

MILKEN INSTITUTE

Supporting Wellness

Initial Findings from a Survey of Lived Experience and Research Priorities of Depression and Bipolar

CARA ALTIMUS



SUPPORTING WELLNESS

Initial Findings from a Survey of Lived Experience and Research Priorities for Depression and Bipolar

OVERVIEW

In 2018, the Milken Institute Center for Strategic Philanthropy (CSP) and the Depression and Bipolar Support Alliance (DBSA) collaborated to develop a first of its kind community survey. The goal was to learn about the experiences of people living with depression and/or bipolar and ultimately to use this insight to guide research prioritization and drug development efforts. The national survey garnered 6,405 responses from people living with depression and bipolar or providing care to someone with one of these conditions.

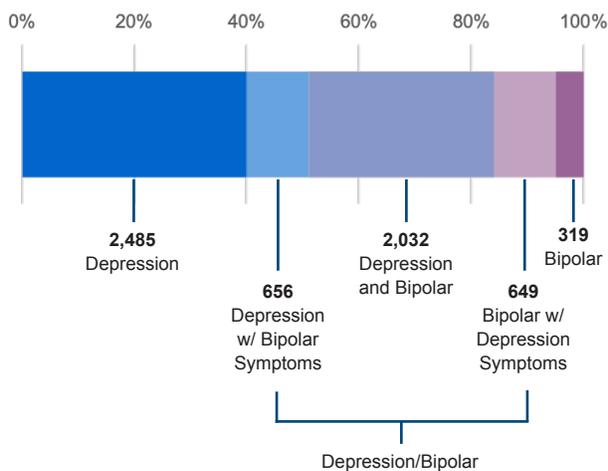
Respondents reported how they experience depression and/or bipolar, when their symptoms began, and how those symptoms impact their ability to function in daily life. In addition, they provided key insights into the research they believe would significantly affect their lives. Overall, the survey informed understanding of how the community experiences these conditions, as well as highlighted significant treatment gaps and research priorities.



UNDERSTANDING SYMPTOMS AND THEIR ONSET

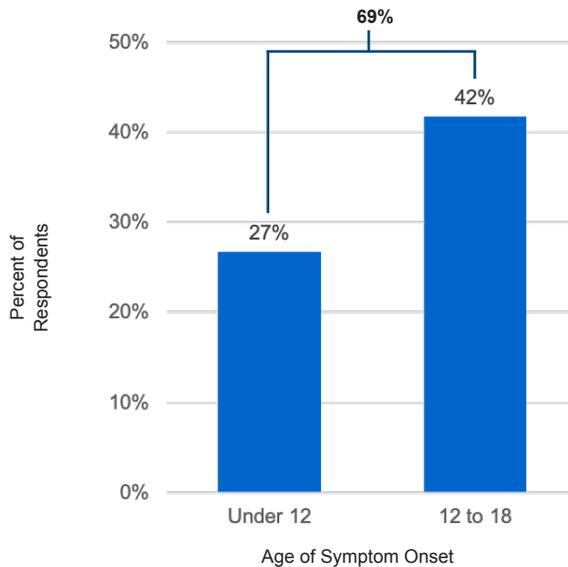
A majority (54 percent) of respondents reported that they experience symptoms of both depression and bipolar. Although research communities characterize mood disorders as falling across a spectrum of conditions, **clinicians often offer discrete diagnoses for their patients. However, these diagnoses may not align with a person's experience or specific treatment needs.**

SELF-DESCRIBED EXPERIENCE



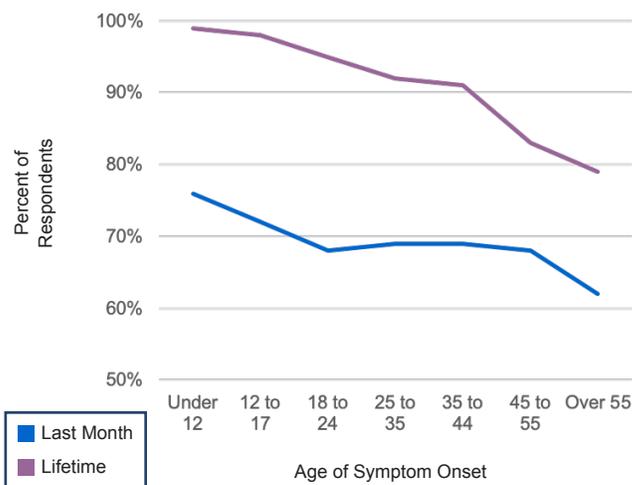
The survey asked participants to identify when their symptoms first started. They could choose categorical answers, for example, “before age 12 (prepubescence),” “between ages 12 and 17 (adolescence),” or ascending categories within adulthood. For **69 percent of respondents, symptoms began in childhood and greater than 25 percent experienced symptoms before age 12. Furthermore, respondents who reported childhood onset have experienced greater impact from their symptoms over their lifetime and within the past month than respondents who reported adult onset.** Many organizations that track the onset of depression and bipolar, as well as those that provide information to the public, report symptom onset as most common in early adulthood.

AGE OF SYMPTOM ONSET



However, our results support an emerging view that childhood onset may be more common for mood disorders and more detrimental to the lifelong outcomes of the individual. **Both the high rate of childhood onset and the significant lifetime impact of symptoms highlight the importance of focusing on childhood mental health in both treatment and research,** as well as providing enhanced education and awareness to professionals who interact with children such as pediatricians, teachers, and social workers.

AGE OF SYMPTOM ONSET INFLUENCES PERCEIVED IMPACT





COMMUNITY-IDENTIFIED RESEARCH PRIORITIES

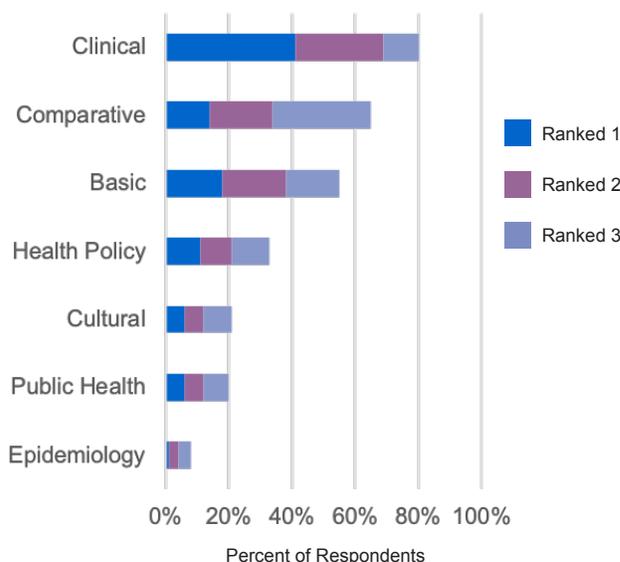
Participants identified the research that would be most important to them via both a rank choice and an open-ended response. Overall, the community saw high value in clinical research to identify the best individual treatment approaches for people living with mood disorders, in addition to basic science to understand the underlying physiology and causes of the conditions.

Open-ended responses revealed several top priorities focused on clinical care:

- Develop new treatments
- Pursue acute treatment for severe episodes
- Minimize side effects caused by the currently available therapeutics
- Bolster the ability to diagnose specific conditions objectively
- Follow precision health approaches to match effective treatments to individual patients

89% of respondents agreed that there should be better ways to treat and provide care

TOP RESEARCH PRIORITIES



"Why aren't there more options in treating depression? Trial and error of creating the right cocktail of drugs should not be commonplace."

Regarding basic science, respondents expressed a strong desire for **increased understanding of the causative factors of depression and/or bipolar** with emphasis on genetics and neural physiology. Additionally, many respondents also expressed a desire for a definitive measure that shows the differences in their genetic make-up or brain that lead to depression and/or bipolar.

"How does my brain function differently than normal people's brains? What chemicals/regions/reactions are part of that? How do these impact the way I process information, feel, and behave?"

The identified research priorities span the continuum from basic science through diagnostic tools and therapeutic development and highlight significant gaps in our current understanding of mood disorders and clinical practice.

"Wellness means stability; well enough to hold a job, well enough to enjoy activities, well enough to feel joy and hope."



WHERE FOCUS IS NEEDED IN DEPRESSION AND BIPOLAR RESEARCH

The survey asked participants to think about their definition of wellness and the resources or differences in health care delivery that could improve their health outcomes. By examining these definitions, we can identify the unmet needs of people living with depression and bipolar and gain insight into how treatment can be enhanced to improve their quality of life. To understand wellness priorities, we asked participants to rank pre-identified priorities from previously published work, as well as to describe wellness in their own words. Of the pre-identified priorities, the top three were:

- Ability to be independent or act according to one's own will
- Purpose in life
- Get through the day

The open-ended responses provided additional insight and specific examples for these priorities.

Nearly one-half of all open-ended responses cited "ability to function" as a wellness priority, with specific examples including employment, social engagement, and maintenance of personal responsibilities.

"[I wish that] the feeling of doom would go away, and I can have happy days."

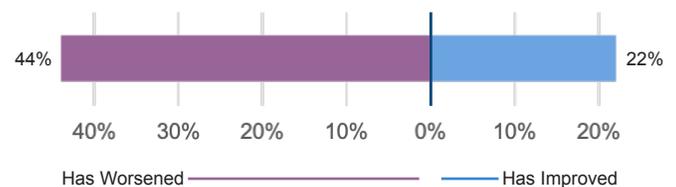


Similarly, greater than 40 percent of all open-ended responses cited general mood attributes, such as feeling happy or not overwhelmed, as a major contributor to wellness. These responses emphasize that nearly one-half of respondents consider overall mood to be a measure of wellness.

Conversely, less than 20 percent of responses cited the absence of acute depression or bipolar symptoms as a measure of wellness. We speculate that the distinction between wellness definitions including overall mood rather than acute symptoms may reflect persistent differences in everyday living, which are not sufficiently alleviated with current treatment plans. We can conclude that respondents value these potential improvements more than a reduction of their symptoms.

Further evidence of this gap can be seen in the answers about overall health, how symptoms of depression and bipolar are experienced, and how the symptoms have impacted respondents' lives. Twice as many respondents reported that their overall health worsened, rather than improved, after symptoms began.

OVERALL HEALTH



In addition, while mood disorders are described as cyclical in nature, with periodic episodes of altered mood, 41 percent of respondents described symptoms as persistent, suggesting that depression and/or bipolar constantly impacts their lives.

41% of respondents define symptom frequency as "persistent"

Varied responses about the impact of depression and/or bipolar on participants' ability to work or attend school, diet, sleep, exercise self-care, and maintain relationships and interests indicate a broad impact across multiple facets of people's lives.



Almost all respondents (97 percent) agreed that their mood disorder has had a lifelong impact; however, the impact on an acute scale is particularly profound, with 72 percent of respondents indicating that their mood disorder significantly affected their lives in the past month.

Overall, input about wellness priorities, general health, how people experience symptoms, and the impact of those symptoms in the short and long terms reveal a constellation of unmet needs. People living with depression and/or bipolar report experiencing more persistent symptoms than explained by our understanding of the conditions. Although the survey does not provide specific data on these persistent symptoms, we speculate that these symptoms are related to the high rate of open-ended responses that discuss “ability to function,” suggesting that these wellness measures drive the individual’s perception of health and may not be sufficiently mitigated by current treatment approaches.

66% of respondents indicated that their health-care team is strongly focused on symptoms, while 91 percent indicated that their goal is to function as well as possible

These symptoms may inhibit people from functioning optimally in life in the ways that are most meaningful to them, such as excelling in work or school, maintaining relationships, and achieving personal goals. Many participants described a decline in overall health coinciding with symptom onset. **The gap between what participants define as wellness and their current state represents the potential of research, treatments, and ultimately the ability to identify the most appropriate treatment for the individual.**

CONCLUSION AND NEXT STEPS

Through this public survey about depression and bipolar, we gained direct insight from the community of people with lived experience. The finding that a majority of respondents experience both depression and bipolar symptoms challenges clinicians’ traditional practice of diagnosing one or the other, and potentially leaving key aspects of the individual’s experience unaddressed. Furthermore, although organizations such as the World Health Organization have quantified depression and bipolar prevalence by age, recent reports exclude prepubescent children (those under 12) and emphasize increased prevalence in adulthood. These studies **may be neglecting a critical period of mood disorder onset**, because participant responses indicated that earlier onset corresponds to greater immediate and lifelong impact.

Research priorities were clearly focused on improving treatments, developing precision medicine approaches, and increasing understanding of the underlying physiological differences. Finally, respondents overwhelmingly expressed a desire for an improved ability to function in daily life as a measure of wellness. Overall, this survey reveals the need not only for research to create better paradigms for treatment, but also for efforts to improve current treatment methods, such as better collaboration among practitioners to improve patients’ overall health.

43% of respondents were not satisfied with their care

Beyond identifying immediate research priorities for the field, this work also highlights the value of input from people with lived experience, which is often missed in traditional methods of study. The Milken Institute and the Depression and Bipolar Support Alliance will continue to use these insights as they work to guide research, programs, and funding within the mental health community.



ACKNOWLEDGMENTS

LEAD AUTHOR

Cara Altimus

Director
Milken Institute Center for Strategic Philanthropy

We would like to thank the [Depression and Bipolar Support Alliance](#) for their partnership throughout the survey development.

Additionally, we would like to thank the following individuals who have contributed to survey development, interpretation, and analysis throughout the project.

EXPERT ADVISORY COMMITTEE

Olga Acosta Price

Associate Professor
George Washington University

Kimberly Allen

Director of Operations
Omega Recovery Services

Nathaniel Counts

Senior Policy Director
Mental Health America

Allen Doederlein

Former Executive Vice President of External Affairs
Depression and Bipolar Support Alliance

Luke Kramer

Executive Director
STARR Coalition

Andy Nierenberg

Director
Dauten Family Center for Bipolar Treatment
Innovation

Sasha Ottey

Founder and Executive Director
PCOS Challenge

SURVEY DEVELOPMENT AND INTERPRETATION

LaTese Briggs

Senior Director
Milken Institute Center for Strategic Philanthropy

Phyllis Foxworth

Advocacy Vice President
Depression and Bipolar Support Alliance

Kim McCleary

Founder and CEO
Kith Collective

Ebony Motley

Associate
Milken Institute Center for Strategic Philanthropy

SURVEY DATA ANALYSIS

Nathalie Gerassimov

Graduate Student
Johns Hopkins University

Kirstie Keller

Senior Associate
Milken Institute Center for Strategic Philanthropy

James Randall

Associate
Milken Institute Center for Strategic Philanthropy

Erin Ross

Consultant
Milken Institute Center for Strategic Philanthropy

COMMITTEE OF INDIVIDUALS WITH LIVED EXPERIENCE

We would like to extend a special thanks to [23andMe](#) and the [23andMe](#) research participants.

