Research Article

Retrospective Accounts of the Process of Using and Discontinuing Psychiatric Medication

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Abstract

Refusal to take psychiatric medication as prescribed is often considered negative, harmful, and even reflective of a sign of one's illness. However, recent research from diverse sources has challenged this axiom. The current study investigated the reasons, processes, experiences, and perceived impacts of medication discontinuation. The study was carried out using the narrative approach to life stories method. Participants were 12 women and 9 men who had discontinued their prescribed medication following psychiatric hospitalization. Four main themes were revealed in the data analysis: (a) the experience with medication, (b) the process of discontinuing medication, (c) elements that helped achieve successful medication discontinuation, and (d) the perceived impact of medication discontinuation. Our findings challenge the widespread notion that discontinuing psychiatric medication is necessarily negative and suggest that, for some, it is a legitimate and meaningful life choice.

Keywords

discontinuation of medication; Israel; narrative interviews; psychiatric care; qualitative research; serious mental illness

Treatment guidelines recommend antipsychotic medication as the core treatment for psychosis (American Psychiatric Association, 2013; National Institute for Health and Care Excellence, 2014). Despite decades of research supporting the effectiveness of psychiatric medication in alleviating symptoms when taken as prescribed (Goff et al., 2017; Leucht et al., 2013; Nathan & Gorman, 2015), it seems that only about half of those administered with medication actually adhere to clinicians' recommendations (Subotnik et al., 2011). The Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study reported that 74% of individuals who were prescribed medication discontinued within 18 months (Lieberman et al., 2005), whereas other trials reported 30% to 50% discontinuation rates (Haddad, Brain, & Scott, 2014; Marshall & Rathbone, 2011).

Traditionally, when mental health service users did not adhere to providers' recommendations (did not take their medication), it was considered harmful and even a reflection of the illness (lack of insight, poor judgment, faulty reasoning; Corrigan, Morris, Michaels, Rafacz, & Rüsch, 2012). The terms "noncompliance" and "nonadherence" critically describe the act of medication discontinuation. Accordingly, the common response to the widespread and well-documented phenomenon of disengagement has been to develop strategies to improve adherence and services utilization (Dixon et al., 2009; Kreynbuhl, Nossel, & Dixon, 2009).

However, recent research from a range of sources has challenged this widely held point of view, which criticizes the discontinuation of psychiatric medication and has begun to expand the professional discussion about nonadherence as a personal and legitimate choice (Roe & Davidson, 2017). The first source of knowledge stems from studies on the long-term impact and side effects of medication, which challenge its positive effects (e.g., weight gain, sedation, and motor symptoms, such as akinesia and other Parkinson-like symptoms (Haddad, Fleischhacker, et al., 2014; Ho, Andreasen, Ziebell, Pierson, & Magnotta, 2011). In addition, brain volume reduction, which has been argued to result from antipsychotic treatment (Ho et al., 2011), and doubts about the long-term positive effect of antipsychotic medication were also raised (Zhao et al., 2016).

The second source of research has challenged whether making health-related decisions, which are not in accord with providers' recommendation, is necessarily negative.

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This source stems from research showing that providers and users disagree about a broad range of treatment issues (Hasson-Ohayon, Kravetz, & Lysaker, 2016; Hasson-Ohayon, Roe, Kravetz, Levy-Frank, & Meir, 2011; McCabe & Priebe, 2004; Roe, Lereya, & Fennig, 2001; Shadmi et al., 2017; Themistocleous et al., 2009). Thus, disagreement on medications use may be seen as part of a broader disagreement, due to discrepancies about how the pros and cons of treatment are perceived. Studies have shown that whereas clinicians emphasize the need to treat positive symptoms (e.g., delusions and hallucinations), service users are more concerned with well-being and self-esteem (Bridges et al., 2013; Moritz, Berna, Jaeger, Westermann, & Nagel, 2016). This may be perceived as a gap between the clinical and personal approaches to recovery. Whereas clinical recovery is focused on symptoms' reduction, personal recovery focuses on values such as autonomy, choice, and agency (Silverstein & Bellack, 2008). Accordingly, from a clinical recovery perspective, discontinuing medication may be seen as potentially harmful. In contrast, from a personal recovery viewpoint, it might signify progress in the form of a manifestation of activating one's self-determination and personal treatment choice, rather than a problem generated by poor mental health (Hasson-Ohayon et al., 2016; Roe & Davidson, 2017; Roe, Gornemann, & Hasson-Ohayon, 2016; Roe et al., 2001).

The third data source includes studies that specifically addressed the subjective experience and the reasons for stopping medication usage, criticizing the assumption that the reasons are related to poor judgment. These few recent publications, mostly qualitative studies, showed that service users choose to stop using medication for a variety of reasons, including because of the way the medication was introduced, prescribed, and administered (Roe, Goldblatt, Baloush-Klienman, Swarbrick, & Davidson, 2009); negative side effects; feeling like a "guinea pig"; stigma (Swarbrick, Brockelman, & Roe, 2011); and having "gain from illnesses" (e.g., voices such as social surrogates, delusional ideas that impart them with meaning and power; Moritz et al., 2013; Moritz et al., 2009).

A recent study has also suggested that decisions about medication use are not linear, but rather vary over time, influenced by one's personal theory of medication need and acceptability (Le Geyt, Awenat, Tai, & Haddock, 2017). An even more recent survey of 250 persons in the United States diagnosed with Serious Mental Illness (SMI; Ostrow, Jessell, Hurd, Darrow, & Cohen, 2017) revealed that factors of support and coping were important during the process of coming off medication. Accordingly, coping mostly through self-education and support from friends and others who went through similar experiences seem to be most helpful in the process. Notably, the survey showed that more than 80% were satisfied with their decision. Salomon and Hamilton (2013) analyzed the responses of 98 persons in Australia who discontinued medication and found that discontinuation was influenced by contextual factors, such as distrust in the biomedical model, side effects, and communication with providers. Thus, studies conducted in a range of countries using different methodologies emphasized the impact of context, support, and coping abilities. From this perspective, nonadherence can be viewed as a personal choice to ensure ongoing participation in valued activities that medication is perceived to interfere with (Roe & Swarbrick, 2007).

Hence, considering that many people diagnosed with SMI express a desire to stop taking prescribed medication, and most do at some point (Haddad, Brain, & Scott, 2014), there is an important need to learn more about the subject and develop evidence-based clinical guidelines for prescribers, to support safe discontinuation, aligned with service-user preferences (Le Geyt et al., 2017). A crucial source for the creation of such guidelines is the lived experiences of individuals who have discontinued medication. The current study is unique in that its focus goes beyond identifying the reasons for discontinuation, and also addresses the process of discontinuing medication and its perceived impact. Hence, the main research questions focused on the reasons and process of discontinuation of psychiatric medications. Specifically, the questions were:

Research Question 1: Why and how did the study participants choose the path of medication discontinuation?
Research Question 2: How did they experience it and assess its impact?

Method

In this study, we utilized a qualitative methodology, by employing the narrative approach to life stories method (Padgett, 2017), in an attempt to gain an in-depth understanding of people's experiences of the process and self-evaluated outcome of the choice to stop taking psychiatric medication.

Participants

Participants were 12 women and 9 men, ages 25 to 65 (the average age was 38), all of whom reported having previously received a diagnosis of a serious mental illness, two thirds reporting a psychotic-related disorder. All participants reported being hospitalized at least once in a psychiatric ward, using psychiatric medication, and receiving a recommendation for further psychiatric treatment. The participants reported all sorts of diagnoses (e.g., schizophrenia, major depression, bipolar, and obsessive-compulsive disorder [OCD]). Accordingly,

they were given a variety of different classes of psychiatric drugs. The length of their hospital stay ranged from 2 days to 3 years, and the period of time during which they did not receive services ultimately ranged from 1 to 26 years ($M = 9.5$). Participants were sampled purposively, to achieve a range of information-rich sources (Patton, 2015). They were located through advertisements on websites and message boards at several universities, as well as through personal acquaintance and via the snowball method. All of the participants who were recruited were eventually interviewed.

The sample size was based on data saturation (Malterud, Siersma, & Guassora, 2016; Morse, 1994). Data collection and analysis were performed in parallel, creating circular connections between the two processes. When data analysis of the first few interviews revealed significant issues, they were added to the interview guide to obtain wider and deeper information in subsequent interviews. The new information was then analyzed, and additional relevant issues regarding the topic under study were integrated into the interview guide. This process continued until data saturation was achieved—when no additional issues were identified, and further data collection became redundant. Such saturation provided a rich understanding of the phenomenon through both themes and meaning (Hennink, Kaiser, & Marconi, 2017).

Procedure

Ethical considerations. The University Committee for Ethical Research with Humans approved the study. All participants received an explanation of the research aims, agreed voluntarily to participate, and signed an informed consent letter. The first author, who was the principal investigator (PI), explained the potential risks involved in participating in the interviews and the available safety venues in case of need (Chan, Teram, & Shaw, 2017). Participants were informed that their privacy would be maintained. Promises to the interviewees were kept. In the following section "Findings," participants' names and all identification data were changed to guarantee confidentiality.

Data collection. Data for this study were collected through in-depth, semistructured interviews, in an attempt to explore the experience of using medication; the reasons, processes, and methods for stopping; and its perceived impact. None of the participants was taking any kind of medication at the time they were interviewed. They were not pressured in any way or under the influence of any mind-altering substance while being interviewed. Each interview lasted 2 hr, on average, was audio-recorded, and later transcribed verbatim. The interviews were held according to participants' preference—in their homes or in public places. The participants first completed a sociodemographic questionnaire. The PI then conducted the interview and encouraged participants to narrate their stories from a reflective position (D'Cruz, Gillingham, & Melendez, 2007).

In the interview guide, which was based on McAdams's method (McAdams, 2008), the participants were asked to divide their life story into different chapters, give them titles, detail the main events that occurred in these chapters, and explain how they relate to one another. For example, we asked,

> Please start thinking about your life as if it were a book. Imagine that this book has a "table of contents" with a list of the main chapters that appear in it: Take a few moments to think about the titles of these chapters.

After this section, the participants were asked clarification questions regarding their entry into the mental health system, the impressions and experiences that it left on them, the experience of distancing themselves from these services, and the tools available to them to maintain their emotional balance.

Data Analysis

Data analysis was conducted in Hebrew. For this article, we translated the participants' narratives into English. Findings were analyzed using thematic content analysis (Smith & Osborn, 2008). The principal researcher managed the entire data analysis process. He read the interviews carefully, performing open coding, during which he marked the meaningful content units that arose from the interviews. Subsequently, the principal researcher implemented axial coding across the interviews, attempting to discover relationships between the significant categories that emerged. He compared experiences as described by different study participants, and conceptualized main themes, which provided a higher level of understanding or the essence of the experience of the phenomenon under study (Moustakas, 1994). The principal researcher organized these data based on themes that arose from participants' narratives (King & Horrocks, 2010), and separated his interpretive notes from the descriptive narratives. Thus, these themes were assumed to represent participants' experiences, rather than views assumed a priori by the principal researcher.

Rigor

The authors have a professional and personal interest in and experience with the topic. The first, third, and fourth authors have extensive experience working as service providers, supervisors, and researchers in mental health. The second author studies people coping with diverse mental and physical health situations. Throughout the

research process, the research team members discussed their personal perspectives of the studied phenomenon, attempting to gain insight into their personal opinions and to bracket-out and discard their biases (Tufford & Newman, 2012). To address potential "blind spots" throughout the study, and to strengthen its credibility (Lincoln & Guba, 1985), each researcher, separately, conducted thematic content analysis of these data in addition to the principal investigator's comprehensive data analysis. They performed interrater reliability by comparing their individual analyses, discussing differences, and pursuing agreement about theme content and interpretation of meaning. Applying interrater reliability and systematic data analysis, grounded in rich description of participants' narratives (Morse, 2015), as well as adherence to the above-mentioned data analysis procedures, strengthened the study's credibility (Lincoln & Guba, 1985).

Findings

In the current study, all the participants used psychiatric medication at some point in their lives. At the time they were interviewed, all participants, aside from two who reported having used medication during a few rare incidences of emergency, had stopped using medication altogether. Most of them described the experience of using medication as a negative one and perceived it as aversive. Some participants, however, said they felt that, for a while, the medication had made life easier for them and helped them overcome their difficulties. Yet, it is important to emphasize that labeling experiences as "negative" or "positive" is somewhat artificial, as in practice, the experience was usually more of a complex combination. The actual process of stopping to use medication varied in its length among participants: For some, it took more than 10 years, whereas others stopped immediately upon their discharge from the hospital.

Four main themes were revealed from the data analysis: (a) the experience with medication, (b) the process of discontinuing, (c) elements that helped achieve successful medication discontinuation, and (d) the perceived impact of medication discontinuation.

The Experience of Using Psychiatric Medication

Use of medication, experienced as traumatic. About half of the participants described their experience of using psychiatric medication as harmful, hindering their quality of life and efforts to rebuild their life. Some pertained to extreme cases in which the use of medication was described as frightening and even traumatic, particularly when it was given in an invasive and coercive manner. Yoav said, "They started stuffing me with pills . . . it made me feel as if two clamps were squeezing my brain." Similarly, Rivka described the experience of being forced to take medication:

> I screamed from the inside, but on the outside I couldn't speak and reacted very slowly . . . it was the most frightening thing that's ever happened to me . . . And all this because I made a fuss about them reading my private diary . . . I felt so abused.

Rivka depicted her experience as a total split between her inner and external space. From within, she was totally overwhelmed; at the same time, she was unable to verbally express her emotional state at a pace that reflected her actual experience. In these types of extreme situations, the participants experienced the use of psychiatric medication as an abusive, punitive act that deprived them of their freedom of thought and sometimes the ability to express themselves verbally in a normal manner. Their prevailing experience was one of panic, distress, and helplessness.

Use of medication, experienced as creating additional problems. Several participants felt that rather than alleviating their suffering, the medication created difficulties that had not been there before. Eric said, "It simply created more 'fronts.'" For him, taking medication was perceived as another source of stress to cope with. Ofri, who was hospitalized for severe anxiety after her son's birth, provides an example of such an additional "front." The medication she received resulted in delusions that did not exist previously:

> I started taking pills, apparently antipsychotic pills, even though my problem was simply anxiety. It was terrible. They [the pills] made me feel much worse than before. I began having all kinds of scary fantasies and thoughts that I might harm the baby.

Ofri felt the medication she received did not suit her distress and even exacerbated it, by undermining her basic instinct to protect her baby. As a mother, she was terrified by the thoughts that arose in her mind of hurting the baby. Therefore, in her experience, the medication that was supposed to alleviate her anxiety actually served to intensify it.

Negative side effects of using medication. Other negative experiences that participants reported were related to the many physical and mental side effects, which included the loss of control of basic body functions: "I felt like I was shaking with these pills. I tried to eat, [but] my hand was trembling and I kept dropping the fork" (Reuven). Frequently, other side effects appeared, including weight gain and disruptions in body image: "Within 2 months, from a

weight of 48 kilos, I reached 97 kilos" (Dorit). Others reported that they felt the pills were harmful to their general physical health: "It's very unhealthy. They [the pills] can damage the body's systems in many ways" (Noa).

Dependency and emotional numbness. Some participants felt they had become dependent on their medication and were addicted: "I was gripped by a wave of anxiety attacks . . . I just trembled and felt like a 'drug addict' . . . I said to myself, 'You've got to stop this!'" (Ilana). Participants also reported feeling numb: "I felt deprived of emotions" (Amira), and lost their sense of identity: "I would look in the mirror, and I didn't know who I was" (Dorit).

Medication perceived as hindering essential inner change. Most of the participants felt that the medication prevented or delayed their ability to feel independent and move on with their lives. They concluded that the medication was not addressing the "real problem," and that if they wanted to reconstruct their lives, they should take active measures to minimize their dependency on medication. Erik, for example, reached this conclusion and described it as follows: "The problem is not really chemical, but the soul itself . . . It is impossible to cure the distress of the soul through chemical change."

Several other participants shared this attitude. They believed that their mental state was a result of their damaged spirit, rather than a neurological problem, and that true healing must come from within—from the spiritual dimension. Accordingly, these participants sought tools from the spiritual/religious world, which provided them with more meaningful and helpful means to cope with mental challenges and difficult mental states. For example, Noa, who was diagnosed at the age of 17 with bipolar disorder, spent 10 years in the mental health system, and later became religious. She said, "They completely missed out on the root cause of what I was going through . . . their understanding of the human soul is very shallow, superficial and limited." Noa lost trust in the therapeutic system. She replaced the pills she took with prayer, meditation, and a rich religious community life as a means of dealing with and overcoming life's challenges.

Overall, the negative experiences related to taking medication ranged from a sense of damaging the body and brain, and feeling a lack of emotion, control, and independence. Such experiences resulted in losing one's sense of self, which served as an incentive to make efforts to reduce or completely stop the use of medication.

Medication perceived as beneficial. In contrast to the negative experiences described above, which colored the entire experience of taking medication, some participants acknowledged the beneficial impact of using medication, and felt that it had helped them and alleviated their distress. Amira mentioned the advantages of medication, despite the emotional price she had to pay. She said, "In retrospect, they [the pills] deprived me of feelings, but I guess I needed that at the time." For Dorit, medication served as an emergency beneficial aid during a time of crisis: "There's a small kit which is always in my bag . . . If something doesn't feel right with me, I can always take a tranquilizer or something; it helps." Even those participants who experienced medication as beneficial, however, did not rely on it as an ultimate means for recovery, but rather as a helpful resource, to be used in specific time-limited situations.

Whether the participants had negative or positive experiences with their psychiatric medication, all of them had stopped using it at the time of the interview, relying instead on other nonpharmaceutical tools to cope with life's challenges. The next section will describe their discontinuation processes.

The Process of Medication Discontinuation

To stop taking medication, participants had to possess high levels of determination, perseverance, and willpower. First, it was necessary to deal with various social pressures, which attempted to persuade them to continue taking their medication as prescribed. Reuven described how both his formal and informal support systems (medical system and parents) resisted his intention to quit taking medication:

> My parents wanted me to take the pills . . . They are very conventional . . . The word of the establishment is very strong . . . The psychiatrist is a doctor; whatever he says should be done . . . I think they [the psychiatrists] created a lot of fear in them [the parents].

Second, participants had to deal with physical and mental difficulties associated with the actual withdrawal. Noa described how difficult it was for her and how she lost control over her body and emotional moods:

> I took huge quantities, doses fit for a horse, without knowing what I was putting into my body at all . . . after meeting someone who guided me, I started dropping a quarter of a pill a week out of the seven I was taking . . . and just that quarter—my legs would start jumping . . . I had no control over my legs . . . my nervous system was a wreck, I felt I had electrical currents running in my body, I couldn't sleep well . . . I was always restless . . . constantly on the verge of crying . . . and this was only because of reducing a quarter of a pill a week!

The actual way in which medication discontinuation took place varied from one participant to another. The first method was stopping the use of medication for a

seemingly arbitrary reason. For some participants, the reduction in medication use was not a preplanned process, but rather a result of a circumstantial event. Ayelet, for example, stopped taking pills for physiological reasons: "Because I had thrombosis, they had to stop the lithium." Ofri stopped when she wanted to become pregnant: "There was a doctor who said, 'You should get off the treatments.'" In these cases, it is important to bear in mind that the participants had the choice to continue medication treatment, but each of them, for his or her own reasons, chose not to. The second method was in collaboration with a psychiatrist. Some of the participants reached the decision to stop taking their medication and eventually informed their psychiatrist. They took this step after a period of time during which they had made up their mind and waited for the right time to propose the idea of stopping the medication. Ayelet, who had been hospitalized five times in the past, decided to stop using medication, among other reasons, due to the sense of personal alienation and distrust she felt toward her psychiatrist. She experienced herself as "not being seen," and decided that if she wanted to move forward in life—she had to be active and take care of herself:

> After meeting with him [the psychiatrist] once every three months, he would always ask me, "What's your name, where do you live?" That was the thing that infuriated me. Why do you not remember the most basic facts about me?! It was so impersonal!

Ayelet felt insulted every time she visited the psychiatrist because of the lack of personal contact. This made her doubt his ability to help her. Eventually, she decided she was ready to stop taking medication, and did so for a few weeks, but, at first, she was afraid to share this with her psychiatrist:

> One day I was struck by the fact that I was, in fact, deceiving myself . . . I was a bit afraid of his reaction, so I told him I was taking less [medication] than what he had prescribed. I did not say I had stopped taking it completely. Then he said, "It's a sign that you don't need the medication." I was completely shocked! Suddenly, I felt it validated what I had always noticed, internally.

Ayelet felt ambivalent toward her psychiatrist: On one hand, she did not value his opinion and the treatment he had prescribed for her; on the other hand, when he said, "It's a sign that you don't need the medication," she felt she had received some kind of confirmation from an authority figure. Later, in the interview, she described the moment when she stopped taking medication as a turning point, after which, her life improved.

Like Ayelet, a number of other participants reported undergoing a similar process with their psychiatrist. Sharon, for example, eventually got up the courage to share her thoughts about lowering the dosage with her psychiatrist:

> I told him that I wanted to lower [the dosage], and all of a sudden he cut my medicine in half . . . I was shocked . . . I began to understand that if I hadn't taken the reins into my own hands, neither the psychiatrist nor anyone else would have done it for me.

Similarly, Sharon realized that her doctor knew just as much as she did about how to help her, so she decided she was prepared to suffer from the depression she was experiencing without taking any shortcuts. She was optimistic, determined, and purposeful: "I saw the light at the end of the tunnel," and she decided to take her fate into her own hands.

Finally, there were those participants who planned to stop taking medication while they were under psychiatric care, but concealed their thoughts and feelings from their caregivers and did it on their own. Talia described her experience as follows: "I read on the Internet, I saw how to get off carefully. Who needs a psychiatrist when you have Google? It's exactly the same, there's not a drop of emotion." This process often required great determination and perseverance, and many times, participants chose to move away from their immediate surroundings, physically or mentally, to accomplish their plan to reduce or discontinue medication. For instance, Noa said, "I really shut myself off from the ordinary world . . . I knew that they could undermine me, and I didn't want to be harassed. I was very determined and discrete."

Regardless of whether the process was done in collaboration with a psychiatrist or alone, or whether it began in a seemingly arbitrary way or through careful planning, it is important to emphasize that the common denominator in all of the cases was that the initiative to stop using medication never came from a professional, but rather always from the participants themselves. The next section focuses on major elements that were found to be beneficial during the process of coming off medication.

Elements That Helped Achieve Successful Medication Discontinuation

Personal qualities were certainly found to be crucial to discontinue medication, particularly in light of the most common obstacles, which were described earlier. For example, traits such as the ability to withstand psychological hardships, strong determination, nonconformism, and a certain type of optimism all helped encourage this process. Besides personal qualities, several other elements were found to be successful in the process of discontinuing medication. We will go on to describe the three most prominent ones. It is important to bear in mind

that not all of these elements were necessarily manifested in each participant's story, but rather some sort of a combination of them.

Receiving support from a significant other. Participants mentioned receiving support during times of crisis from people who believed in them and wanted the best for them. The participants considered this support a crucial component in the medication-discontinuation process. An analysis of the interviews revealed that unconditional acceptance and a true belief in one's potential contributed greatly to the process. Such dedication and support, which some (but not all) of the participants received, usually came from spouses, professionals, or family members. Sharon described how her father's support and nonjudgmental attitude helped her survive the depressive period she experienced after being released from the hospital, and deciding to stay away from meds:

> During the depression, the person who helped me the most was my father. His ability to express love and caring wasn't necessarily conveyed in words: he would give me ice cream when I was watching television, cut up some watermelon for me . . . things like that. He didn't expect me to speak when it was hard for me. To this day, it's an emotional subject for me, as you can see [Sharon is crying]. That was one of the things that helped me the most—unconditional love from my father.

Sharon's father was not critical of her and did not pressure her to "function" or change. He gave her unconditional love, which was not expressed in words, but in simple gestures that made her feel he was on her side and "with her" during her most difficult moments. Because of his belief and support, Sharon could gradually believe in herself, begin to overcome the crisis, and rebuild herself—all without the aid of medication.

Supporting others. Participants who chose the route of providing emotional support to others in distress reported that such an act was meaningful and helpful to themselves as well. It improved their self-confidence, sense of competence, and the feeling of being needed. This increased confidence further supported the process of stopping to take medication. Sharon describes this experience as follows:

> I entered the position of the giver and the listener, and I felt that I had helped the people who were there. Providing others with help and support helped my own rehabilitation. Being able to help other people is very empowering. Shifting from a place of shattered confidence to sitting on a stage in front of 1,000 people, managing a conference, or being on television, the radio, the Internet, and challenging my limits . . . helped me rebuild my self-confidence. Self-confidence is very helpful for mental stability.

Sharon's self-confidence, she says, was shattered by the crisis, but providing others with help, both in and out of the hospital, helped her to rebuild herself and find mental stability—which eventually led to finalizing her decision to stay away from medication.

Emotional processing, reconciliation with the past, and development of self-awareness and coping skills. An analysis of the interviews revealed how, upon discharge from the hospital, some of the participants underwent a deep process of introspection, reconciling with their past, and working through their traumas. This journey involved developing a strong sense of self-awareness. They learned a lot about themselves, which ultimately contributed to their ability to discontinue medication and manage on their own.

Some described going through the process independently (usually far from home), some were supported by a professional, and others—through artistic activities, including writing, sculpting, dancing, or connecting to a more structured method (such as "12-step programs"). Talia depicted how she overcame her eating disorder through a process of deep introspection that made the medication unnecessary:

> From the age of 13 until 2 years ago, I had an eating disorder. A very long period of time . . . slowly, I understood where the eating disorder really came from. Once you understand that, you can deal with it. A pill won't help. It's impossible for psychiatry to cure [this type of problem] . . . I had to deal with my demons . . . We live in a society with the constant threat of falling and crashing. Therefore, we live in fear of failing. Once you decide you won't fall and stumble anymore, you don't need the pill.

Talia received psychiatric pills, as well as psychological treatment, but it did not help her gain a full understanding of the source of her eating disorder. Through a deep introspective and spiritual process, she reached meaningful insights into herself, echoing her spiritual worldview and enabling her to defeat the disorder she had suffered from for many years. This journey of internal investigation enabled Talia to transform, showing her that, despite society's threats of failing, her inner decision to overcome her demons had proved itself even without medication.

Participants' Descriptions of the Impact of Medication Discontinuation

The discontinuation of medication was experienced by the participants as a very important step in the process of disengagement from the mental health services and moving toward a healthy and independent lifestyle. This process, which for some required great determination and

willpower, symbolized in many cases the final moving away from the system and the transition to a new chapter in life. Noa, for example, describes how after 9 years of receiving "very high doses of medication, doses fit for a horse," she came to a resolution to stop taking psychiatric medication:

> Coming off [of the medication] involved quite a lot of suffering and hardship—I was always restless, constantly on the verge of crying . . . In retrospect, it symbolized for me the transition from the identity of a person with a disease and disability to a healthy person.

Like Noa, Ayelet's narrative presents the point at which she stopped taking medication as a turning point, from which her life improved: "From that period [when I stopped taking medication], life gradually started getting better. Still, there were a lot of ups and downs, but the general direction was positive."

Analysis of these data reveals how in many cases, discontinuation of medication helped participants' restore control over their lives, increased their independence, contributed to their ability to believe in themselves, and improved their self-image. It is important, however, to emphasize that although the participants themselves had discontinued the use of medication, most of them did not fully support the notion that others should necessarily do the same. Their explanation for this was, for the most part, that the specific circumstances of each person should dictate the use or nonuse of medication. Ofri, for example, said,

> If you ask me, one should start reducing very, very slowly, only if he or she has a good and stable life: if they have a solid family and job, and feel like they are in a positive place in life. Otherwise, it could be very dangerous. One might end up in a situation where he winds up taking an even higher dose—which is something I know about from my own experience . . . Generally, I'm not in favor of someone "losing it," just for the sake of not taking psychiatric medication.

Ofri, similarly to other participants, believes that one should try to come off psychiatric medication, but not at any cost. According to her, uncontrolled reduction, under the wrong conditions, may cause more harm than good.

Discussion

The purpose of the present study was to investigate the reasons, process, experience, and perceived impact of discounting psychiatric medication. The study follows a number of recent studies (e.g., Le Geyt et al., 2017), which have attempted to better understand this process. This study is unique in that it is based on the qualitative analysis of interviews conducted with people who have managed to stay off medication and includes participants' perceived retroactive impact. Most of the study participants experienced their medication use as negative, and some, even as traumatic. The degree of perceived coercion involved in the use of medication was a major determinant of its perceived impact. Some experienced the medication as beneficial, at least for a while, and even as lifesaving. Regardless of their experience of medication usage, all participants decided to discontinue, with the most common reason being side effects. Other important reasons included the desire to reclaim oneself and the wish to deal with painful and difficult personal issues, which medication usage made them less accessible to. Regarding the discontinuation process, ways of stopping medications included seemingly arbitrary decisions, collaborative decisions with a psychiatrist, and independent decisions. The implications of stopping medication were mostly reported as reflecting and facilitating a positive turning point.

The current study results are consistent with previous studies, which showed that the experience of medication usage might interfere with one's daily living and create "Medication-Related Burden" (MRB; Mohammed, Moles, & Chen, 2016). Naturally, when the benefits of medication are no longer perceived as outweighing the MRB, then doubts about continuing to use it are inevitable. These doubts can be experienced in isolation or, preferably, may be shared and discussed with care-providers and natural supports. Obviously, alliance and trust are crucial for a meaningful and constructive dialogue to take place with the care team. In addition, a supportive environment is essential to developing effective ways to successfully cope with the challenging process of discontinuing medication. Results of the current study reveal that mental health users do not always experience these fundamental mechanisms, which might be particularly important during the challenging phase of tapering. Instead, study participants often reported concealing their initial decision from professionals, due to fear of disapproval, thus, missing the opportunity for support, which is clearly needed. Being discrete about stopping medications is in line with previous findings that many people who have successfully come off their psychiatric medication did so against the advice of mental health professionals (Crepaz-Keay, 1999).

In accord with previous research, the current study reports that reasons for stopping medications include negative side effects (Larsen-Barr, 2016), few perceived benefits (Roe et al., 2009), and a feeling that while symptoms may be under control—the day-to-day existence often entails a sense of profound loss and emptiness, which medication causes and, thus, cannot address (Davidson et al., 2010). Previous studies have also suggested that people often want to stop taking medication

because it is a reminder of the illness and stigma associated with it (Staiger, Waldmann, Krumm, & Rüsch, 2016; Usher, 2001). Interestingly, even when medication is experienced as effective in reducing symptoms, in some cases, people may feel ambivalent about using it because of losing the "gains from illness" and missing the symptoms when entirely gone (Moritz et al., 2013; Moritz et al., 2009). Therefore, when participants stopped using medication, they felt free, each one in his or her own unique way, of these conditions that had burdened them while they had been on the medication.

Thus, participants in the current study reported mainly negative experiences of taking medications and described a range of reasons that motivated their discontinuation. Nonetheless, the actual ways and implications of discontinuing were described as a challenge, and emphasized the importance of developing resilience though self-reflection, coping skills, and maintaining relationships. These findings are important considering the growing interest in the possibility of discontinuing medication and the dearth of research findings, which are essential for developing guidelines to aid this process.

With regard to the consequences of stopping medication, the current study revealed interesting findings. A few of the participants not only felt they had managed to control their symptoms without the use of medication, but rather that they had fully recovered or had been cured from their psychiatric problems, and, therefore, felt that medication use was no longer relevant to them. Other participants concluded that discontinuing medication was a necessary act for their personal healing to occur. While previous research has revealed how side effects and paternalistic administration of medication are often barriers to recovery (Mancini, Hardiman, & Lawson, 2005), the current study suggests that for some people, discontinuing medication was perceived as a central necessity. For them, recovery was not about living within and beyond the limits of the illness, but rather about stopping to believe they have an illness and need medication.

Most of the literature, in contrast, advocates for medication use (Higashi et al., 2013), and views discontinuation and nonadherence as a problem that needs to be fixed (Haddad, Brain, & Scott, 2014). In fact, not adhering to effective medication has traditionally been attributed to some of the core features of the illness, such as poor judgment and/or lack of insight (e.g., Mohamed et al., 2008). The current study findings suggest that, for many people, the process of discontinuation involves self-reflection, consideration of the pros and cons, and feeling that they have the right to make and implement their own choices.

Moreover, participants reported experiencing more autonomy and authenticity; in other words—being true to one's real self and real identity and freeing oneself of the medications' side effects. This sense of mastery, control, and agency are fundamental components of personal recovery (Leonhardt et al., 2017). Therefore, for some participants, discontinuing the use of medication seems to have contributed to their feeling more free from conditions that had burdened them while they had been on the medication. This may be explained by self-determination theory (SDT; Deci & Ryan, 2000; Ryan & Deci, 2000), which entails the construct of autonomy, and emphasizes that when people are more autonomously engaged in the therapeutic process and experience a more internal perceived locus of causality for treatment (Ryan & Connell, 1989), they have a better chance to make and experience positive changes. Interestingly, recent studies indicate that discontinuation of medication may increase the chances of recovery (Gleeson et al., 2013; Harrow, Jobe, & Faull, 2014; Wunderink, Nieboer, Wiersma, Sytema, & Nienhuis, 2013). The causal relationship, however, is not clear, as it is possible that people who are more self-reflective and have a higher sense of agency are more likely to stop taking medication in the first place. Further research is needed to clarify the complex relationship between personal recovery and choosing to get off medication.

In addition, it has, thus, been argued that rather than nonadherence being perceived as a problem, sine qua non, person-centered care should support the dialogue between service users and their prescribers about continuing and/or discontinuing medication (Le Geyt et al., 2017). An important and rapidly growing approach, which is in accord with this line of thinking, is Shared Decision Making (SDM; Morant, Kaminskiy, & Ramon, 2015; Zisman-Ilani, Roe, Scholl, Härter, & Karnieli-Miller, 2017).

Study Limitations

The study results should be considered along with its limitations. The sampling method might include bias for people who have experienced more negative experiences with psychiatric medication, as well as positive experiences with medication discontinuation, compared with the general population. In addition, the sample may have overrepresented participants more likely to use the Internet and motivated to share their experiences, rather than people with lower cognitive functioning who were less likely to hear about the study and possibly less motivated to participate. In addition, participants described their experience of discontinuation with different types of psychiatric medication, not all of which were antipsychotic medications. Thus, different mental illnesses and different medications would have resulted in varying experiences that were not addressed in the current study. Therefore, caution should be used when applying the findings to additional groups of people who had previously been diagnosed with SMI and currently stopped

using psychiatric medicine. Yet, we assume that the qualitative study method and the manner of data collection and analysis enabled a deep understanding of the studied experience.

Implications

Implications of the current research should be considered. In terms of policy, it is important to acknowledge that people often stop taking their medication and that, aside from some extreme cases, should be considered and referred to as a legitimate choice that requires and justifies appropriate support. On an individual level, the current study results help to identify some of the challenges experienced during discontinuation, as well as factors that are helpful. These are essential in shedding light on the necessary support needed to facilitate medication discontinuation and guide its development and success. In addition, future research involving gender differences, as well as differences among age groups and cultures around the topic of discontinuation should be conducted to expand the existing knowledge on this phenomenon. Finally, implications for research include the importance of studying the experiences of those who chose to stop medication over time and linking such information with a broader range of functional, clinical, and recovery variables to better understand its long-lasting impact on a wide range of domains.

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