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Public stigma of prolonged grief disorder: An experimental study

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ABSTRACT

Prolonged grief disorder (PGD), characterized by severe, persistent and disabling grief, is being considered for inclusion in the International Classification of Diseases' 11 (ICD-11) and a related disorder, Persistent Complex Bereavement Disorder (PCBD), is included for further investigation in the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5). Establishing diagnoses for pathological grief may lead to stigmatization. Additionally, it has been argued that people experiencing severe grief responses after loss of non-family members (i.e., disenfranchised grief) may experience more stigmatizing reactions. Yet, no research to date has investigated this. To fill this gap in knowledge, 379 adults from the general population were randomly allocated to read one of 4 different vignettes of a person with and without a grief disorder diagnosis who had lost a friend or a spouse. After reading the vignettes, we assessed: 1) characteristics ascribed to the person, 2) emotional reactions to the person, and 3) desire for social distance. Notably, people with a diagnosis were attributed relatively more negative characteristics, and elicited more anger, anxiety and pro-social emotions and a stronger desire for social distance. Stigmatization and its negative consequences appear a valid concern to the establishment of pathological grief disorders in diagnostic manuals.

1. Introduction

There is increasing recognition that bereavement can lead to severe, persistent and disabling grief reactions, also named 'complicated grief' or 'prolonged grief', among a minority of bereaved individuals (Lundorff et al., 2017; Boelen and Smid, 2017). Currently, prolonged grief disorder (PGD) is under consideration for inclusion in the International Classification of Diseases'11 (ICD-11; Maercker et al., 2013), and a related disorder, Persistent Complex Bereavement Disorder (PCBD) is included in the Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5: American Psychiatric Association, 2013) as a diagnosis for further study. The most recent proposed criteria for PGD hold that one must experience severe yearning for the deceased and/or cognitive preoccupation with the deceased and three of five additional symptoms (i.e., difficulty accepting the loss, feelings of guilt, feelings of anger, feeling a part of oneself died, difficulty engaging in new activities) until at least six months after bereavement (Maercker et al., 2013; cf. Prigerson et al., 2009).

Proponents of the establishment of grief disorders argue that it will lead to increased research into (and clinical application of) grief-specific treatments that effectively reduce PGD or PCBD (Doering and Eisma, 2016), yet researchers, clinicians and members of the public have flagged potential negative consequences of this development, such as stigma (Bandini, 2015; Breen et al., 2015; Ogden and Simmonds, 2014). Stigma has been defined as the co-occurrence of labeling, stereotyping, separation, status loss, and discrimination in a context in which power is exercised (Link and Phelan, 2001). Indications of stigma, such as negative attitudes, negative emotional reactions and a larger preferred social distance toward persons with a mental disease, have been observed towards individuals suffering from a wide range of mental disorders (Pescosolido et al., 2010; Schomerus et al., 2012).

Public stigma towards people with a mental illness can have severe adverse consequences. Mental health stigma is associated with self-stigma (Evans-Lacko et al., 2012), depression and suicidality (for a review: Carpiniello and Pinna, 2017), reduced help-seeking from mental health services (for a review: Clement et al., 2015), and disruption of mental health treatments (Sirey et al., 2001).

Despite the clinical importance of stigma for grief-related disorders, no studies to date have examined this topic. However, research has demonstrated that individuals bereaved by suicide or other violent loss, and people who experience severe loss-related distress perceive more stigmatizing reactions from others (Chapple et al., 2015; Johnson et al., 2009; Pitman et al., 2016). For instance, suicide bereaved persons perceived more discrimination and loss of social support by others than people who experienced other types of bereavement (Pitman et al., 2016). Relatedly, it has been argued that experiencing disenfranchised grief (i.e., grief after a loss that is not or cannot be openly acknowledged, publicly mourned, or socially supported) might increase negative reactions of and reductions in support from one's social network (Doka, 1989). Additionally, if a person does not follow "appropriate"

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grieving rules (e.g., grieving too long), his or her grief can also become disenfranchised (Corr, 2002), and this may elicit similar negative reactions. Indeed, a recent systematic review shows (Logan et al., in press) that greater social recognition may be given to bereaved children, spouses and parents, than to more distal relatives and friends (e.g., Thornton et al., 1991; Johnsen and Dyregrov, 2016). As such, developing PGD after the death of a non-family member could elicit more stigmatizing responses as less severe grief is expected in response to such events.

Against this background, it was hypothesized that, in a vignette-based experiment, people may be particularly likely to show stigmatizing reactions (i.e., negative attributions, negative emotional reactions, larger preferred social distance; Link and Phelan, 2001) in response to people diagnosed with a PGD diagnosis (versus without), especially when developed in response to the loss of a friend, instead of a spouse.

2. Methods

2.1. Sample and procedure

Recruitment took place in several locations in a village and a city in the Netherlands, and through posting ads on Facebook (on publicly accessible community websites). The study could be accessed via a weblink that could be accessed online or via e-mail. The study had an experimental design and was programmed in Qualtrics. Only adults (age > 18 years) were allowed to participate. All participants read information about the study aims and procedure and provided informed consent. Table 1 shows sample characteristics of all 379 participants. Compared to the general Dutch population (CBS, 2017), the sample had a similar age (M = 38.3 vs. M = 41.5), yet contained more people with higher educations (47.8% vs. 30.0% college/university) and more females (82.7% vs. 50.5%).

2.2. Materials

2.2.1. Vignettes

The vignettes developed for this study varied on the independent variables presence of a grief disorder (PGD diagnosis and symptoms vs. no PGD diagnosis and symptoms) and relationship with the deceased (spouse vs. friend), creating four unique vignettes (see Table 2). Conditional criteria (i.e., time since loss, impairment in functioning) and five symptoms were selected to meet the proposed criteria for PGD by (Prigerson et al., 2009), which forms the basis for newer proposals for PGD (Maercker et al., 2013). The design of the vignettes was partly based on research into public stigma for bereaved individuals (Penman et al., 2014). The time since loss in each vignette was set at two years, as this is beyond the timing criteria for both PGD (6 months) and PCBD (12 months) (American Psychiatric Association, 2013; Maercker et al., 2013). Gender was not varied in the vignettes, as previous similar research indicated no influence of gender on public stigma for bereaved persons (Penman et al., 2014). Another reason not to include gender in the vignettes was to limit the number of independent variables so that the power of the experiment would not be compromised. Each participant was presented with one of these four vignettes, which was randomly selected by Qualtrics. Participants could revisit the vignette if they wanted to.

Table 2
Vignettes.

Vignette 1: grief disorder after conjugal loss
Fifty year-old Carl has lost his wife to a stroke two years ago. He finds this extremely difficult and does not function well at work nor at home. Since the loss he yearns strongly for his deceased wife. Additionally, he has difficulties accepting the loss, does not want to be reminded of the loss, finds his life meaningless and has difficulties trusting others. On the basis of this behavior a mental health professional diagnoses him with a complicated grief disorder (prolonged grief disorder).
Vignette 2: grief disorder after friend loss
Fifty year-old Carl has lost his friend to a stroke two years ago. He finds this extremely difficult and does not function well at work nor at home. Since the loss he yearns strongly for his deceased wife. Additionally, he has difficulties accepting the loss, does not want to be reminded of the loss, finds his life meaningless and has difficulties trusting others. On the basis of this behavior a mental health professional diagnoses him with a complicated grief disorder (prolonged grief disorder).
Vignette 3: no grief disorder after conjugal loss
Fifty year-old Carl has lost his wife to a stroke two years ago. While he was very sad the first few months after the loss, he now has learned to live with the loss. He functions well both at work and at home. Carl has accepted the loss of his wife more, occasionally engages in fond reminisces of her and feels his life is meaningful.
Vignette 4: no grief disorder after friend loss
Fifty year-old Carl has lost his friend to a stroke two years ago. While he was very sad the first few months after the loss, he now has learned to live with the loss. He functions well both at work and at home. Carl has accepted the loss of his friend more, occasionally engages in fond reminisces of her and feels his life is meaningful.

2.2.2. Questionnaires

A background questionnaire was administered prior to presentation of a vignette and all other questionnaires were administered after a vignette was shown.

2.2.2.1. Background questions. A self-constructed questionnaire was used to assess gender, age (in years), education level (primary school, high school, vocational education, college/university), religiosity (yes/no), employment status (student, full-time, part-time, unemployed, incapacitated, retired, housewife/houseman – multiple answers possible), and the experience of bereavement in the past year (yes/no).

Table 1
Sample characteristics.

	PGD disorder spouse (N = 90)	PGD disorder friend (N = 94)	No disorder spouse (N = 92)	No disorder friend (N = 103)	Total (N = 379)
Female (N (%))	72 (80.0)	78 (83.0)	78 (84.8)	43 (91.5)	313 (82.6)
Age in years (M (SD))	38.1 (15.6)	38.5 (14.9)	37.5 (15.3)	38.3 (15.1)	38.3 (15.2)
Lower education (N (%))	51 (56.7)	45 (47.9)	57 (62.0)	45 (42.7)	198 (52.2)
Higher education (N (%))	39 (43.3)	49 (52.1)	35 (38.0)	58 (57.3)	181 (47.8)
Work status (N (%))					
Student	27 (30.0)	26 (27.7)	26 (28.3)	24 (23.3)	103 (27.2)
Full-time employed	19 (21.1)	28 (29.8)	27 (29.3)	29 (28.2)	103 (27.2)
Part-time employed	32 (35.6)	36 (38.3)	31 (33.7)	42 (40.8)	141 (37.2)
Other	25 (27.7)	13 (13.8)	18 (19.6)	17 (16.5)	73 (19.2)
Religious (N (%))	27 (30.0)	20 (21.3)	22 (23.9)	20 (19.4)	89 (23.5)
Bereaved past year (N (%))	24 (26.7)	35 (37.2)	31 (33.7)	27 (26.2)	117 (30.9)

Note. Lower education = primary school, high school or vocational school. Higher education = college or university. Bereaved past year = loss of any close other in the past year. Work status: Other = unemployed, pensioner, housewife/houseman, or incapacitated. Work status does not add up to 100% because categories are not mutually exclusive. No significant differences between groups were detected.