

# Use of Photovoice to Understand the Experience of Taking Psychotropic Medications

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## Abstract

Previous work has reported that medication experience may affect medication-related problems, adherence, and quality of life. The purpose of this study was to explore medication experience of individuals taking psychotropic medication from the patient perspective using photovoice methodology. Nineteen participants were given a camera and were asked to photograph their medication experience. Individual and focus group sessions were held for photo reflection and discussion. Transcript data were analyzed to arrive at a model of medication experience. Specific medication experiences, including recognizing medication's benefits, occurrence of side effects, developing medication-taking routine, feeling burden from medications, and benefiting from nonmedication therapies, influenced medication acceptance, but in varying ways. Participants wanted their providers to understand their medication experience. Health care providers should consider exploring medication experience of patients with mental illness. Additional research is needed to evaluate whether exploring patients' medication experience in the clinical setting can improve patient-centered health care outcomes.

## Keywords

medication experience; photovoice; mental illness; psychotropic medication; qualitative; Photovoice; Midwestern USA

*Medication experience* has been defined as “an individual's subjective experience of taking a medication in his/her daily life” (Shoemaker & Ramalho de Oliveira, 2008; p. 90). Initial findings indicate that patient medication experience(s) can have a large influence on medication adherence, quality of life, and medication-related problems and their detection (Moncrieff, Cohen, & Mason, 2009; Ramalho de Oliveira, Shoemaker, Ekstrand, & Alves, 2012; Sajatovic et al., 2011). Individuals without prior experience were twice as likely to discontinue antipsychotic treatment compared with individuals who had prior experience taking an antipsychotic (Vanelli, Coca-Perraillon, & Troxell-Dorgan, 2007). Similarly, antidepressant discontinuation within the first 30 days was 2 times higher in those with recent prior antidepressant experience compared with those without prior antidepressant history (Vanelli & Coca-Perraillon, 2008). These findings suggest that experience with psychotropic medication may confer a powerful influence on acceptance of medication going forward. Yet, little is known about the nuances of patients' medication experiences and how they may affect medication use.

Unfortunately, the experience of taking a medication from the independent perspective of the individual patient has infrequently been explored. Several studies about patient

medication experiences have taken only clinicians' perspectives of patients' experiences (Carrick, Mitchell, Powell, & Lloyd, 2004; Shoemaker, Ramalho de Oliveira, Alves, & Ekstrand, 2011). A moderate number of studies have asked structured interview questions of patients about their medication experience, often prompting patients as to which areas they should comment on with regard to their medications. To our knowledge, no previous study has elicited the medication experience from patients in a participant-directed fashion.

For this reason, the participatory action research methodology known as “photovoice” was chosen for this study. Pioneered by Wang and Burris, photovoice is a process in which individuals use cameras to photograph their everyday realities, thereby focusing on issues of greatest importance to them (Baker & Wang, 2006; C. Wang & Burris, 1997). Photovoice studies typically invite participants who have firsthand experience with

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the phenomenon under study and invite them to capture the experience from their own perspective using photographs. Participants in photovoice studies then reflect on their photos with one another, often leading to the creation of a shared perspective or collective voice about the phenomenon, which can then be shared to promote social change. This methodology has been successfully used to document and share the experience of people who may not otherwise have a voice about a particular topic, including those with mental disorders (Catalani & Minkler, 2010; Cabassa et al., 2013; Han & Oliffe, 2016). Photovoice has not been applied to the medication experience of individuals prescribed psychotropic medications. The primary aim of this study was to use photovoice to characterize medication experience from the perspective of individuals prescribed psychotropic medication with the intent to inform mental health care communities about patient-centered approaches to medication use. This article is devoted to discussion of themes specific to medication experience that were brought up by the participants.

## Method

### Setting

Participants were recruited via written advertisement from four ambulatory behavioral health clinics and one partial hospital program in a midwestern city. In its entirety, this study was run in three separate cohorts over an 18-month period from 2012 to 2013. Each individual's participation in the study lasted approximately 2 months.

### Sample

Included participants were those who had been prescribed at least one medication to treat a mental health condition. Participant self-reports were relied upon, and no diagnostic criteria, assessment tools, or participant chart reviews were utilized for confirmation. Individuals who were below the age of 18 years or were assigned a legal guardian were not eligible to participate in the study.

### Study Procedure

Interested individuals were invited to Meeting 1 to learn about the photovoice process and were given the opportunity to give their informed consent. Individuals who chose to participate were then given a 27-exposure disposable camera and a 100 page journal. These individuals were asked to imagine that they were being paid to mount a photographic display with the title "Living With My Medication." The participants were informed that they could take any number of photos they wished up to 27. At

**Table 1.** The SHOWED Technique (National Association of County and City Health Officials [NACCHO], 2016).

S	What is <u>Shown</u> here?
H	What is <u>really</u> <u>Happening</u> here?
O	How does this relate to <u>Our</u> (your) lives?
W	<u>Why</u> are things this way?
E	How could this image <u>Educate</u> people?
D	What should be <u>Done</u> about this?

a minimum, participants were asked to make a journal entry with each photo captured to document their thoughts behind the photograph. Participants were encouraged to use their journal as often as they liked, in addition. After 10 days, participants mailed their cameras back to the researchers who developed the photos and contacted each participant individually to set Meeting 2. Participants were given meeting reminders by phone approximately 2 days prior to each meeting.

At Meeting 2, each participant met individually with the researchers to reflect on his or her photos and journal entries. The researchers not only guided the reflection about each photo using the SHOWED technique (Table 1; National Association of County and City Health Officials [NACCHO], 2016) but also encouraged the participants to share additional thoughts and feelings. At the end of Meeting 2, each participant chose five photos of greatest significance for discussion with the other participants at Meeting 3.

Meeting 3 was a focus group with all study participants invited. Each participant's photos were displayed on a projector for the group to see. No discussion guide was used by the researchers during the focus group; however, the participants used the SHOWED technique (Table 1) to introduce the majority of their photos. After each photograph was introduced, other members of the group were encouraged to discuss the photograph.

In Cohort 1, participants were then encouraged to attend Meeting 4, to which 150 area health care providers were also invited. The intent of Meeting 4 was to bring together participants and health care providers to promote shared understanding and discussion of potential change proposed by the participants regarding effective use and prescribing of mental health medications. Due to lack of provider attendance at Meeting 4 in Cohort 1, this step was eliminated in subsequent cohorts. Instead, interested participants in Cohorts 2 and 3 were invited to join the authors in presenting information about the study and their photos to an audience of mental health providers as an installment in a previously established monthly educational series (alternate Meeting 4). During each of these meetings, participants were asked to introduce their five selected photos to the audience, where again, discussion was encouraged.

Meetings 2, 3, and 4 (traditional and alternate forms) were audio-recorded and later transcribed. Participants were provided with a US\$10 gift card at the end of each meeting they attended. Meals were provided for all in attendance at Meetings 1, 3, and 4.

### Analysis

Data were analyzed using a modification of the three-stage participatory group analysis developed by Wang and colleagues (C. Wang & Burris, 1997; C. C. Wang, Yi, Tao, & Carovano, 1998). The three stages are (a) selecting photographs that most accurately reflect the participants' views, (b) contextualizing the photographs, and (c) codifying issues, themes, or theories that emerge. Stages (a) and (b) were completed by the participants in Meetings 2 and 3 as described above. The researchers collaborated to complete a qualitative analysis for Stage (c). A theme, identified as a concept that emerged from the written or spoken expression of a participant, included secondary themes with common identifiers that were grouped together to provide structure. Authors Werremeyer and Skoy independently performed line-by-line coding of data from Cohort 1. Discussion of emergent themes and reconciliation of discordant themes were done in concert with author Aalgaard Kelly, which resulted in a basic thematic framework and emerging model of medication experience. Author Werremeyer completed line-by-line coding of Cohorts 2 and 3, adjusting the thematic framework and model periodically to fit the data. Author Skoy reviewed data of Cohorts 2 and 3 and offered adjustments to result in the final model. Participants in attendance at Meeting 4 sessions were given opportunity to comment on the preliminary findings of the analysis, thus validating findings. The institutional review board approved all study procedures.

### Results

A total of 23 participants gave informed consent and were issued a camera and journal. Nineteen participants captured photos and attended Meeting 2 to reflect on their photos. The photos and transcripts from meetings attended by each of these 19 participants were included in the analysis. The demographic characteristics of the participants are listed in Table 2. The participants captured an average of 13 photos per person with a range of two to 27. None of the participants expressed a desire to have any of their photos removed from dissemination.

Saturation of emergent themes was reached by the eighth participant with no additional major conceptual themes emerging in analysis of additional participants. Most participants' depiction of their experience with medications was positive overall. However, each participant

**Table 2.** Sample Characteristics.

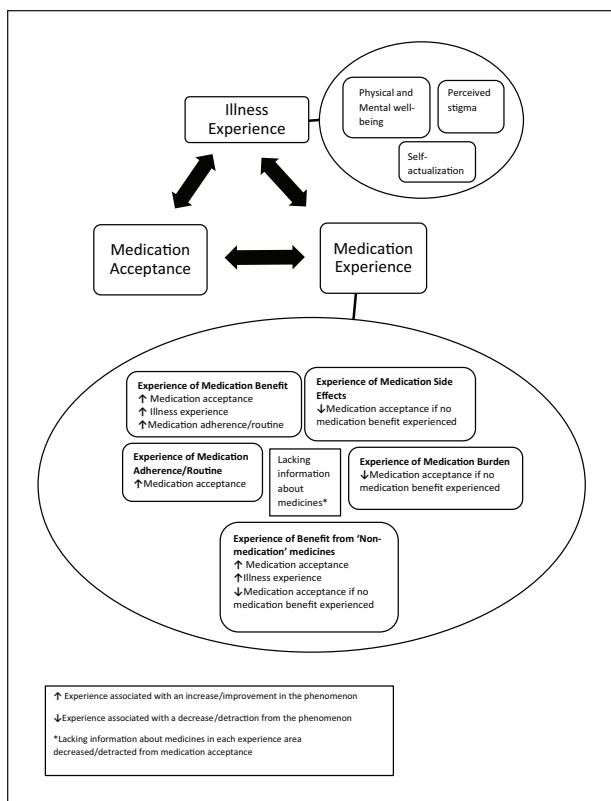
Characteristic	Result (N = 19)
M age (years)	35.9
Gender (% male)	16
Race/ethnicity (% non-Caucasian)	11
Mental illness diagnoses (n, %)	
Unipolar depression	13 (68)
Anxiety	13 (68)
Schizophrenia or other psychotic disorder	4 (21)
ADHD	3 (16)
Bipolar disorder	3 (16)
Substance use disorder	3 (16)
Borderline personality disorder	2 (11)
Prescribed medications (n, %)	
Antidepressant	17 (89)
Benzodiazepine	10 (53)
Other antianxiety medication	8 (42)
Mood stabilizer	7 (37)
Stimulant	5 (26)
Other sedative/hypnotic medication	5 (26)
Antipsychotic	4 (21)
Mean number of medications per person	9.4 (range: 2-28)
Mean number of psychotropic medications per person	3.6 (range: 2-6)
Mean number of years since most remote mental illness diagnosis	8.7 (range: 0.2-25)

Note. ADHD = attention deficit hyperactivity disorder.

identified some areas of their experience that detracted from their overall opinion of their medications. In general, the participants had realistic expectations of their medications, but all cited "wish-list" items that would improve their medication experience—especially wishing for psychotropic medications that worked on the first try and worked more quickly.

### Medication Acceptance

A core concept of "medication acceptance" emerged that was interrelated with and influenced by several categories of specific medication experiences as well as overall illness experience. The model in Figure 1 illustrates the relationship of these themes as emphasized by the participants. In this study, medication acceptance was conceptualized as willingness to embrace, receive, or take on medication due to a fundamental understanding of its effect on life/self improvement. Medication acceptance was often accompanied by a willingness to endure a negative aspect of medication to reap the benefits. Without using the words "medication acceptance," each of the participants described their thoughts and/or feelings

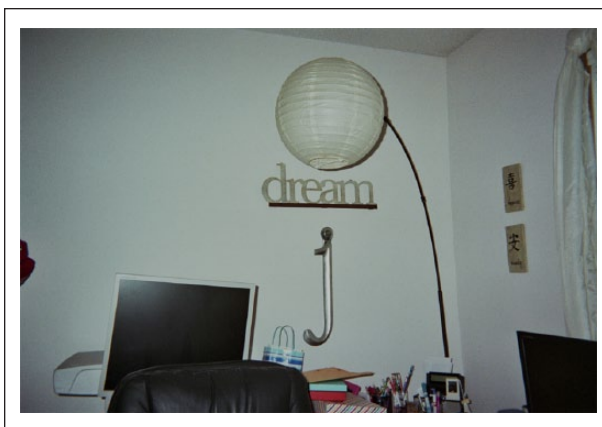


**Figure 1.** Medication Experience Model.

about their medications in relation to who they are as a person. The participants' dialogue highlighted a conceptualization of what the presence of medications meant for their independence, function, and self-examination. One female participant articulated her version of medication acceptance in this way: "I don't know if [my choice to wear baggy clothing is] because of my meds or because I'm me, but then I thought 'I'm me and I take medication,'" indicating that she has accepted medication to the degree that her medication is part of who she is.

### Mental Illness Experience

Participants highlighted that medication acceptance and psychotropic medication experiences are rarely viewed as separate from experience of mental illness. All participants, when asked to share their medication experience, captured and described items that initially seemed disconnected from medications. For example, a female participant with recurrent depression captured a photo of a wall decoration showing the word "DREAM" and said, "I often stare at [my dream decoration] when I'm depressed and sick and it helps me to relax and take a breath and think of my future dreams and aspirations" (Figure 2). This participant chose to portray the difficult aspects of



**Figure 2.** Dream.

dealing with her depression, highlighting that medication was not always at the forefront of her experience of living with her depression. In addition, many participants captured images that represented the depth of struggle they experience because of their illness. Another female participant with depression and anxiety captured a photo titled "Blur" and said, ". . . the last 2 years I've had this major decline with my depression that everything has just become a huge blur." Several similar symbols of what it is like to be depressed, anxious, unsure of reality, and so on were depicted and discussed by the participants, indicating that the illness itself was a significant area of focus, even as the participants were being asked to describe their medication experience. Perception of stigma associated with mental illnesses was also evident, which shaped the illness experience for many. A strong desire to eradicate public stigma associated with mental illness predominated. This was associated with the thought that images portraying the illness experience could make it more real to nonsufferers and reduce stereotypes about mental illnesses. A sense of pride in having dealt with and survived mental illness emerged as a strong aspect of the illness experience. The participants portrayed aspects of their self-actualization with mental illness and their recognition of the interaction between mental illness and physical illness as well. These illness experience-related themes have been described in more detail elsewhere (Werremeyer, Aalgaard-Kelly, & Skoy, 2016).

It was evident that mental illness experience affected medication acceptance and vice versa. Many participants had a general sense of recognition that symptoms of their illness necessitated medication treatment, thereby promoting their acceptance of medications. Furthermore, the experience of taking medication for the illness often shaped the illness experience thereafter, making it seem less daunting. Conversely, a sense of doubt about whether the illness was correctly diagnosed conferred a lower



**Table 3.** Specific Aspects of the Medication Experience.

Theme	Subthemes
Medication benefit	<ul style="list-style-type: none"> <li>• Need for additional information</li> <li>• Commitment to taking the medication when it is beneficial</li> <li>• Goal setting and hope based on medication-related improvements</li> <li>• Frustration when no benefit or quits working</li> <li>• Frustration with repeated trials or waiting until medication works</li> </ul>
Medication side effects	<ul style="list-style-type: none"> <li>• Need for additional information</li> <li>• Impact on function, quality of life</li> <li>• Choice between benefits and risks</li> <li>• Fear of long-term side effects</li> <li>• Difficulty with deciphering side effect versus illness itself</li> </ul>
Routine and adherence	<ul style="list-style-type: none"> <li>• Need for additional information</li> <li>• Importance of routine</li> <li>• Consequences and effects of nonadherence</li> </ul>
Burden, responsibility	<ul style="list-style-type: none"> <li>• Need for additional information</li> <li>• Exhausting, overwhelming to keep up with</li> <li>• Cost</li> </ul>
Nonmedication therapies as medicine	<ul style="list-style-type: none"> <li>• Need for additional information</li> <li>• Pets</li> <li>• Exercise</li> <li>• Supportive other</li> </ul>

subjective medication acceptance attitude. The three participants in our study, who had been diagnosed with a mental illness less than 1 year prior to enrolling in the study, tended to express more ambivalence about medication acceptance, indicating that a time course of illness experience may be influential in promoting medication acceptance.

**Specific Aspects of Medication Experience**

Many specific aspects of the medication experience (Table 3) were contributory to medication acceptance in various ways, some promoting greater acceptance of medication, others detracting from it. Some of the detractors’ effects were lessened as medication acceptance grew. For example, a patient initially experiencing shame as a result of needing antidepressant medication described a significant reduction (but not elimination) in the perception of shame as the medication was increasingly beneficial and she grew to accept it. The initial shame experienced was nearly enough to convince the patient not to take the medication, but her experience convinced her otherwise. In this way, growth of medication acceptance also fed back to the specific aspects of the medication experience to make



**Figure 3.** Medication benefit.

the participant experience them as more tolerable. This pattern was exemplified repeatedly.

Within every specific aspect of the medication experience, there was discussion about lack of information. Lacking information or having unrealistic expectations of a medication detracted from the overall quality of medication experience, the illness experience, and medication acceptance.

*Medication benefit.* The most emphasized aspect of the medication experience was recognition of medication benefit. The participants depicted in their photos the sometimes dramatic difference they noticed in themselves when their medications were perceived to be working to improve symptoms. This was often accompanied by descriptions of expanded functioning and return to previous life roles, which buoyed their spirits further. For example, a female participant used the photo in Figure 3 to illustrate the following:

With the medications, I can tell my mind is clear and I’ve been able to take some online classes . . . The meds help to keep me from getting angry and rage. I can control things better now . . . Meds can help you be more social and help you maintain and sustain relationships.

The more the participants recognized benefit from their medications, the more likely they were to accept them. A male patient with bipolar disorder stated, “I did not want to take medications, I felt so defeated . . . then one day it works and you feel so grateful. I realize that I will always need to manage my mood.” There was a strong emphasis on the benefits of medications being a strong “convincer” to be adherent to taking medications. A female patient with depression said,

Sometimes your meds can take a back seat to what is going on in your life, but if they do then that’s going to negatively

affect your life later on . . . I'm making myself choke down these pills. I don't like taking these meds in the morning because they make me feel sick, but I know that I have to or I won't be in control of my own head and that's when I get really scared.

Recognition of the benefit of medications also often led participants to set goals or articulate hope for the future based on medication-related improvements.

The participants also frequently emphasized the struggle when medication benefit is lacking or significantly delayed. A female patient with anxiety used a photo of her bed to illustrate this, stating,

It is just very difficult when you change a med . . . as you are waiting for them to change the situation [and] make it feel better . . . The bed was very representative of how I spent most of my winter and spring months until I got on the meds that I'm on now.

Like most of the other participants, this participant expressed concern about not being informed about the time it would take for the medication to become effective nor how to manage in the interim, "I was just waiting for the meds to start working. I think as a provider you could say to people, you may have ups and downs [while waiting for the medication to work.]" Participants described times of lack of medication benefit as "being at the medication's mercy," frustrated that they had to rely on and wait for medication to work, yet many of them did not doubt that it would eventually work. This lack of doubt generally came from their past experiences (and/or experiences shared by others—see "Nonmedication Therapies as Medicine" section) when medication benefits brought them to a state of good symptom control.

*Side effects/fear of long-term effects.* The participants described many problems they experienced with side effects of their medications. The most common side effects that had a significant impact on the participants were weight gain, sleepiness, and cognitive concerns (feeling like a zombie). The participants depicted the ways in which side effects negatively affected their function and contributed to their sense of helplessness when dealing with their medications. Many participants commented that they were not informed about what to expect and wished they had known sooner how they could better manage side effects. For example, a female participant with schizophrenia used the photo in Figure 4 to describe the following:

[This] shows my weight gain as a side effect. The Zyprexa, I gained 70 pounds, which is a lot to gain . . . Some people just blame you that you are just eating too much, but they could educate you more about eating healthy . . . [I was not aware], of the possibility of weight gain, I looked it up on my own, no one really told me.



**Figure 4.** Scale wars.

Another female participant with depression and anxiety said,

I think I feel really cloudy a lot of the time . . . sleeping all the time, you just kind of feel dazed over all the time . . . Just showing how severe the side effects of the medication can really be.

The experience of impactful side effects detracted from the participants' acceptance of their medication but often was not of high enough significance as to overcome perceived medication benefits. Participants framed this idea in terms of the pros and cons of a particular medication or combination of medications, many times citing their preference for continuing to experience the side effect over the symptoms associated with the untreated illness. For example, a female participant with anxiety commented,

"I have not much energy . . . just really sleepy. I think it is mainly a side effect . . . [but] I would rather be tired than feeling like I am so jumpy all day."

The participants also articulated fear of long-term side effects from taking medications. For example, a male participant with recurrent depression stated, "[I] lined up all my meds and I thought, how can this possibly be good for me and at what point do the positives of medicine turn into a negative?" In general, this was emphasized much less that the actual occurrence of side effects. However, it did contribute to participants' sense of unease about their medications and detracted from their acceptance of them. Finally, the participants described uncertainty about whether something they felt was a true side effect or a symptom of suboptimally treated illness. Confusion about this nuance often contributed to frustration about medications and detracted from acceptance of them.



**Figure 5.** Medication routine and lifestyle.

How do you in your mind decide if it is your illness or medication causing the symptoms? . . . I don't know if it is the medication that isn't working well or is the depression getting worse . . .

**Routine of taking medications/lifestyle.** The importance of the lived experience of establishing and keeping routines surrounding medications was emphasized by participants. They described ways in which they had learned to manage to regularly take medications and organize their lifestyle and habits to maintain this regularity. Participants also depicted times in which they abandoned their routine of medication-taking. They depicted the lived consequences they experienced in these instances. For example, a female participant with depression stated,

One time I was so fed up [with medication] that I said I was over it and stopped taking it and I went out drinking and ended up hospitalized and wanted to kill myself . . . I don't think I knew how bad it could be and that you should not stop taking medication unless you have talked to someone about it first . . . The other week I had to get one of the pill containers and literally had to dose out my week because it is complicated . . .

Establishment of a medication routine was often related to medication acceptance, but in varying ways. Some participants described establishing a routine as a means to get their life back in order, which was followed by acceptance of medication as a part of that process. Conversely, and more often, participants described recognizing the need for routine only after repeated experiences of suboptimal illness control associated with sporadic or nonexistent medication-taking patterns. Either way, the medication experience informed the routine and the recognition of its importance for the individual. A male participant with bipolar disorder used the photo in Figure 5 to illustrate this theme in this way:

Represents that alcohol was a depressant and coffee would provide the opposite, I had to learn that if I was having a

bad day, then no alcohol at all. I am very good about not mixing alcohol with the mental health medications . . . As far as coffee, energy drinks, it could trigger a mood swing. I drank an energy drink, but forgot that I had taken a Ritalin. I started getting very angry and everything was bothering me . . .

This participant and others also pointed out that they lacked education about this important aspect of optimizing medication effect at the outset, and he recommended that such a vital conversation should take place.

“ . . . As far as learning how to manage medication and caffeine and alcohol, [these] were never discussed with me. I think this is something that professionals should be aware of and talk to patients about that.”

**Burden/responsibility.** The burden and responsibility of continually managing medications was emphasized. Participants portrayed this concept as adding one more task on top of their already overwhelming collection of responsibilities. For example, a female participant with depression and anxiety when discussing her photo depicting a pile of medication bottles stated,

“It is one thing to say that I take these, but then when I look at all of them it is so overwhelming.”

Participants described occasionally getting fed up with the task of taking medications or feeling exhausted by all that medication-taking required. Sometimes this exhaustion with medications was further fueled by financial burdens caused or contributed to by medication costs or poor insurance coverage of medications. Overall burden/responsibility of medications was portrayed as detracting from medication acceptance. Most participants seemed to be equally likely to report feeling the burden of medications at times. However, in those with a qualitatively higher level of medication acceptance, the burden of medications was less prominent.

**Nonmedication therapies as medicine.** In addition to the pills, tablets, capsules, injections, and patches, the participants considered their medications; they also conceptualized many other items as “medication.” When people, animals, ideas, or experiences were able to help bring about peace, health, and/or healing, the participants often referred to them as part of their medication(s). Several participants stated that while they knew that traditional prescribed medications had an important place in their treatment, other approaches were often just as necessary to achieve full wellness. For example, a female participant with depression and anxiety used a photo of a tree in a park to illustrate this point:



I think the ability to go out and experience the day is the medication I receive . . . I think that people don't realize that it is more than medication, that there is counseling, and talking out the problems and the issues.

Many other participants captured photos of pets and relayed statements similar to the one made by a female participant with depression and substance use disorder,

"[My cats] are probably just as therapeutic as any other tool to handle stress."

The participants urged health care providers to incorporate these nonmedication medicines in their overall approach to managing mental illness with their patients. Several participants expressed gratitude for having been encouraged to engage in these nonmedication approaches and highly encouraged others to do so. Interestingly, the identification of valuable nonmedication medicines did not detract from overall medication acceptance. The participants acknowledged that these nonmedication medicines were best if used alongside their traditional prescribed medications, but not replacing medications altogether.

Many participants specifically identified the presence of a supportive person in their lives who helped them to grasp important information about medications, see past a stigmatized view of psychotropic medications, and/or to focus on bettering themselves. Furthermore, participants frequently commented that hearing about the medication experience(s) of others helped them to overcome doubts, shame, or frustrations they had about their own medications. The presence of a supportive person was described as a helpful tool supporting medication acceptance and overall improvement in illness experience. The following three quotations exemplify these sentiments as described by three different participants:

. . . [My classmate and I] got along well together. I was dealing with many symptoms . . . one night I told her I had taken a Xanax and was too tired to work. It opened up communication and she told me she was on medication for mental health . . . We still talk about how we are managing things . . . Support is really important . . . to have a support who knew what I was going through was very good. I think that is something that should be encouraged is to see what others are experiencing too.

I had a friend who was on the same meds and she said it would get better as I got used to it.

[Female in photograph] has dealt with a lot of the issues like I have. She was just somebody that takes medicines and has depression and has just been a real good support . . . she was actually the one who suggested [that I take] the Vivarin [to combat medication-induced sedation]. She said, "Why don't you just try it until you can see your doctor?"

*Photovoice benefit.* Although not a major point of emphasis of the participants, or directly part of the medication experience, several of the participants pointed out the beneficial effect of having participated in this photovoice study. The opportunity to reflect on their experiences seemed to confer a subjectively positive effect on mood and other symptoms. Also, individual participants pointed out instances where their participation in this photovoice study increased their medication adherence, increased their awareness of their own symptoms, increased their motivation to improve, and enhanced their buy-in to various types of treatment modalities. For example, a female participant when reflecting on a photo of her medication box commented,

"I feel like since I wrote this down and took this photo I'm doing better at [taking my meds on time]."

Finally, many participants commented on the support they felt from other study participants and were encouraged by the sense of community they felt with others who were also living with a mental illness.

## Discussion

This study is the first to examine the experience of living with psychotropic medications from a participatory action approach. This is significant as it left the possible areas of discussion about medication experiences wide open for the participants, allowing them to choose any and all topics to share. In addition, this approach allowed the participants to begin to propose preliminary solutions to medication and illness-related problems associated with their medication experiences. The participants were able to highlight areas of additional education and shared experience of others that would have been helpful on their medication and illness journey.

We found that asking about the medication experience led to an open conversation about the patient's medication acceptance and illness experience as well. This wealth of patient perception about what he or she is dealing with was highly revealing. It told not just whether a patient would take or respond to a medication but detailed how the medication realistically fit into the person's life and understanding of who they are. This goes beyond a simple discussion of medication adherence. It goes deeper into the root of the patient's views about the medication and its effects, which is likely to affect medication-taking behavior. Exploring the medication experience allowed the individual to describe the "why" and "how" and "what it feels like" regarding taking (or not taking) psychotropic medications, not just the "if." Many times the participants in our sample were surprised that we wanted to know this experience from their perspective, as they



had not ever been asked about it by health care providers. Many of the participants were also quick to point out how important the underlying experiences were for their providers to understand. A female participant with depression stated to providers:

Always be inquisitive . . . ask patients if [they] have had or made any changes since [they] have been on a medication . . . if you are not on medications or [do not] have this [illness], you may not know what questions to ask your patients.

The participants made it clear that when clinicians tell a patient to take a medication for a mental health condition without exploring the items in the model in Figure 1, there is a disconnect. Many participants expressed sentiments similar to “I wish my prescriber would see what this is like . . .” or “I wish my prescriber would have told me . . .” Some participants even described their prescriber blaming them for side effects or lack of response. This disconnect between what the patient is experiencing and what the provider understands about him or her seems to serve as a barrier to full acceptance and utilization of medication, with the patient suffering the consequences of that fallout. Making the connection between the patient, their medication experience, and their medication acceptance may promote optimal medication prescribing and/or monitoring by the prescriber, and optimal acceptance and adherence by the patient. This study suggests further research is needed to explore the impact of patient’s medication experience in the clinical setting to determine whether important patient-centered outcomes such as medication adherence, medication tolerability, symptom control, and quality of life can be improved.

This study adds to what is already known about patient’s perceptions and experiences with their medications. Several authors in recent years (Malpass et al., 2009; Moncrieff et al., 2009; Singh et al., 2010) have called for greater attention to the patient’s subjective experience of medications, and this study adds additional emphasis to this call, illustrating that the patients themselves see this as vitally important. Moncrieff et al. (2009) found that the subjective experience of cognitive and physical side effects from antipsychotic medications was commonly reported by people taking them. This study supports these findings and adds a much broader perspective, adding several additional aspects of psychotropic medication experience. Moncrieff and colleagues also reported that patients commented on the “difficult balance between the negative impact of the drugs and the improvement of symptoms,” which was found to be especially important in the current study. This finding underscores the importance of the medication experience discussion, as the patient’s own perception of the pros and cons of taking the medications may be a driving

factor in their acceptance of and adherence to them. The participants in the current study suggested that a provider may be able to leverage the positive medication experiences in a patient’s history as motivation for continued treatment benefit. Malpass and colleagues (2009), in their meta-ethnography of patients’ experiences of antidepressants, concluded that patient experience with antidepressants is composed of a decision-making process (whether to take the medication) and a meaning-making process (how antidepressants affect self-concept). The current study findings regarding medication acceptance and recognition of medication benefits appear to support the concept that the patient’s experiences with their illness and medication are likely to influence their willingness to accept and/or take medication going forward. The current study findings appear to add additional structure to the specific aspects of the medication experience and their possible influence on medication acceptance. In addition, findings here do not delineate separate processes of decision making and meaning making involved with the medication experience but portray medication acceptance as a weaving together of various aspects of medication and illness experiences that come together to form the individual’s attitude of acceptance of medication.

This study is the first to examine the medication experience of persons taking medications from more than one class of psychotropics. For example, three of the participants were taking an antidepressant and an antipsychotic in combination while 16 of participants were taking an antidepressant in combination with an additional psychotropic medication (benzodiazepine, mood stabilizer, etc.). This may explain why “burden/responsibility” of medications emerged as a significant theme in the current study whereas it has not been identified as a major finding in other studies reporting on psychotropic medication experiences. For many types of mental illness, prescription of more than one psychotropic is very common (Mojtabai & Olfson, 2010). Therefore, it is especially important for health care providers caring for patients with mental illness to explore the patient’s experience with the overall burden that medications confer on their lives.

The participants indicated that it was rare for a health care provider to explore the patient’s individual medication experience(s). This is perhaps not surprising given the recent trends in health care provider shortage and pressure for providers to see more patients in shorter periods of time. It may also be indicative of suboptimal understanding of the importance of the medication experience from the patient’s perspective. Future studies should explore additional ways in which the medication experience can be elicited from the patient with a mental health condition. Although the use of photovoice powerfully illustrated patients’ medication experience, it would not be practical

to conduct the photovoice process for every patient seen in a provider's office. Alternative methods for initiating the medication experience conversation between health care providers and patients should be developed. Furthermore, providers should consider how the collective medication experiences of patients they have encountered in their practice might be useful as well. The current study findings suggest that sharing the real experiences of other patients is quite instructive to and desired by individuals taking psychotropic medications. Vanelli's findings (Vanelli & Copperrailon, 2008; Vanelli et al., 2007) coupled with the current study findings suggest that secondhand shared experience regarding antidepressants and/or antipsychotics may be better than none.

The early saturation of themes and previous precedence of photovoice studies of this size (Cabassa et al., 2013; Jurkowski & Paul-Ward, 2007; Thompson et al., 2008) may minimize the limitation in sample size. In addition, consistent with the photovoice's participatory action spirit, participants' self-report of their diagnoses, medications, and medication experiences were relied upon. This could have resulted in false information being reported. Neither was medication adherence assessed by any validated means nor were any other quantitative assessments performed to measure items such as medication acceptance, medication attitudes/beliefs, quality of life, or disease/symptom control.

## Conclusion

Exploration of medication experience of patients taking psychotropic medications reveals much about their illness experience and medication acceptance. Many aspects of the medication experience may affect a patient in everyday life and influence his or her view of medications. Health care providers should be encouraged to explore the medication experiences of their patients with mental illness.

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