

Blog of the Month

AMPJ Blog of the Month: January 2022 Edition

Dr Philippa McFarlane is an Internal Medicine Trainee in London and current president of the APMJ. For this month's APMJ blog post, Philippa shares with us an essay from her recent MSc in Palliative Care. Thank you, Dr McFarlane!

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Assignment: Human grief is socially patterned and channelled. Critically examine the evidence for this claim, appraising the available literature and making reference to own work practice and setting

Abstract

The emergence and use of social networking sites have exploded in recent years, transforming the nature of social interactions, including how people express and exhibit their grief. In the UK, the bereaved have traditionally hidden their mourning and grieved in private. Social media, however, challenges the sequestration of death and instead facilitates a public media centric death. Studying grief within the digital setting is particularly relevant in the backdrop of the COVID-19 pandemic which has not only caused an estimated 34.2 million bereavements, but also reinforced the developing reliance on social media for social interactions.

The evidence describing the social determinants of grief is explored and critiqued in the context of digital grief culture, considering the contemporary paradigm shift towards public mourning, virtual relationships with the deceased and role of social factors on digital behaviour such as culture, age and gender. Clinical implications and the value of grief work are also considered as the application and access to thanatechnology expands.

While there are undeniable, and excruciating, biological and physical experiences of grief, the way in which human grief is experienced, expressed and performed online through current digital behaviour is socially patterned and channelled. The development of thanatechnology has the potential to empower mourners independently in their grief work, and facilitate large scale cost-effective clinical interventions. Internet-based research, however, presents methodological

challenges relating to sampling bias and availability of sample demographic information, limiting much of the current body of work. Work exploring the impact on digitally excluded groups is also lacking. Particularly in the wake of COVID19, further research with robust considered methodologies is essential to explore theory, inform policy and ensure safe, effective interventions can be accessed in the shadow pandemic of grief.

Abbreviations

PGD – Prolonged Grief Reaction SNS – Social Networking Sites

Introduction

The loss of a significant person from death, recognised as bereavement (1), prompts a multifaceted reaction of intense emotional and physical suffering, described as grief (2, 3). Experiencing a bereavement is an inevitable human experience, with grief regarded as a universal feeling from which most people recover over time and through mourning (4). Although frequently taken in tandem with grief, mourning is seen as the social process of reorienting to accommodate the loss in the external world (5, 6). With a broad range of psychological responses related with grief, many prominent researchers, have considered grief a complex emotional syndrome (7). Little consensus remains, however, on the combination, severity and duration of the symptoms to define the syndrome (2). Medically, it is considered that mourners should begin progressing beyond the debilitating phase of grief within 6 months of the death. Those who have persistent symptoms at this stage, prohibiting the fulfilment of normal roles, are diagnosed with Prolonged Grief Disorder (PGD) which is associated with negative health outcomes and is now listed in the ICD11 and DSM5 (8).

Key grief frameworks have created landmarks in the history of grief theory and debated understanding. Most relevant for a digital context are the stage-based theories and attachment and continuing bonds theories. In Mourning and Melancholia (9), Freud proposed grief as depression-like, describing a need to recover the loss and reinvest the attachment into another object. His

theories were unexamined, however, and critiqued for implications that grief is uniform. Bowlby (10) and Parkes (11) later developed attachment theory, presenting four stages of numbness, yearning, despair and recovery. Although based on experimental evidence, the methodologies and evidence for moving through the stages are, however, limited. Kubler-Ross (12) presented a linear stage-based process of adaptation described as the "five stages" of denial, anger, bargaining, depression, and acceptance. The model has been critiqued for its limited evidence base and implied strict route through the simplistic stages. Klass, Silverman and Nickman (13) present the theory of continuing bonds whereby an ongoing attachment to the deceased is essential for supporting adaptation to the bereavement. Most evidence is, however, based on historical and observational studies meaning that evidence of the value of continuing bonds is poor, failing to demonstrate a causational argument for positive grief outcomes.

The emergence and use of social networking sites (SNS), has burgeoned in recent years, transforming the nature of social interactions, including how people express and exhibit their grief (14). In the UK, mourners have traditionally hidden their mourning, grieving in private. Social media, however, challenges the sequestration of death and instead facilitates a public media centric death (15, 16). Within the digital revolution, Sofka et al.

(17) coined the term thanatechnology to describe communication technology used to provide death education and grief counselling. Studying grief within the digital setting is particularly relevant in the backdrop of the COVID-19 pandemic which has not only caused over 3.8 million deaths worldwide (18) with an estimated 34.2 million bereavements (19), but also reinforced the developing reliance on social media for social interactions. This essay will evaluate the claim "human grief is socially patterned and channelled" within the contemporary context of digital culture in the UK, considering the spectrum of micro level individual factors to macro societal factors.

Forces of Grief

Contemporary and Cultural Factors

The contemporary context of this essay implores consideration of the modern manifestations and culture of grief in society. Culture can be defined as the shared knowledge and schemes created by a group of people for perceiving, interpreting, expressing and responding to the social realities around them (20). Grief culture plays an important role in both the experience and outward expression of grief with significant differences noted across world cultures (21). Society has a policing role in determining forms of loss which are acceptable, those that are not recognised as legitimate are described as disenfranchised grief (22). The emergence of digital and media networks, and in turn

digital cultures has transcended into cultural norms observed in the UK, challenging the national culture of grief.

The death of Princess Diana in 1997, and the unprecedented intensity of the media reaction

(23), is associated with a paradigm shift towards public mourning which had first been seen following the Hillsborough disaster in 1989 (24); SNS have since fuelled this trend (25). It has been argued that these events re-educated the British public on how to "do" death, reviving mourning traditions, such as a minutes silence and creating shrines for the dead, which had been lost in the post-war culture of death denial (24). More recently, the footage of George Floyd's death in 2020 demonstrated how SNS can facilitate a global grief reaction, sparking international protests and demonstrations of unaccepted mourning. With the visual nature of death in these discussed examples, it is challenging to separate out the innate reactions from the mediated, socially generated ones. Furthermore, it has been suggested that powerful sensationalist media can condition the public to learn their mediated grief, demonstrating a socially constructed emotional contagion spreading through networks rather than an expression of universal feeling (23, 26, 27). Many of the emotions voiced following celebrity deaths echo the grief frameworks of Kubler-Ross (12), despite the recognised academic and medical limitations of stage-wise grief theory and emphasised individual grief reaction (28). The contemporary grief culture of public mourning on SNS, however, demonstrates the policed expectations of how the bereaved should experience, exhibit and perform grief (27, 29). SNS rituals are specific to the platforms centrality of convergence, pulling together public mourning and personal sense-making (30). Many cultures perform prescriptive mourning rituals, associated with positive outcomes, to alleviate grief and find comfort (31, 32); the socially patterned ritualistic process of engaging with mourning online has been argued to provide similar aid to the bereaved (14, 33). Research thus far, however, employs self-selected non-diverse sample populations, further purposive work is needed to examine online mourning across different cultural groups. Recent work, as SNS use has expanded, and systematic reviews on this question are also lacking.

The COVID-19 pandemic places a spotlight on death and human mortality; undoubtedly the combination of mass bereavement and reliance on digital technology in the COVID-19 pandemic will have created a "new normal" for digital grief culture. While much work so far has considered the bereavement risk in the perfect storm of visiting restrictions, social isolation and sense of injustice, a study reviewing the role of SNS in supporting the bereaved highlights the culture of expressing intense emotional states online (34). A therapeutic role in connecting experiences offering condolences, communal mourning and the facilitation of community support was also identified, suggesting that in addition to driving a socially constructed grief culture, perhaps SNS also provide a structured, supported mourning environment. SNS carry

unique biases, however, with users posting exaggerated content as well as a sampling bias with varied engagement across the population resulting in an underrepresented sample. As we emerge from the pandemic, it is essential that bereavement research continues to explore the consequences and cultural adjustments resulting from the shadow pandemic of grief.

Contemporary cultural factors observed in the last 30 years, fuelled by SNS, have facilitated socially constructed, mediatised rituals of mass mourning clearly supporting the notion that human grief is socially patterned and channelled. Many individual factors, including the relationship with the loss, and previous life experiences can also impact on the personal expression and experience of grief.

Individual Factors

The relationship between the mourner and the deceased holds an important role in the grief response and is recognised as a risk factor for PGD (35, 36). Considering the impact of the relationship with the deceased within the digital context, the influence of immemorial profile pages and the construction of virtual "parasocial" attachment bonds must be evaluated, particularly relating to attachment and continuing bonds theory.

It is anticipated that by 2100, 4.9 billion memorial Facebook profiles will exist through which mourners are able to virtually relive memories and communicate with the deceased and other mourners (37). Studies have shown that the use of SNS can impact on relational termination through continued connections (38). To facilitate an adaptive process, however, it is essential mourners can recognise the continued bonds with the deceased are virtual and different from when they were alive. Failure to identify the altered relationship may present a continued maladaptive bond expression which could promote PGD (39, 40). Fields work, however, does not draw causational conclusions and additional factors are likely to be linked to maladaptive bond expression. Furthermore, SNS are associated with depression, a leading risk factor for PGD (41, 42), and grief-based support groups may paradoxically enhance social isolation and reduced face-to-face support, further potentiating PGD (43). The role of attachment and continuing bonds in grief theory highlights the psychobehavioural components of grief, however the social patterns of digital behaviour may further compound the grief response.

Fame is closely associated with SNS, with celebrities cultivating virtual bonds and parasocial connections with their fans (44). 2016 saw a series of prominent celebrity deaths and displays of public mourning; the loss of David Bowie, in particular, prompted over 4 million SNS posts within the first 24-hours of his death (45). While the SNS activity around these deaths speaks to the community of grief established, and the developing modern digital grief culture (45), it also highlights how the response to the loss of parasocial connections mirrors the grief reaction to the loss of physical relationships (44). Moreover, the grief may be compounded by the projection of the

mourner's past experiences and fears (46), reinforcing the notion that grief is socially channelled. Longitudinal, qualitative research evaluating the course and duration of parasocial grief beyond the initial media flurry is lacking; further research could investigate how the intensity and duration of the response differs to that of the loss of a close physical relationship which may carry a stronger bio-psycho components.

Social Factors

Many social factors have been described as contributing to the experience and expression of grief, in addition to culture which has already been considered in a contemporary setting, gender and age are particularly relevant to the digital context of this essay.

Stereotypical gender-related grief patterns have been extensively described (47). Women have been found to display a "feminine" grief pattern with intuitive responses associated with increased displays of intense affect, early expression of emotion and support seeking behaviour. Men alternatively exhibit a "masculine" pattern with instrumental responses associated with assuming a managerial role, reporting anger and fear, and being more private about their grief (48, 49). Such differences in grief behaviours contribute to a complex interplay between biological and cognitive processes and cultural conditioning (47). When exploring engagement in online mourning, Egnoto et al.(50) found persistent genderrelated differences in behaviour, particularly reporting that women were more manipulated by the perception of social normalcy within their social network, with increased acceptability resulting in higher online grieving activity, highlighting the influence of social channels on human grief. The sample population had a strong female bias, however, which may distort the differences found. Within her analysis of bereavement vlogs, Gibson (51) also commented on differences in the emotional exchange between genders, highlighting a clear pattern of same-gender commentary reinforcing the role of gender identity within the behaviour. The comments and those making them are not clearly described, however, and it likely they underrepresented the general population. While current work suggests clear socially patterned gender-differences in activity, research with representative samples is essential to comprehensively understand how gender-patterns are reflected in digital behaviour.

Evidence focusing on disenfranchised grief supports arguments that ageist stereotypes and assumptions exclude both spectrum ends of older adults and adolescents and children from cultural expressions of grief (52). As they approach life expectancy, older adults can be expected to accept their age and the concept of their approaching death (53). Yet they are more vulnerable to social isolation and loneliness, and suffer a cumulative impact of loss which can further complicate their grief reaction (54). Moreover, as digital grief culture drives a shift towards online public mourning

rituals, given their reduced access to SNS, older adults will be further excluded (55); falling outside of social forums, their grief may be further disenfranchised. Research exploring this is sparse, however, and is imperative to expand theory, inform policy and prevent further ageist health inequalities from developing.

Contrastingly amongst adolescents, SNS are a dominant form of communication, and as such, online grieving has been particularly studied in the context of adolescent grief with theories of 'enfranchising' grief. Following the loss of a peer with a significantly mediated online presence, the concept of continuing bonds has also been explored. While this may potentiate a maladaptive grief reaction, as discussed with adults, in adolescents the freedom and time to reflect on their friendship may instead provide coping strategies when mourning lost opportunities and information-seeking in a less intense environment (56, 57). Work so far is compromised, however, by the sampling complexities of internet-based research and the activity reviewed has mostly been confined to a few SNS.

Concerns regarding the vulnerability of adolescents on SNS have also been raised. Additional to safety concerns, research reviewing neural activity of reward-related pathways has associated increased activity in both SNS use and adolescence PGD; Adolescents may be foregoing their bio-psycho resilience for a socially liberated grief, with unknown long-term consequences (58, 59). These theories, however, have not been examined experimentally. Robust research, allowing for the methodological challenges of internet-based research, is essential to explore this potential threat to a generation's mental health.

The Value of Grief Work

Grief work, its associated confrontational strategy and universal application has long been challenged (60). Differences observed between gender-related outcomes have been particularly identified, with widowers deriving more benefit from formal grief work, highlighting the impact of socially complex grief expression. Modern customs of public, digital mourning may, however, promote and facilitate a more informal setting for grief work, where mourners are encouraged to publicly work through their emotions and access other sources of thanatechnology (61). Blogs and vlogs are viewed as more intimate forms of SNS where creators share narratives of their lives with their audience base, who are mostly strangers (62). Gibson's (51) analysis of bereavement vlogs finds a beneficial narrative process with an emotional exchange and comfort between strangers. Gibson highlights that some content was created and shared within hours of the bereavement, suggesting that publicly grieving and seeking support from strangers is a normal social act. Some vlogs had also been created at the viewers request. While Gibson comments that the audience is engaged with the vlogger's diaries, perhaps this also demonstrates a role for the mourner to perform

and exhibit grief in a certain way (27), supporting claims that grief, and grief work is socially patterned. As rich qualitative work, Gibson only reviewed 11 vlogs and her findings are therefore vulnerable to sampling bias. Overall, however, the work highlights the value of grief work, supporting the role of thanatechnology to empower mourners to engage with their mourning process.

Clinical Implications

Comprehensive research evaluating clinical grief interventions remains sparse and following the recognition of PGD in the ICD11 and DSM5 much of the work that exists is focused on this patient population rather than those experiencing "regular" grief (63). While the individual nature of the grief experience requires tailored interventions and presents challenges for large scale analysis, the absence of a Cochrane review of interventions is stark.

Identification of high-risk grievers is based on clinical intuition rather than established guidelines and policy with 50-60% of the bereaved lacking formal support (64, 65). Furthermore, if people are experiencing disenfranchised grief their vulnerabilities may not be fully acknowledged without development and employment of a robust screening tool (66). For those accessing clinical interventions, social patterns of mourning must also be considered to prevent disempowerment associated with a prescribed grieving style (67). Particularly with the ageist bias of deaths from COVID-19, concerns regarding the clinical implications of the pandemic generating a disenfranchised grief have been raised (68). These concerns don't however consider the impact on online bereavement support which has been shown to provide free space to discuss more tabooed deaths, thus conversely enfranchising grief (69).

The role of thanatechnology to support mourners has been increasingly recognised, both for empowering mourners in their grief work but to also provide cost-effective, accessible clinical interventions. Before access to SNS the grief theories provided a reassuring framework for sensemaking, however, in the current realm of public mourning and shared experiences people can seek out similar experiences and reactions to understand their emotions in a publicly private and privately public sphere (70, 71). As such, communities of mourning can be sought to provide bereavement support which might have been otherwise lacking or socially restricted (51). Hartig et al.(72) describe a positive association between duration of time engaging with online support and psychosocial outcomes. The sample, however, was majority female and included grievers at different stages of mourning which may confound the results. Concerns also exist regarding potentially harmful consequences of online forums, such as prolonged suffering in bereavement, compounding effects of other loses within the forum and social isolation with an over reliance on

technology (8, 73). Further longitudinal work is needed to better understand the safety and efficacy of online bereavement support.

When correctly delivered, some clinical internet-based psychological interventions are as effective as face-to-face interventions (74), presenting a diverse means of delivering interventions (75, 76). Although sparse, work exploring grief-specific interventions is also promising (77); in the wake of the COVID-19 pandemic with bereavement services already stretched beyond their capacity, further work evaluating the safety and effectiveness of the clinical role of thantechnology is paramount to generate novel interventions and inform policy.

Conclusions

Grief is a multifaceted complex interaction of biological, physical, psychological and social mechanisms. Re-evaluating the manifestation of grief in the context of modern digital behaviour is particularly relevant following the COVID-19 pandemic which will have undoubtedly created a "new normal" for digital grief culture given the combination of mass bereavement and increased reliance on digital communication.

Emerging contemporary culture for online public mourning displays clear social constructs, individual and social factors relating to online grief, however, have more complexly woven bio-psycho-social influences. Despite this, digital social patterns hold a key role in either empowering or disabling mourners in the expression, performance and therefore experience of their grief. While grief brings undeniably excruciating biological and physical suffering, overall the evidence reviewed suggests the way human grief is manifested and experienced online through current digital behaviour is socially patterned and channelled. Increasingly SNS are being recognised as a form of thanatechnology, providing support to the bereaved through communal mourning and community sense-making. SNS also present a gateway to accessing other online support forums and interventions which can be delivered on a large, cost-effective scale. Although in its infancy, reviews of online grief interventions show a promising clinical role in an increasingly overburdened system; ongoing work is need to comprehensively evaluate their safety and efficacy, and facilitate the development of novel interventions and policy.

With SNS now firmly embedded in modern life, extensive research is needed to fully evaluate its role in developing a modern response to death. Internet-based research, however, presents methodological challenges relating to sampling bias and availability of sample demographic information, limiting much of the current body of work. Work exploring the impact on digitally excluded groups is also lacking. Particularly in the wake of COVID-19, further research with robust, considered methodologies is essential to explore theory, inform policy and ensure safe, effective interventions can be accessed in the shadow pandemic of grief.

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