



The stigma perceived by people bereaved by suicide and other sudden deaths: A cross-sectional UK study of 3432 bereaved adults



Alexandra L. Pitman^{a,b,*}, David P.J. Osborn^{a,b}, Khadija Rantell^c, Michael B. King^{a,b}

^a UCL Division of Psychiatry, University College London, Gower St, London WC1E 6BT, United Kingdom

^b Camden and Islington NHS Foundation Trust, St Pancras Hospital, 4 Saint Pancras Way, London NW1 0PE, United Kingdom

^c Education Unit, UCL Institute of Neurology, United Kingdom

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ABSTRACT

Objective: To test the hypothesis that perceived stigma scores in young adults bereaved by suicide are significantly higher than in young adults bereaved by other sudden deaths, whether blood-related to the deceased or not. **Methods:** We conducted a cross-sectional study of all staff and students aged 18–40 at 37 UK higher educational institutions in 2010, and identified 3432 respondents who had experienced a sudden bereavement of a close contact since reaching the age of 10, either due to sudden natural causes, sudden unnatural causes, or suicide. We used multivariable regression to compare scores on the stigma, shame, responsibility and guilt subscales of the Grief Experience Questionnaire, adjusting for socio-demographic factors and pre-bereavement psychopathology. **Results:** People bereaved by suicide ($n = 614$) had higher stigma scores than people bereaved by sudden natural death ($n = 2106$; adjusted coefficient = 2.52; 95% CI = 2.13–2.90; $p = <0.001$) and people bereaved by sudden unnatural death ($n = 712$; adjusted coefficient = 1.69; 95% CI = 1.25–2.13; $p = <0.001$). Shame, responsibility and guilt scores were also significantly higher in people bereaved by suicide, whether compared with bereavement by sudden natural death or sudden unnatural death. Associations were not modified by whether the bereaved was blood-related to the deceased or not.

Conclusions: Stigma was perceived more acutely by the relatives and friends of those who died by suicide than those bereaved by other causes of sudden natural or sudden unnatural death. Their high levels of perceived stigma, shame, responsibility and guilt require qualitative investigation to identify whether these grief dimensions limit social functioning, help-seeking behaviour and/or support offered.

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1. Introduction

Supporting people bereaved by suicide is a key objective of many international suicide prevention strategies [1,2], and this group are now known to have an increased risk of suicide, depression, and psychiatric admission compared with people bereaved by other mortality causes [3]. UK evidence shows that the risk of suicide attempt applies whether blood-related to the deceased or not [4], indicating that explanations for these adverse outcomes lie beyond familial factors. Suggestions include assortative relating, shared social adversity, stigma, and social modelling [3]. Identifying explanatory factors is a key step in designing suicide prevention interventions targeted at people bereaved by suicide, but as yet our understanding of these mechanisms remains theoretical. Stigma is of interest because it is distressing, influences help-seeking, limits support available, is linked to risk factors for suicidality (such as social isolation and hopelessness [5]), and may be more modifiable than

other explanatory factors [6]. There is tentative evidence for its contribution to explaining adverse outcomes in people bereaved by suicide [4]. However, stigmatising attitudes are not unique to suicide, and may also be directed at people bereaved by accidental deaths [7] or preventable natural causes [8] for their links with someone judged to have exhibited risky health behaviour. To begin to understand the role of stigma after sudden death, we need to start by confirming whether the degree of stigma associated with suicide bereavement exceeds that associated with other losses [3].

Stigma is a term more commonly applied to characteristics such as psychiatric [5] or neurological illnesses [9], but is also well-described in relation to people who have experienced bereavement, particularly after suicide [6–8] and other unnatural losses [7]. Dimensions of stigma include public or personal stigma, perceived stigma, and self-stigma. Public and personal stigma are forms of enacted (or objective) stigma, manifested in mistrust, fear, negative bias, and stereotyping of the bereaved, as well as social embarrassment and avoidance [10]. Public stigma towards people bereaved by suicide originated in the Middle Ages, when legal, religious, and social sanctions against suicide arose as a deterrent within Roman Catholic, Jewish and Islamic communities [10,11].

* Corresponding author at: UCL Division of Psychiatry, Maple House, 149 Tottenham Court Road, London W1T 7NF, United Kingdom.
E-mail address: a.pitman@ucl.ac.uk (A.L. Pitman).

Such sanctions persist in the tendency of life insurance companies to re-fuse policies for families with a history of suicide, or delay pay-outs after suicide. Personal stigma is apparent in attitudes towards suicide as a failure of problem-solving, blaming both the deceased and their friends and family [10]. US studies of non-bereaved subjects show a greater tendency to ascribe blame to a person bereaved by suicide than one bereaved by accidental death, homicide, or natural death [12], and to avoid the bereaved for fear of the social rules governing such interactions [13]. Perceived stigma describes the awareness of others' stigmatising attitudes, and is a form of felt (or subjective) stigma [14]. For example, US parents bereaved by a child's suicide reported hurtful responses from family and friends after their loss [15]. When perceived stigma is internalised as self-stigma, it engenders feelings of shame and worthlessness [5,9]. Whilst perceived and self-stigma can reduce help-seeking and awareness of support available, public and personal stigma can reduce others' willingness to offer support [10].

The stigma associated with suicide and other deaths has been documented extensively in the qualitative literature [7,10,16], but is less well described quantitatively [3]. Surveys have demonstrated higher stigma and shame scores in people bereaved by suicide when compared with people bereaved by natural mortality causes [3]. Direct comparisons with people bereaved by non-suicide unnatural causes, however, show that people bereaved by suicide report higher shame scores but no differences on stigma [3]. This would appear to suggest that feeling highly stigmatised applies to all those bereaved by unnatural causes (perhaps due to others' distaste over the nature of the loss), and that shame characterises suicide bereavement specifically. However, methodological problems, such as small sample sizes, unvalidated scales, and unadjusted analyses, render these findings inconclusive [3,15].

Our objective was to determine, in a UK sample, whether people bereaved by suicide have a higher risk of suicide attempt and feel more stigmatised than those bereaved by other sudden mortality causes. We chose to focus on young adult, given concerns about their vulnerability to social modelling of suicidal behaviour [17]. Our study was primarily designed to test the hypothesis that young adults bereaved by suicide report higher rates of incident suicidal thoughts and attempts than young adults bereaved by other causes of sudden death. Our findings supporting this hypothesis are reported separately [4]. The current paper reports on the testing of our additional hypothesis that significant differences exist between stigma scores for people bereaved by suicide, sudden unnatural death, and sudden natural death. We predicted that stigma scores would be highest in people bereaved by suicide, lowest in people bereaved by sudden natural causes, and intermediate to the two in those bereaved by sudden unnatural causes. We predicted that the same patterns would apply to three other components of grief: shame, responsibility, and guilt. We also examined whether the predicted associations would apply whether the bereaved were blood-related to the deceased or not.

2. Methods

2.1. Study design and participants

We invited all young adults working or studying at UK higher education institutions (HEIs) to participate in a closed online cross-sectional survey about sudden bereavement: the UCL Bereavement Study. We considered this sampling frame to provide the most efficient, comprehensive and pragmatic means of recruiting a hard-to-reach population of young adults [18], whilst simultaneously minimising traditional biases associated with recruiting a help-seeking sample. All 164 HEIs in the UK in 2010 were invited to participate, following-up non-responding HEIs to encourage broad socio-economic and geographic representation. Over 20% of HEIs (37/164) agreed to take part, with a higher response (40%) from those classified as the more prestigious Russell Group universities. This provided an estimated sampling frame of 659,572 staff and students. The majority of participating HEIs agreed

to send an individual email invitation with embedded survey link to each staff and student member, as per study protocol. For reasons of sensitivity ten HEIs modified this strategy, for example by emailing students only, using their weekly news digest email, or advertising via staff and student intranet. All recipients (whether bereaved or not) were invited to take part in a survey of "the impact of sudden bereavement on young adults", with the aim of masking them to the specific study hypotheses. There was no accurate way of measuring response, as the denominator of bereaved people was not ascertainable using routine data or survey methods.

Inclusion criteria were as follows: people aged 18–40 who, after ten years of age, had experienced sudden bereavement of a close friend or relative. Early childhood bereavements were excluded to minimise recall bias, and to capture adult cognitive processing of negative life events. Sudden bereavement was operationalised as "a death that could not have been predicted at that time and which occurred suddenly or within a matter of days". Exposure status was sub-classified, via self-report, as: bereavement by suicide, bereavement by sudden natural causes (e.g. cardiac arrest), and bereavement by sudden unnatural causes (e.g. road deaths). For respondents who had experienced more than one mode of sudden bereavement, we adopted a hierarchical approach: all those bereaved by suicide were classified as such, regardless of other bereavements. Those bereaved by non-suicide deaths were classified according to the person they had felt closest to. We based our sample size calculation on the primary outcome for our main study; suicide attempt. We estimated that a minimum of 466 participants would be required in any one group (two-tailed analysis; 90% power) to detect a doubling of the UK community prevalence of lifetime suicide attempt (6.5%) in young adult samples [19].

The study was approved by the UCL Research Ethics Committee in 2010 (ref: 1975/002). All participants provided online informed consent.

2.2. Procedures

Our online questionnaire (see Supplementary material) was designed in consultation with a group of young bereaved adults and bereavement counsellors, and piloted with individuals accessing support from four national bereavement support organisations in the UK. The questionnaire elicited quantitative data on socio-demographic and clinical characteristics, including eight putative confounding variables identified from existing literature and clinical judgement: age, gender, socioeconomic status (using the UK Office for National Statistics Standard Occupational Classification [20]), pre-bereavement depression, pre-bereavement suicidal self-harm, pre-bereavement non-suicidal self-harm, other family history of suicide (excluding index bereavement), years since bereavement, and kinship to the deceased.

Our primary outcome was perceived stigma using the 10-item stigmatization subscale of the Grief Experience Questionnaire (GEQ) [21]. The GEQ is a standardised, validated, self-administered instrument for the assessment of the phenomenology of grief. It was developed following qualitative interviews with US individuals bereaved by natural causes, accidental death, and suicide [22]. The original scale was further validated and refined using factor analysis of responses from a sample of Canadian adults bereaved by natural causes, accidental death, and suicide [21]. The resultant eight subscales are: abandonment/rejection, stigmatization, search for explanation, guilt, somatic reactions, responsibility, self-destructive orientation, and shame/embarrassment. Responses to items in each subscale are rated using a 5-point Likert-style frequency scale, to generate a subscale score of 5 to 25. As in previous studies comparing the impact of different modes of bereavement, we compared GEQ subscales rather than overall GEQ score to delineate specific components of grief [23–25]. The stigmatization subscale (Box 1) captures perceived rather than personal stigma, and includes items describing discrimination and loss of social support [21].

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