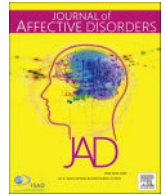


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## “Supporting Wellness”: A depression and bipolar support alliance mixed-methods investigation of lived experience perspectives and priorities for mood disorder treatment

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## ABSTRACT

**Background:** The lived experience of people with mood disorders may be leveraged to inform priorities for research, define key treatment outcomes, and support decision-making in clinical care. The aim of this mixed-methods project was to provide insight into how people with depression and bipolar disorder experience the impact of symptoms, their treatment preferences, and their definitions of wellness.

**Methods:** The project was implemented in two phases. In Phase 1, community-based participatory research was used to develop a web-based survey enquiring about living with a mood disorder, treatment experiences, and wellness priorities. In Phase 2, a series of focus groups were conducted to explore aspects of wellness in greater detail.

**Results:** Respondents ( $n=6153$ ) described the symptoms of mood disorders as having a significant, chronic impact on their lives. A holistic approach to treatment was desired by participants, but not necessarily experienced. Qualitative findings were used to further describe four highly ranked wellness priorities identified in the survey: ability to act independently or according to my own will; purpose in life; getting through the day; and contentment.

**Limitations:** Experience of a mood disorder was self-reported, and no formal confirmation of diagnosis occurred. Although the survey could not incorporate all possible wellness definitions, this was supplemented by qualitative focus groups.

**Conclusion:** The present findings provide important insights from the perspectives of individuals with lived experience of mood disorders. Implications of this for research and clinical practice are discussed, particularly with regards to measurement-based care and use of wellness-oriented clinical outcome assessments.

## Abbreviations

BD Bipolar disorder  
CBPR Community-based participatory research

DBSA Depression and Bipolar Support Alliance  
MDD Major depressive disorder  
PROM Patient-reported outcome measure  
COA Clinical outcome assessment

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QoL      Quality of life  
 FDA      Food and Drug Administration

## Introduction

Worldwide, mood disorders are one of the most prevalent and burdensome mental health conditions. Major depressive disorder (MDD) has an estimated 12-month prevalence of 3% (Ferrari et al., 2013b), and bipolar disorder (BD) has an estimated 12-month prevalence of 1.2% (Clemente et al., 2015). Optimizing treatment for mood disorders is a public health priority: MDD and BD are ranked by the World Health Organization as the first and fifth leading causes of disease burden among mental disorders (Ferrari et al., 2013a). However, the subjective burden of mood disorders is not always encompassed by narrowly defined diagnostic symptom criteria. Incorporating the patient perspective is key to identifying relevant treatment outcomes and informing best practices for clinical care.

People with lived experience of mood disorders hold unique views regarding the impacts of these conditions and their treatment goals, which may not align with clinician or researcher perceptions. For example, one survey found that patients with MDD reported a higher impact of mood, physical, and cognitive symptoms on psychosocial functioning in the post-acute and remission phases than healthcare providers (Baune and Christensen, 2019). In BD, more patients than clinicians rated depressive episodes as the most burdensome mood state, relative to mixed or manic episodes (Maczka et al., 2010). Similar discrepancies exist in evaluations of treatment impacts: almost half of patients with MDD meeting criteria for symptomatic remission did not consider themselves to be in remission (Zimmerman et al., 2012). These individuals had worse quality of life (QoL) and functional impairment than self-perceived remitters, a finding echoed in other clinical remission samples (Demyttenaere et al., 2008; IsHak et al., 2015; Morton et al., 2020; Zimmerman et al., 2006b).

Treatment decisions founded on symptom status alone may therefore not sufficiently address outcomes valued by people with lived experience. To redress this, patient-centered frameworks have been increasingly formalized in clinical practice, research, and service evaluation. Patient-centered research is principled on the meaningful involvement of people with lived experience across the research process (i.e., from identification of research questions, through shaping the design and conduct of research, to the dissemination of findings), while patient-centered care positions the individual's needs and desired outcomes as fundamental in treatment planning. Embedded within these frameworks is use of patient-reported outcome measures (PROMs) to represent the lived experience perspective of positive and negative impacts of treatment (Food and Drug Administration 2009; Snyder et al., 2012). The mood disorders literature has similarly recognised this zeitgeist, with calls to broaden consideration of optimal treatment outcomes to include patient-valued constructs such as satisfaction with care, QoL, and psychosocial functioning (Harvey, 2006; Keller, 2003; McIntyre et al., 2020). Some attempts have been made to use patient input to develop instruments that capture the impacts of mood disorders more broadly, such as the Quality of Life in Bipolar Disorder scale, a BD-specific instrument developed through qualitative research and community involvement (Michalak and Murray, 2010), and the Remission from Depression Questionnaire which included patient focus group input on items and patient surveys regarding the scale's content validity (Zimmerman et al., 2011; Zimmerman et al., 2014; Zimmerman et al., 2013). However, by and large the patient perspective has only been incorporated to a limited extent in the development of and selection of outcome measures (Wiering et al., 2017).

Greater involvement of patients in defining treatment outcomes has been called for, with leading journals questioning whether change in (often clinician-rated) symptom measures “actually represent a meaningful improvement in the life of someone living with depression?” (The Lancet Psychiatry 2020). This has also been emphasized by regulators

(21st Century Cures Act 2015): the FDA was mandated to incorporate a summary of how the patient experience was factored into a product's review, and develop guidance to support patient engagement in the medical product development and regulatory decision-making process (including the selection of clinical outcome assessments; COAs). The Depression and Bipolar Support Alliance (DBSA), the leading United States-based peer-directed organization for people living with mood disorders, observed incongruities between what patients were seeking from treatment and what they reported receiving, recognizing that related patient-focused outcomes were generally not measured in clinical trials of investigational new depression treatments, DBSA sought FDA advice on engaging the patient community, clinical experts, and other stakeholders in identifying outcomes and related measures that provide evidence of the benefits of depression treatments based on what patients value. Based on FDA input and their good research practice guidelines on COAs, DBSA implemented the ‘Supporting Wellness’ project as an initial step towards the goal of identifying a valid, wellness-focused COA to support the incorporation of peer-preferred treatment outcomes in the medical product development process. Here, we report quantitative and qualitative findings from two phases of this initiative, describing how individuals with MDD or BD perceive the impact of these conditions, their experiences of treatment, and their definition of wellness.

## Method

### Design

The “Supporting Wellness” project was initiated and led by DBSA, a peer-directed organization aiming to improve the lives of people who have mood disorders through advocacy, education, support, and research. DBSA facilitates over 600 online and local peer-led support groups, and has over 120 independent affiliated chapters. DBSA uses the term “peer” to describe people with lived experience of mood disorders; this term is preferred over “patient” as it is not specific to interactions with the medical system.

The project was implemented over a two-year period using an explanatory sequential mixed-methods design (Ivankova et al., 2006). In the first phase, a web-based survey was used to solicit lived experience perspectives regarding mood disorders treatment and research. In the second phase, DBSA conducted qualitative focus groups to deepen understanding of survey findings. As the following results are based on a secondary data analysis of information collected to improve practice and inform policy, it was deemed non-human subjects research by the Human Subjects Office Institutional Review Board of The University of Iowa (Project 202101518).

### Community-based participatory research framework

The project was conducted within a community-based participatory research (CBPR) framework. CBPR is based on the philosophy that research attempting to describe challenges experienced by people with mental illness and interventions meant to remedy them needs to be conducted by teams that include partners with lived experience (Israel et al., 2012). Along with researchers and providers, people with lived experience on the CBPR team have full responsibility in developing understanding of mental health conditions, as well as creating and evaluating interventions (Petelka et al., 2020). Each phase of data collection from surveys to focus groups utilised peer input (described below).

### Phase 1: Supporting wellness survey

DBSA partnered with the Milken Institute Center for Strategic Philanthropy to develop and conduct a web-based survey. Survey items were iteratively developed through consultation with an expert advisory

board consisting of researchers and clinicians ( $n=8$ ), as well as a peer council consisting of individuals with lived experience of mood disorders ( $n=10$ ). Members of the expert advisory group were asked to identify needs within the field from a scientific perspective. Peers were consulted to ensure the survey reflected lived experience perspectives. Meetings with the groups were alternated so that input from one group could be integrated prior to sharing the updated instrument with the other. This arrangement led to some key differences in the material that was included and excluded in the survey when compared to instruments developed by clinicians and/or researchers. Most notably, the peer council strongly recommended excluding language around diagnosis, comorbidities, suicidality, and number of mood episodes, as these topics were identified as potentially highly distressing. Following this process, the survey was piloted ( $n=50$ ) to obtain feedback about flow, readability, and length.

The final survey consisted of multiple choice, ranking, and open-ended responses. Respondents were asked to provide demographic details, describe their experiences with mood disorders, their current and preferred treatment, their definitions of wellness, and their priorities for mood disorders research (Supplementary Appendix A). Data collection occurred between August 1, 2018 through November 30, 2018.

Recruitment for the survey occurred via a number of avenues. The survey was advertised through the DBSA network (including the DBSA homepage, social media, newsletters, local DBSA peer support chapters, and affiliated regional advocacy organisations), on the Milken Institute and various partner organisations websites, and in a press release. Survey invitations were sent to users of the direct-to-consumer genetic testing company 23andMe who identified as experiencing depression and/or BD ( $n=23,374$ ) enrolled in a study investigating genes associated with mood disorders (Hyde et al., 2016). Printed advertisements were distributed in clinics and university campuses by researchers and clinicians affiliated with the study.

The survey was open to people with a self-identified mood disorder and caregivers/family members living in the United States. In the present analysis, only individuals who self-identified as having experienced BD (or a period of mania) and/or depression were included. Key findings are summarized using descriptive statistics. Respondents were not required to answer all items; percentages are provided relative to the number of non-missing responses.

#### Phase 2: Supporting wellness focus group

In November 2018, survey findings were presented to clinical, regulatory, industry, lived experience and caregiver stakeholders during an externally-led Patient Focused Drug Development meeting – a parallel program to the FDA's Patient Focused Drug Development Public meetings. Based on this input, a series of follow-up focus groups were planned to deepen understanding of survey findings. To address stakeholder concerns regarding the representativeness of survey respondents, focus groups participants were purposefully selected to foster diversity in education levels, professional work experience, gender, and ethnicity.

Four focus groups were conducted between August and September 2019. Eligible participants self-identified as having depression or BD, and had experienced at least a mild impact of their mood disorder over their lifetime and in the past 30 days. Recruitment emphasized populations that had been underrepresented in the Supporting Wellness survey: one group consisted of Hispanic men (Pasadena, CA), one of Asian women (Pasadena, CA), one of urban residents (Chicago, IL), and one of rural residents (Greensboro, NC). Purposive sampling was used, with potential participants identified via a combination of DBSA networks (Chicago), recruitment firms (Greensboro), and patient registries (Pasadena).

A semi-structured interview guide was developed building on themes identified in the 'Supporting Wellness' survey. Interview guides were reviewed by a group of peers recruited by DBSA, who provided feedback to ensure that questions were easy to understand, used peer-preferred

language, and addressed the above-stated goals. The peer council met once after reviewing the initial interview guide, and again after their input was incorporated to ensure the peer perspective was accurately captured. Interview topics included the experience and impact of living with a mood disorder, goals for treatment, and wellness definitions. All focus groups were conducted by coauthor PD, a trained qualitative researcher, and lasted two hours. Participants received oral information about the purpose of the focus groups, and written consent was obtained.

Focus groups were digitally recorded and transcripts analyzed inductively using qualitative content analysis (Patton, 2002). Transcripts were read to obtain overall impressions and develop preliminary codes. Each transcript was then coded, with primary codes grouped into sub-codes upon review both within and across focus groups. The analyses were conducted by the primary moderator, with codes and preliminary findings discussed with the DBSA team.

## Results

### Phase 1: Supporting wellness survey

A total of 6153 respondents indicated they were currently living with, or had in the past, depression ( $n=5034$ ) or BD ( $n=2937$ ); 32.3% ( $n=1988$ ) reported currently or previously living with *both* depression and BD. Sample characteristics are presented in Table 1. The modal age range was 25–34 years (28.3%;  $n=1735$ ). Respondents were predominantly female (80.1%;  $n=4916$ ), married or cohabitating with a significant other (55.3%,  $n=3393$ ), heterosexual (72.7%,  $n=4462$ ), and of White ethnicity (84.8%,  $n=5206$ ).

Respondents described a significant burden associated with living with a mood disorder. The modal self-reported age of symptom onset was 12–17 years (41.6%,  $n=2558$ ). When asked to quantify the frequency of mood episodes, the most endorsed response indicated participants experienced their symptoms as persistent throughout their life (37.6%,  $n=2230$ ). As summarised in Table 2, respondents described the impact of depression and/or bipolar symptoms on their ability to function and maintain good health as significant over their lifetime (72.7%,  $n=4316$ ). Almost half of participants described their overall health as generally worse since they first began experiencing symptoms (43.7%,  $n=2591$ ). However, more promisingly, respondents described their ability to manage their health (46.4%,  $n=2740$ ) and access to appropriate care and treatment (40.5%,  $n=2392$ ) as generally better since symptom onset.

Respondents were asked to describe their experiences and opinions of mental health treatment (Table 3). For ease of analysis, the bottom two ("Strongly disagree" and "Disagree") and top two ("Strongly agree" and "Agree") ratings were combined to indicate 'Disagree' and 'Agree', respectively. Percentage calculations do not include the proportion of respondents who indicated that they did not have a healthcare team. While participants were generally satisfied with the care and treatment options available to them (54.7%,  $n=2623$ ), the vast majority expressed a desire for better ways to treat and provide care for people with mood disorders (92%,  $n=4582$ ). Notably, a distinction emerged between patient preferences for treatment and their experiences of care. For example, while the majority of respondents agreed with the statements "I think of my health in terms of how well I function at work, at play, and in connection with others" (86.2%;  $n=4279$ ) and "My goal in seeking healthcare is to function as well as possible" (93.5%;  $n=4604$ ), many experienced their mental health treatment as less holistic. A substantive proportion of respondents (75.9%,  $n=3360$ ) described their healthcare team as focused on minimizing symptoms, and approximately one third (38.9%,  $n=1717$ ) felt that their healthcare team focused on one issue at a time, rather than taking a whole-health approach.

Respondents were asked to assign priority (high, medium or low) to various aspects of wellness (Table 4). The characteristics most commonly endorsed as having high priority were "the ability to be

**Table 1**  
Sample demographics.

Demographics	N (%)
Gender	Total responses: 6138
Male	1044 (17%)
Female	4916 (80.1%)
Non-binary	131 (2.1%)
Age	Total responses: 6137
18–24 years	708 (9.9%)
25–34 years	1735 (28.3%)
35–44 years	1567 (25.5%)
45–54 years	1131 (18.4%)
55–64 years	737 (12%)
≥65 years	359 (5.8%)
Relationship status	Total responses: 6132
Single	1794 (29.3%)
Married/Cohabiting with a significant other/Domestic partnership	3393 (55.3%)
Divorced/Separated	739 (12.1)
Widowed	105 (1.7%)
Sexual orientation	Total responses: 6136
Straight/Heterosexual	4462 (72.7%)
Gay/Lesbian	350 (5.7%)
Bisexual	977 (15.9%)
Race/ethnicity	Total responses: 6138
White/Caucasian	5206 (84.8%)
Asian/Pacific Islander	131 (2.1%)
Black/African American	196 (3.2%)
Hispanic	262 (4.3%)
Native American or Alaskan Native	43 (0.7%)
Self-reported diagnosis	Total responses: 6153
Depression	5034 (81.8%)
Bipolar disorder	2937 (47.7%)
Depressive symptoms	5330 (86.6%)
Manic symptoms	3055 (49.6%)
Age of symptom onset	Total responses: 6145
<12	1641 (26.7%)
12–17 years	2558 (41.6%)
18–24 years	1109 (18%)
25–34 years	481 (7.8%)
≥35 years	332 (5.5%)
Number of mood episodes	Total responses: 5933
One	33 (0.6%)
2–10	1425 (24%)
>10	1776 (29.9%)
Symptoms are persistent and constantly impact my life	2230 (37.6%)
Cannot recall or estimate	470 (7.9%)

independent or act according to my own will” (86.1%, *n* = 4401), “get through the day” (80.8%, *n* = 4116), “a sense of influence over the events in my life” (74.8%, *n* = 3821), “purpose in life” (74.4%, *n* = 3795), and “self-acceptance” (72.9%, *n* = 3718). The item most commonly assigned a low priority was “cheerful mood” (13.8%, *n* = 706).

*Phase 2: Supporting wellness focus group*

Across the four focus groups, a total of 31 individuals were interviewed; 52% of participants were women, and ranged in age from 21 to over 65. Participants identified as White (26%), Black (23%), Asian (16%), and Hispanic (19%). The demographic composition of each focus group is summarised in Table 5.

Several key aspects of wellness were identified through focus group discussions. Participants were clear that wellness encompasses and is shaped by both physical and mental health, and desired treatments that address both aspects. While symptom reduction was seen as contributing to wellness, participants noted that one could experience symptoms and still be “well.” As one participant explained, “If I am feeling better and

**Table 2**  
Burden of living with a mood disorder.

Perceived impact of depression/bipolar symptoms on work, school, diet, sleep, self-care, relationships and interests	No impact			
	Minimal impact	Some impact	Significant impact	
Over your lifetime ( <i>n</i> = 5935)	18 (0.3%)	183 (3.1%)	1418 (23.9%)	4316 (72.7%)
Over the past year ( <i>n</i> = 5900)	131 (2.2%)	727 (12.3%)	2184 (37%)	2858 (48.4%)
Over the past month ( <i>n</i> = 5890)	371 (6.3%)	1288 (21.9%)	2103 (35.7%)	2128 (36.1%)
Today ( <i>n</i> = 5800)	1132 (19.5%)	1622 (28%)	1669 (28.8%)	1377 (23.7)
Change in health since onset of symptoms	Generally better	About the same	Generally worse	Don’t know
Overall health ( <i>n</i> = 5935)	1328 (22.4%)	1770 (29.8%)	2591 (43.7%)	246 (4.1%)
Stability of your health ( <i>n</i> = 5920)	1246 (21%)	2199 (37.1%)	2249 (38%)	226 (3.8%)
Access to care and treatment that meets your needs ( <i>n</i> = 5906)	2392 (40.5%)	2133 (36.1%)	115 (1.9%)	230 (3.9%)
Your ability to manage your health with appropriate information and sense of empowerment ( <i>n</i> = 5910)	2740 (46.4%)	1857 (31.4%)	1032 (17.5%)	281 (4.8%)

**Table 3**  
Experiences of mental health treatment.

Statement (Valid responses)*	Disagree	Neutral	Agree
I think of my health in terms of how well I function at work, at play, and in connection with others ( <i>n</i> = 4965)	238 (4.8%)	448 (9%)	4279 (86.2%)
I have a wellness plan or goals ( <i>n</i> = 4856)	916 (18.9%)	1119 (23%)	2821 (58.1%)
My goal in seeking health care is to function as well as possible ( <i>n</i> = 4926)	76 (1.5%)	210 (4.3%)	4640 (94.2%)
My health care support team works with me to maximize my health and wellness ( <i>n</i> = 4430)	460 (10.4%)	814 (18.4%)	3156 (71.2%)
My health care support team is focused on minimizing symptoms in connection with my diagnosis ( <i>n</i> = 4424)	336 (7.6%)	728 (16.5%)	3360 (75.9%)
My health care support team focuses on one issue at a time rather than my whole health ( <i>n</i> = 4418)	1574 (35.6%)	1127 (22.5%)	1717 (38.9%)
My health care support team is focused on achieving certain test results or scores (like ideal weight or normal thyroid level) with regard to my health ( <i>n</i> = 4381)	1634 (37.3%)	1086 (24.8%)	1661 (37.9%)
When discussing treatment options with members of my health care support team, I feel that I can generally gain adequate information about how well those options meet my personal health goals ( <i>n</i> = 4435)	650 (14.7%)	944 (21.3%)	2841 (64.1%)
I follow recommendations made by my health care support team ( <i>n</i> = 4465)	150 (3.6%)	678 (15.2%)	3637 (81.5%)
I take medications prescribed for me as directed ( <i>n</i> = 4693)	224 (4.8%)	250 (5.3%)	4219 (89.9%)
I am generally satisfied with the care and treatment options available to me ( <i>n</i> = 4798)	1266 (26.4)	909 (18.9%)	2623 (54.7%)
I believe there should be better ways to treat and provide care for people with depression and/or bipolar ( <i>n</i> = 4982)	84 (1.6%)	316 (6.3%)	4582 (91.9%)

\* For ease of interpretation, response counts do not include the proportion of respondents who indicated that they did not have a healthcare team.



**Table 4**  
Wellness priorities.

Wellness aspect	High priority	Medium priority	Low priority
Ability to be independent or act according to my own will (n = 5109)	4401 (86.1%)	633 (12.4%)	76 (1.5%)
Get through the day (n = 5095)	4116 (80.8%)	840 (16.5%)	140 (2.7%)
A sense of influence over the events in my life (n = 5105)	3821 (74.8%)	1156 (22.6%)	129 (2.5%)
Purpose in life (n = 5102)	3795 (74.4%)	1052 (20.6%)	256 (5%)
Self-acceptance (n = 5101)	3718 (72.9%)	1095 (21.5%)	289 (5.7%)
Positive relations with others (n = 5103)	3621 (71%)	1300 (25.5%)	183 (3.6%)
Wake up feeling rested (n = 5099)	3587 (70.3%)	1230 (24.1%)	283 (5.6%)
Personal growth (n = 5095)	3467 (68%)	1405 (27.6%)	224 (4.4%)
Act with thought and purpose (n = 5084)	3435 (67.6%)	1405 (27.6%)	245 (4.8%)
Maintain focus (n = 5099)	3431 (67.3%)	1438 (28.2%)	231 (4.5%)
Recover quickly from difficulties (n = 5094)	3288 (64.5%)	1562 (30.7%)	245 (4.8%)
Follow through on ideas and intentions (n = 5096)	3232 (63.4%)	1594 (31.3%)	271 (5.3%)
Calm and relaxed presence (n = 5099)	3225 (63.2%)	1585 (31.1%)	290 (5.7%)
Interest in activities (n = 5099)	3213 (63%)	1600 (31.4%)	287 (5.6%)
Interest in other people (n = 5096)	2329 (45.7%)	2144 (42.1%)	624 (12.2%)
Cheerful mood (n = 5099)	1975 (38.7%)	2419 (47.4%)	706 (13.8%)

experiencing wellness, then I can get over my symptoms.” Wellness could therefore be supported by the ability to develop and implement coping strategies. Participants were asked to elaborate on specific aspects of wellness identified as important in the Supporting Wellness survey: (1) ability to act independently or according to my own will; (2) purpose in life; (3) getting through the day; and (4) contentment. Focus group responses (both positive and negative) to these aspects of wellness are summarised in Table 6.

Participants described the “ability to act independently or according to my own will” as indicating that they were able to be present and in control of their emotions and decisions. This was contrasted to the feeling of being “controlled” by symptoms, with one participant describing their mood disorder as “a monster that takes over.” Participants also noted that acting independently indicated freedom from dependence on “people, places, or substances” and a break from co-dependent relationships. A small number of participants perceived the idea of “independence” differently. These tended to be individuals who had the experience of isolating themselves from positive social connections in the past. For these participants, independence signified potentially dangerous withdrawal from others. As one participant described, “my connections with others...are tethers to keep me on the dock, make sure my boat isn’t drifting. The independence is nice...but having this interdependence and this connectedness is essential.”

“Purpose in life” was defined in terms of playing a specific function or role, both in relation to someone else (e.g., being a spouse or parent), and also in terms of general connections to other people. Participants also described purpose in terms of making a difference through their actions, whether small or large in scale. Notably, many participants expressed that having purpose could be found in small moments. As one participant described, “Sometimes it’s not that deep. It may just be “What is my purpose for today?” Another explained, “Just making connections with people, just enjoying each day is more meaningful than some big grand purpose.”

As an aspect of wellness, “getting through the day” resonated with

**Table 5**  
Qualitative focus group demographics.

	NC (Rural) n = 12	Chicago (Urban) n = 10	Pasadena (Asian women) n = 4	Pasadena (Hispanic men) n = 5	Total n = 31
<b>Gender</b>					
Men	5 (42%)	5 (50%)	4 (100%)	5 (100%)	15 (48%)
Women	7 (58%)	5 (50%)			16 (52%)
<b>Age</b>					
18–24	1 (8%)	1 (10%)	1 (25%)	2 (40%)	5 (16%)
25–34	2 (17%)	3 (30%)	1 (25%)	1 (20%)	7 (23%)
35–44	4 (33%)	1 (10%)	1 (25%)	2 (40%)	6 (19%)
45–54	3 (25%)	1 (10%)	1 (25%)		6 (19%)
55–64	1 (8%)	3 (30%)			4 (13%)
65+	1 (8%)	1 (10%)			2 (6%)
<b>Race/Ethnicity</b>					
White	4 (33%)	4 (40%)	4 (100%)	5 (100%)	8 (26%)
Black	4 (33%)	3 (30%)			7 (23%)
Asian	2 (17%)	1 (10%)			3 (10%)
Hispanic	2 (17%)	1 (10%)			3 (10%)
Mixed		1 (10%)			1 (3%)
Other					6 (19%)
<b>Education</b>					
Less than HS	1 (8%)	2 (20%)	1 (25%)	1 (20%)	2 (6%)
High school	3 (25%)	4 (40%)	1 (25%)	2 (40%)	6 (19%)
Associate’s	3 (25%)	4 (40%)	2 (50%)	1 (20%)	7 (23%)
Bachelor’s	3 (25%)			1 (20%)	4 (13%)
Technical	1 (8%)				1 (3%)
Master’s	1 (8%)				1 (3%)
<b>Employment</b>					
Employed FT	5 (42%)	5 (50%)	1 (25%)	1 (20%)	11 (35%)
Employed PT	3 (25%)	1 (10%)	1 (25%)	1 (20%)	4 (13%)
Student	1 (8%)	1 (10%)	2 (50%)	1 (20%)	2 (6%)
Homemaker	1 (8%)	1 (10%)		1 (20%)	3 (10%)
Unemployed	1 (8%)	2 (20%)		1 (20%)	3 (10%)
Disabled	1 (8%)				1 (3%)
Retired					5 (16%)
<b>Mood disorder*</b>					
Depression or feeling sad	12 (100%)	7 (70%)	4 (100%)	5 (100%)	28 (90%)
Bipolar or heightened mood	3 (25%)	5 (50%)	3 (75%)	3 (60%)	14 (45%)

\*Respondents were permitted to self-identify as having experiences of both depression and BD.

some participants, but not with others. For some, “getting through the day” was seen as a helpful concept that indicated a “one day at a time” approach to their mental health, marked by specific milestones such as getting out of bed, eating, taking care of personal hygiene, and/or going to work or school. As one participant described, “people don’t realize how big of an accomplishment that is some days.” “Getting through” could also indicate that sometimes you need to make it through a bad

**Table 6**  
Qualitative focus group findings summary: perceptions of positives and potential negatives of various definitions of wellness.

Wellness Aspect	Positive	Potential Negative
Ability to act independently or according to my own will	Being present and in control of emotions and decisions, experiencing freedom from co-dependence	Being isolated from relationships and positive social connections
Experiencing purpose in life	Having a specific role and function, making a difference through actions and relationships	None mentioned
Getting through the day	Accomplishing aspects of one's daily routine successfully, managing through difficult days	Going through the motions of a routine without meaning or engagement
Contentment	Experiencing an overall and consistent sense of being settled in one's life	Being complacent and settling for minimum happiness

day in hopes that the next one will be better. However, for several participants, the idea of “getting through the day” set a low bar for wellness, indicating a state of going through the motions without engaging meaningfully in life.

With regard to the idea of contentment, many participants equated this aspect of wellness with acceptance of self, being settled in one's current life, and feeling satisfied with what one has. Participants specifically contrasted contentment and happiness; as one participant noted, “Happiness is an emotion that can come and go, and contentment is kind of like a state of being.” Participants often described contentment as being reflected and recognized in small moments. “Contentment is like, I've got through work for the day, and I spend a little time on the back porch, watch a good movie. It's nothing big, but I'm content.” Similar to “getting through the day,” a small number of participants described contentment as “settling for minimum happiness.” These participants equated contentment with complacency, rather than a sense of peace.

## Discussion

The mixed-methods DBSA ‘Supporting Wellness’ project provides valuable insights from the perspectives of individuals with lived experience of MDD and BD. Results emphasised the profound impact of mood disorder symptoms, the breadth of outcomes prioritised by peers, and the existence of unmet needs in regards to treatment. Key findings from the survey and focus groups are summarised below, along with implications for mood disorders research and care.

Results of the Supporting Wellness survey highlight ways in which the subjective experience of a mood disorder differs from traditional clinical conceptualisations. Although MDD and BD are defined as episodic conditions, respondents emphasised their chronicity, with 37.6% describing persistent symptoms. This finding is consistent with prior research showing that people with BD experience subsyndromal depressive or manic symptoms up to half of the time (Judd et al., 2003; Judd et al., 2002). Similarly, many people with MDD do not fully recover – up to two thirds continue to experience substantial symptoms following initial antidepressant treatment (Kolovos et al., 2017; Warden et al., 2007), and peers with MDD typically report a greater number of and more burdensome symptoms in the post-acute and ‘remission phase’ relative to healthcare providers (Baune and Christensen, 2019).

However, it is not merely ongoing subsyndromal symptoms which account for the subjective experience of persisting impairments despite clinical remission (Zimmerman et al., 2012; Zimmerman et al., 2006a). A number of key aspects of wellness were emphasised by respondents, including a sense of independence and influence over one's own life, getting through the day, a sense of purpose in life, and self-acceptance. Qualitative findings largely reinforced the importance of these outcomes from a peer perspective and elaborated on key aspects of their definition.

Our findings echo a body of prior work on patient-valued goals for mood disorders treatment: people with lived experience of MDD consistently emphasize positive mental health, improved social relationships, a return to acceptable standards of functioning, and minimizing symptoms as key treatment outcomes (Battle et al., 2010; Chevance et al., 2020; Demyttenaere et al., 2015; Uebelacker et al., 2008; Zimmerman et al., 2012; Zimmerman et al., 2006a; Zimmerman et al., 2006b). Substantively less research has considered the goals and preferences of people with BD: prior DBSA work investigated the subjective experience of treatment effectiveness and medication tolerability in people with MDD and BD, highlighting the importance of both symptom reduction, restoration of functioning, and feelings of wellbeing (Rosenblat et al., 2019). To our knowledge, only one qualitative study has asked people with BD to define the domains of QoL most important to them (Michalak et al., 2006); social support, mental health, financial status, work functioning, and independence were ranked among the most important contributors to good QoL. The present survey adds to this body of research through its relatively large sample size, mixed-methods approach, and substantive proportion of respondents with a self-reported BD diagnosis.

The wellness priorities described by peers with mood disorders provides some contextual explanation for their experiences of and preferences for clinical care. Respondents in the present survey described thinking of health in terms of functioning (in work, leisure, and social contexts), with a return to optimal functioning as a key treatment goal. However, healthcare was experienced as primarily focused on minimizing symptoms. The finding that peers value (but do not necessarily experience) a ‘whole health’ framework when receiving care accords with earlier research. Similar to the present study, people with BD reported a belief that clinicians focused primarily on symptom reduction, with less emphasis placed on QoL, while their own treatment goals elevated QoL improvements over symptom change (Maćzka et al., 2010). People with MDD are more likely to describe mood, physical, and cognitive symptoms as inadequately treated across all phases of illness (Baune and Christensen, 2019), and people with BD have described receiving inadequate support with their QoL goals (Morton et al., 2017). Studies on the kinds of wellness strategies employed by people with MDD and BD demonstrate peer enthusiasm for holistic approaches to treatment (Murray et al., 2011; Rosenblat et al., 2018). This discrepancy has implications for therapeutic alliance: patients may have more positive perceptions of treatment when they feel their experiences and desired outcomes are taken into account, which may enhance both engagement with clinical interventions (Battle et al., 2010; Berk et al., 2004; Kessing et al., 2006; Skantze and Malm, 1994) and treatment outcomes. For example, satisfaction with one's treatment provider is associated with improved coping and a positive outlook in BD (Hirschfeld et al., 2003). Patient-centered care frameworks incorporate the patient's understanding of wellness as an essential element in the shared-decision making process (Davidson, 2016). A wellness-oriented formulation requires the clinician to ‘know the patient’, including their personal values and aspirations, as well as the clinician knows the specific mood disorder that is to be treated. This should include what relationships, vocational/leisure activities, and skills the patient values most, and whether/how these are threatened by the illness. The patient and clinician may also collaborate in the selection of measures that best reflect the most salient treatment goals; multiple instruments may be needed to represent the spectrum of outcomes that reflect patient and clinician priorities.

The findings of this research program, in conjunction with earlier work identifying outcomes of importance for people living with major mood disorders, also reinforce the importance of using COAs and PROMs that represent patient priorities in clinical trials. In addition to the value placed on wellness-oriented outcomes by people with lived experience, use of such measures offers unique information on the course and outcomes of mood disorders. As previously mentioned, patients experiencing clinical remission from a mood disorder may not agree with this

assessment if they experience ongoing QoL and functional impacts (Zimmerman et al., 2012; Zimmerman et al., 2006b). Further, it cannot be assumed that such outcomes will linearly improve as a result of symptomatic improvement; improvements in these outcomes are often delayed relative to symptom change (Hirschfeld et al., 2002; Namjoshi et al., 2002). Such evidence has implications for the interpretation of clinical trials, as people may be classified as meeting criteria for improvement despite persisting subjective impacts, which may result in approval of interventions which do not lead to sufficient improvements from the patient perspective. Finally, broader patient-valued outcomes likely have a reciprocal relationship with symptoms: for example, poor QoL and functioning is predictive of depressive relapse in MDD (Ishak et al., 2013; Solomon et al., 2004), and worse manic and depressive symptoms in BD (Morton et al., 2018): as such, if full recovery is not achieved from the patient perspective, this may have consequences for the long-term efficacy of treatments.

However, it is important to note that our call for recognition of broader treatment outcomes prioritized by people with lived experience of mood disorders is not intended to de-emphasize the value of traditional metrics of clinical improvement, nor treatments aimed at reducing the impact of symptoms. For example, a validation study of a recovery framework with people with BD, MDD and schizophrenia found that people still desired practical support with illness management, including issues of diagnosis and medication (Bird et al., 2014). Indeed, some focus group participants in the present study held reservations that ‘contentment’ and ‘getting by’ may imply a minimum acceptable standard of wellness instead of complete recovery. It has similarly been questioned whether improvements in self-reported QoL despite persistent symptoms may indicate resignation to unhappy circumstances (Katschnig, 2006), raising concerns for the interpretation of PROMs. In line with such concerns, peers at the DBSA Patient Focused Drug Development meeting noted that observer (clinician or family member) input remains valuable, as the person living with a mood disorder may not always be in a position to accurately gauge progress. In light of these observations, we note those models of shared decision-making typically do not prioritize either the clinician or patient perspective (Charles et al., 1999; Slavney and McHugh, 2016); rather, should a patient report achieving wellness in the absence of clinical remission, this is grist for therapeutic discussion. Given the heterogeneous nature of personally valued outcomes, the construction of a reliable and valid PROM is challenging (Stuart et al., 2017); continued use of traditional clinical outcomes (including symptoms, functional impacts, and cognitive difficulties) provides an important, standardized frame of reference for interpreting change. However, research on patient preference, taken together with the findings of the present study, presents a clear case for the inclusion of co-designed, wellness-oriented measures that quantify the broader impacts of mood disorders in clinical trials.

### Future directions

Work towards the overarching DBSA goal of identifying a valid, wellness-focused COA for medication trials related to depression remains in progress. Building off present findings, a panel of researchers, clinicians, and people with lived experience reviewed existing literature on wellness definitions to create a preliminary concept map (Corrigan et al., 2021). A preliminary literature review highlighted over 100 wellness measures. To focus this work, a survey was sent to peers, family members, and the scientific community to understand what features are prioritised in wellness-focused COAs (e.g., administration format, psychometric properties, specificity to mood disorders populations, ability to detect change, and relevance for diverse languages/cultures). Findings from these CBPR priority-setting activities will be used to guide a forthcoming literature review mapping existing wellness-focused COAs that incorporate expert and peer preferred features. This review may inform continuous quality improvement initiatives within healthcare organisations, and provide clinicians and researchers with a guide to

measuring and interpreting wellness as defined by people with lived experience of mood disorders.

### Limitations

An overarching issue regarding the design of the survey is that we did not ask about some issues that may be expected from a mood disorders survey, such as the unipolar/bipolar distinction, suicidality, discrete number of episodes, and comorbidities. This was done in consideration of response burden and the distress associated with answering such items (as identified by the peer council). While these items are important to characterizing the individuals who responded to the survey, on balance, we believe that the exclusion of these supported a very high response rate and completion rate. However, this limited the degree to which we could interrogate the relationship between sample characteristics and wellness priorities. First, respondents were asked to self-report experiences of depression and/or BD. Diagnostic status was not formally assessed (although we note that self-identified diagnostic status overlaps to a large degree with clinical assessments; (Kupfer et al., 2002)). Further, based on feedback from people with lived experience, survey respondents were allowed to select a history of both depression and BD. While this may more accurately describe the subjective experience of living with mood disorder symptoms, it presented challenges for identifying wellness priorities that may be specific to MDD or BD. Many treatment goals are shared between these diagnostic groups, however there may also be points of divergence. For example, while a study comparing subjective indicators of treatment effectiveness and reasons for medication discontinuation between people with MDD and BD identified many overlapping priorities, some differences emerged (Rosenblat et al., 2019). People with BD placed greater emphasis on improved neurocognitive function and sleep, and held greater concerns regarding weight gain and trembling. As such, while our survey findings call attention to the need to consider wellness priorities more broadly across people living with a mood disorder, the experiences and preferences of specific diagnostic groups should be taken into account in future research and instrument development.

Relatedly, we did not ask individuals to comment on comorbid diagnoses that are common for people with mood disorders. Physical health impacts are common in this population (McIntyre et al., 2008; Ramasubbu et al., 2012), as are anxiety disorders (Schaffer et al., 2012). The presence of comorbidities may contribute to experiences of treatment and wellness priorities; future research will elucidate this relationship. In the interim, use of both a condition-specific and generic (i.e., designed for the general population) instrument is recommended for capturing both the specific impacts of a mental health condition and the individual’s overall presentation, comorbidity included (Seow et al., 2019).

As the sample was self-selected, responses may differ from a community-based sample. A primary recruitment stream was the DBSA network; as this organization offers both self-management education and peer support, individuals involved with DBSA may have a higher level of knowledge about their condition and engagement with treatment. This has two implications for the generalisability of survey findings. First, respondents who engage with the DBSA network may be more motivated to engage in treatment. We note that agreement with the statement “I take medications prescribed for me as directed” was very high (89.9%), contrasting with prior literature on adherence in mood disorders populations that suggests adherence may be as low as 50% in patients with BD and MDD (Ho et al., 2016; Jawad et al., 2018). While this may be reflective of social desirability and recall bias, two common issues in medication adherence self-report measures (Stirratt et al., 2015; Velligan et al., 2010), it may also be indicative of differences in the experiences and attitudes of survey respondents as compared to community-based samples. Given concerns regarding both the validity of self-report and potential sample bias, experiences of treatment described here should be interpreted cautiously. Second, respondents

engaged in the DBSA network may have a higher degree of experience with self-management of their condition, and therefore be in a position to consider wellness priorities outside of symptom reduction. It has been noted that the degree of emphasis on treating symptoms versus broader impacts of a mental health condition may need to be tailored according to an individual's recovery stage (Leamy et al., 2011). Individuals who have not come to terms with a mental health diagnosis or whose symptoms are not well-managed may have different wellness priorities to those who are actively engaged in their treatment. The role of recovery stage should be considered in future research on wellness priorities and associated instrument development.

Survey length and response burden was a key consideration, and as such we may not have included all potentially relevant wellness definitions. People's goals for treatment are highly heterogeneous, and balancing the feasibility of survey completion with representation of diverse priorities may mean that some items which may be spontaneously offered in other forms of data collection (e.g., qualitative interviews) are not captured (Uebelacker et al., 2008). For example, our item "staying focused" may not have captured the spectrum of cognitive impairments commonly experienced in mood disorders (MacQueen and Medvedovich, 2017), which includes changes in attention, memory, and executive function. However, a strength of the survey is that the initial item set was developed in consultation with researchers, clinicians and individuals with lived experience of mood disorders, enhancing the likelihood that included items were relevant to the target population. In addition to this, qualitative methods were used to elaborate on specific wellness priorities. Although there are some limitations to the qualitative convenience sample in terms of generalisability, the target demographics were chosen to address underrepresentation of specific groups in the survey. Future phases of this DBSA project also address this limitation by integrating existing literature on wellness definitions with present findings through a CBPR lens (Corrigan et al., 2021).

## Conclusion

Understanding the patient experience of the impacts of illness, treatment, and improvement is critical to guide research and clinical practice. This mixed-methods exploration of the lived experiences of people with MDD and BD underscores a number of practical considerations for treatment and research. The DBSA 'Supporting Wellness' project represents a foundational step in an initiative to ensure that peer-identified and preferred treatment outcomes are operationalised throughout the entire healthcare delivery ecosystem, from medical product development, regulatory approval, and clinical practice to third-party reimbursement. Wellness priorities identified herein will support DBSA's overarching goal to identify COAs that best align with peer-preferred treatment outcomes for use in future clinical trials.

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## Data access

Data are not publicly available in accordance with ethics approval given by the ethics board from the participating university. Interested investigators may submit inquiries to the corresponding author.

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## Authorship

Emma Morton drafted the manuscript. The original study concept and design is attributed to Phyllis Foxworth. Pam Dardess conducted and analysed the qualitative focus groups and drafted the reporting of findings. Cara Altimus led the collection of quantitative data. Carolyn Turvey conducted the analysis of quantitative data. All authors contributed to the analysis plan, interpretation of findings, drafting of the manuscript, and provided critical revision of the final manuscript.

## Supplementary materials

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