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Examining public stigma and expectations of grief following medical aid and dying in the US: A vignette-based experiment

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Abstract

Objectives. Families bereaved following Medical Aid in Dying (MAID)-related death express concerns about public stigma. As access to MAID expands, research examining MAID is needed, including understanding stigma toward family members. This study examines if stigmatization exists toward bereaved individuals whose family member utilized MAID at differing ages and assess if expectations of grief differ between bereaved individuals whose family member utilized MAID compared to bereaved individuals whose family member died of an illness.

Methods. This study utilized a randomized, between-groups, vignette-based experiment to test the effects of cause of death (MAID vs. illness-related death) and age (28, 38, 70, and 80 years) of the deceased on indicators of public stigma. Participants ($N = 428$) were recruited from mTURK ($M_{age} = 42.54$; $SD_{age} = 16.50$).

Results. Analyses showed a statistically significant interaction between age and the mode of death ($F(7, 400)$, $p = 0.001$, $\eta_p^2 = 0.06$) and the main effect for age ($F(5, 401)$, $p = 0.004$, $\eta_p^2 = 0.04$) on expectations of grief, whereas emotional reactions and wanting social distance were not significant ($p > 0.05$). Participants expected more maladaptive grief among family members of 28- and 70-year-olds who died of illness compared to 28- or 38-year-olds who utilized MAID [28-year-old ($M = 44.12$, $SD = 12.03$) or 70-year-old ($M = 44.32$, $SD = 10.29$) illness-related death vs. 28-year-old ($M = 39.3$, $SD = 11.56$; $p = 0.01$) or 38-year-old ($M = 38.71$, $SD = 11.56$; $p = 0.007$) MAID-related death].

Significance of results. Findings suggest that direct stigma does not exist toward family members of individuals engaging in MAID. The American public may expect that family members of young individuals who utilize MAID are accepting of the death and expect them to experience fewer maladaptive grief symptoms. Future research should investigate differences in bereavement outcomes based on age of bereaved caregivers of individuals engaging in MAID.

Introduction

Medical Aid in Dying (MAID)[1] allows terminally ill patients to make a voluntary, informed decision to obtain a physician's prescription for oral medications to end their life. MAID is legal in 11 states in the USA (Pope, 2020), representing 72 million people (or 22% of the US population). It is estimated that over 200 million people now have access to MAID around the world (Mroz et al., 2021) and in most countries where MAID is legal, public opinion is overwhelmingly in support. Similarly, studies have shown strong public support for extending patient rights beyond MAID to include active euthanasia in some countries (e.g., Netherlands and Canada).

Although a growing number of people in the USA have access to MAID, general public opinion remains divided with 54% of the US population in support (Duckett, 2019). As a result, individuals engaging in MAID in the USA, and their loved ones, may fear being stigmatized by others (Srinivasan, 2019). Evidence from Switzerland suggests that families engaging in MAID may keep participation hidden, with potentially significant consequences for the bereaved family member if they feel they are alienated from social support as a consequence of the decedent's choice to use MAID (Wagner et al., 2012; Gamondi et al., 2015, 2018, 2019). Thus, as access to MAID continues to expand, there is a need for research examining different facets of MAID, including public perceptions of those who utilize MAID and their family members.

[1]MAID will be used throughout this paper to refer to MAID, Voluntary Assisted Dying, and Death with Dignity.

Stigma is an aspect of public perception that is typically categorized as self-stigma and public stigma (Livingston and Boyd, 2010; Eisma et al., 2019). This paper will focus on public stigma, but it is important to note that research has found that public stigma leads to self-stigma (Evans-Lacko et al., 2012). Researchers have generally defined public stigma as exhibiting negative emotions and attitudes toward, as well as a preference for social distance, an individual (Eisma, 2018; Eisma et al., 2019; Gonschor et al., 2020). Public stigma has been found to increase negative long-term outcomes for bereaved individuals whom the stigma is towards, including depression and suicide (Carpiniello and Pinna, 2017; Eisma, 2018) and Prolonged Grief Disorder (Gonschor et al., 2020; Dennis et al., 2021) (PGD). Stigmatizing public reactions, such as negative emotions about and attributions of the bereaved and a larger preferred social distance from the bereaved, are indicators of public stigma (Wagner et al., 2012; Eisma, 2018; Gonschor et al., 2020; Dennis et al., 2021). The provision of social support is regulated by norms, which are the rules that govern acceptable behavior, such as expectations about the expression of grief (Penman et al., 2014).

Research has shown that bereaved persons are expected to show outward displays of intense grief, yet doing so leaves them open to public stigma (McLean et al., 2021) and often these individuals do not receive the quantity or quality of social support needed (Aoun et al., 2015) due to not following social norms. Not conforming to publics expectations of grief can lead to public stigma, which should be of concern, as it can result in a loss of social support, feelings of being ostracized, and risk of experiencing additional severe mental health problems (Johnson et al., 2009; Chapple et al., 2015; Pitman et al., 2016).

To our knowledge, only one study has examined differences in stigma toward bereaved individuals whose family member died of illness as compared to MAID (Philippkowski et al., 2021). This study was conducted in Australia and found that MAID did not elicit any more stigma toward family members than if a person died of a life-limiting illness. However, 80% of Australians support MAID (Duckett, 2019). In contrast, MAID has been a highly controversial and highly debated topic in the USA (White and Willmott, 2018; Pope, 2020). It is possible that differences may emerge when comparing public stigma toward bereaved individuals who lost a loved one due to MAID, compared to other types of death in America.

One aspect that has affected the perception and attitudes toward MAID is the age of the person who utilized MAID. Studies have found that the general public and health professionals are more comfortable with older adults utilizing MAID rather than younger adults (Lamers and Williams, 2016), or children (Bevacqua and Kurpius, 2013; Stolz et al., 2015). Philippkowski et al. (2021) identified age as an important factor to consider when examining stigma toward bereaved individuals whose family member utilized MAID. Their vignette-based study used 28- and 80-year-olds and found death at a young age (28 years) was significantly associated with stronger negative emotional reactions of fear and anger, two subcategories of stigma, than the 80-year-old. Using only 28-year- and 80-year-olds was a limitation identified by the authors, as other studies have found differences in the acceptability of MAID across many age ranges (Frileux, 2003; Rae et al., 2015). Therefore, understanding differences in stigma across a greater range of ages and within key developmental periods (e.g., 70 and 80; 28 and 38) could improve the identification of bereaved individuals at higher risk of public stigma.

We aimed to replicate and extend the study of Philippkowski et al. (2021) by examining whether there were any differences in public stigma based on mode of death (i.e., MAID vs. illness), age of the deceased individual (i.e., 28, 38, 70, and 80 years of age), or the interaction of mode of death and age, in a sample of adults living in the USA. We hypothesized that bereaved individuals whose family member who is younger (i.e., 28 and 38) engaged in MAID would experience more stigma than bereaved individuals whose family member who is older (i.e., 70 and 80) died of an illness-related death or MAID. Also, we examined if expectations of grief differ between bereaved individuals whose family member utilized MAID compared to bereaved individuals whose family member died of an illness, and if that differs based on age of deceased. We hypothesized that participants would expect more grief symptoms among family members whose loved one was younger and had an illness-related death compared to family members whose loved one was older and utilized MAID.

Methods

Participants

A total of 428 participants (265 females) were enrolled in this study. An *a priori* power analysis (Faul et al., 2007) estimated that 146 participants would be required to achieve 95% power to detect a moderate ($f^2 = 0.15$) effect; thus, the study was sufficiently powered. The mean age of the sample was 42.54 ($SD = 16.00$), with a range of 18–93 years. The sample was predominantly White ($n = 315$; 73.6%), with small subsamples of African-American or Black ($n = 270$; 16.4%) and Asian-American ($n = 27$; 6.4%) adults.

Procedure

The study approval was granted by the Blinded for Review. The study utilizes cross-sectional data including demographics, vignettes, and stigma measures, which were collected on MTurk. We utilized a 2 (cause of death: MAID vs. illness-related death) × 4 (age of the deceased: 28-, 38-, 70-, and 80-year-olds) randomized between-groups, vignette-based experiment. We picked these ages in order to replicate the study of Philippkowski et al. (2021) participate in this study, participants had to have an MTurk account, be English proficient, a US resident, and 18 or older. Participants were credited $1.15 to their account upon completion of this 10-min survey. MTurk samples have been found to generalize in multiple fields, including trauma, suicide, depression, and addiction (Sheehan, 2018; Klik et al., 2019; Engle et al., 2020). MTurk has also been utilized in numerous studies examining stigma (e.g., Sheehan, 2018; Goodyear and Chavanne, 2021).

Measures

Vignettes

We used vignettes developed by Philippkowski et al. (2021) and added four additional vignettes to include all levels of the independent variables. Vignettes have been used in hundreds of studies to approximate real-life responding, including articles that have examined stigma in different contexts (Hughes and Huby, 2004). Studies examining public stigma and expectations of grief symptomatology have used vignette-based experimental design and been validated in numerous studies (e.g., Penman

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et al., 2014; Eisma, 2018; Logan et al., 2018; Eisma et al., 2019), including bereaved individuals whose loved one utilized MAID (Philippkowski et al., 2021).

Stigma

Emotional Reactions Scale. Angermeyer and Matschinger (2003) described three types of emotional reactions to people with mental illness: fear, anger, and pro-social reactions. The Emotional Reactions Scale was developed to assess each of these emotional reactions (Link et al., 2004). For example, "When I read about C.G. I feel annoyed." The Emotional Reactions Scale is a 13-item Likert response scale, with a range of 1 (strongly disagree) to 4 (strongly agree). This scale has been used in numerous studies examining stigma (Eisma, 2018; Eisma et al., 2019; Philippkowski et al., 2021) and demonstrates good internal consistency in the general population, $\alpha = 0.85$ (fear), $\alpha = 0.82$ (anger), and $\alpha = 0.75$ (prosocial behavior). Higher scores indicate more negative emotional reactions toward the person. The scale demonstrated good internal consistency in the current study ($\alpha = 0.89$ (fear), $\alpha = 0.87$ (anger), and $\alpha = 0.78$ (prosocial)).

Social Distance Scale. The Social Distance Scale was derived by Link et al. (1999) and is used to measure preferred social distance within a vignette. The scale used in this study has been used in other vignette-based studies (Eisma, 2018; Eisma et al., 2019; Philippkowski et al., 2021). Questions investigate the degree to which a participant reports willingness to interact with the person/character in the vignette (e.g., "How would you feel having someone like C.G. as a neighbor?"). The Social Distance Scale is a 17-item scale, with responses ranging from 1 (definitely willing) to 4 (definitely unwilling). Higher scores indicate a need for social distance from the person. For further details, see Philippkowski et al. (2021). Internal consistency for this measure has been good in past studies ($\alpha = 0.84$; Philippkowski et al., 2021) and was $\alpha = 0.88$ in the current study.

Expectations of Grief Symptomatology Scale. The Expectations of Grief Symptomatology Scale (Penman et al., 2014) measures participant's expectations of the intensity of another person's grief. The Expectations of Grief Symptomatology scale is a 12-item scale, which is a modified version of the PG-13, a measure of PGD symptoms. Penman et al. (2014) modified the scale from the first to third person to allow for more general judgments of expectations of grief symptomology. Responses range from 1 (Never) to 4 (Always). Higher scores indicate that more intense grief was expected (Logan et al., 2018). Internal consistency for this measure has been good in the past ($\alpha = 0.87$ (Penman et al., 2014); $\alpha = 0.88$ (Philippkowski et al., 2021)) and was $\alpha = 0.94$ in the current study.

Data analysis

First, we calculated means and standard deviations of measures of stigma, which were used as the dependent variables in this study. We used a two-way multivariate analysis of variance (MANOVA) and interpreted Roy's Largest Root to determine significance. Mode of death (i.e., MAID and illness-related death) and age of the deceased (i.e., 28, 38, 70, and 80), as well as their interaction, were entered as fixed factors. Anger, fear, prosocial emotions, social distance, and expectations of grief symptomatology were entered as outcome variables. If any significant multivariate effects were identified, univariate ANOVAs were used to identify which outcome variables differed between the group(s) and in which direction. For all results, partial eta-squared (η_p^2) is presented as a measure of effect. A value of $\eta_p > 0.06$ is considered a "medium" effect, and $\eta_p > 0.14$ considered a "large" effect (Cohen, 2013).

Results

Table 1 documents the means and standard deviations of measures of stigma. There were no differences in age, sex, race/ethnicity, and education between groups ($p > 0.05$).

MANOVA identified a significant interaction effect between age of the deceased and the mode of death (Roy's Largest Root = 3.62, $F(5, 400)$, $p = 0.001$, $\eta_p^2 = 0.06$) on indicators of stigma and a statistically significant main effect for age of the deceased (Roy's Largest Root = 3.50, $F(5, 401)$, $p = 0.004$ $\eta_p^2 = 0.04$) on indicators of stigma. The mode of death was unrelated to indicators of stigma (Roy's Largest Root = 0.771, $F(5, 401)$, $p = 0.57$, $\eta_p^2 = 0.01$).

Following the MANOVA, post-hoc ANOVAs were used to examine the interaction between age and the mode of death on expectations of grief symptomatology, emotional reactions (i.e., fear, prosocial, and anger), and social distance (see Table 2). Post-hoc ANOVAs revealed that participants expected the bereaved individual whose 28-year-old spouse died from an illness-related death ($M = 44.12$, $SD = 12.03$) would experience more maladaptive grief symptoms than a bereaved individual whose 28-year-old ($M = 39.3$, $SD = 11.56$; $p = 0.01$) or 38-year-old ($M = 38.71$, $SD = 11.56$; $p = 0.007$) spouse who utilized MAID. Also, participants expected the bereaved individual whose 70-year-old spouse died from an illness-related death ($M = 44.32$, $SD = 10.29$) would experience more maladaptive grief symptoms than a bereaved individual whose 28 ($M = 39.3$, $SD = 11.56$; $p = 0.02$) or 38-year-old ($M = 38.71$, $SD = 11.56$; $p = 0.008$) spouse who utilized MAID. The interaction effects between age and the mode of death on emotional reactions (i.e., fear, prosocial, and anger) and social distance were not significant ($p > 0.05$).

Post-hoc ANOVAs were used to further examine the main effects of age (28, 38, 70, and 80 years) on the outcome variables (see Table 3). There were no significant main effects of age on social distance, anger, prosocial behavior, or fear (all Fs < 1.57, all ps > 0.05). However, there was a significant main effect of age on grief expectations ($F(1,400) = 3.72$, $p = 0.010$, $\eta_p^2 = 0.03$). Specifically, participants expected the bereaved 38-year-old ($M = 38.88$, SD = 10.97) to experience less maladaptive grief than a bereaved 28-year-old ($M = 44.27$, $SD = 12.20$; $p = 0.02$) or 70-year-old ($M = 44.32$, $SD = 10.29$; $p = 0.01$), irrespective of how their family member died. There was no significant difference between the 80-year-old family member, no matter type of death, compared to other ages (ps > 0.05).

Discussion

There is a well-documented negative opinion toward MAID in the USA (Verbakel and Jaspers, 2010; Duckett, 2019). Yet, MAID is legal in 11 states and more legislation is being written to legalize MAID in other states (Pope, 2020). With an increase in utilization and access to MAID, a greater number of bereaved individuals will be grieving the loss of their family member via this method. This is the first study, to our knowledge, to investigate the effects of mode of death (MAID vs. illness-related death) and age of death (28, 38, 70, and 80 years) on American adults' public stigma and expectations of grief symptoms toward bereaved individuals.

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Table 1. Demographics: participants' characteristics and vignettes

	Overall	Vignette 1	Vignette 2	Vignette 3	Vignette 4	Vignette 5	Vignette 6	Vignette 7	Vignette 8
Age in years (SD)	42.54 (16.50)	45.43 (17.89)	43.14 (17.04)	43.54 (16.90)	39.25 (15.94)	41.56 (14.30)	42.87 (16.62)	41.83 (16.15)	42.48 (17.26)
Ethnicity									
White	315 (73.59%)	38 (67.86%)	42 (76.36%)	40 (76.92%)	38 (73.08%)	42 (77.78%)	44 (80%)	38 (73.08%)	33 (66%)
African-American/ Black	70 (16.36%)	11 (19.64%)	9 (16.36%)	7 (12.96%)	7 (13.46%)	7 (12.96%)	8 (14.55%)	9 (17.31%)	12 (24%)
Asian-American	27 (6.31%)	6 (10.71%)	3 (5.45%)	4 (7.41%)	4 (7.69%)	3 (5.56%)	3 (5.45%)	2 (3.85%)	2 (4%)
Gender									
Female	265 (61.9%)	28 (50%)	31 (56.36%)	34 (62.96%)	32 (61.54%)	35 (64.81%)	34 (61.82%)	39 (75%)	32 (64%)
Male	159 (37.1%)	28 (50%)	24 (43.64%)	20 (37.04%)	18 (34.62%)	19 (35.19%)	20 (36.36%)	13 (25%)	17 (34%)
Other	4 (.90%)	0 (0%)	0 (0%)	0 (0%)	2 (3.85%)	0 (0%)	1 (1.82%)	0 (0%)	1 (2%)
Education									
High school diploma	117 (27.3%)	11 (19.64%)	18 (32.73%)	21 (38.89%)	18 (34.62%)	14 (25.93%)	13 (23.64%)	11 (21.15%)	11 (22%)
Some college	118 (27.6%)	15 (26.79%)	10 (18.18%)	16 (29.63%)	13 (25%)	12 (22.22%)	18 (32.73%)	21 (40.38%)	13 (26%)
4-year college degree	66 (15.4%)	7 (12.5%)	13 (23.64%)	6 (11.11%)	9 (17.31%)	9 (16.67%)	7 (12.73%)	6 (11.54%)	9 (18%)
Other	128 (29.7%)	23 (41.07%)	14 (25.45%)	11 (20.37%)	12 (23.08%)	19 (35.19%)	17 (30.91%)	14 (26.92%)	17 (34%)

Table 2. Age × mode of death interaction univariate ANOVAs

Outcome	$F(1, 403)$	BH-corrected p-value	η_p^2
Grief expectations	2.56	0.01	0.04
Social distance	0.72	0.66	0.01
Anger	0.34	0.94	0.01
Prosocial behavior	0.86	0.54	0.02
Fear	0.98	0.45	0.02

Interestingly, there was no interaction of effects on direct stigma (i.e., emotional reactions and public stigma). These results indicate that, though there is a public criticism of use of MAID (Duckett, 2019), individuals are unlikely to stigmatize the family members and loved ones of individuals who decide to use MAID. It is possible that the general public attributes the decision to use MAID to the patient, rather than their loved ones; therefore, they may believe that bereaved individuals should not be stigmatized for a decision that is not entirely in their control.

There were, however, significant interactions when examining expectations of grief symptoms. The data showed two significant interactions between age and the type of death. First, participants felt that bereaved individuals whose 28-year-old spouse dies from an illness would experience more maladaptive grief symptoms than bereaved individuals whose 28-year-old or 38-year-old spouse utilized MAID. Second, participants endorsed that bereaved individuals whose 70-year-old spouse passed away from an illness-related death would experience more maladaptive grief symptoms than bereaved individuals whose 28-year-old or 38-year-old spouse utilized MAID. These results, in addition to research showing that more intense grief reactions are likely to elicit public stigma (Eisma, 2018; Gonschor et al., 2020; Dennis et al., 2021), suggest that bereaved individuals who lost someone to an illness will be stigmatized more. However, it could be hypothesized that bereaved individuals who lost someone to MAID are expected to grieve less and accept the death easier than a bereaved individual who lost someone due to illness. This perception could lead to a lack of support provided to bereaved individuals who lost someone to MAID as the layperson's perception is "they should be fine" following the loss.

Regardless of the mode of death, there was a significant main effect of age on participants' perceptions of the bereaved individual's grief response. Interestingly, participants endorsed that they expect bereaved family members of 38-year-olds to experience less maladaptive grief symptoms than bereaved family members of 28- or 70-year-olds. Contrary to the findings of Philippkowski et al. (2021), we did not find any difference in negative emotional reactions of fear or anger when assessing age differences between 28- and 80-year-old decedents. It is important to note that the mean age of study participants was 42, and therefore, participants may have identified most closely with the vignettes describing 38-year-old decedents. Young middle-aged (e.g., 38-year-old) individuals in America may be perceived to have a greater range of resources to support socioemotional functioning. Research has shown that individuals in their middle to late 20s or between 65 and 70s are in transition periods, characterized by instability and stress (Beaujot, 2017; Hawkley and Kocherginsky, 2018). For example, 28-year-olds are more likely to be newly engaged/married (average age of marriage in the USA is 28), not have children, and not be financially stable or have job security (Rudolph et al., 2021; U.S. Census Bureau, Decennial Censuses, 1890 to 1940, and Current Population Survey, Annual Social and Economic Supplements, 1947 to 2020, 2020). Therefore, 28-year-olds may have historically received most of their positive reinforcement from their spouse who passed away, whereas 38-year-olds may have children, which is a protective factor for maladaptive grief symptoms (Hibberd et al., 2010; Heeke et al., 2017). Also, research has found that, as age increases, a person has more work satisfaction and feels more secure in their job (Rudolph et al., 2021). These multiple identities that exist outside of young middle-aged marriages (e.g., having children; work success) have been shown to be protective factors against maladaptive grief symptoms (Papa and Lancaster, 2016). Regarding the difference between 38-year-olds and 70-year-olds, a similar argument could be made, as Carstensen's Socioemotional Selectivity Theory (Carstensen, 1992) states that, as a person ages, their social network decreases and their relationships become more important. Therefore, a person might perceive a 70-year-old to have a smaller social network, which could result in expectations of higher grief symptoms following the loss of a spouse, a key member of their social network. It is imperative to directly explore whether public perceptions and stigma may be guided by developmental theories explaining changes in socioemotional resource capacity across the lifespan.

Table 3. Age main effect from univariate ANOVAs

	$F(1, 400)$	BH-corrected p-value	η_p^2
Grief expectations	3.72	0.01	0.03
Social distance	0.69	0.56	0.01
Anger	0.26	0.85	0.00
Prosocial behavior	1.25	0.29	0.01
Fear	1.57	0.20	0.01

Limitations

There were limitations in this study that should be considered in interpreting the study findings. First, this was an online study and results might not generalize to samples recruited using other methods. It should be noted, however, that MTurk has been used in other studies (e.g., suicide; stigma) and with findings comparable to the general population (Sheehan, 2018; Klik et al., 2019; Engle et al., 2020). Second, this study does not provide insights into the underlying reason(s) for individuals' perceptions regarding differences in stigma depending on bereaved person's age and the type of death. Third, this study only focused on spousal bereavement. Participants' perceptions of stigma, including their assumptions about the emotional reactions of bereaved individuals, might differ based on the bereaved individual's relationship to their loved one. Fourth, we cannot comment on differences in stigma toward bereaved family members depending on the race of the participant.

Conclusions

This is the first study to examine public stigma and expectations of grief symptomology toward bereaved individuals whose family member utilized MAID with an American sample. Results were

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similar to Philippkowski et al.'s study with Australian adults that concern MAID elicits direct public stigma appear unfounded. However, unlike Philippkowski et al., individuals in the USA expect more maladaptive grief symptoms when grieving the death of a younger person from illness. Such expectations of grief displays might leave them susceptible to indirect stigma. Future research should examine additional factors that may influence public perceptions of grief reactions to MAID, specifically more granular ages, gender, and relationship of the bereaved, and race, ethnicity, and other sociocultural factors. In addition, studies should investigate the experience of stigma for bereaved family members of those using MAID at various ages. Finally, based on the findings, it may be important to better understand the grieving process for bereaved individuals who have lost someone to MAID and educate clinicians and the public about their possible unique grieving process.

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Conflicts of interest

All authors have nothing to disclose.

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