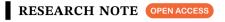
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The Iatrogenic Consequences of Medicalising Grief: Resetting the Research Agenda

¹University of Massachusetts, Counseling and Psychology, BEAHR Lab, Boston, Massachusetts, USA | ²Department of Psychiatry, Faculty of Medicine, University of Belgrade, Beograd, Serbia | ³University of Essex, School of Health and Social Care, Deputy Director of IPHW, Colchester, UK

 $\textbf{Correspondence:} \ Sarah \ Gurley-Green \ (sarah.gurleygreen 001 @ umb.edu; \ sgurleygreen @ gmail.com)$

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ABSTRACT

When the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) was published in 2013, there was a firestorm of controversy about the elimination of the bereavement exclusion. Proponents of this change and of the proposed "complicated grief" designation believed that this change would help clinicians recognise major depression in the context of recent bereavement. Other researchers and clinicians have raised concerns about medicalising grief. In 2022 "prolonged grief disorder" (PGD) was officially included in the DSM-5-TR in the trauma- and stressor-related disorders section. Not surprisingly, there has been a push to identify biomarkers and to use neuroimaging to identify the neurobiological basis of PGD. Some researchers have even suggested that PGD is a 'reward circuit disorder' akin to addiction and that naltrexone, an opioid antagonist, may be a promising treatment. The purpose of this paper is to show how medicalising grief reinforces a research agenda dedicated to the search for pharmaceutical and psychological 'magic bullets.' Following George and Whitehouse (2021), we propose that an ecopsychosocial approach—one that incorporates environmental and contextual factors—is needed.

1 | Introduction

When the Diagnostic and Statistical Manual of Mental Disorders (DSM) III was published in 1980 (American Psychiatric Association 1980), the manual officially adopted a medical model. There was optimism that by adopting a medical model, the diagnostic manual would provide increased reliability (Kawa and Giordano 2012). It was believed that enhanced reliability would lead to improved validity and breakthroughs in neuroscience (leading to the development of disease specific psychotropics). In the period after the DSM-III was published, the pharmaceutical industry, along with organised psychiatry, promoted a biomedical theory regarding the aetiology of mental disorders (e.g., the serotonin dysfunction hypothesis of depression). Indeed, in 1984, psychiatrist Nancy Andreasen, editor of the *American Journal of Psychiatry*, stated that the disorders in the DSM "should be considered medical illnesses just as

diabetes, heart disease and cancer are" (Andreasen 1984). Around this time, leading members of the DSM-III Task Force were working as consultants or in partnership with pharmaceutical companies; some began working with these companies on the development of outcome measures and diagnostic tool alignment with DSM criteria. For example, these collaborations led to the now widely used PHQ-9 measure of depression, developed by Robert Spitzer and Janet Williams (respectively chair and member of the DSM-III Taskforce), funded by and in collaboration with Pfizer (Kroenke, Spitzer, and Williams 2001).

Despite the wide-spread adoption of the medical model in psychiatry over the last 4 decades, the development and publication of the DSM-5 in 2013 (American Psychiatric Association 2013) created a firestorm of controversy. Much of the specific criticism centred around the elimination of the bereavement exclusion and the recommendation to include 'complicated grief' as a disorder.

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Allen Frances, the chair of the DSM-IV, had been highly critical of the medicalisation of grief during the fieldwork stage of the development of the DSM. He did not mince words when he argued that "[M]edicalizing normal grief stigmatises and reduces the normalcy and dignity of the pain, short-circuits the expected existential processing of the loss, reduces reliance on the many well-established cultural rituals for consoling grief, and would subject many people to unnecessary and potentially harmful medication treatment" (Frances, Pies, and Zisook 2010). In contrast, proponents of the proposed "complicated grief" designation argued that if the DSM were to officially include the disorder, clinicians would be more likely to recognise major depression in the context of recent bereavement. They supported this position, in part, by estimating that approximately 7% of individuals who suffer a loss would meet diagnostic criteria for complicated bereavement (Shear 2010). Estimates now range as high as 20% (https://prolongedgrief.columbia.edu/what-it-is/), but no explanation for why there has been an almost three-fold increase in this estimate has been given.

Concerns about medicalising grief notwithstanding, complicated grief—renamed 'prolonged grief disorder' (PGD)—has now been officially codified in the DSM-5-TR (American Psychiatric Association 2022). According to the DSM, PGD may be diagnosed 12 months after the death of a loved one (6 months in children and adolescents) and is characterised by "intense yearning for the deceased person or preoccupation with thoughts of the person" [there is a] "persistent grief response...which has been present most days to a clinically significant degree" (American Psychiatric Association 2022, 323). Since the death, the individual experiences symptoms such as "identity disruption (e.g., feeling as though part of oneself has died), intense emotional pain; intense loneliness; marked sense of disbelief about the death; emotional numbness; feeling that life is meaningless" (American Psychiatric Association 2022, 323). No research evidence is given to support the 1-year cut off, and although the descriptor "intense" is invoked a number of times (e.g., intense loneliness), this designation relies on the clinician's subjective judgement. Further, there is no guidance about what constitutes "clinically significant" or how to differentiate when the processing of loss becomes pathological and should be considered "persistent symptoms" of prolonged grief disorder.

2 | Will Biology Provide Answers?

The hope that the field of neurobiology will provide important information regarding the aetiology of mental disorders, including but not limited to PGD, has been a significant driver of contemporary psychiatric research. Yet, this hope has not been brought to fruition (Venkatasubramanian and Keshavan 2016). In fact, the literature in this area has been plagued by the recognition of numerous false positive findings (Border et al. 2019; Hong et al. 2019) and small methodological and design differences that actually led to large differences in the reported results (Botvinik-Nezer et al. 2020). Further, there are many low-quality studies that have been published asserting that there are various neurobiological substrates for mental health conditions, but the results have not been replicated (Kennis et al. 2020). Research

examining the neurobiological basis of PGD is no exception (Kakarala et al. 2020).

Nonetheless, the most recent biologically based hypothesis is that PGD is a 'reward circuit disorder' akin to addiction. This view was summed up explicitly by researchers advocating for the development of pharmacological agents: "PGD can be conceptualised as a disorder of addiction and therefore could benefit from being treated with medications that are currently used to treat such disorders" (Gang et al. 2021, 1). Neuroimaging studies are cited to support the belief that naltrexone, an opioid antagonist, may be a promising treatment. For example, the authors of a protocol for a randomised clinical trial suggest that "detachment from the deceased is a necessary first step towards being able to connect with living others...we predict that naltrexone will provide a pharmacological way to dampen the benefits of social bonding" (Gang et al. 2021, 3).

Gang et al's conceptual and normative framework runs counter to the extensive research by Klass, Silverman, and Nickman. (2014) that clearly demonstrates that bereaved people have evolving and significant relationships with the people for whom they mourn. Their work clearly shows that there is nothing problematic or psychologically concerning about these continued relationships. In fact, the continued relationships offer solace and a way to reengage with the world. Importantly, the suggestion that treatment for grief should involve 'dampening the benefits of social bonding' with psychotropics contradicts the extensive sociological scholarship which recognises emotions as social and embodied (Cottingham, Olson, and Bendelow 2024).

3 | The Iatrogenic Consequences of Medicalising Grief

Although in Western medical literature much weight has been given to pathological aspects of grief and mourning, concepts of grief as a coping process or growth response can be found in the wider sociological and psychosocial studies literature. In examining the multiple ways that adolescents respond to loss, for example, Balk (2014) presents grief as an adaptive process through which young people at key developmental stages in life learn, grow and mature. This concept of grief as growth has been linked to the concept of post-traumatic growth (Tedeschi et al. 1998) and led to non-pathological grief models such as the "personal growth construct" and the "grief to personal growth theory" (Hogan and Schmidt 2002). This capacity for growth and maturation can be lost through the medicalisation of grief.

Certainly, some individuals who struggle profoundly with grief may need psychological support or may be helped in the short term by taking psychotropic medication. However, pathologising grief qua disorder may have the unintended consequence of minimising the suffering that comes with "normal" grief and preventing personal growth. Most important, medicalising grief as a psychiatric disorder deflects attention away from the ubiquitous character and existential aspects of loss and fuels a research agenda dedicated to the search for pharmaceutical and

psychological 'magic bullets.' This is because the language of the medical model, when imported into the the mental health field, supports biological reductionism and the search for quick fixes with dubious results (Ormel et al. 2022). As Whitehouse astutely notes, "He/she/they that control language also control resources and manipulate the sources of hope" (Thus, the medicalisation of grief may have a number of iatrogenic consequences; conceptualising grief qua psychiatric disorder may take a human and cultural experience and turn it into a condition to be treated). It also, perhaps unintentionally, may serve the purpose of 'treating' rather than accepting/tolerating diverse and strong affective experiences. Additionally, people diagnosed with PGD may come to believe that their grieving is pathological or at the very least not congruent with a 'natural' trajectory of the stages of grief (i.e., they are unable to reach the acceptance stage). Indeed, bio-psychiatric discourse reinforces the hope that neuroscience will provide answers to the aetiology of and treatment for mental disorders. It is therefore not surprising that there has been a push to identify biomarkers and to use neuroimaging to identify the neurobiological basis of PGD.

It is also important to consider how the medicalisation of grief might influence one's sense of self and self-efficacy. As philosopher Ian Hacking notes, psychiatric classification changes people. Systems of classifications such as the *DSM* encourage people to create general truths about themselves and, in so doing, frame their suffering in specific ways. As Hacking's work on the "looping effect" (Hacking 1995; Lindholm and Wickström 2020) demonstrates, attempts to *classify* patterns of behaviour simultaneously *create*—and sometimes foreclose—possibilities for subjectivity. He writes, "I began with the thought that a new classification may not just sort people in a new way, but also bring into being a new kind of person, a new way to be a person" (Hacking 2007, 351). One might ask then, what kind of 'new way' to be a person might be engendered by a diagnosis of prolonged grief disorder?

For example, people diagnosed with 'PGD' might come to experience themselves as not only struggling intensely with loss but also as having a 'disordered' brain. Additionally, when explaining the disorder via the language of neuroscience (e.g., a reward circuit dysfunction), it is likely that this will lead to prognostic pessimism (Lebowitz and Ahn 2015). That is, neurobiological explanations tend to foster the belief (for both clinicians and clients) that mental health conditions are more or less fixed and unlikely to resolve without medication. Further, the next step after assigning a psychiatric diagnosis of PGD, to prescribe a medical treatment (and a prescription is a logical step when you have identified a disorder), has even more farreaching consequences and iatrogenic effects: it changes the person into a patient. Moreover, exposing a person to any medical treatment comes with potential risks of harmful effects. Psychotropic medications pose particular risks given their action on neural mechanisms, the potential harmful effects in both the short and long term and the difficulty some people have tapering or discontinuing them (Hengartner 2020; Read et al. 2023; Cosgrove et al. 2020). It should also be pointed out that psychological treatments also have potential to cause harm although these have tended to be under-researched (McPherson, Wicks, and Tercelli 2020). The suggestion that naltrexone may be helpful in providing "a pharmacological way to dampen the benefits of social bonding" (Gang et al. 2021) runs counter to one of the central tenets of grief therapy, that attempts to repudiate a connection with the deceased are counterproductive. Also, the suggestion that it may be helpful to 'dampen the benefits of social bonding' belies the experience of many people who take antidepressants—emotional dampening may undermine the ability to process important affective experiences (Moncrieff 2018). We describe below how an ecopsychosocial approach refuses the dubious logic of medicalising grief and developing drugs to treat 'it.'

4 | Resetting the Research Agenda: Towards an Ecopsychosocial Approach as a Research Priority

Critics of biomedical psychiatry have argued that medicalisation of normal human emotions (including grief) has a broad and pernicious impact (Rapley, Moncrieff, and Dillon 2011). This argument has gained significant momentum and support in recent years and is allied to critical perspectives on psychiatry more generally which include concerns about the human rights implications of many biomedical treatments for mental distress (Cosgrove and Jureidini 2019). The growing momentum behind this position was reflected in a series of reports by the UN special rapporteur on the right to health 2014-2020 criticising biomedical approaches to psychiatry generally and across the globe (e.g., United Nations Human Rights Council Report A/ HRC/35/21). Organised psychiatry has tended to respond to these forms of critique by alluding to the biopsychosocial model as a solution to all disagreements, claiming that it offers a broad church under which all psychiatrists applying different models and theories can unite (Oute and McPherson 2024). However, calls for this model tend to gloss over the epistemological challenges associated with accepting all points of view on mental distress (Miresco and Kirmayer 2006). In terms of the medicalisation of grief, the biopsychosocial model cannot address the concerns outlined above about the iatrogenic effects of diagnosing and treating grief as though it were an illness.

Moreover, as Whitehouse and colleagues (George and Whitehouse 2021; Whitehouse 2013) note, the biopsychosocial model, despite sounding interdisciplinary and inclusive, is actually inadequate to the task of setting a research agenda for health. This is because the biopsychosocial model is, at its core, a biomedical model and "fundamentally ignores the environment, the eco" (George and Whitehouse 2021). Working in the field of cognitive ageing, they propose that the term ecopsychosocial be used to signal a more systemic and deeper way to think about health. They further note that in contrast to the term 'nonpharmacological' when referring to health interventions, the term ecopsychosocial is reflective of a much broader range of interventions: "Instead of defining research in terms of what it is not-not pharmaceutical-the term ecopsychosocial incorporates the full breadth and complexity of area[s] of inquiry" (Zeisel et al. 2016).

Importantly, an ecopsychosocial framework requires a *trans*-disciplinary way of thinking and thus has the potential to liberate grief from the grip of psychiatry and related disciplines. The dominance of the psychological/psychiatric lens can be

seen by examining what interventions are currently being trialled for grief. Using the search terms 'prolonged grief disorder' and 'complicated bereavement' on clinicaltrials.gov, we found forty-six trials, the vast majority of which are focused on intraindividual treatments. With the exception of the trial for naltrexone, most focused on manualised therapy and web-based interventions and nine were aimed at developing diagnostic tools and screening instruments. Only two trials included psychosocial or familial-based support interventions.

5 | What Forms Might an Ecopsychosocial Approach Take?

Scholars in sociology and death studies research have noted that it is critically important to address the significant methodological issues in this field (Borgstrom and Ellis 2017; Woodthorpe 2009), including but not limited to the "methodological complexities of producing emotionally-sensed knowledge about responses to death" (Evans et al. 2017). They have also long argued for demedicalising and de-individualising grief and recommended a more relational and community-based approach. For example, 25 years ago, Walter (2000, 2017; see also) described how medicine has 'colonised' and 'policed grief'.

In contrast to a colonised and intra-individual approach, we need to heed the words of grief activist and author Francis Weller, "the psyche knows we are not capable of handling grief in isolation" (McKee 2016). This insight is congruent with an ecopsychosocial approach; what is needed is an environment to both self-reflect and connect with a compassionate community. Thus, an ecopsychosocial lens could animate our ethical imaginations and research agendas by encouraging us to incorporate insights from fields as diverse as human rights, urban planning and community studies. For example, and similar to the questions that George and Whitehouse (2021) pose regarding treatment for dementia, researchers might ask: What does it mean to grieve in a neoliberal climate marked by austerity, precarity and disparity? Should supporting someone who is grieving perhaps take place in a social/community space rather than in a predominantly psychological/psychiatric space? These questions are critical because they are rooted in the realisation that we are fundamentally social and communal beings. That is why philosopher Martin Heidegger described 'Dasein' as mitdasein; being-in-the-world is always being-with-others (Martin Heidegger 1962).

The insight that we are inherently social is also why psychiatrist Mindy Fullilove, who has been described as the "shrink who puts whole cities on the couch" (Sullivan 2015), has studied the effects of serial forced displacement in US cities. Her work is grounded in the recognition that main streets and community areas contribute to community social cohesion, a well-documented factor in improving mental health. Yet, cities have become fragmented and isolating which has resulted in a host of psychosocial problems and exacerbates the precarity incurred by growing economic inequality. Dr. Fullilove has worked with the French architect Michel Cantal-Dupart and urban planners to redesign parts of cities and towns so that there are robust main streets and community spaces—ones that can facilitate social

cohesion. A lesson that can be learnt from Fullilove's work is that an ecopsychosocial approach to grief must address—and work towards ameliorating—the 'eco' conditions that undermine the curative effects of community. The impetus for the compassionate communities movement, which developed in response to the increasing professionalisation of palliative care (Breen et al. 2022; Kellehear 1999), also serves as a model for the curative effects of community. This movement emphasises the power and importance of community spaces—a paradigm shift that is essential for the de-medicalisation of grief.

In addition to work like Fullilove's, an ecopsychosocial approach would also include a public health lens. As Aoun et al. (2012) suggest, a public health lens would allow for a more tailored approach to developing interventions, as not all bereaved individuals benefit from support groups and individual therapy. Additionally, public policy work (e.g., developing and advocating for legislation for bereavement leave) is needed. As human rights activists have argued, bereavement support is an inalienable human right, one that is centred on the right to health and wellbeing, for "bereavement health is as intrinsic to our humanity as any other aspect of health and citizenship" (Macaskill 2022). That is why there are increasing calls for investing in bereavement as a public good and for "cultivat[ing] a bereavement-conscious workforce." (Lichtenthal et al. 2024, e273). As Lichtenthal note, it is not only clinicians but also institutions and systems that must "shift bereavement care from an afterthought to a public health priority."

Clearly, an ecopsychosocial approach could take many forms. Regardless of the specific form, the end result would be an "epistemic disruption" (Yamin 2019, 369) of the entrenched belief that our research needs to be limited to intra-individual interventions and the search for magic bullets.

Author Contributions

Sarah Gurley-Green: conceptualisation (lead), writing-original draft (lead), writing-review and editing (lead). Lisa Cosgrove: conceptualisation (equal), investigation (equal), writing-original draft (equal), writing-review and editing (equal). Milutin Kostic: conceptualisation (equal), investigation (equal), writing-original draft (equal), writing-review and editing (equal). Lauren Koa: writing-review and editing (supporting). Susan McPherson: writing-original draft (equal), writing-review and editing (equal).

Data Availability Statement

The data that support the findings of this study are available from the corresponding author, SGG, upon reasonable request.

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