Identifying and describing patient perspectives on long-term antidepressant use

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Abstract: Background: Major depression is a chronic disease which often requires long-term antidepressant use. Prescriptions of antidepressants have increased in the past two decades in the US. Although current clinical data support the treatment efficacy of antidepressants, early discontinuation of their use by the patient is common. Aim: To identify the treatment experiences of patients, including their perceptions on antidepressant effects, changes in personality, and addiction. Overall goal was to identify factors for larger studies on patterns of antidepressant medication use. Method: This cross-sectional, descriptive study interviewed 45 adults in a large metropolitan city in the US using a structured interview guide that consisted of: demographic characteristics, depression and medication history, antidepressant drug taking behaviors, and antidepressant drug effects. Results: All 45 patients had health insurance. 71.1% of the subjects reported mild to moderate feelings of depression at the time of interview. Almost all (93.3%) patients felt that their antidepressants had made their depression better. 53.3% of patients perceived a change in their personality due to antidepressant use. A third (31%) perceived their antidepressant use to be their choice, while 69% stated it was a necessity. A majority (63.6%) felt they were dependent on their antidepressant, but 88.6% felt they were not addicted to their medication. Conclusions: Overall, important factors on long-term antidepressant use from the patient’s perspective were obtained in this study. Thus these study data can be considered pilot information since it will help to develop tailored intervention studies to improve long-term antidepressant adherence.

ABOUT THE AUTHORS
Reshmi Singh’s primary interest in research revolves around patient-centered issues in medication use and overall health care experiences. I have examined specifically antidepressant experiences in college students previously and currently exploring patient health care experiences in rural and vulnerable populations such as those with disabilities and chronic diseases. Overall, health care access and disparities by virtue of rural location are issues that affect patients’ “care seeking,” outcomes and communities at large. My research agenda is to further ways and means to improve patient health care engagement and examine the role of health literacy in patients’ seeking of and access to health care. I do this by bringing forth the patient voice and experiences to the health care professionals and scientists and policy-makers.

PUBLIC INTEREST STATEMENT
Discontinuing antidepressants by patients with chronic depression not only has a high cost on society but takes a toll on the patients themselves since it results in recurring depressive symptoms. This study brings forth the perceptions and experiences of using antidepressants in the long term from the viewpoint of patients themselves. The importance for understanding what works and what doesn’t for the patients is that ultimately they will decide whether or not to take their antidepressants as prescribed whether for short term or long term. The factors identified from this study will help pharmacists and providers counsel patients in a tailored way to truly help them in the process of taking antidepressants as long as needed to improve their depression to feel better.

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1. Introduction

Major depression is a chronic disease not an acute condition with a one-time occurrence (Keller, 2003). There are various therapies available to treat depression, such as cognitive and behavioral therapies, counseling, medications, and others. Of these, medications are considered effective in providing faster reduction of depressive symptoms as well as prolonging remission (Geddes et al., 2003; Hinkes & Alvarez, 2001). Also, according to the American Psychiatric Association (2010), medications are the preferred treatment especially for patients with moderate to severe depression. Many patients however discontinue medication therapy too soon and as a result experience relapse, resulting in increased costs to the health care system (David & Dunner, 2000; El-Mallakh & Briscoe, 2012).

Antidepressant medications are the main source of treatment for a majority of Americans suffering from depression. Antidepressant medications are the most popular form of pharmaceutical therapy in western societies (Ambresin et al., 2015). Antidepressant use in the US has increased from 5.84% of the population in 1996 to 10.12% of the population in 2005, representing more than 27 million people (Olfson & Marcus, 2009).

Clinical research has been conducted on the efficacy and safety of long-term antidepressant therapy, but very few studies have focused on the patients’ perspective of their long-term use of antidepressants. Despite the great attention called to antidepressant medications and possible adverse effects, there is little knowledge of the experience of patients using antidepressants for long periods of time. The objective of this cross-sectional, interview-based study is to identify and describe factors that affect the perspectives of patients who have used antidepressant medications over a long period of time.

2. Study methods

The study was comprised of 45 subjects and collected quantitative, descriptive information from subjects. The study protocol, interview guide, and informed consent form were approved by the College’s Institutional Review Board (IRB). Participants for this study were selected through advertising for volunteers and an initial telephone screening process. Ads describing the study, eligibility criteria, and contact information were placed in a local, daily newspaper. Potential participants were asked to contact the investigators at the College. Calls were received by an administrative assistant who was trained to screen callers on the eligibility criteria and type of medication they were using and who described the purpose of the study and nature of the interview.

Antidepressant users who fulfilled the criteria and consented to participate were scheduled an appointment. The name and contact information of the participants were kept by the administrative assistant and not revealed to the investigators; each participant was given a subject number for the interview. The location for the interviews was in the primary researchers’ personal offices at the College and interviews were scheduled during summer break according to the interested participant and researcher availability at all times of the day. Upon arrival for the interview, participants were given a detailed informed consent form to read and sign, and then the interview was held in one of the investigators’ offices at the College. Participants who completed the interview were compensated with a $25 gift card to a local grocery or bookstore.

Eligibility criteria were: 18 years of age or older, living in the metropolitan area, use of antidepressant medications for more than one year, and use of current antidepressant for more than three months specifically for the diagnosis of depression. We excluded those who were taking their current antidepressant for diagnosis other than depression and also those who had been diagnosed with first
time depression for less than one year. Interview appointments were rescheduled only if the subject called and requested to do so. The interview instrument consisted of four sections: demographic characteristics of the subject, including family history of depression; depression history and the various types of antidepressant medications that have been used; antidepressant drug taking behaviors; and antidepressants effects including changes in effects over time and unexpected effects.

3. Results
Demographic characteristics of the 45 study participants, hereafter called patients, are presented in Table 1. The study sample tended to be older, mostly 40 to 59 years of age, white, though one-quarter were black, and with slightly more female than male patients. The racial and gender mix of

| Table 1. Descriptive characteristics of study participants (N = 45) |
|---------------------------------------------------------------|
| **Age (mean age = 51 years old)**                             |
| Younger than 30 years old                                     | 2 | 4.4 |
| 30–39 years old                                               | 3 | 6.7 |
| 40–49 years old                                               | 15| 33.3|
| 50–59 years old                                               | 16| 35.6|
| 60 years and older                                            | 9 | 20.0|
| **Race**                                                      |
| White                                                         | 25| 55.6|
| Black                                                         | 11| 24.4|
| Hispanic                                                      | 2 | 4.4 |
| Asian                                                         | 1 | 2.2 |
| Other                                                         | 6 | 13.3|
| **Gender**                                                    |
| Male                                                          | 19| 42.2|
| Female                                                        | 26| 57.8|
| **Education**                                                 |
| Some high school                                             | 3 | 6.7 |
| HS diploma / GED                                              | 5 | 11.1|
| Some college                                                  | 16| 35.6|
| Associate’s degree                                            | 3 | 6.7 |
| Bachelor’s degree                                             | 6 | 13.3|
| Some grad school                                              | 11| 24.4|
| Completed grad school                                         | 1 | 2.2 |
| **Marital status**                                            |
| Single                                                        | 28| 62.2|
| Married                                                       | 5 | 11.1|
| Divorced                                                      | 6 | 13.3|
| Widowed                                                       | 2 | 4.4 |
| Separated                                                     | 4 | 8.9 |
| **Drug insurance coverage**                                   |
| Yes                                                           | 45| 100|
| No                                                            | 0 | 0  |
| **Immediate family history of depression**                    |
| Yes                                                           | 30| 66.7|
| No                                                            | 12| 26.7|
| Don’t know                                                    | 3 | 6.6 |
this purposeful sample reflected that of the metropolitan city population from which it was obtained. (Population in 2014 = 655,884; Racial make-up (2013): W = 53%; B = 24%; Hispanic = 19%; Native American = 0.4%; female: male ratio = 10 to 9.2).

Twenty-eight (62.2%) study patients were single, they tended to be an educated group with over half completing some college and about a quarter completing some graduate school work. All of the patients had health insurance. Patients also ranged quite a bit in their reported occupation from unemployed to student to health care professionals. Two-thirds of the patients stated that an immediate family member had a history of depression. The patients were on a wide variety of antidepressants over the period of their long-term use. Most of the current antidepressants used by the respondents were from either the Selective Serotonin Reuptake Inhibitors class (e.g. Sertraline, Fluoxetine) or Tetracyclic Compounds (e.g. Venlafaxine, Bupropion) class of antidepressants.

The patients’ depression histories are presented in Table 2. Twelve (26.7%) participants were diagnosed more than 20 years prior to this study. For a majority (N = 26; 60.5%) of patients, their diagnosis was made by a psychiatrist. Slightly less than one-half (N = 21; 47.7%) of the patients had been hospitalized for depression. Twenty-nine out of 45 (64.4%) patients stated they had attempted suicide at least once in their life. At the time of their interview, 71.1% (N = 32) of patients stated they were experiencing mild to moderate symptoms of depression.

|                         | N  | (%)  |
|-------------------------|----|------|
| **First diagnosed with depression (N = 45)** |    |      |
| Less than 5 years ago   | 13 | 28.9 |
| 5–10 years ago          | 8  | 17.8 |
| 11–20 years ago         | 12 | 26.7 |
| More than 20 years ago  | 12 | 26.7 |
| **Who made the diagnosis (N = 43)** |    |      |
| Psychiatrist             | 26 | 60.5 |
| Psychologist             | 7  | 16.3 |
| Social worker            | 2  | 4.7  |
| Primary care physician   | 5  | 11.6 |
| Other doctor             | 1  | 2.3  |
| Other                    | 2  | 4.6  |
| **Severity of depression at time of interview (N = 45)** |    |      |
| Mild                     | 20 | 44.4 |
| Moderate                 | 12 | 26.7 |
| Severe                   | 2  | 4.4  |
| Not depressed at all (no symptoms) | 9  | 20.0 |
| Day by day               | 2  | 4.4  |
| **Hospitalized for depression (N = 44)** |    |      |
| Yes                      | 21 | 47.7 |
| No                       | 23 | 52.3 |
| **Suicide attempts (N = 45)** |    |      |
| Yes                      | 29 | 64.4 |
| No                       | 12 | 26.7 |
| No answer/comment        | 4  | 8.9  |
The patients’ medication taking behaviors are presented in Table 3. A vast majority—40 out of 45 (90.9%) patients stated they intended to take their first antidepressant medication when it was first prescribed after their initial diagnosis. Twenty-two (52.4%) patients had planned or attempted to cease their medication use at some point. Forty out of 42 (95.2%) of the patients said their family and close friends are aware of their use of antidepressant medications. Thirty-five (81.4%) patients felt they had received adequate information regarding their medications.

Patient experiences with their antidepressant medication specific to its effects are presented in Table 4. Twenty-two of (3171%) respondents had experienced changes in the effects of their medications from past antidepressants they had used to the current ones they use. Equally, one-half of patients had experienced changes in the effects of their current antidepressants while one-half had not, and a most (N = 27; 62.8%) had not experienced unexpected effects from their current antidepressants. Almost all 43 (93.3%) patients felt that their antidepressants had made their depression better—an improvement in symptoms. A slight majority, 24 (53.3%) patients have perceived a change in their personality as a result of their use of antidepressants. As to perceiving use of their antidepressants as a choice or a necessity, 31% (13) stated their use was their choice while 69% (29) stated their use was a necessity. As to perceiving their use as a dependency or addiction, 63.6% (28) felt they were dependent on their antidepressant, but 88.6% (39) felt they were not addicted to the medication. It was interesting to note that most patients agreed that they were dependent but not addicted to their depression medication and a few answered “I don’t know.”

Of the 29 who felt taking their medications was a necessity, 20 stated they were not addicted, while of the 28 who felt they were dependent on their medications, 25 clearly specified that they were not addicted to their medications. It was interesting and unexpected to note that patients themselves made a clear distinction between the two terms—be it to avoid stigma associated with the term addiction more than dependency or the fact that they perceived some control over being addicted but none over being dependent.

| Table 3. Antidepressant medication taking behaviors of study patients |
|---------------------------------------------------------------|
|                  | N     | (%)    |
| Intention to take first antidepressant medication when first prescribed (N = 44) |       |        |
| Yes              | 40    | 90.9   |
| No               | 4     | 9.1    |
| Patient planned or attempted to stop medication (N = 42) |       |        |
| Yes              | 22    | 52.4   |
| No               | 20    | 47.6   |
| Patient’s family and friends are aware of patient’s antidepressant use (N = 42) |       |        |
| Yes              | 40    | 95.2   |
| No               | 2     | 4.8    |
| Patient received sufficient information from health provider (N = 43) |       |        |
| Yes              | 35    | 81.4   |
| No               | 8     | 18.6   |
4. Conclusions and discussion

Depression is often treated as a short-term, self-limiting condition so long-term management is not well practiced (Schwartz & Peterson, 2006). Of those treated, 30–50% continued to experience symptoms of depression; others respond but over time the therapeutic effects are lost. Our study respondents also showed changes in effects over time with having to change antidepressants long term. Predictors of relapse are all patient-focused (disease history, symptoms, patient characteristics), not the drug therapy or health provider, and patient non-adherence, not the provider’s care such as changing drugs too quickly (Borges et al., 2014; Diniz & Reynolds, 2014). Side effects are seen as the primary reason for non-adherence so clinicians monitor for them and adjust medications or add new ones to the patient’s regimen. It is becoming increasingly apparent to clinicians and patients alike that long-term adherence with treatment is necessary to successfully recover from depression and restore the premorbid level of functioning (Altamura & Mauri, 1985; Popovic, Vieta, Fornaro & Perugi, 2015).

### Table 4. Patients’ treatment experiences with antidepressant medications

|                                                                 | N  | (%) |
|-----------------------------------------------------------------|----|-----|
| Experienced changes in effects between current and past antidepressants (N = 31) |    |     |
| Yes                                                             | 22 | 71.0|
| No                                                              | 9  | 29.0|
| Experienced change in effects in current antidepressant over time (N = 42) |    |     |
| Yes                                                             | 21 | 50.0|
| No                                                              | 21 | 50.0|
| Experienced unexpected effects from antidepressant use (N = 43) |    |     |
| Yes                                                             | 15 | 34.9|
| No                                                              | 27 | 62.8|
| Don’t know                                                      | 1  | 2.3 |
| Current antidepressant’s effectiveness “has made depression” (N = 45) |    |     |
| Better                                                          | 42 | 93.3|
| Same                                                            | 3  | 6.7 |
| Worse                                                           | 0  | 0   |
| Other                                                           |   | 0   |
| Medication is working for patient (N = 43)                     |    |     |
| Yes                                                             | 40 | 93.0|
| No                                                              | 3  | 7.0 |
| Patient’s perception of personality change from antidepressant (N = 45) |    |     |
| Yes                                                             | 24 | 53.3|
| No                                                              | 20 | 44.4|
| Don’t know                                                      | 1  | 22  |
| Patient’s perception of dependence on antidepressant (N = 44)   |    |     |
| Yes                                                             | 28 | 63.6|
| No                                                              | 14 | 31.8|
| Don’t know                                                      | 2  | 4.6 |
| Patient’s perception of addiction to antidepressant (N = 44)    |    |     |
| Yes                                                             | 5  | 11.4|
| No                                                              | 39 | 88.6|
| Patient’s perception of antidepressant use as: (N = 42)         |    |     |
| Choice                                                          | 13 | 30.9|
| Necessity                                                       | 29 | 69.1|


Studies suggest that 90% of patients achieve recovery from their depression over long periods of time such as decades (Keller & Boland, 1998; Solomon et al., 1997). For patients who have been depressed for long periods of time, such as five years, up to 40% achieved remission from depression over the following five years if on continuous pharmacotherapy (Mueller, Leon, Keller, et al., 1999; Mueller et al., 1996). Discontinuation of treatment at less than 4 months has been shown to greatly increase the occurrence of relapse, thus the traditional recommendation is for treatment to be continued for six to nine months after initial full response (Clinton, 1993). Geddes et al. (2003) performed a meta-analysis of 31 randomized trials of continuing treatment with antidepressants in patients who responded to acute treatment. They found that continued therapy reduced the odds of relapse by 70% compared to placebo. Elfenbein (1995, 1996) stated that “most patients’ accounts indicated positive effects and outcomes, most were happy to have their antidepressants, some called them magic.”

Our study confirmed some of the above findings. Information from this study can help clinicians and suicide prevention groups set priorities for intervention programs. Thus these study data can be considered pilot information since it will help to develop tailored intervention studies to improve long-term antidepressant adherence. Also the Healthy People (2020) includes national objectives to increase treatment for depression in adults stressing the public health importance of depression treatment.

Our study was different in that it focused on long-term antidepressant user experiences to see what works and what helps them continue their medications. Patient perceptions of dependency on and addiction to antidepressants need to be examined in further detail. It is positive that most long-term users perceived a change in effects from their antidepressants over time and it was for the better. While most patients in this study were satisfied with the information obtained from their providers, we identified topics such as length of use, expected and unexpected effects over time and side effects that need to be discussed more with patients taking antidepressants to address their concerns right from the first visit. The ultimate goal for these long-term antidepressant users is not just avoiding relapse but to actually be on the path to recovery.

5. Limitations
Low sample size limited the kind of statistical analysis that could be conducted; however this pilot sample provided sufficient descriptive information with regard to the purpose of this paper. Self-Report of respondents is presented in this study, so patients who may have had more positive experiences could have approached us to participate. However, the long-term experiences indicated that while current experience was positive these patients had undergone both positive and negative experiences through their antidepressant use journey. Adherence to the interview appointment was an issue for some potential participants in this study. A number of callers scheduled an appointment only to later reschedule the appointment; some never showed up for the appointment and there was no further contact with them. The administrative assistant did not follow up with callers who missed their appointment. Subjects who did reschedule and who also participated in the interview commented that their ability to make a scheduled appointment usually was due to how they were feeling that day. If depressive symptoms were significant enough on the day of the appointment, they would call and ask to reschedule it. It is assumed that this also was the case for those who never made their appointment for the interview.

6. Future research
While addiction and dependency are not necessarily considered or seen as separate by health professionals or in the related science literature, respondents making that distinction certainly merits further delving into this idea. In fact this study research team plans on a qualitative write-up about understanding the meaning of antidepressants and delving further into patient perceptions on their long-term use.
Also, this study only focused on the antidepressant experience for patients with depression. Other studies need to include further factors such as counseling or therapy that would also affect patient recovery in the long term. Similarly, it would be important to get other perspectives on long-term antidepressant use including that of health care professionals and caregivers of patients with depression to gain more understanding of its effectiveness.

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Competing Interests
The authors declare no competing interest.

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References
Altmura, A. C., & Mauri, M. (1985). Plasma concentrations, information and therapy adherence during long term treatment with antidepressants. British Journal of Clinical Pharmacology, 20, 714–716. http://dx.doi.org/10.1111/bcp.1985.20.issue-6
Ambresin, G., Palmer, V., Densley, K., Dowrick, C., Glichrist, G., & Gunn, J. (2015). What factors influence long-term antidepressant use in primary care? Findings from the Australian diamond cohort study. Journal of Affective Disorders, 17, 125–132.
American Psychiatric Association. (2010). Practice guideline for treatment of patients with major depressive disorder (3rd ed.). Washington, DC. Retrieved from http://www.psychiatryonline.com/practGuide/practGuideTopic_7.aspx
Borges, S., Chen, Y. F., Laughrn, T. P., Temple, R., Patel, H. D., David, P. A., … Khin, N. A. (2014). Review of maintenance trials for major depressive disorder. The Journal of Clinical Psychiatry, 75, 205–214. http://dx.doi.org/10.4088/JCP.13r0872
Clinton, J. J. (1993). Depression in primary care. JAMA: The Journal of the American Medical Association, 270, 172. http://dx.doi.org/10.1001/jama.1993.03510020036008
Diniz, B., & Reynolds, C. (2014). Major depressive disorder in older adults: Benefits and hazards of prolonged treatment. Drugs & Aging, 31, 661–669. http://dx.doi.org/10.1007/s40266-014-0196-y
David, L. & Dunner, M. D. (2000). Introduction: New strategies for improving the treatment of depression. The Journal of Clinical Psychiatry, 61(suppl 11), 1–1.
Ellenbein, D. (Ed.). (1995). Living with Prozac and other selective serotonin-reuptake inhibitors: Personal accounts of life on antidepressants. New York, NY: Harper Collins.
Ellenbein, D. (Ed.). (1996). Living with tricyclic antidepressants: Personal accounts of life on imipramine, nortriptyline, amitriptyline. New York, NY: Harper Collins.
El-Mallakh, R. S., & Briscoe, B. (2012). Studies of long term use of antidepressants. CNS Drugs, 26, 97–109. http://dx.doi.org/10.1007/s40266-011-0159-k
Geddes, J. R., Carney, S. M., Davies, C., Furukawa, T. A., Kupfer, D. J., Frank, E., … Goodwin, G. M. (2003). Relapse prevention with antidepressant drug treatment in depressive disorders: A systematic review. The Lancet, 361, 653–661. http://dx.doi.org/10.1016/S0140-6736(03)12599-8
Hinkes, R., & Alvarez, M. (2001, June 3–6). Adherence to antidepressant therapy in an outpatient psychiatric population. In Program and abstracts of the ASPH Annual Meeting.
Keller, M. (2003). Past, present, and future directions for defining optimal treatment outcome in depression. JAMA, 289, 3152–3160. http://dx.doi.org/10.1001/jama.289.23.3152
Keller, M. B., & Boland, R. J. (1998). Implications of failing to achieve successful long-term maintenance treatment of recurrent unipolar major depression. Biological Psychiatry, 44, 348–360. http://dx.doi.org/10.1016/S0006-3223(98)00110-3
Mueller, T. I., Keller, M. B., Leon, A. C., Solomon, D. A., Shea, M. T., Coryell, W., … Endicott, J. (1996). Recovery after 5 years of unremitting major depressive disorder. Archives of General Psychiatry, 53, 794–799. http://dx.doi.org/10.1001/archpsyc.1996.01830090040006
Mueller, T. I., Leon, A. C., Keller, M. B., Solomon, D. A., Endicott, J., Coryell, W., … Maser, J. D. (1999). Recurrence after recovery from major depressive disorder during 15 years of observational follow-up. American Journal of Psychiatry, 156, 1000–1006.
Olsson, M., & Marcus, S. C. (2009). National patterns in antidepressant medication treatment. Archives of General Psychiatry, 66, 848–856. doi: http://dx.doi.org/10.1001/archgenpsychiatry.2009.81
Popovic, D., Viete, E., Fomano, M., & Perugi, G. (2015). Cognitive tolerability following successful long term treatment of major depression and anxiety disorders with SSRI antidepressants. Journal of Affective Disorders, 17, 3211–3215.
Schwartz, T. L., & Peterson, T. J. (Eds.). (2006). Depression: Treatment strategies and management. New York, NY: Taylor and Francis Group.
Solomon, D. A., Keller, M. B., Leon, A. C., Mueller, T. I., Shea, M. T., Warshaw, M. … Endicott, J. (1997). Recovery from major depression. Archives of General Psychiatry, 54, 1001–1006. http://dx.doi.org/10.1001/archpsyc.1997.018302.0033005
