AMA Journal of Ethics®

February 2017, Volume 19, Number 2: 192-198

POLICY FORUM

Seeking Legitimacy for *DSM-5*: The Bereavement Exception as an Example of Failed Process

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Abstract

In 2013 the American Psychiatric Association (APA) published the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*). Even before publication, *DSM-5* received a torrent of criticism, most prominently over removal of the "bereavement exclusion" for the diagnosis of major depression. We argue that while the APA can claim legitimate authority for deciding scientific questions, it does not have legitimacy for resolving what is ultimately a question of ethics and public policy. We show how the "accountability for reasonableness" framework for seeking legitimacy in health policy could have been used to achieve a better resolution of the conflict than actually occurred.

Introduction

In 2013 the American Psychiatric Association (APA) published the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*). The manual sets the global standard for psychiatric diagnosis and shapes how psychiatry is understood and practiced worldwide. But even before publication, *DSM-5* received a torrent of criticism—most prominently over removal of the "bereavement exclusion" for the diagnosis of major depression—from psychiatrists and other mental health clinicians, researchers, and commentators who felt that US health care too frequently medicalized normal conditions.

We believe that the rancorous debate about the bereavement exclusion exemplifies an important issue about achieving legitimacy in health policy. We argue that while the APA can claim legitimate authority for deciding *scientific* questions, it does not have legitimacy for resolving what is ultimately a question of *ethics* and *public policy*. The APA's scientific and clinical expertise is necessary but not sufficient for resolving the debate. To achieve a legitimate outcome and one potentially more acceptable to the clinical community and concerned members of the public, a more inclusive form of public deliberative process is required.

History of the Bereavement Exception in the *DSM*

The bereavement exception only became an issue with the publication of *DSM-III*. *DSM-I* (published in 1952) and *DSM-II* (published in 1968) based diagnoses on the hypothetical etiologies believed in at the time [1]. But when researchers demonstrated that American and British psychiatrists shown videotapes of the same patients made very different diagnoses [2], and that sham-patients who claimed to hear voices saying "empty," "hollow," or "thud" but then acted entirely normal were diagnosed with schizophrenia and hospitalized [3], it became clear that a new approach to diagnosis was needed.

DSM-III (published in 1980) sought to bring reliability to this chaotic situation by basing diagnoses on explicit checklists of symptoms. If a patient displayed a specified number of well-defined symptoms, the diagnosis was made [4]. But for the diagnosis of major depression, *DSM-III* and *DSM-IV* made an exception for patients whose symptoms could warrant the diagnosis if they occurred in the context of bereavement.

> After the loss of a loved one, the symptoms [do not] persist for longer than 2 months or are [not] characterized by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation [5].

The *DSM-5* Task Force chose to eliminate the bereavement exclusion for three main reasons. First, depressive illnesses that follow bereavement are clinically similar to depressive illnesses that occur in nonbereavement contexts [6]. Second, it seemed arbitrary to single out bereavement as the only exception to stress-induced conditions. What about divorce, loss of employment, or diagnosis of a serious illness [7]? Finally, since depressive illness includes the risk of suicide, missing the diagnosis because of the bereavement exclusion could cause serious consequences [8].

The two "sides" in the debate have published more in professional journals and popular media and on social media sites than we can summarize in detail in this brief article. But our reading of *DSM-5* [9] and the major arguments for retaining [10, 11] or eliminating [12, 13] the exclusion suggest that although the distinction between severe "normal" grief and depressive illness can be fuzzy, the two "sides" would actually treat patients in a very similar manner. Patients seen as experiencing normal grief might be treated for symptoms like insomnia but would be given reassurance that their painful state was "normal" and would resolve over time, while patients seen as suffering from depressive illness would be treated with psychotherapy, medication, or a combination thereof.

Where the "sides" differ is in their trust of the medical profession and their view of risk of "medicalizing" normal human phenomena like grief. Kendler pictures a clinically careful response to the bereaved person:

> As with the psychiatric response to the … major stressors to which we humans are all too frequently exposed, good clinical care involves first doing no harm, and second intervening only when both our clinical experience and good scientific evidence suggests that treatment is needed [12].

Frances, chair of the *DSM-IV* Task Force, does not share Kendler's optimistic view of psychiatric practice:

> Medicalizing normal grief … 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 [14].

After weighing the pros and cons, Pies concludes: "Given the serious risks of unrecognized major depression—including suicide—eliminating the bereavement exclusion from *DSM-5* was, *on balance, a reasonable decision*" (emphasis added) [15].

In the remainder of this essay we ask: Who has legitimate authority to do the balancing?

Legitimate Authority in the *DSM-5* Process

The APA tried valiantly to make the *DSM-5* process trustworthy, by such means as a strong conflict of interest policy that sharply limited commercial ties, substantial work group participation by nonmedical experts, international participation, and extensive opportunity for online comments on drafts (well over 10,000 comments from clinicians, researchers, and the public were received and reviewed) [16, 17]. And with regard to the dispute over whether to drop or retain the bereavement exclusion, the work group on mood disorders responded thoughtfully to those who favored keeping it, citing the research evidence that led to its conclusion [18].

But the equally expert group that favored retaining the bereavement exclusion was not persuaded [18]. And in the stalemate, each "side" leveled *ad hominem* attacks against the other.

We believe that the "accountability for reasonableness" framework we developed in *Setting Limits Fairly: Learning to Share Resources for Health* [19] to explain how private health plans and public programs like Medicare and Medicaid can achieve fairness and legitimacy for their limit-setting policies sheds light on the stalemated argument over the bereavement exclusion. The framework specifies that to claim fairness and legitimacy, three substantive conditions must be met: *publicity* (the rationales for policies must be publicly accessible); *relevance* (the rationales must provide a reasonable

justification for the policies), with "reasonable" being defined as considerations fair-minded people (those committed to seeking mutual justification for their views) see as relevant; and *revision and appeal* (dispute resolution mechanisms allowing challenge to policy and, more broadly, opportunity for revision in light of new evidence and arguments).

The *DSM-5* process met the publicity condition by explicating in great detail the rationale for dropping the bereavement exclusion. But it did not respond to its critics with adequately relevant reasons. The two "sides" agreed that bereaved persons who were suffering from depressive illness should be treated for the illness and that bereaved persons whose symptoms mimicked the symptoms of depression but who did not have depressive illness should be regarded as normal grieving persons [7, 11]. The disagreement was about whether the potential harms caused by dropping the exclusion outweighed the potential benefits from dropping it.

In clinical care it is well established that the role of the physician is to present the *facts* about a potential intervention, but the *values* of the patient should ultimately determine whether or not the intervention is undertaken. If physicians disagree with their patients' choices, they should elicit the *reasons* for the choices and, if they wish, try to persuade the patient to a different conclusion.

In similar fashion, the *DSM-5* process needed to engage more fully with the reasons that motivated opponents of the proposed change. We would have recommended convening a deliberation that included stakeholders in addition to the dueling experts—individuals and families with experience of bereavement, grief counselors, clergy, and others. That process would have demonstrated that the dispute was primarily about values, not about the validity of research findings, and values provide reasons within the deliberative process.

The APA placed greatest weight on the risk that the bereavement exclusion would lead to misdiagnosing depressive illness as normal grief. The other "side" would have countered that the risk of misdiagnosing grief as depressive illness was worse and that the pharmaceutical industry would seduce grieving persons and physicians into prescribing unneeded medication. This dispute over how to "weigh" competing values is a disagreement over ethics and policy, not over a matter of scientific fact.

Even if the *DSM-5* leaders held to their view that the bereavement exception should be eliminated, if a deliberative process like the one we would have recommended had occurred, the stakeholders' sense of legitimacy and fairness would probably have been different. The "opponents" would have known that their concerns about medicalizing normal grief and the ensuing prescription of unneeded medication had been heard, understood, and responded to, even if not agreed with. And the APA would have had a

better understanding of the fears that motivated the opponents of elimination. A skillful facilitator would have clarified the degree to which the disagreement was about the different weights the APA and the critics gave to the *risks* entailed by keeping or eliminating the exception, not primarily about the *facts* about bereavement and depression.

Our guess is that if a deliberative process of this kind had been convened, the distance between the contending perspectives would have been reduced, and the "sides" would have ended agreeing to disagree. The APA could then have invoked the revision and appeal condition and said—"we will go ahead with the plan to drop the bereavement exclusion, but let's specify how to evaluate the impact over the next two years. But if it turns out that your concerns were correct, we will reinstate it…"

Although the APA made reasonable arguments for its view of the bereavement exception, it did not engage adequately with the concerns of those who argued for retention. As a result, the opponents—including the *DSM-III* and *DSM-IV* leaders—lost trust in the *DSM-5* decision-making process and saw it as an assertion of power, perhaps motivated by the pharmaceutical industry [11]. This was an avoidable outcome in an area of deep concern. Sadly, by a failure of process, it was not avoided!

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ISSN 2376-6980