigma reduction programs to minimise stigma development. For example, healthcare settings could assess all bereaved individuals to determine if they have PGD symptoms, the level of bereavement care they require, and refer them to care that is available and accessible to them (Lichtenthal et al., 2024). At the same time, there is a need to

implement stigma reduction programs to minimize stigma development by the public. Additionally, bereaved people could be assisted, perhaps by a grief counsellor or similar person, to manage the stigmatized responses they might encounter.

Conclusions

Overall, these findings show that COVID-19 deaths are potentially stigmatizing regardless of UMC, with high levels of public stigma reported by both groups. Furthermore, this study supports the robust finding that bereaved individuals with PGD are at risk of stigmatization and this finding is generalizable across Western cultures (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020). With an increased potential risk of developing prolonged grief during the pandemic (Eisma et al., 2021), further research is required to better understand public bereavement stigma and how to increase help-seeking behaviors of the bereaved and assist with appropriate support being offered to meet their needs.

Chapter 4 General Discussion and Conclusions

Overview of Aims

The aim of this research was to investigate the effects of cause of death by COVID-19 and PGD diagnosis on participants' reported public stigma towards the bereaved. The first project investigated the effects of COVID-19 death (versus brain haemorrhage death) and PGD (versus without PGD) on participants' reported public stigma towards the bereaved. The second project investigated the effects of COVID-19 death with UMC (versus COVID-19 death without UMC) and PGD (versus without PGD) on participants' reported public stigma towards the bereaved.

Key Findings

The results from Study 1 showed that participants reported significantly more public stigma towards a bereaved individual with PGD (versus without PGD), by specifically judging the bereaved individual with PGD to be less competent and emotionally stable, but more dependent and sensitive. Participants also reported an increased desired social distance, more prosocial emotions, and more fear toward the bereaved person with PGD than without PGD. However, participants did not assess less warmth or more anger for an individual with PGD than without PGD. There was no interaction between COVID-19, PGD, and public stigma, indicating stigma was not more intense for individuals bereaved by COVID-19 death with PGD. There was not significantly more stigma reported toward an individual bereaved by COVID-19 death (versus brain haemorrhage), although high levels of stigma were reported for both causes of death.

Similarly, the results from Study 2 and Study 1 align showing that participants reported significantly more public stigma toward a bereaved individual with PGD than without PGD, by specifically judging the bereaved individual with PGD to be less competent and emotionally stable, but more dependent and sensitive. Participants also reported more pro-social emotions, fear, and desired social distance toward an individual with PGD than without PGD. However, participants did not report less warmth or more anger for an individual with PGD than without PGD. There was also no interaction between COVID-19 death with UMC, PGD, and public stigma, indicating the stigma was not intensified for individuals bereaved by COVID-19 with UMC and PGD. Participants did not report significantly more stigma toward an individual bereaved by COVID-19

death with UMC than without UMC, although high levels of stigma were reported for both causes of death.

Overall, these studies show that individuals with PGD experience stigma across seven of nine public stigma indicators for Study 1 and Study 2, as participants specifically judged them to be less competent and emotionally stable, but more dependent and sensitive. Participants also reported an increased desired social distance, more prosocial emotions, and more fear towards an individual with PGD, but did not assess them as having less warmth or more anger. These results align with that of previous studies (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020) and is evidence of a robust finding that the general public are likely to stigmatise individuals with PGD. This finding is alarming, considering that these bereaved individuals require more grief support, yet are at risk of receiving much less than non-stigmatised grieving persons.

Both projects showed there was not a significant interaction between COVID-19 death, PGD, and public stigma, or COVID-19 death with UMC, PGD, and public stigma, indicating the stigma was not more intense for those bereaved by COVID-19 with PGD or COVID-19 with UMC and PGD. There was also not significantly more stigma reported toward an individual bereaved by COVID-19 death (versus brain haemorrhage), or COVID-19 death with UMC (versus without UMC), although high levels of stigma were reported for both causes of death.

Clinical Implications

Overall, both projects support the robust finding that a bereaved individual with PGD is significantly more likely to experience public stigma than a bereaved individual without PGD. If the rates of PGD also increase due to the pandemic, and much research is suggestive of this, this means that bereaved people who are most at risk of PGD may also be at an increased risk of stigma. A major concern of bereaved individuals with PGD being significantly more likely to be stigmatised relates to them being more vulnerable and therefore requiring more bereavement support, although they may be less likely to seek and receive it (Gonschor et al., 2020). Before the pandemic, bereavement research conducted in Australia and Ireland showed that 30% of participants reported the bereavement care they received did not meet their needs, with those not receiving adequate support reporting the highest deterioration in well-being (Aoun et al., 2020). During the pandemic, it is now even less likely that people who are most at risk will seek and receive appropriate bereavement support. This means intervention is required in healthcare

settings, including grief screening to identify individuals with PGD, assessments to establish the support required, and access to appropriate bereavement care to assist the bereaved with their prolonged grief and reduce their risk of public stigma. These issues were identified as challenges prior to the pandemic (e.g., Lichtenthal, 2018) and the research presented here suggests that reducing barriers to support, improving screening and assessment, refining the efficacy of therapies, and increasing the workforce of grief specialists is especially timely.

Strengths and Limitations

The strengths of both studies include being an experimental vignette design investigating the effects of COVID-19 and PGD on participants' reported public stigma towards the bereaved. These studies used a robust experimental design, with multiple measures of stigma, randomisation of participants to vignettes, and manipulation checks for participants.

The limitations include these studies being cross-sectional, and therefore conclusions cannot be made about the components causing bereavement stigma to develop and change over time. The participants in the studies were mainly female and highly educated, this may potentially limit the generalisability of the findings. Participants being from multiple locations may affect bereavement stigma due to differing social and cultural factors, however, previous studies conducted with varying Western cultures, education and genders showed similar results (Dennis et al., 2022; Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020; Singer et al., 2022). The stigma measures used were developed for mental illness rather than bereavement. However, even though PGD is a mental illness the measures may potentially not assess bereavement stigma accurately, although they have been used in multiple studies of PGD.

Recommendations for Future Research

Future research could alter the vignettes to investigate bereavement stigma using the different variables that follow: gender, as stronger stigma responses are reported towards bereaved men than bereaved women, through desiring a greater social distance (Gonschor et al., 2020); age, as a younger bereaved spouse has been shown to be more stigmatised than an older bereaved spouse (Philippkowski et al., 2021); long COVID-19 diagnosis, as more stigma is reported towards individuals diagnosed with long COVID than individuals without a diagnosis (Pantelic et al., 2022); UMC, as some UMCs such as obesity may be more stigmatised than other UMCs, this may be associated with the

media's reporting style of obesity being a risk factor for more severe COVID-19 (Pearl & Schulte, 2021). Future research could also conduct a longitudinal study to investigate if stigma reported toward a bereaved individual changes over time, whether personal COVID-19 bereavement experience affects stigma reported towards the bereaved, and investigate the negative mental health effects of stigma reported towards COVID-19 bereaved individuals and whether it leads to self-stigma for the bereaved.

Conclusions

Public stigma being reported towards bereaved individuals with PGD is a robust finding across many studies. This "shadow pandemic" of grief (Neimeyer & Lee., 2022) shows that people with PGD are likely to be stigmatised for their grief, which is an additional burden for them to bear and reduces their recovery potential. They also require substantial bereavement support, but the public stigma they face is likely to limit the support they seek and receive compared to the bereaved without PGD. The pandemic has further complicated the grief experience for COVID-19 bereaved individuals with PGD through layers of stigma regarding bereavement and mental illness, making bereavement extraordinarily difficult, especially with access to adequate bereavement support being problematic before the pandemic. Therefore, the stigmatisation of bereaved people with PGD must be addressed through active interventions to identify, assess, and provide access to appropriate bereavement support to reduce the distress and functional impairment endured by the most vulnerable bereaved people.

References

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed., text rev.). https://doi.org/10.1176/appi.books.9780890425787

Angermeyer, M. C., & Matschinger, H. (2003). The stigma of mental illness effects of labelling on public attitudes towards people with mental disorder. *Acta Psychiatrica Scandinavica, 108*(4), 304-309. https://doi.org/10.1034/j.1600-0447.2003.00150.x

Aoun, S., Keegan, O., Roberts, A., & Breen, L. (2020). The impact of bereavement support on wellbeing: a comparative study between Australia and Ireland. *Palliative Care and Social Practice*, *14*. https://doi.org/10.1177/2632352420935132

Australian Institute of Health and Welfare. (2022). *Deaths in Australia.* https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/multiple-causes-of-death

Bauld, C. M., Letcher, P., & Olsson, C. A. (2021). Supporting the dying and bereaved during COVID-19. *Australian Psychologist*, *56*(4), 269-273. https://doi.org/10.1080/00050067.2021.1937924

Boelen, P. A., & Lenferink, L. I. (2022). Prolonged Grief Disorder in DSM-5-TR: Early predictors and longitudinal measurement invariance. *Australian & New Zealand Journal of Psychiatry*, *56*(6), 667-674. https://doi.org/10.1177/00048674211025728

Boelen, P. A., & Smid, G. E. (2017). The Traumatic Grief Inventory Self-Report version (TGI-SR): Introduction and preliminary psychometric evaluation. *Journal of Loss and Trauma, 22*(3), 196–212. https://doi.org/10.1080/15325024.2017.1284488

Boerner, K., Stroebe, M., Schut, H., & Wortman, C. B. (2016). Grief and bereavement: Theoretical perspectives. In N. A. Pachana (Ed.), *Encyclopedia of Geropsychology* (pp. 1-10). Springer Singapore. https://doi.org/10.1007/978-981-287-080-3_133-2

Bracke, P., Delaruelle, K., & Verhaeghe, M. (2019). Dominant cultural and personal stigma beliefs and the utilization of mental health services: A cross-national comparison. *Frontiers in Sociology*, *4,* 40. https://doi.org/10.3389/fsoc.2019.00040

Breen, L. J., Lee, S. A., Mancini, V. O., Willis, M., & Neimeyer, R. A. (2022a). Grief and functional impairment following COVID-19 loss in a treatment-seeking sample: The mediating role of meaning. *British Journal of Guidance & Counselling, 1*(12). https://doi.org/10.1080/03069885.2022.2075540

Breen, L. J., Lee, S. A., & Neimeyer, R. A. (2021). Psychological risk factors of functional impairment after COVID-19 deaths. *Journal of Pain and Symptom Management*, *61*(4), e1–e4. https://doi.org/10.1016/j.jpainsymman.2021.01.006

Breen, L. J., Mancini, V. O., Lee, S. A., Pappalardo, E. A., & Neimeyer, R. A. (2022b). Risk factors for dysfunctional grief and functional impairment for all causes of death during the COVID-19 pandemic: The mediating role of meaning. *Death Studies, 1*(10). https://doi.org/10.1080/07481187.2021.1974666

Breen, L. J., Penman, E. L., Prigerson, H. G., & Hewitt, L. Y. (2015). Can grief be a mental disorder?: An exploration of public opinion. *Journal of Nervous and Mental Disease*, *203*(8), 569-573. https://doi.org/10.1097/nmd.0000000000000331

Cohen, J. (2013). *Statistical power analysis for the behavioral sciences*. Academic Press.

Corrigan, P. W. (2005). *On the stigma of mental illness: Practical strategies for research and social change.* American Psychological Association. https://doi.org/10.1037/10887-000

Corrigan, P. W., & Watson, A. C. (2002). Understanding the impact of stigma on people with mental illness. *World Psychiatry*, *1*(1), 16–20.

Costa, B. M., Hall, L., & Stewart, J. (2007). Qualitative exploration of the nature of grief-related beliefs and expectations. *Omega: Journal of Death and Dying, 55*(1), 27–56. https://doi.org/10.2190/CL20-02G6-607R-8561

Demirtaş-Madran, H. A. (2020). Exploring the motivation behind discrimination and stigmatization related to COVID-19: A social psychological discussion based on the main theoretical explanations. *Frontiers in Psychology*, *11*, 569528. https://doi.org/10.3389/fpsyg.2020.569528

Dennis, H., Eisma, M. C., & Breen, L. J. (2022). Public stigma of Prolonged Grief Disorder: An experimental replication and extension. *The Journal of Nervous and Mental Disease*, *210*(3), 199–205. https://doi.org/10.1097/NMD.0000000000001427

Dietl, L., Wagner, B., & Fydrich, T. (2018). User acceptability of the diagnosis of Prolonged Grief Disorder: How do professionals think about inclusion in ICD-11? *Journal of Affective Disorders, 229*, 306-313. http://doi.org/10.1016/j.jad.2017.12.095

Djelantik, A. A. A. M. J., Smid, G. E., Mroz, A., Kleber, R. J., & Boelen, P. A. (2020). The prevalence of prolonged grief disorder in bereaved individuals following unnatural losses: Systematic review and meta regression analysis. *Journal of Affective Disorders, 265*, 146-156. https://doi.org/10.1016/j.jad.2020.01.034

Doka, K. J. (2021). *Death, grief and loss in the context of COVID-19* (P. Pentaris, Ed., 1st ed., pp. 31–32). Routledge. https://doi.org/10.4324/9781003125990

Eisma, M. C. (2018). Public stigma of Prolonged Grief Disorder: An experimental study. *Psychiatry Research*, *261*, 173-177. https://doi.org/10.1016/j.psychres.2017.12.064

Eisma, M. C., & Boelen, P. A. (2023). Commentary on: A call to action: Facing the shadow pandemic of complicated forms of grief. *OMEGA - Journal of Death and Dying, 87*(1), 334–340. https://doi.org/10.1177/00302228211016227

Eisma, M. C., & Tamminga, A. (2022). COVID-19, natural, and unnatural bereavement: comprehensive comparisons of loss circumstances and grief severity. *European Journal of Psychotraumatology, 13*. https://doi.org/10.1080/20008198.2022.2062998

Eisma, M. C., Tamminga, A., Smid, G. E., & Boelen, P. A. (2021). Acute grief after deaths due to COVID-19, natural causes and unnatural causes: An empirical comparison. *Journal of Affective Disorders*, *278*, 54–56. http://doi.org/10.1016/j.jad.2020.09.049

Eisma, M. C., Te Riele, B., Overgaauw, M., & Doering, B. K. (2019). Does prolonged grief or suicide bereavement cause public stigma? A vignette-based experiment. *Psychiatry Research, 272*, 784-789. http://doi.org/10.1016/j.psychres.2018.12.122

Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G*Power3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*, 175-191. https://doi.org/10.3758/bf03193146

Feldman, D., & Crandall, C. (2007). Dimensions of mental illness stigma: What about mental illness causes social rejection? *Journal of Social and Clinical Psychology*. 26. 137-154. 10.1521/jscp.2007.26.2.137.

Field, A. (2018). *Discovering statistics using IBM SPSS statistics* (5th ed.). Sage Publications.

Gang, J., Falzarano, F., She, W. J., Winoker, H., & Prigerson, H. G. (2022). Are deaths from COVID-19 associated with higher rates of Prolonged Grief Disorder (PGD) than deaths from other causes? *Death Studies, 46*(6), 1287-1296. https://doi.org/10.1080/07481187.2022.2039326

Gonschor, J., Eisma, M. C., Barke, A., & Doering, B. K. (2020). Public stigma towards Prolonged Grief Disorder: Does diagnostic labeling matter? *PloS One, 15*(9), 1. http://doi.org/10.1371/journal.pone.0237021

Gronholm, P. C., Nosé, M., van Brakel, W. H., Eaton, J., Ebenso, B., Fiekert, K., Milenova, M., Sunkel, C., Barbui, C., & Thornicroft, G. (2021). Reducing stigma and discrimination associated with COVID-19: Early stage pandemic rapid review and practical recommendations. *Epidemiology and Psychiatric Sciences*, *30*, e15. https://doi.org/10.1017/S2045796021000056

Harrop, E., Goss, S., Farnell, D., Longo, M., Byrne, A., Barawi, K., Torrens-Burton, A., Nelson, A., Seddon, K., Machin, L., Sutton, E., Roulston, A., Finucane, A., Penny, A., Smith, K. V., Sivell, S., & Selman, L. E. (2021). Support needs and barriers to accessing support: Baseline results of a mixed-methods national survey of people bereaved during the COVID-19 pandemic. *Palliative Medicine*, *35*(10), 1985-1997. https://doi.org/10.1177/02692163211043372

Johnson, J. G., First, M. B., Block, S., Vanderwerker, L. C., Zivin, K., Zhang, B., & Prigerson, H. G. (2009). Stigmatization and receptivity to mental health services among recently bereaved adults. *Death Studies*, *33*(8), 691–711. https://doi.org/10.1080/07481180903070392

Jorm, A. F., & Oh, E. (2009). Desire for social distance from people with mental disorders. *The Australian and New Zealand Journal of Psychiatry*, *43*(3), 183–200. https://doi.org/10.1080/00048670802653349

Kamara, S., Walder, A., Duncan, J., Kabbedijk, A., Hughes, P., & Muana, A. (2017). Mental health care during the Ebola virus disease outbreak in Sierra Leone. *Bulletin of the World Health Organization*, *95*(12), 842-847. https://doi.org/10.2471/BLT.16.19047

Knesebeck, O. v. d., Kofahl, C., & Makowski, A. C. (2017). Differences in depression stigma towards ethnic and socio-economic groups in Germany – Exploring the hypothesis of double stigma. *Journal of Affective Disorders*, *208*, 82-86. https://doi.org/10.1016/j.jad.2016.08.071

Lee, S. A., & Neimeyer, R. A. (2022). Pandemic Grief Scale: A screening tool for dysfunctional grief due to a COVID-19 loss. *Death Studies*, *46*(1), 14-24. https://doi.org/10.1080/07481187.2020.1853885

Lee, S. A., Neimeyer, R. A., & Breen, L. J. (2021). The utility of the Pandemic Grief Scale in identifying functional impairment from COVID-19 bereavement. *Journal of Palliative Medicine*, *24*(12), 1783-1788. https://doi.org/10.1089/jpm.2021.0103

Lee, S. A., Neimeyer, R. A., Mancini, V. O., & Breen, L. J. (2022). Unfinished business and self-blaming emotions among those bereaved by a COVID-19 death. *Death Studies*, *46*(6), 1297-1306. https://doi.org/10.1080/07481187.2022.2067640

Lenferink, L. I. M., Eisma, M. C., Smid, G. E., de Keijser, J., & Boelen, P. A. (2022). Valid measurement of DSM-5 persistent complex bereavement disorder and DSM-5-TR and ICD-11 prolonged grief disorder: The Traumatic Grief Inventory-Self Report Plus (TGI-SR+). *Comprehensive Psychiatry*, *112*. https://doi.org/https://doi.org/10.1016/j.comppsych.2021.152281

Lichtenthal, W. G. (2018). Supporting the bereaved in greatest need: We can do better. *Palliative & Supportive Care*, *16*(4), 371-374. https://doi.org/10.1017/S1478951518000585

Lichtenthal, W. G., Nilsson, M., Kissane, D. W., Breitbart, W., Kacel, E., Jones, E. C., & Prigerson, H. G. (2011). Underutilization of mental health services among bereaved caregivers with prolonged grief disorder. *Psychiatric Services*, *62*(10), 1225–1229. https://doi.org/10.1176/ps.62.10.pss6210_1225

Lichtenthal, W. G., Roberts, K. E., Donovan, L. A., Breen, L. J., Aoun, S. M., Connor, S. R., & Rosa, W. E. (2024). Investing in bereavement care as a public health priority. *The Lancet Public Health*, *9*(4), e270-e274. https://doi.org/https://doi.org/10.1016/S2468-2667(24)00030-6

Link, B. G., Cullen, F. T., Frank, J., & Wozniak, J. (1987). The social rejection of ex-mental patients: Understanding why labels matter. *American Journal of Sociology*, *92*, 1461-1500. https://doi.org/10.1086/228672

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27,* 363–385. https://doi.org/10.1146/annurev.soc.27.1.363

Link, B. G., Yang, L. H., Phelan, J. C., & Collins, P. Y. (2004). Measuring mental illness stigma. *Schizophrenia Bulletin*, *30*(3), 511–541. https://doi.org/10.1093/oxfordjournals.schbul.a007098

Little, R. J. A. (1988). A test of missing completely at random for multivariate data with missing values. *Journal of the American Statistical Association*, *83*(404), 1198-1202. https://doi.org/10.1080/01621459.1988.10478722

Livingston, J. D., & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science & Medicine, 71*(12), 2150-2161. http://doi.org/10.1016/j.socscimed.2010.09.030

Logan, E. L., Thornton, J. A., & Breen, L. J. (2018a). What determines supportive behaviors following bereavement? A systematic review and call to action. *Death Studies, 42*(2), 104-114. http://doi.org/10.1080/07481187.2017.1329760

Logan, E. L., Thornton, J. A., Kane, R. T., & Breen, L. J. (2018b). Social support following bereavement: The role of beliefs, expectations, and support intentions. *Death Studies, 42,* 471-482. https://doi.org/10.1080/07481187.2017.1382610

Lundorff, M., Holmgren, H., Zachariae, R., Farver-Vestergaard, I., & 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. http://doi.org/10.1016/j.jad.2017.01.030

Mayland, C. R., Harding, A., Preston, N., & Payne, S. (2020). Supporting adults bereaved through COVID-19: A rapid review of the impact of previous pandemics on grief and bereavement. *Journal of Pain and Symptom Management, 60*(2), e33-e39. http://doi.org/10.1016/j.jpainsymman.2020.05.012

Neimeyer, R. A., & Lee, S. A. (2022). Circumstances of the death and associated risk factors for severity and impairment of COVID-19 grief. *Death Studies*, *46*(1), 34–42. https://doi.org/10.1080/07481187.2021.1896459

Ogden, S. P., & Simmonds, J. G. (2014). Psychologists' and counsellors' perspectives on prolonged grief disorder and its inclusion in diagnostic manuals. *Counselling and Psychotherapy Research*, *14*(3), 212-219. https://doi.org/https://doi.org/10.1080/14733145.2013.790456

Pantelic, M., Ziauddeen, N., Boyes, M., O'Hara, M. E., Hastie, C., & Alwan, N. A. (2022). Long Covid stigma: Estimating burden and validating scale in a UK-based sample. *PLoS ONE, 17*(11): e0277317. https://doi.org/10.1371/journal.pone.0277317

Pearce, C., Honey, J. R., Lovick, R., Zapiain Creamer, N., Henry, C., Langford, A., Stobert, M., & Barclay, S. (2021). 'A silent epidemic of grief': A survey of bereavement care provision in the UK and Ireland during the COVID-19 pandemic. *BMJ Open, 11*(3), 1. http://doi.org/10.1136/bmjopen-2020-046872

Pearl, R. L., & Schulte, E. M. (2021). Weight bias during the COVID-19 pandemic. *Current Obesity Reports*, *10*(2), 181-190. https://doi.org/10.1007/s13679-021-00432-2

Penman, E. L., Breen, L. J., Hewitt, L. Y., & Prigerson, H. G. (2014). "Pathologising" grief: An exploration of public expectations and grieving norms. *Grief Matters*, *17*(1), 21. https://search.informit.org/doi/10.3316/informit.234710722574153

Penman, E. L., Breen, L. J., Hewitt, L. Y., & Prigerson, H. G. (2014). Public attitudes about normal and pathological grief. *Death Stud*, *38*(6-10), 510-516. https://doi.org/10.1080/07481187.2013.873839

Philippkowski, S., O'Connor, M., Eisma, M. C., Willmott, L., Johnson, A. R., & Breen, L. J. (2021). Does voluntary assisted dying cause public stigma for the bereaved? A vignette-based experiment. *Palliative & Supportive Care, 19*(5), 558-562. http://doi.org/10.1017/S1478951520001352

Pituch, K. A., & Stevens, J. P. (2016). *Applied multivariate statistics for the social sciences: Analyses with SAS and IBM's SPSS (6th ed.)*. Taylor & Francis Group.

Prigerson, H. G., Boelen, P. A., Xu, J., Smith, K. V., & Maciejewski, P. K. (2021). Validation of the new DSM-5-TR criteria for prolonged grief disorder and the PG-13-Revised (PG-13-R) scale. *World Psychiatry*, *20*(1), 96–106. https://doi.org/10.1002/wps.20823

Qureshi, K., Evered, J., Toyomoto, R., Urbanowicz, A., Sawada, A., Smith, L., Sato, R., & Rai, T. (2023). Covid-19 trouble at work: A comparative qualitative analysis of disclosure, sickness absence and return-to-work in the UK, the USA, Australia and Japan. *SSM - Qualitative Research in Health*, *4*, 1–9. https://doi.org/10.1016/j.ssmqr.2023.100307

Schaub, J. (2021). *Death, grief and loss in the context of COVID-19* (1st ed.; P. Pentaris Ed.). Routledge. https://doi.org/10.4324/9781003125990

Schneider, S., Rerick, P. O., Cummings, C., McLean, E., Breen, L. J., & Singer, J. (2023). Pandemic grief risk factors and prolonged grief disorder in bereaved young adults during COVID-19. *Palliative and Supportive Care*, 1-7. https://doi.org/10.1017/s1478951523000160

Selman, L. E., Farnell, D., Longo, M., Goss, S., Seddon, K., Torrens-Burton, A., Mayland, C. R., Wakefield, D., Johnston, B., Byrne, A., & Harrop, E. (2022a). Risk factors associated with poorer experiences of end-of-life care and challenges in early bereavement: Results of a national online survey of people bereaved during the COVID-19 pandemic. *Palliative Medicine*, *36*(4), 717-729. https://doi.org/10.1177/02692163221074876

Selman, L. E., Farnell, D. J. J., Longo, M., Goss, S., Torrens-Burton, A., Seddon, K., Mayland, C. R., Machin, L., Byrne, A., & Harrop, E. J. (2022b). Factors associated with higher levels of grief and support needs among people bereaved during the

pandemic: Results from a national online survey. *OMEGA - Journal of Death and Dying*. https://doi.org/10.1177/00302228221144925

Shear, M. K. (2012). Grief and mourning gone awry: pathway and course of complicated grief. *Dialogues in Clinical Neuroscience*, *14*(2), 119-128. https://doi.org/10.31887/DCNS.2012.14.2/mshear

Singer, J., Breen, L. J., & Loggers, E. (2022). Examining public stigma and expectations of grief following medical aid and dying in the US: A vignette-based experiment. *Palliative and Supportive Care,* 1-7. http://doi.org/10.1017/S1478951522000852

Somse, P., & Eba, P. M. (2020). Lessons from HIV to guide COVID-19 responses in the Central African Republic. *Health and Human Rights*, *22*(1), 371-374.

Stroebe, M., & Schut, H. (2021). Bereavement in times of COVID-19: A review and theoretical framework. *OMEGA - Journal of Death and Dying, 82*(3), 500–522. https://doi.org/10.1177/0030222820966928

Tang, S., & Xiang, Z. (2021). Who suffered most after deaths due to COVID-19? Prevalence and correlates of prolonged grief disorder in COVID-19 related bereaved adults. *Globalization and Health*, *17*(1), 19. https://doi.org/10.1186/s12992-021-00669-5

Verdery, A. M., Smith-Greenaway, E., Margolis, R., & Daw, J. (2020). Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the United States. *Proceedings of the National Academy of Science of the United States of America*, *117*(30), 17695-17701. https://doi.org/10.1073/pnas.2007476117

Venkatakrishnan, A. J., Pawlowski, C., Zemmour, D., Hughes, T., Anand, A., Berner, G., Kayal, N., Puranik, A., Conrad, I., Bade, S., Barve, R., Sinha, P., O'Horo, J. C., Badley, A. D., Halamka, J., & Soundararajan, V. (2021). Mapping each pre-existing condition's association to short-term and long-term COVID-19 complications. *NPJ Digital Medicine*, *4*(1), 117. https://doi.org/10.1038/s41746-021-00484-7

Vogel, D. L., Wade, N. G., & Hackler, A. H. (2007). Perceived public stigma and the willingness to seek counseling: The mediating roles of self-stigma and attitudes toward counseling. *Journal of Counseling Psychology, 54, 40-50*. https://doi.org/10.1037/0022-0167.54.1.40

World Health Organization. (2019). ICD-11: International classification of diseases (11th Revision). Retrieved from https://icd.who.int/ https://www.who.int/publications/i/item/social-stigma-associated-with-covid-19

World Health Organization. (2020). *A guide to preventing and addressing social stigma associated with COVID-19*. https://www.who.int/publications/i/item/social-stigma-associated-with-covid-19

World Health Organization. (2022). *WHO Coronavirus (COVID-19) Dashboard*. Retrieved 6 September, 2022. https://covid19.who.int/

World Health Organization. (2023). *Coronavirus disease*. https://www.who.int/health-topics/coronavirus#tab=tab_1

World Health Organization. (2024). *WHO Coronavirus (COVID-19) Dashboard*. Retrieved 24 March, 2024. https://covid19.who.int/

Zammit, T., Mancini, V. O., Reid, C., Singer, J., Staniland, L., & Breen, L. J. (2023). Public stigma toward prolonged grief and COVID-19 bereavement: A vignette-based experiment. *Death Studies*, 1-11. https://doi.org/10.1080/07481187.2023.2192010