

Patient attitudes toward and goals for MDD treatment: a survey study

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Background/Objectives: Major depressive disorder (MDD) is a highly prevalent disorder, frequently diagnosed and treated in a primary care setting; however, little information is available about the treatment decision-making process between MDD patients and their providers. A shared decision-making and goal attainment approach to establishing and tracking progress toward treatment goals that are meaningful to individual patients is explored in this survey study. In addition, information about patient perspectives on setting treatment goals, medication selection/switching, and engaging patients with their health care professionals was also collected and evaluated.

Methods: A 50-question online survey was administered to members of the PatientsLikeMe community who indicated an MDD diagnosis and a switch in antidepressant medications within the past 2 years. Follow-up interviews were also conducted with a small subset of these participants.

Results: Of the 200 participants who completed the survey, 42% reported currently having goals for MDD treatment. These goals were typically in the areas of physical health (62.7%), cognitive functioning (60.2%), and social aspects of life (57.8%). A majority of survey participants (61%) believed the goal attainment approach would be helpful to set and evaluate treatment goals.

Conclusions: The data provide important insights into patient perspectives on the development of formal treatment plans and goals for MDD. In addition, the data also support the use of a patient-centric approach to shared decision-making by using a goal attainment scale to establish and track progress toward treatment goals that are meaningful to MDD patients in real-world clinical practice. The results of this study can be used to inform best practices in patient-clinician communication when developing an MDD treatment plan and goals.

Keywords: goal attainment scale (GAS), PatientsLikeMe, treatment goals, depression, antidepressant, patient-centric

Introduction

Major depressive disorder (MDD) is a heterogeneous, debilitating mental disorder that can cause emotional, physical, and cognitive dysfunction.¹ Diagnostic criteria state that patients with MDD experience at least 5 of the following symptoms for at least 2 weeks: depressed mood, loss of interest in almost all activities, weight change, insomnia or hypersomnia, psychomotor agitation or retardation, fatigue, feelings of worthlessness or excessive guilt, recurrent thoughts of death and/or suicidal ideation, and diminished concentration.¹ Depression affects more than 300 million people globally,² and in 2016, an estimated 16.2 million adults in the United States (6.7% of the population) had

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at least 1 major depressive episode.³ An even more recent report cites the 12-month and lifetime prevalence of MDD at 10.4% and 20.6%, respectively.⁴

Depression is frequently treated with antidepressant medications, psychotherapy, or a combination of these approaches.⁵ Despite the availability of effective options for treatment, a structured literature review suggested that many individuals with depression do not seek treatment; for individuals with a major depressive episode or disorder, the treatment-seeking rates ranged between 27.6% and 60.7%.⁶ Although a substantial number of patients may go untreated, rates of those seeking treatment have increased over the years, possibly because of improved public education and increased screening and detection by health care providers (HCPs).⁶

Once a patient seeks treatment, however, questions remain as to how the ensuing conversation between the patient and clinician will guide or affect the development of and adherence to a treatment plan.⁷ With pharmacological interventions, it can take 2–4 weeks for a patient to start to feel any improvements, and often improvements in mood-related symptoms occur after physical or cognitive ones.³ Because of this, it is critical that patients maintain communication with their doctors to ensure that they are responding to and tolerating the prescribed treatment, and further, to ensure that any required changes can be implemented early in the care pathway.⁵ Even in combination with psychotherapy, patients do not always achieve complete remission from depressive symptoms.⁸ In turn, these factors can influence medication switching, adherence, and discontinuation. For example, in a survey study of patients with depression who were prescribed selective serotonin reuptake inhibitor therapy, findings indicated that a majority of patients who discontinued medication did so without consulting their physician.⁹ Reasons cited for premature treatment discontinuation included lack of patient–physician communication, lack of family support, treatment nonresponse, and tolerability concerns.⁹ Responses also highlighted a communication gap between patients and physicians regarding expected treatment duration and possible adverse effects.⁹

There is a need to better understand the challenges that contribute to poor engagement between HCPs and patients, including motivations behind medication switching or lack of adherence, as well as patients' expectations and goals for treatment. In the Group, Individual, Family Treatment of Depression (GIFT) program, outpatients with MDD worked with therapists to set treatment goals at treatment initiation.¹⁰ Patients who

participated in the GIFT program mostly expressed goals that related to improving family or other social relationships, increasing positive health behaviors, finding a job, or organizing a home—goals that are related to everyday functioning.¹⁰ Because HCPs typically focus on symptom reduction as a treatment goal, results of the study highlighted the importance of assessing and prioritizing patients' nonsymptom-related goals as well.¹⁰ Doing so may, in turn, help to make treatment more meaningful for patients, with a resulting positive impact on adherence.¹⁰

When patients participate constructively in their own care, research has shown it can positively affect health outcomes.¹¹ Simmons et al reported a correlation between positive outcomes related to chronic disease and the corresponding level of patient engagement in their own treatment across a number of chronic illnesses.¹¹ Engaging patients in a goal-setting process can be an effective approach to shared decision-making and for aligning patient and HCP expectations regarding treatment. To facilitate this alignment, it is helpful to define goals that are specific, measurable, achievable/attainable, realistic, and time bound (SMART),¹² and then to assess progress toward these goals using a goal attainment scale (GAS), a semiquantitative methodology that assesses treatment goals identified together by the patient and the HCP.¹³ The major benefit of the GAS is the ability to tailor the approach to individual patients and their goals while allowing for the monitoring and assessment of progress toward goal achievement.¹³

In this study, we aimed to explore treatment goal-setting experiences among a population of patients with MDD from the PatientsLikeMe (www.patientslikeme.com) community, an online network that provides a platform for patients to share their disease experiences and treatment outcomes and improve overall care through peer-to-peer contact. Using semistructured interviews and an online survey, we sought to understand whether patients set goals for treatment, and if so, the types of treatment goals that were important to them. In addition, we studied the role of the clinician in establishing treatment goals, as well as factors that motivate patients when seeking a medication switch. Patients were also asked to evaluate the extent to which their goals reflected SMART criteria and were presented with a GAS example to assess its usefulness in setting and potentially attaining MDD treatment goals. Finally, a small sample of patients were invited to participate in a postsurvey interview with a GAS expert to walk through the approach and gather their feedback.

Methods

Survey development and fielding

To inform survey development, semistructured interviews were conducted with a small sample of patients with MDD to gain an initial understanding of their MDD health history, personal treatment goals (including the process of establishing goals with their HCP), medication switching, and perceived treatment effectiveness. A total of seven 60-min interviews were conducted via phone or video with patients ≥ 18 years of age from the United States who had switched antidepressant medication in the past 2 years. Interviews were transcribed and qualitatively reviewed to identify recurring themes and patterns using content analysis. Overall, a diverse range of goal-setting experiences (from self-directed to defined by HCP) and goal types (eg, attending to personal self-care and increased social interaction) were reported. Also, patients reported use of antidepressant medications to help reduce MDD symptoms and did not express expectations that antidepressant medications would directly help them attain nonsymptom-related goals. Rather, antidepressant medications were viewed as tools to help patients “feel better,” which in turn allowed them to work toward achieving other goals. These observations and themes were used to inform the framing and flow of survey questions and response options.

A high-level example of the GAS approach was also created for the survey to provide patients with an opportunity to assess its potential usefulness in setting and measuring progress toward attaining MDD treatment goals. Briefly, the GAS approach is generally characterized as follows: 1) problems specific to an individual patient are identified and then framed into goals; 2) measurable outcomes and specific goals are set using SMART ; 3) progress toward each goal is assessed by assigning a distinct level of achievement (-2, -1, 0, 1, 2), where level -2 signifies baseline performance, level 0 denotes that the targeted outcome is achieved (most likely outcome), and level 2 denotes outstanding goal achievement; and 4) calculation and interpretation of GAS scores, which includes several potential methods such as the use of weighted averages for the goal achievements, is performed.

The 50-question survey was made available to members of PatientsLikeMe between July 28 and August 3, 2016. Invitations to participate were sent to patients who were over 18 years of age, from the United States, and who indicated having MDD as a condition; patients who

had not switched antidepressant medication within the past 2 years were screened out of participation. The invitation to participate in the survey contained a brief explanation and a link to participate; users who did not complete the survey within 3 days were sent an e-mail reminder to encourage completion.

Analysis

Descriptive statistics were used to characterize participant characteristics across all survey questions. Summary statistics for continuous variables included the number of participants, mean, SD, and median for non-normally distributed variables. Categorical variables were summarized as frequency and percentage. Data for free-text survey responses were reviewed for patterns and themes and were qualitatively coded with a content-analysis approach. All analyses were run with SAS[®] 9.4 software (SAS Institute, Cary, NC, USA).

Postsurvey GAS feedback interviews

In an effort to further explore patients' opinions and reactions to the GAS approach in a qualitative manner, a small number of patients who completed the survey were invited to participate in a postsurvey feedback interview with one of the authors, a GAS expert (Mark Opler). During the exploratory, semistructured interview, patients were led through an example of the GAS approach with the intent of determining whether they thought it would be a helpful or valuable tool for setting and benchmarking treatment goals. Patients were also asked to identify potential obstacles to using the GAS approach with the MDD patient population.

Results

Survey

Participant characteristics

Of the 5,338 patients who met the inclusion criteria and were invited to take the survey, 884 viewed the invitation, with a 43.4% participation rate and a 76.0% completion rate (excluding those patients who were screened out), to yield 200 patients who completed the survey. Participant characteristics are summarized in [Table 1](#). Participants had a mean age of 50.1 years and were predominantly white (86%); the majority were women (80%), and most participants had received at least some college education (89%). The average age when the participants first experienced depressive symptoms was 18.2 years; however, on average, they did not receive a diagnosis until 7.5 years

Table 1 Participant characteristics

	Survey (N=200)	Postsurvey GAS patient feedback (N=5)
Age	Average of 50.1 years	Range of 29–63 years
Sex, n (%)		
Male	36 (18)	2 (40)
Female	160 (80)	3 (60)
Did not disclose	4 (2)	NA
Education level, n (%)		
Some high school	1 (0.5)	0 (0)
High school	19 (9.5)	0 (0)
Some college	102 (51.0)	3 (60)
College	49 (24.5)	1 (20)
Postgraduate	27 (13.5)	1 (20)
I prefer to skip	1 (0.5)	0 (0)
Missing	1 (0.5)	0 (0)
Number of patients with existing treatment goals, n (%)	83 (42)	3 (60)

Abbreviations: GAS, goal attainment scale; NA, not applicable.

later (average age at diagnosis: 25.7 years). In terms of treatment, over the duration of their illness, more than half of the survey participants (62%) had taken more than 6 medications for depression. Approximately half of the participants had started their current medication regimen within the past 6 months, and participants were taking an average of 2.5 medications to treat their depression. Despite receiving treatment, more than half of the participants (62%) felt that depression currently had a great impact on their daily life.

Treatment goals

Eighty-three participants (42%) reported currently having goals for MDD treatment, with the majority (89.5%) citing “to feel better” as a treatment goal. In addition to wanting to feel better, patients aimed for improvements in overall physical health (62.7%), cognitive function (60.2%), and social/interpersonal aspects of life (57.8%) (Figure 1A).

When participants were asked to specify their physical health, social, and cognitive goals, the most commonly reported specific physical health goal was “to exercise” (63%) (Figure 1B), the most common social goal was “to increase social engagement” (48%) (Figure 1C), and the most common cognitive goal was “to improve memory” (32%) (Figure 1D). When asked if a specific HCP helped set their physical health, social, and cognitive goals, participants most commonly reported that a “therapist or counselor” helped them (40%, 52%, and 34%, respectively). The percentages of participants who reported that no HCP helped them to set goals and they “set them on my own”

for the physical health, social, and cognitive goals were 17%, 17%, and 22%, respectively (Figure 2).

Finally, participants who reported setting goals were asked to reflect on whether their goals met SMART criteria. Those reporting physical, social, or cognitive goals believed them to be attainable (65% to 75%), realistic (63% to 67%), and to a lesser extent measurable (46% to 62%) and specific (43% to 58%). Most goals were not perceived to be time bound (13% to 37%).

Medication switching

With regard to when they last switched medications, approximately half (52%) of the participants reported that this decision was made in collaboration with their HCP, whereas about a quarter (26%) came to this decision independently and informed their HCP. Lack of symptom improvement (38%) and side effects (27%) were frequently noted as reasons for switching medications. Survey results also showed that approximately half of the participants who set treatment goals would be “likely” or “extremely likely” to switch medications if physical (52%) and social (54%) goals were not being met, and 78% would switch medications if cognitive goals were not being met (Figure 3).

GAS example

Survey participants were also presented with an example of the GAS and asked whether this tool would be helpful for evaluating their treatment goals. Sixty-one percent of participants “agreed” or “strongly agreed” that it could be a helpful approach (Figure 4). Participants were also given

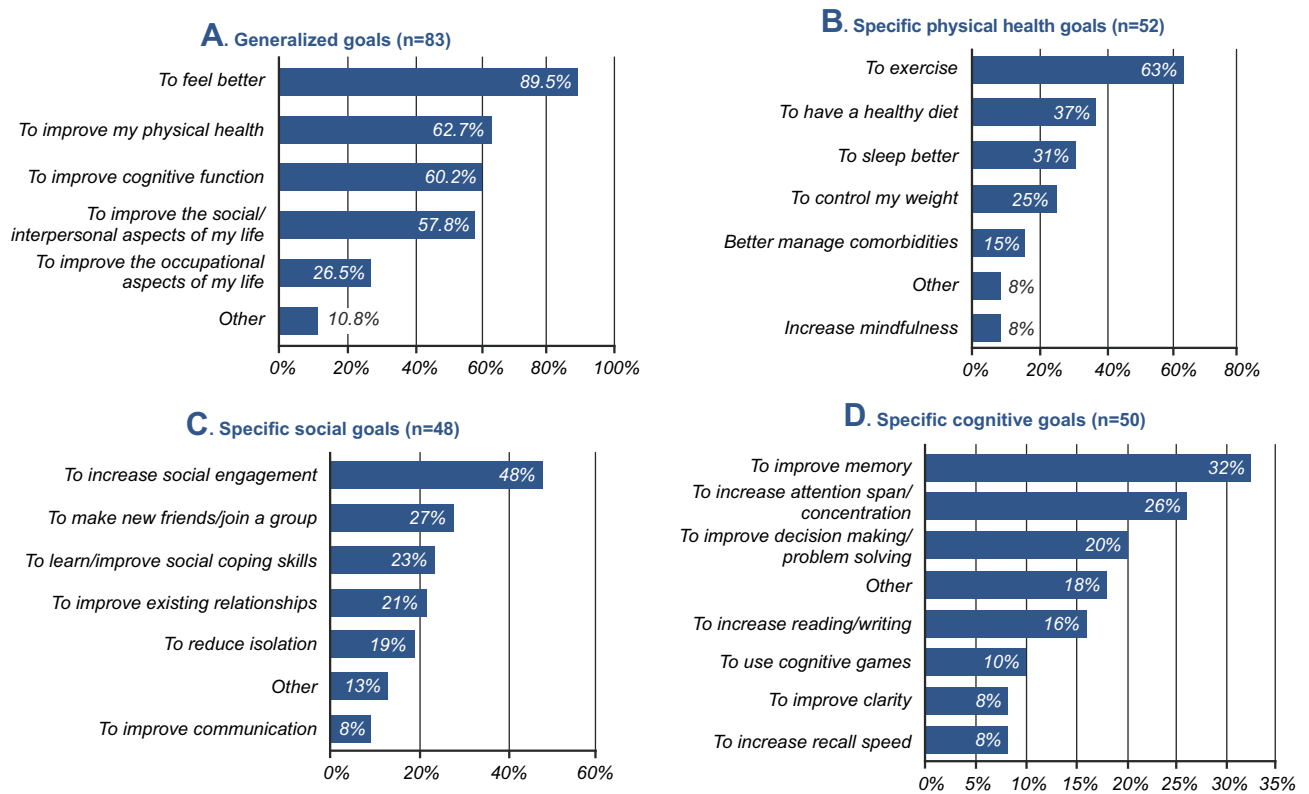


Figure 1 Evaluation of goal setting in patients with MDD. (A) Patients' reported generalized goals. (B-D) Patients identified specific goals according to physical, social, and cognitive well-being. Treatment goal categories were not mutually exclusive; patients could report more than one treatment goal and goals in more than one category. **Abbreviation:** MDD, major depressive disorder.

Survey Question: what type of professional helped you set your goals related to:

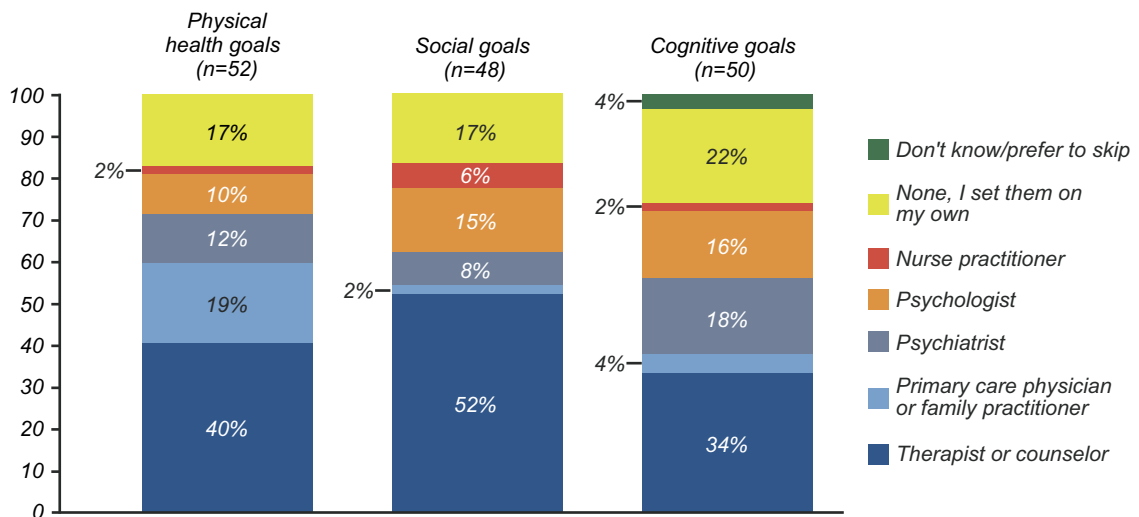


Figure 2 Patients with MDD receive goal-setting assistance from multiple types of HCPs. Patients were asked about the specific HCP who helped them to set their physical, social, and/or cognitive goals. **Abbreviations:** HCP, healthcare provider; MDD, major depressive disorder.

the opportunity to provide additional feedback regarding the approach. Such feedback included comments noting that the GAS would encourage their participation and would help in setting clear expectations and providing

a means to measure and assess progress. Participants also expressed concerns, however, that the GAS approach might be too challenging and that it might require too much concentration.

If you did not experience any improvement in the following areas during treatment, how likely would you be to want to switch medications?

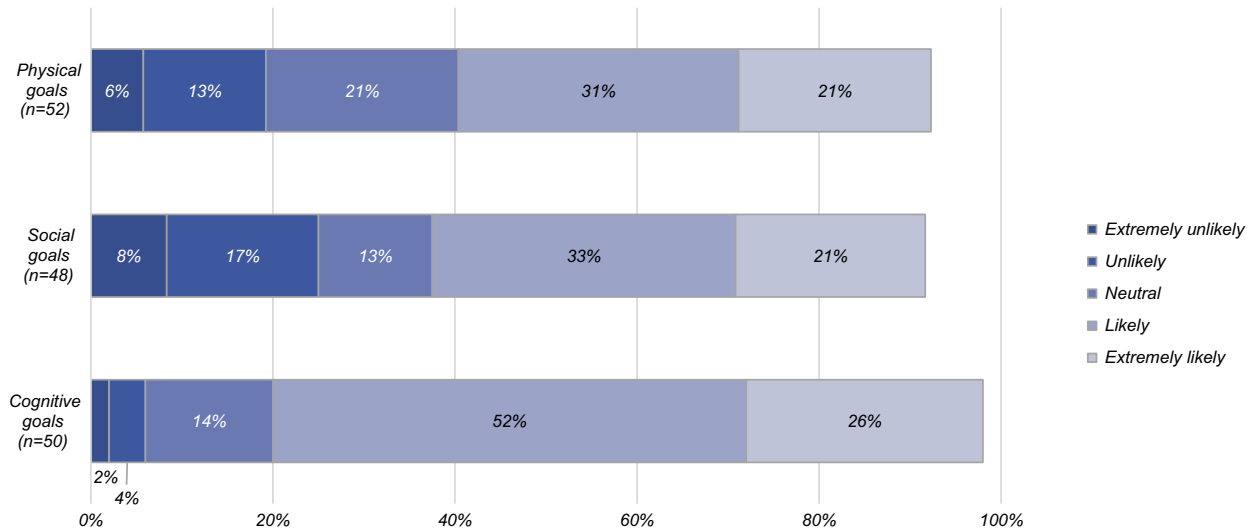


Figure 3 Medication switching in the context of goal setting. Percentage of patients who would likely switch medications if their physical health goals (n=52), social goals (n=48), and cognitive goals (n=50) were not met.

In your opinion, to what extent do you feel that this evaluation would be helpful? (N=200)

GAS example

Imagine that one of your depression treatment goals is to be able to improve aspects of your social life. In this scenario, you would like to be able to increase the frequency in which you see friends and family and/or attend social gatherings.

To help you track your progress towards this treatment goal, your provider suggests that you both establish a framework for assessment. Together, you create the following scoring matrix to evaluate your progress.

In this example, you and your provider agree that a goal would be for you to schedule and attend one social event a week. You also agree that not scheduling or attending a social event would represent less than expected progress and that scheduling and attending more than one social event would represent more than expected progress.

Goal attainment level	Score	Goal: increase social engagement
Much better than expected	2	Scheduled and attended two social events in the past week.
Somewhat better than expected	1	Scheduled two and attended one social event in past week
The expected level of attainment	0	Schedule and attend one social event in past week.
Somewhat less than expected	-1	Scheduled but did not attend one social event in the past week.
Much less than expected	-2	Did not schedule or attend a social event in the past week.

At your first meeting, you and your provider would identify your current status in the assessment matrix which would represent your baseline or the point from which your progress would be measured. Over the course of your treatment, you would meet with your provider approximately every 6 weeks to assess your progress attaining your goal. At the end of treatment, your provider would determine your outcome in relation to the assessment matrix and your progress would be scored resulting in a numeric representation of your goal attainment.

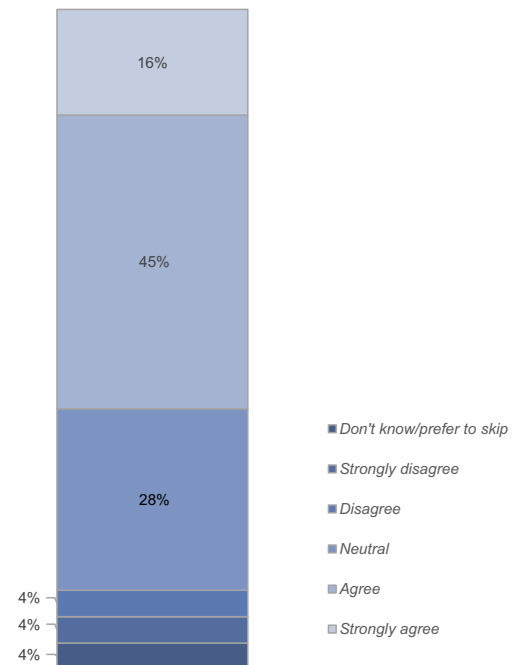


Figure 4 Results from the post-interview survey. **Abbreviation:** GAS, Goal Attainment Scale.

Postsurvey GAS feedback interviews

Of the 200 survey participants, 105 were invited to take part in a postsurvey interview with a GAS expert regarding the GAS approach. In total, 28 patients responded to the invitation (26.7% response rate), 10 were scheduled (35.7% schedule rate), and 5 completed the interview (50% completion rate). In

the follow-up interviews, patients reported that they saw value in the framework that the GAS provided to design treatment plans and evaluate progress, and all of them indicated that the GAS could help them work toward treatment goals. The patients also indicated that time constraints, lack of motivation, and poor patient–HCP communication were potential barriers

to using this approach. Nonjudgmental support from HCPs and patient engagement were noted as being paramount for productive implementation of the GAS approach.

Discussion

This study provides important insights into the treatment decision-making process for patients with MDD, highlighting the need for clearly defined treatment plans, ones with specific goals or objectives, and follow-up assessments determined upfront. Fewer than half of the participants in our survey study reported currently having established treatment goals, and among these participants, a lack of improvement would increase the likelihood of wanting to switch medications, irrespective of goal type. Furthermore, a spectrum of approaches, from self-directed to engaging with one's HCP, were reportedly used when study participants defined goals for treatment or when they determined that a medication switch was necessary.

The published literature cites patient–clinician engagement as playing an important role in a patient's health, with increased communication between the patient and caregiver serving to positively affect treatment outcomes.¹¹ This knowledge, coupled with the recognized heterogeneity of MDD symptoms, underlines the need for HCPs to learn about the specific symptoms impacting each of their patients. Only then can the HCPs work with their patients to help them establish individualized, meaningful goals.

In addition to helping the patient identify meaningful treatment goals, our study suggests that the HCP needs to go even further, guiding the patient in the development of treatment goals that meet SMART criteria. Although most study participants with established treatment goals expressed that goal setting has importance (95%), only 49% of these participants were satisfied with their progress toward their goals at the time of the survey. Participants were able to express their physical, social, cognitive, and occupational goals, yet when qualitatively reviewed, these goals rarely met all SMART criteria. Although goals such as “[being] able to sleep at night,” “[getting] along better with my mate and family,” and “showing up on time” highlighted the general areas in which patients sought improvement, these goals lack many of the SMART characteristics, such as being measurable and specific. These examples might reflect difficulties with goal setting and progress assessment caused by a lack of structure, and could be part of what makes the use of the GAS approach appealing. Patients with clearly defined, realistic, and attainable treatment goals might feel more

motivated and likely better equipped to assess their progress toward reaching their goals.

Overall, patient feedback regarding the GAS approach was positive, with study participants citing the need for a structured framework for defining goals and assessing progress toward goals. Patients did think that for the GAS approach to be implemented successfully HCPs would need to provide a supportive and nonjudgmental environment in which they could engage patients in the goal-setting process. It could prove useful to provide patients with a GAS form before they meet with an HCP to help explain the process and prompt patients to consider goals before the appointment.

A few study limitations should be noted. First, study participants represent a convenience sample of members of the PatientsLikeMe platform. By nature of the platform, all participants had access to a computer and the Internet, with a majority being women with a minimum of some college education. As such, one might imply the study population had greater access to resources in general. These characteristics limit the representativeness of the patient population to the global MDD community. Second, patients self-report their diagnosis of MDD on the PatientsLikeMe platform and diagnoses were not independently verified. However, while there may always be a chance for inaccuracies, a recent study attempting to confirm self-reported diagnoses through PatientsLikeMe with medical claims data found very high rates of concordance, indicating patients are generally able to accurately self-report their diagnoses.¹⁴ Reported measurements were also not clinically validated and are subject to recall and social desirability bias.

Conclusions

The findings of this survey study suggest that there is an unmet need for a more formal, structured goal-setting process for MDD treatment plans that fosters collaboration and shared decision-making between the patient and HCP. The goal attainment approach can provide this framework for the goal selection and assessment process, as well as facilitate communication between patients and HCPs. This increased patient–clinician engagement may improve the likelihood of a successful treatment outcome, helping patients achieve the treatment goals that matter most to them.

Ethical Considerations

This study was deemed exempt from IRB review by the New England Independent Review Board because all research with participants used survey and interview procedures, and

participants could not be identified nor were they considered to be placed at any risk. All participants provided informed consent. In addition, all participants of the PatientsLikeMe community were informed of their potential involvement in research activities through the user agreement and privacy policy before joining the site.

Abbreviation list

GAS, goal attainment scale; GIFT, Group, Individual, Family Treatment of Depression; HCP, health care provider; MDD, major depressive disorder; SMART, specific, measurable, attainable, realistic, time bound.

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Author contributions

All authors contributed to data analysis, drafting or revising the article, gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

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