

Using Photovoice to explore patients' experiences with mental health medication: A pilot study

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Abstract

Introduction: The objective of this research is to explore and share the medication experience of those with a mental illness in order to gain understanding of the patient's medication perceptions as well as the impact of medication upon patients' lives.

Methods: Patients with a mental disorder were given cameras and asked to capture the experience of "living with my medication." Using Photovoice methodology, participants reflected on their photos individually and in focus groups. Conceptual themes were drawn from the data.

Results: Five participants captured an average of 14 photos each. Self-efficacy with mental illness, mental and physical health connections, and education were the 3 most prominent themes. Aspects of medications were interwoven within these themes but were not the primary focus of the participants.

Discussion: Medication experiences of patients with mental illness may encompass much more than the medications themselves.

Keywords: medication, Photovoice, mental health, mental disorders

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Introduction

Mental disorders account for a substantial amount of the disease burden in every country of the world.¹ Mental disorders can be treated using a variety of treatment modalities. One of these modalities, prescribing of medication, is frequently employed. Medications to treat mental disorders accounted for 14 of the top 100 most frequently dispensed prescription medications in the United States in 2013.² Although countless studies

describe successful treatment outcomes with the use of psychotropic medications,^{3,4} many others also describe challenges, including side effects,⁵ high rates of non-adherence,^{6,7} and significant financial expense.⁸ These challenges have been identified, and yet adherence rates, achievement of symptom remission, and approaches to mental health care remain suboptimal.⁹⁻¹¹

Individuals with mental disorders are often marginalized and/or stigmatized.¹² They may have little input into their own health care, including medication decisions, and may receive less than adequate education about their condition and its treatment.^{13,14} They may also have limited ability or opportunity to speak out about discrimination, health policy, and other issues that may disproportionately affect this population.^{14,15} Prescribers may not take the time to explore a patient's acceptance or preferences of psychotropic medication. However, this medication experience from the patient's perspective may offer rich



- S What is Seen here?
- H What is really Happening here?
- O How does this relate to Our lives (your life)?
- W Why are things this Way?
- E How could this image Educate others?
- D What can we Do about it?

FIGURE 1: The SHOWED technique

information that can improve medication offerings, education, and outcomes for individuals. The medication experience has been defined as “an individual’s subjective experience of taking a medication in his daily life.”^{16(p86)} Previous research has suggested that knowledge of patients’ medication experiences may serve as a guide for tailoring education about medications¹⁷ and may help prevent and solve medication-related problems.¹⁸ Hence, examination of a patient’s medication experience is important for health care providers in order to inform better patient care.

Photovoice participatory action research methodology seeks the voice of marginalized individuals and groups. Pioneered by Wang and Burris,¹⁹ Photovoice is a process in which individuals use cameras to photograph their everyday realities, thereby focusing on issues of greatest importance to them and communicating these issues to those who can make changes.²⁰ Photovoice studies typically invite participants who have first-hand experience with 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 explore, document, and share the experience of people who may not otherwise have a voice,²¹⁻²⁴ including those with mental disorders.²⁵⁻²⁷ To our knowledge, Photovoice has never been applied to the medication experience of individuals with mental disorders. The prior success of this methodology in sharing the perspective of individuals with mental disorders led us to choose it to explore the medication experience in this group.

With this exploratory study, using Photovoice methodology, we sought to describe the lived medication

experience of individuals who were prescribed a medication to treat a mental disorder. We aimed to gain understanding of patients’ perceptions of their medications as well as the impact of medications on the lives of patients with mental disorders. To date, 3 cohorts of participants have completed the study. The methods and results of the first pilot cohort (n = 5) are reported here.

Methods

Participants were recruited from a mental health partial hospitalization program via flyers and verbal announcement. Inclusion criteria were age 18 or greater and having been prescribed at least 1 medication to treat a mental disorder. No diagnostic criteria, assessment tools, participant chart reviews or minimum lengths since diagnosis or medication receipt were utilized; participant self-reports of the above criteria were relied upon for inclusion. Any individuals who had been assigned a legal guardian would have been excluded due to inability to independently give consent to participate in research. Interested individuals were invited to a meeting (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 a minimum, participants were asked to make a journal entry with each photo captured to document their thoughts and reasoning behind the photograph. Participants were also encouraged to use their journal as often as they liked. After 10 days, participants mailed their cameras back to the researchers who developed the photos and contacted each participant individually to set up the next meeting (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 guided the reflection about each photo using the SHOWED technique²⁸ (Figure 1) but also encouraged the participants to share additional thoughts and feelings. At the end of meeting 2, each participant chose 5 photos of greatest significance for discussion with the other participants at meeting 3.

Next, all participants were invited to a focus group (meeting 3). 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 technique²⁸ to

TABLE 1: Sample characteristics

Characteristic	Value (n = 5 participants)
Female	4
Mean age, years	37 (range: 19 to 48)
Education	
Some college	1
College degree	4
Mean number of medications per person	6.8 (range: 4 to 10)
Mean number of medications for mental disorders per person	3.6 (range: 2 to 5)
Prescribed an antidepressant	5
Prescribed a benzodiazepine	3
Prescribed a nonbenzodiazepine anxiolytic	3
Prescribed a nonbenzodiazepine hypnotic	2
Prescribed a stimulant	1
Average annual income, US dollars	46 000
Mental disorders	
Depressive disorder	5
Anxiety disorder	5
Attention deficit hyperactivity disorder	1
Substance use disorder	1
Physical disorders	
Insomnia	2
Hypertension	2
Stomach problems	2
Diabetes with microvascular complications	2
Fibromyalgia	2
Hypothyroidism	2
Dyslipidemia	2

introduce the majority of their photos. After each photograph was introduced, other members of the group were encouraged to discuss the photograph.

Participants were then invited to another group meeting with the researchers to which 150 area health care providers were also invited to attend (meeting 4). During this meeting, participants were asked to introduce their 5 selected photos to the group, and, again, discussion was encouraged. The intent of meeting 4 was to bring together participants and health care providers to promote shared understanding of the medication experience of the participants and to provide a venue for discussion and potential change proposed by the partic-

ipants regarding effective use and prescribing of mental health medications.

Meetings 2, 3, and 4 were audio recorded and later transcribed. Participants were provided with a gift card at the end of each meeting they attended. Meals were provided for all in attendance at Meetings 1, 3, and 4.

The researchers analyzed written transcripts of Meetings 2, 3, and 4 along with participant photos to identify conceptual themes. A theme, identified as a concept or idea that emerged from the written or spoken expression of a participant, included several secondary themes with similarities or common identifiers that were grouped together to provide structure for a phenomenon. Themes were extracted from the data using line-by-line coding performed by author 2, a medical sociologist with extensive training in qualitative methods. The themes that emerged were then organized by frequency. Next, another line-by-line coding was completed (by authors 1 and 3), which provided greater depth and interconnections of the themes. Finally, the themes were reorganized or combined by means of emphasis, frequency, or interconnections to further identify emergent primary and secondary themes. The computer software ATLAS.ti²⁹ was used to upload the voice recordings and transcriptions for each participant. The researchers created, organized, and interconnected each code and conceptual theme, and the software allowed for an organized means of analyzing the data. The institutional review board reviewed and approved all study procedures.

Results

Here the results of the first pilot cohort (n=5) of this research study are reported, in which 5 individuals chose to participate in the research and captured photos. Four of these individuals attended an individual reflection meeting, and 3 of these individuals attended both focus group sessions. The characteristics of the 5 participants are listed in Table 1. No health care providers attended meeting 4.

The participants captured an average of 14 photos per person (a range of 7 to 26 photos).

Living With My Medication Conceptual Themes

In this section, the 3 most emergent primary themes and their supporting secondary themes are summarized in Table 2. These represent the most discussed and most emphasized issues for the participants as they captured their medication experience. Space limitations prevent in-depth discussion of all 8 primary themes (Supplementary Table, available online at <http://dx.doi.org/10.9740/mhc>.

TABLE 2: Summary of themes

Primary Theme	Self-Actualization With Mental Illness	Mental and Physical Health Interconnections	Education
Secondary themes	Mental disorder perceptions Questioning self Advocating for oneself Day-to-day struggle Self-doubt Breaking point Mental disorder acceptance	Body image/physical well-being Physical description of self Depression and anxiety and their symbols Inheritance/generations Sleep Work: ability or inability	Education through experience Formal education Research study participation reaction
Summary	Taking responsibility and goal setting for improved mental disorder management Recognition and acceptance of mental disorder's impact on one's life Recognition of warning signs for relapse Desire to correct others' misunderstandings/stigmas about mental disorders Desire and commitment to overcome difficulties	Burden of pain and other physical conditions while dealing with a mental disorder Recognition of importance of healthy lifestyle Fear or dislike of physical effects of taking medications Physical manifestations of mental disorders Body image Genetic contribution to mental disorders	Importance of getting educated Encouragement to seek help when struggling and never give up Emphasis on lifestyle and avoidance of mood-altering substances Promote mental disorders/ substance abuse awareness in schools Tips for health care providers

2016.05.142.S1) that emerged from the data. Notably, “medication” was the eighth most frequently occurring primary theme. Although aspects of medication were interwoven among the 3 most frequently emerging primary themes, the participants generally gave voice to other areas of higher importance to them even as they described their medication experience.

Self-Efficacy With Mental Illness

The self-efficacy theme in this study was conceptualized as the process of the participants’ growth in their potential to manage and live with their mental disorder(s). This primary theme was supported by secondary themes listed in Table 2. The participants commented on the process of acceptance and incorporation of their mental disorder into their lives and understanding of themselves. For example, participant 2, when reflecting on a photo of her wheelchair and all the life struggles it represents in her life, said, “I have accepted the depression. I have surrendered to the depression and anxiety and that I can manage it.”

The participants discussed a desire to persevere in the face of struggles with mental disorders and a commitment to doing the work required to get and stay well. All of the participants commented that acceptance of their illness and desire to persevere hadn’t been with them since day 1 of their diagnosis but had been a process that took place over time. One participant in the group acknowledged that she was still on the path to fully accepting.

The participants also described growth in their understanding of the need to recognize signs of their disorders

and respond to those in healthy ways. Participants described that through their illness experience(s) they were able to identify patterns that to them indicated improvement or worsening of their condition. Participant 5 depicted his recognition of how his mental illness has been exacerbated (rapids/rough waters) and then overcome at various times (calm waters on the other side of a dam) throughout his life (Figure 2A).

The participants spoke passionately about their desire for others to understand the severity and impact of mental disorders on one’s life and their desire to help erase misperceptions about mental disorders. Participant 1, when reflecting on a photo of herself on what she described as “a really good day,” touched on the primary theme of self-efficacy (having an understanding of what it takes to manage her illness) and the secondary themes of mental disorder perceptions and day-to-day struggle simultaneously. She said, “Um...I really want people to recognize that depression and things like that are not a crazy person’s disease, cuz that’s what I thought growing up. ...It can affect anyone, and when it does, it can be one of the most challenging things in your life to get a hold of, and it takes a long time to get you where you need to be, and even then, it’s constant work every day.”

In addition, participants commented on their recognition of the need to advocate for themselves in their family and work communities and with health care providers in order to make sure all of their physical and mental disorder challenges were being addressed.

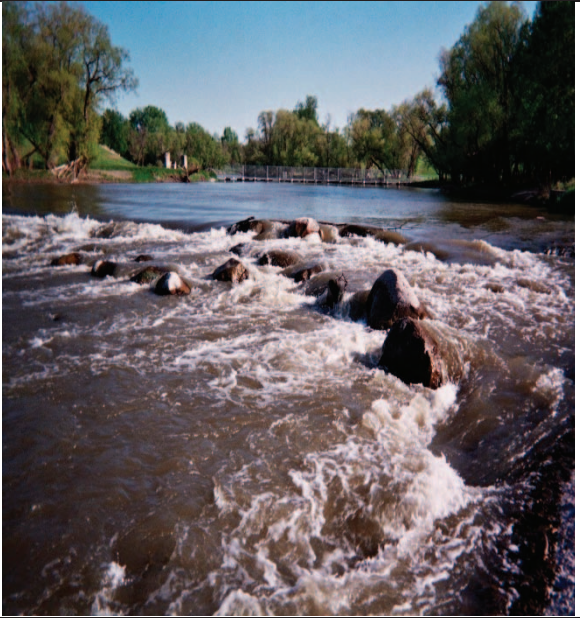

A	<p>Participant: “Before the dam it is as smooth as glass and then all of a sudden it turns into the white water rapids...I have had 4 episodes of major depression and all of them have been related to jobs... depression just tends to sneak up on you and you don’t see it coming and by the time you see it, you feel it is too late...Right now I feel like it is the calm.”</p>	
B		<p>“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.”</p>

FIGURE 2: Example photos and quotations on self-efficacy with mental illness theme

As described above, the participants captured and discussed the necessity of taking ownership of their mental disorder and the effort required to set and achieve goals for their illness management. This acceptance and ownership of the mental disorder(s) was at times accompanied by incorporation of the participants’ medication(s) into their lives. A sense of understanding medication’s role in the participants’ ability to be the best version of themselves and/or vowing to persist in finding the right medication to achieve their best function were mentioned. The photo and quotation by Participant 1 are an example of the incorporation of medication into this theme (Figure 2B). However, medication was often not the main focus of discussions about accepting mental disorders in one’s life or committing to overcome mental disorder symptoms.

Mental and Physical Health Interconnections

The primary theme of medical and physical health interconnections encompassed participants’ identification of the connections they perceived between their physical wellness/illness and their mental wellness/illness. This theme is supported by secondary themes listed in Table 2. All of the participants described and/or depicted physical manifestations of their mental illness (eg, weight

gain, poor diabetes control, poor personal hygiene or appearance) or their concern that such manifestations would eventually occur (organ damage). Participant 3, when reflecting on a picture of a moving leaf, described how her mental illness affects her physically (Figure 3A).

Additionally, the participants described the challenge of struggling with physical and mental disorders simultaneously. At times, this resulted in a cycle of poor physical health leading to worsening of mental health, which led to a worsening of physical health, and so on. This comment, provided by participant 1 when reflecting on a photo of her television is illustrative of the compounding of her mental and physical disorders: “This is what I do for relaxation, fun, and entertainment because with my depression I’m an isolator. I don’t like to go out and do things. With my chronic pain, I can’t go out and do things for longer than 20 minutes without having to take a break and lie down. And...that’s not healthy obviously to only be at home watching TV because you don’t feel like doing anything or your body won’t let you.”

Within this theme, medication was depicted by the participants as a tool to aid in mental and physical wellness simultaneously but one that could also exacerbate a physical illness, cause a new one, or induce



A		<p>“I shake when my anxiety gets really bad. I can try [to stop the shaking], but it doesn’t work.”</p>
B	<p>“[This is] just showing, the process you have to go through and because of my diabetes and [the] condition I’m in all the different depression and anxiety [medications] I’m on now and if I would have taken care of myself and taken my medication and exercised, I would be healthy and I wouldn’t need ¾ of these medications.”</p>	

FIGURE 3: Example photos and quotations within mental and physical health interconnections theme

apprehension about a new one occurring. Medications were also described as a burden by each of the participants at times, especially when several medications were needed to treat coexisting physical and mental health conditions. For example, participant 2 depicted the amount of medication she needed as well as a recognition that perhaps better self-care in the past would have reduced the current medication need (Figure 3B). The participants also commented on the passing on of mental disorders in a physical way through genetics. Descriptions of mental disorders suffered by grandparents were accompanied by discussion about mental disorders running in families. The participants voiced concerns that they may also pass on mental disorder susceptibility to future generations.

Education

Consistent with the SHOWED technique used in the methodology of this study, the participants voiced ideas about how their photos could educate others. The secondary educational themes are described in in Table 2. Health care providers and fellow mental disorder sufferers were identified by the participants as the main target populations for education.

All of the participants related their experiences in dealing with their mental disorders and their medications in terms of things they had learned. They often felt that these insights would be useful and educational if shared with others. Figure 4A contains photos and quotations that are suggestions made by the participants about how their photos could educate others with mental disorders.

Additionally, the participants commented on the education they received from health care providers, and they described ways in which they felt education could be improved. One participant even suggested that health care providers ought to hold patients more accountable for following through on treatments and lifestyles that would improve their health status. The photos and quotations in Figure 4B are suggestions or comments made by the participants about how their photos could educate mental health care providers when providing education to their patients.

Participants also described how important formal and informal education has been for them and ways in which educational systems could improve to better serve those who suffer from mental disorders. One participant stated, “The school system is set up for the average kind of kid. They want things done one way and they are not open to different ways. School wants quiet, no talking and organization, and that is the total opposite that kids with ADHD have, and the school doesn’t want to educate them that way.”

They also commented on the pride they held in regard to their own educational achievements and how no matter what they struggled with, their education could never be taken away from them. Finally, the participants briefly discussed how their participation in the study had served as an educational activity for them in that it helped them to reflect on their experiences and understand them better.






A. Photos and quotations that can educate others with mental disorders	
	<p>“Stay on the meds, keep up with therapy, keep working.”</p>
<p>“I think that people know meds are already expensive...I have changed to generic drugs to help with costs.”</p>	
	<p>“It could educate them on being or having a goal and not wanting to have to be a prisoner all my life. I have things I want to do in my life. I want to run a marathon, I was a runner before I lost my health...I want people to see they can overcome their bumps in the road too.”</p>
<p>“It could educate them about the benefits of physical exercise when you are going through difficult times and don’t put it on the side burner. It would have helped me through this past year more.”</p>	
	<p>“Get help if that is how depressed you are if you are seeing things as a dripping faucet... Easiest [way to get help] would be for people to call their doctor, one they can trust and take their advice.”</p>

FIGURE 4: Photos within education theme






<p>“Just to remind people who have not gone to school or have dropped out and feel it is too late, I believe it is never too late...”</p>	
	<p>“I think it is for other people to see that they can do it and they can pursue their dreams and it is never too late. If that is your dream of being educated then go for it and don’t let anybody tell you differently.”</p>
<p>B. Photos and quotations that can educate mental healthcare providers</p>	
	<p>“...Provide the education on how people can deal with stress.”</p>
<p>“[Tell your patients] not to abuse alcohol...Let people know about abuse. I had no idea there was a drug that would make you sick if you drank.”</p>	
	<p>“All the people and physicians don’t push people hard enough, that could be something they could do better.”</p>

FIGURE 4: Photos within education theme (continued)

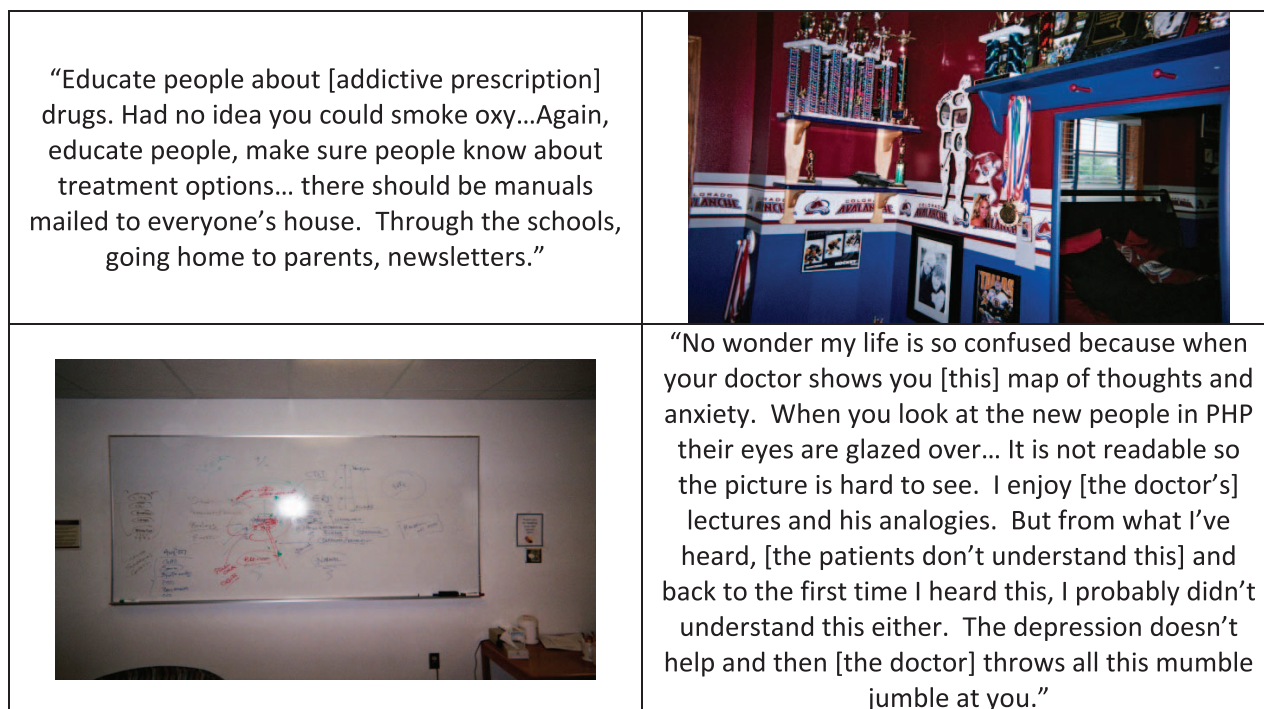


FIGURE 4: Photos within education theme (continued)

Discussion

Although the participants in this study mentioned their medications relatively frequently, they did not often focus solely on medication as they described their individual and collective experience of “living with my medication” through Photovoice. Instead, they tended to focus on their experience as they struggled to fit their illness into their lives, and to come to terms with it. Even as the researchers asked the participants to specifically capture their medication experiences, the participants universally broadened their medication experience to discussion of their illness experience. They commented on their bodies and their minds and how they work together, discussing medication’s impact on that interface but also focusing on the life impact of having their minds and bodies function suboptimally. This patient perspective of the inseparability of the medication from the disease process could be extremely instructive for health care providers who seek to partner with their patients to improve psychiatric disease through use of medications. Our findings are consistent with the adaptive response to serious illness theory suggested by Fife,^{30,31} wherein individuals make meaning of their illness experience based on how the illness affects their identity as well as the social circumstances surrounding the illness. The participants in this study portrayed “meaning making” of their disorders (both mental and physical) and medications as they captured and described their self-awareness of the symptoms and impacts of their disorders simultaneously with their recognition of the way others viewed their

disorders. Perhaps internalizations of the disorder along the lines of those captured in this study are necessary in an individual before medication can take on its own meaning. This is consistent with the findings of Malpass et al³² in their meta-ethnography of patients’ experiences of antidepressants, wherein decision making and meaning making were 2 important processes in the taking of antidepressants. The participants in this study had recently recovered from a serious episode of their mental disorder, and as such, perhaps they were wading through the process of meaning making anew as they adjusted. Future research might explore the medication experience of individuals who are farther removed from a serious episode of their illness as compared with those who have recently recovered. In addition, examination of patients’ internalization of the meaning of psychiatric illness and its association with medication adherence may be an avenue of further study.

The findings in this study illustrate that the lived medication experience is much more than the pills themselves. The emphasis by our participants on self-efficacy and mental and physical health interconnections suggests that perhaps patient-provider discussion that focuses explicitly on medication is not appropriate to many with mental disorders. The lower emergence of the medication-focused theme as compared to the theme of self-efficacy in our results suggests that helping patients to link the meaning of the medication to their meaning of the disorder may be beneficial to furthering acceptance of the medication itself.

Previous research has examined the medication experience of patients from the perspective of the pharmacist. The research of Shoemaker and Ramalho de Oliveira¹⁶⁻¹⁸ has highlighted that examination of the patient's medication experience may be useful to direct the education provided to patients and may lead to uncovering of medication-related problems. Our findings, taken from the perspective of the patient, support these conclusions, but also may significantly broaden their interpretation. Shoemaker et al¹⁷ concluded that, based on a patient's medication experience, medication information can be tailored to individuals to optimize outcomes, and we suggest that medication information in isolation may not be relevant for people with mental disorders but instead can be put into context by connecting with information about disease. Connecting medication information to patients' self-efficacy process as they maximize their potential to successfully internalize and manage their disorder may be valuable. Our findings also suggest that educating mental disorder patients about the connection between their minds and bodies and the ways they can keep both healthy, including appropriate use of medications, is welcomed and needed. Furthermore, it became apparent that mental disorder sufferers may have specific educational suggestions for their providers and may be able to help direct their own education if health care providers ask them. Finally, unlike Shoemaker and Ramalho de Oliveira¹⁶ in their definition of the medication experience, we specifically chose and used the language "living with my medication" rather than the language "taking medication" to avoid any assumption that patients were taking their medications because not taking medication (intentionally or unintentionally) is also part of the medication experience. The implications of this difference in verbiage may deserve further study.

To our knowledge, Photovoice methodology has not previously been used to explore medication experience in persons with mental disorders. The use of Photovoice allowed the participants in this study to express their perspective on living with their medication in their own unique ways and to completely direct the discussion and areas of emphasis. The benefit of this opportunity to share their health realities on their own terms is similar to what has been described in previous research employing Photovoice methodology with participants who suffer from mental disorders.²⁵⁻²⁷ It is unclear how the use of Photovoice to examine the medication experience may differ from other approaches, including survey or qualitative interviewing methods. Our findings suggest that rich perspective about medication experience can be gathered with a Photovoice approach, and it even led to deep reflection and understanding on the part of our participants. Further research should specifically examine the effects of Photovoice participation as well as compare the

different methodologic approaches for examining the medication experience.

Our findings should be viewed with several limitations in mind. Our sample size was small and, therefore, limits the generalizability of our findings. However, there is precedent for small sample sizes such as this according to previous published work utilizing Photovoice methodology.^{23,33,34} The fact that the participants in our study were recently recovered from a serious episode of their mental disorder may also limit the generalizability of our results to other patients with mental disorders. In addition, the researchers may have unknowingly imparted their biases during their interactions with the participants and/or during the data analysis. The separate layers of data analysis likely reduced but did not eliminate the imposition of bias. We did not assess the participants' medication adherence prior to or during their participation in the study and, therefore, cannot comment on whether participants who were indeed taking their medications had a qualitatively different experience than those who were not. Further research should explore correlations between medication experiences and medication adherence among people with mental disorders. Finally, the lack of health care provider attendance at meeting 4 of this study is troubling. It may simply reflect busy provider schedules or inconvenience of traveling off-site from their health care practice sites to attend the meeting. However, it may also suggest lack of interest on the part of the health care provider to explore the medication experience of patients. The researchers plan to adjust the methodology in the future in order to bring the participants and health care providers together.

Conclusion

The medication experiences of those with mental disorders as explored with Photovoice methodology may encompass much more than the medications themselves and may include their self-efficacy with disease management, connection between mental and physical disorders, and aspects of education surrounding mental disorders.

The implications of this research suggest that information about medications may be most meaningful for those with mental illness when it can be put into context with information about the disorder and connected with the patient's process of self-actualization with their disorder. Our findings also suggest that educating mental disorder sufferers about the connection between the health maintenance methods for both their mental and physical conditions, including appropriate use of medications, is desired. This education may be best delivered via methods suggested by the patients themselves.

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