Understanding Delivery of Collectively Built Protocols in an Online Health Community for Discontinuation of Psychiatric Drugs

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People often turn to online health communities (OHCs) for peer support on their specific medical conditions and health-related concerns. Over time, core members in OHCs build a shared understanding of the medical conditions they support. Although prior work has studied how individuals function differently in active sensemaking mode compared to habitual mode, little is known about how OHCs disseminate their advice once their core members operate primarily in habitual mode. We qualitatively observe one such OHC, 'Surviving Antidepressants', to understand how collectively-built protocols are disseminated in the important domain of discontinuing psychiatric drugs. Psychiatric drugs are widely prescribed to treat mental health diagnoses, but, in certain cases, discontinuation might be clinically advisable. Unfortunately, some people experience severe withdrawal symptoms upon discontinuation, even when following medical advice, and thus turn to OHCs for support. We find that collectively-built protocols resemble medical advice and are delivered in a top-down fashion, with staff members being the primary source of informational support. In contrast, all members provide emotional support and exchange advice on navigating the medical system, while many express their distrust of the medical community and pharmaceutical companies. We also discuss the implications of OHCs offering advice outside of the medical system and offer suggestions for how OHCs can collaborate with healthcare providers to advance scientific knowledge and better support people living with medical conditions.

CCS Concepts: • **Human-centered computing** → *Empirical studies in collaborative and social computing*;

Additional Key Words and Phrases: online health communities; sensemaking; psychiatric drugs; medical distrust; withdrawal syndromes

1 INTRODUCTION

People frequently turn to Online Health Communities (OHCs) for advice and assistance in health management from peers with a shared diagnosis or medical condition. OHCs often support *collective*

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sensemaking, using personal experiences and advances in the medical literature to better understand shared medical conditions and diagnoses and provide support for one another [63]. To understand how people analyze the literature and disclose their personal experiences when offering advice or seeking support, collective sensemaking has been examined in OHCs supporting a range of conditions, such as diabetes [62, 72], fertility [22], and migraines [78]. Some OHCs that persist for long periods build a shared understanding of the condition or how to care for it, with core members preserving institutional memory [46, 49]. Mamykina et al. describe individuals functioning in a 'habitual mode', where they rely on preexisting mental models and new experiences do not create gaps in understanding [63].

While research has identified how OHCs build and reach a steady state of understanding of health conditions, less work has examined how members disseminate that understanding to provide informational and emotional support to new members who seek to better understand or manage their condition. Many people use OHCs to supplement or substitute support from traditional healthcare systems, particularly around conditions where they feel their medical providers are not providing adequate support. For example, people struggle to receive support from clinical providers around enigmatic or rare conditions that their providers may not understand, and appreciate the support and advice of OHCs [61, 110]. Understanding how OHCs share the knowledge they have developed can help further describe the role that OHCs play in clinical care relative to traditional systems.

In this paper, we focus on understanding the dissemination of informational and emotional peer support in the important domain of discontinuation of psychiatric drugs. Every year, nearly 1 in 5 U.S. adults experience a diagnosable mental illness, such as depression, anxiety, or bipolar disorders [2]. Similar trends are reported globally [74]. Providers often prescribe psychiatric drugs, such as antidepressants, to help manage mental illnesses, with 1 in 6 U.S. adults filling one or more prescriptions annually [67]. While long-term treatment with psychiatric drugs may be indicated in certain cases, treatment discontinuation is often clinically advisable. For example, some patients experience significant side-effects or achieve relief from mild, transient symptoms that are not anticipated to recur [13]. Upon treatment discontinuation, as many as a quarter of people experience side-effects of withdrawal, with symptoms that can be severe and last for several weeks, months, or even years [29]. Unfortunately, few clinical studies have evaluated optimal strategies for safely discontinuing psychiatric drugs, and the psychiatric community acknowledges that there is a paucity of evidence-based discontinuation guidelines [23, 24, 28, 75]. Patients in multiple countries have described that prescribers frequently do not disclose the potential risk of withdrawal symptoms [34, 87] and do not provide adequate support for their safe discontinuation [88]. In this climate, OHCs have emerged as alternative resources for informational and emotional support for discontinuation of psychiatric drugs.

We qualitatively observe 'Surviving Antidepressants'[1], one of the most popular and longest-running OHCs that offers peer support for discontinuation of psychiatric drugs. We analyze 8,713 posts from 176 threads in the 'Introduction and updates' subforum. We find that core members of the forum have reached a shared understanding of how to safely stop psychiatric drugs without engaging with the medical system and have devised their own protocols on how to handle the informational needs of the members. Informational support is centralized and such questions are handled by forum staff who help members design gradual discontinuations and make sense of their health status in an effort to minimize withdrawal symptoms. In contrast, emotional support is provided by all members, similarly to previously studied OHCs. We also observe that members find themselves in need of maintaining relationships with their prescribers, while largely distrusting

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[1]https://www.survivingantidepressants.org/

the medical community and the pharmaceutical companies. Finally, we document the tension that can arise because of the different understandings of discontinuation and the contradictory advice between the forum and the prescribers.

In examining the case of 'Surviving Antidepressants', we contribute an understanding of how OHCs can fill perceived gaps in healthcare that the medical community has left. We also discuss the implications of the distribution of medical advice outside of the medical system. To help remedy this tension, we propose solutions that allow healthcare providers and OHCs to collaborate in their efforts to advance scientific knowledge and better support people who need healthcare.

2 BACKGROUND ON STARTING AND DISCONTINUING PSYCHIATRIC DRUGS

The rise in the diagnosis of mental health illnesses [2] has been followed by a rapid increase in prescription of all classes of psychiatric drugs: antidepressants, anxiolytics, anti-psychotics, mood stabilizers, and stimulants, with antidepressants being the most commonly prescribed psychiatric drugs [83]. One in eight adults in the United States was prescribed antidepressants in 2012, compared to only one in fourteen in 2000 [51]. Similarly, in the United Kingdom, the number of prescriptions of antidepressants more than doubled between 2005 and 2015 [40].

Literature on antidepressant medications has outlined the potential risks and benefits of short- and-long-term use as well as treatment discontinuation. Given that they are the most commonly prescribed class of psychiatric drugs, antidepressants offer a useful case study for understanding these issues as they relate to psychiatric drugs in general. Antidepressants have demonstrated efficacy in the treatment of several psychiatric disorders, including major depressive disorder and generalized anxiety disorder [9, 19]. Long-term treatment is often indicated, such as in patients experiencing several prior major depressive episodes and demonstrating ongoing therapeutic bene-fit [7, 73]. However, discontinuation of antidepressants (and all psychiatric drugs) may be clinically indicated in a number of scenarios, including: (1) reported intolerable side effects, such as nausea, fatigue, sexual side effects, weight gain or emotional numbing [8, 34, 37, 43]; (2) lack of efficacy in treating the targeted condition after an adequate trial [13]; (3) complete symptom remission for a prolonged duration of time [7]; or (4) special conditions in which case the antidepressant is temporarily discontinued (e.g., during pregnancy or breastfeeding [84]). The psychiatric provider in collaboration with the patient must continually assess whether the risks of continuing a psychiatric drug, such as side effects, outweigh potential risks of discontinuation, such as disorder relapse or drug withdrawal.

Discontinuing antidepressants is often not a trivial task. A systematic literature review [23] found that 56% of people discontinuing antidepressants experience withdrawal reactions. Withdrawal symptoms are generally nonspecific, and may include flu-like symptoms, nausea, insomnia, and/or sensory and gastrointestinal disturbances and have been most frequently reported with SSRI (selective-serotonin reuptake inhibitor) and SNRI (serotonin-norepinephrine reuptake inhibitor) antidepressants [88, 98]. Withdrawal symptoms have also been established for other classes of psychiatric drugs such as benzodiazepines [6]. When symptoms persist for months after drugs have been discontinued, they are characterized as *persistent post-withdrawal disorders* [15]. Failure to recognize withdrawal syndromes can lead to an array of new psychiatric problems (e.g., suicidal and homicidal thoughts [36]), medical misdiagnoses (e.g., neurologic conditions [38]), and risky medical interventions [105].

Antidepressants can either be ceased abruptly ('cold turkey') or weaned through a gradual reduc-tion known as a *taper*. Clinical guidelines recommend antidepressant tapers but are generally vague, offering little detail beyond a recommended taper duration. For example, the UK National Institute for Health and Care Excellence (NICE) recommends a taper of 4 weeks [31], while the American Association of Psychiatrists simply states the need to taper "over the course of at least several

weeks" [7]. Guidelines have also been criticized by psychiatrists for underreporting the potential severity and duration of withdrawal symptoms, prompting calls for urgent revision [23, 24, 28, 75]. Package inserts from drug manufacturers are similarly vague, indicating that abrupt discontinuation is not recommended and that tapering should be monitored for withdrawal symptoms [76]. Likely in response to these concerns, NICE depression guidelines are currently undergoing revision to reflect the potential severity and protracted nature of withdrawal, and the potential utility of a more gradual taper [32, 48].

To date, short tapers have been found to have no [100] or little effect [66] in preventing withdrawal syndrome. There is also concern that current dosage strengths are not small enough for sufficiently gradual tapers to mitigate withdrawal symptoms [93]. Recent research has shown that exponentially decreasing tapers that incorporate subtherapeutic doses and span months may reduce withdrawal symptoms [44].

Despite their prevalence, withdrawal syndromes are rarely discussed by prescribers. In a study involving 1829 participants who had been prescribed antidepressants, only 1% recalled being told about any withdrawal effects, dependence, or withdrawal syndromes [87]. Patients also report not being given enough information on the side-effects of the medication or other treatment options, such as therapy [34]. As a result of inadequate information regarding withdrawal syndromes and optimal taper strategies, patients struggle to successfully discontinue psychiatric drugs, even when following their prescriber's advice. Discontinuing psychiatric drugs is further complicated in the presence of two or more psychiatric drugs, a phenomenon known as *polypharmacy* [56]. Cross-drug interactions can decrease the efficacy of medication and can increase or cause unexpected side effects [2]. To the extent of our knowledge, there are no published clinical guides for how to stop multiple psychiatric drugs. One of our authors, a licensed psychiatrist, suggests that clinicians devise their own protocols: some discontinue all of them simultaneously while others assess the type, frequency, necessity, and medical risk of each drug and accordingly recommend which one to discontinue first.

3 RELATED WORK

Online health communities supplement medical care by offering informational and emotional support to their members. Sensemaking processes have also been observed on these communities, in the form of individually and collectively building an understanding of health issues, often through the use of self-tracking data. Research has examined technological support around clinically-addictive substances and mental well-being more broadly, though needs around psychiatric drugs in the absence of medical support introduce further challenges.

3.1 Online Health Communities

Online health communities (OHCs) are virtual spaces where people gather to discuss a number of shared health-related issues and medical conditions [50]. These communities can function as dedicated sites, like forums [85], or be integrated into social media platforms, like Facebook [111]. OHC membership might be exclusive to peers [90] or include other stakeholders, such as caregivers and healthcare providers [59]. Past studies have shown that OHCs primarily provide informational and emotional support [89] and members assume different roles and functions within the community. For example, there are 'leaders' or 'influential members' [10] who provide emotional support, among other emergent roles that members assume and which correlate with how long they will continue to participate in the OHC [107]. For some OHCs, a small, densely-connected core of members generates most of the support and is responsible for most of the activity [49]. OHCs provide a safe

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[2]https://www.drugs.com/drug_interactions.html

space for members to share concerns about their health and exchange informational support [102]. Members also frequently exchange ideas on how to navigate the medical system to get better support for their health concerns. For example, they often share advice on how to prepare for a doctor's appointment and how to communicate with their providers [45, 55]. The ability to exchange health-related information with people who have analogous experiences is one of the most valued aspects of OHCs [47]. This is particularly important in contexts where members do not receive adequate medical attention (e.g., enigmatic illnesses [110]) and feel dismissed by their doctors. In analyzing Facebook groups associated with antidepressant withdrawal, White et al. [106] suggest that patients turn to peer communities after not receiving desired support from their prescribers.

In addition to informational support, members of OHCs often provide each other emotional support by showing concern, understanding, and empathy [101]. Peer support can provide members with more autonomy, a higher sense of competence, and feelings of empowerment [55]. People also often bring up sensitive topics in OHCs to increase awareness and advocate for destigmatizing topics, e.g., pregnancy loss [3]. Nevertheless, individuals in online health groups occasionally face tension or hostility from their peers. This tension can often be caused by contradictory expectations from the OHC, such as a need for diversity in opinions versus members' tendency toward homophily [72].

Prior literature has quantitatively analyzed the impact of participation in OHCs on the mental well-being of members [81] and the thematic similarities across different mental health OHCs [82]. Researchers have additionally created automated ways to detect mental health episodes in social media activity [25]. Although psychiatric drug discontinuation is intricately tied to individual's mental health, our work instead qualitatively analyzes how OHCs distribute advice and support. We extend the research on OHCs by examining the roles of members, the types of support they request and provide, and the medical distrust that exists within OHCs when they disseminate information around conditions which are not well-supported.

3.2 Sensemaking

OHCs are spaces where members develop an understanding of health-related topics of shared interest, both at an individual and collective level. Sensemaking is a framework that describes a process by which individuals encounter, process, and incorporate complex information into mental representations, in this case, around a health-related issue. Previous work has explored sensemaking for diverse health concerns, such as fertility [21] and migraines [78], with an emphasis on how individuals construct mental frameworks that inform their health decisions [86]. Mamykina et al. [63] distinguish between: (1) an explicit and effortful 'sensemaking mode', where individuals analytically engage with a novel situation that creates a gap in understanding (*perception*) and actively construct explanations (*inference*) that are integrated within their operational model (*action*); and (2) a more implicit and passive 'habitual mode' in which new experiences do not create gaps in understanding as the individual can utilize and reflect on preexisting mental models.

Although sensemaking is typically understood from the perspective of an individual, *collective sensemaking* refers to how individuals interact to collectively make sense of new information [62]. Research has shown that OHCs can facilitate this process, as members generate shared vocabularies [96] and construct shared meaning through discussions in information-driven and experience-driven threads [62]. Many also engage with differing and sometimes conflicting opinions to inform their understanding of a particular topic [64]. Some longstanding OHCs reach a common understanding, which is explained as the product of years-long sensemaking activities [46]. This common understanding can be an indication of an emergent collective intelligence, which is associated with a stabilization and refinement of advice given by a core group of members that sustain the community's institutional memory [49]. We build on this work by studying how 'Surviving

Antidepressants' delivers protocols that are a result of collective sensemaking that has already occurred.

In some OHCs, members engage with self-tracking of their symptoms, triggers, and care strategies, sharing their data to facilitate collective sensemaking and the creation of individualized management plans [110]. Members can re-contextualize information shared by others and apply it to their own situation, often collaboratively [22]. Although self-tracking practices are employed for mental health issues [69], they have typically focused on tracking aspects of the issue itself, such as moods or episodes [71], instead of the associated prescription plans. Our work builds on these findings to examine how OHCs use the logs of members to support them.

3.3 Technology Support for Drug Discontinuation

Within the field of Human-Computer Interaction, research has examined how technology can support discontinuation of clinically-addictive substances such as alcohol and tobacco. Both substances of abuse and psychiatric drugs have potent psychoactive effects and are associated with potential debilitating withdrawal symptoms upon discontinuation [44], making technology support for symptom monitoring during discontinuation valuable. But in contrast to substances of abuse, psychiatric drugs (with the notable exception of benzodiazepines and stimulants), are not considered to have acute reinforcing and pleasurable effects when taken as directed and are not associated with cravings and impaired control over use [41].

To facilitate withdrawal, systems often support self-monitoring of consumption of the substance as well as resulting side effects [103, 109]. However, self-monitoring might introduce feelings of guilt and judgment, especially when discontinuation is not as successful as desired [92]. When offering suggestions for how technology could support drug discontinuation, people often recommend technological assistance for social support [79, 92, 108]. Self-management systems have included opportunities for targeted social support, such as reaching out to personal coaches [80] or sharing their personal stories with others also trying to stop using a substance [97]. A few recent technology interventions have aimed to support discontinuation of psychiatric drugs, primarily aiming to build confidence in the achievability and safety of the process [11, 54]. These interventions focus on providing resources for patients on managing withdrawal symptoms and provide success stories.

People often use social media or OHCs to chronicle their experiences trying to discontinue substance use [70] and to give or receive advice [90]. Although there is some evidence that these social sites can be helpful for withdrawal [60], they can also promote alternative and potentially dangerous treatment plans, like the use of untested drugs during opioid withdrawal [14]. Past work has leveraged people's posts to social media about psychiatric drugs and addictive substances to understand people's withdrawal and recovery trajectories and to monitor for potential adverse drug reactions [77, 91, 99]. Relatedly, research has sought to understand withdrawal symptoms resulting from discontinuation of antidepressants by analyzing posts to OHCs manually and through text mining [1, 42, 98]. We extend prior work on OHCs that support psychiatric drug withdrawal and on technology support for drug discontinuation by describing how OHCs provide support for drug discontinuation, understanding the kinds of support people ask for and provide, and highlighting the consequences of providing and receiving medical advice outside the medical setting.

4 METHODS

To understand how OHCs deliver advice when their core members operate primarily in habitual mode, we analyzed data from the forum 'Surviving Antidepressants' (SA). SA is one of the most popular online peer support communities on discontinuation of psychiatric drugs. Based on personal communication with its owner, it was founded in 2011 and has about 14,000 registered members, mostly from English-speaking countries (about half are from the US). The majority of the forum's

resources are open to the public and searchable, and the forum averages 33,000 visitors and 230,000 pageviews per month. SA has similar goals to other peer-support communities around psychiatric drug withdrawal and tapering, most being private Facebook groups with memberships typically in the low thousands and only focusing on specific psychotropics or general classes of psychiatric drugs. Among forums, the only larger one is 'Benzo Buddies' which specializes in benzodiazepines and has more than 75,000 members. We chose SA due to its popularity, public nature, and its focus on all types of psychiatric drugs versus a specific class. SA currently contains more than 450,000 posts that are first organized in threads and then in 12 subforums. The community provides peer support; no medical background is required of SA's staff members (administrators and moderators). Rather, they are all volunteers in various stages of tapering their own psychiatric drug prescriptions and have acquired their expertise through personal lived experiences. In the posts we analyzed, we did not encounter any members who identified themselves as a medical professional. However, we know that some psychiatric care providers are members of SA but not in a supervising capacity.

4.1 Data Collection

Two researchers initially read around one thousand posts in 43 threads across multiple subforums, while noting general themes to inform our research questions and the development of a codebook. Based on this open-ended observation, we decided to focus on the most popular sub-forum, 'Introductions and updates', which includes around 80% of all posts (over 6,000 unique threads). Each thread presents the progress of an individual member (also known as the original poster or OP). Within their own thread, the OPs first introduce their history with psychiatric drugs, ask questions, and later return to report and discuss their experiences with discontinuation. According to staff, the organization of posts in OP-based threads has been chosen to ensure that *"random threads do not pop up for every question."* Members are recommended to *"search the forum for keywords you are interested in order to identify threads with similar stories to yours."* This structure is unusual among OHCs. Typically conversations are structured around individual posts that offer prompts for all members to participate, e.g., [82]. Instead, in SA, members visit an individual's thread to engage with the more recent posts in the OP's journey, a characteristic that as we further discuss in Section 6.4 is unique even among other OHCs that support psychiatric drug withdrawal.

Prior to analyzing threads, we gained approval from our Institutional Review Board (IRB) and permission from the owner of SA. We focused on recent threads which have their first post between 2017 and 2020 to capture the current state of sensemaking and nature of interactions. We did not analyze any posts from 2020 that explicitly engaged with the COVID-19 pandemic. Three researchers analyzed posts from 25 threads to inform our codebook. They then analyzed another 148 threads. We reached theoretical saturation [20] at about 120 threads, and continued to code the remaining threads. In total, our analyzed dataset includes 8,713 posts from 176 threads. As a point of comparison, past qualitative studies of OHCs have examined 1,963 [22], 186 [45], and 600 posts [35].

Table 1 describes the number of posts and unique members in our corpus by member rank. The threads we analyzed spanned on average 276 days (median: 150 days, std: 310 days, min: 1 day, max: 1072 days). The length of the posts varied from a handful of sentences to lengthy narrations.

4.2 Data Analysis

To develop a codebook, the three researchers open-coded [20] the same 25 threads (200 posts in total), discussing and iterating on a codebook of 34 codes. The codes capture the starting point of the OP's medical journey (e.g., ongoing taper, first attempt), reasons for posting (e.g., seeking informational or emotional support or navigating the medical system), and the perspectives and

Number of posts		% posts	Unique members		% members
regular members	6,297	72.27%	regular members	480	92.84%
OPs	*3,661*	*42.02%*	*OPs*	*177*	*34.23%*
non-OP members	*2,636*	*30.25%*	*non-OP members*	*303*	*58.61%*
staff members	2,416	27.73%	staff members	37	7.16%
moderators	*1,688*	*19.37%*	*moderators*	*34*	*6.58%*
administrators	*728*	*8.36%*	*administrators*	*3*	*0.58%*
Total posts	**8,713**	**100%**	**Total members**	**517**	**100%**

Table 1. The total number of posts as created by regular members (including OPs) and staff members (moderators and administrators) and the number of unique members in each category.

views expressed by members on the medical system and their experiences with it. The full codebook can be found in the supplementary material of the paper.

We labeled individual posts, rather than threads, according to these codes. To assess the inter-rater reliability, three new threads (153 posts) were selected. We defined agreement for a given code as all researchers applying or not applying the code to each of the 153 posts, using Fleiss' Kappa as a measure which accounts for the relative frequency of each code. The researchers had significant agreement (Fleiss' $\kappa > 0.8$) on 13/34 codes, substantial agreement ($\kappa > 0.6$) on 9/34 codes, and moderate agreement ($\kappa > 0.4$) on 6/34 codes. The codes with high disagreement were rare, present on one thread by one rater. The research team resolved all discrepancies through discussion, further refining code definitions. They then coded 148 threads (about 50 each), meeting weekly to discuss new themes.

To include quotes that exemplified our findings, we contacted post authors via SA's built-in direct messaging system. We explained the nature of our research and the quote(s) we wanted to use and provided them with an IRB-approved release form to agree to. Quotes that we did not receive a reply for are paraphrased to retain the anonymity of the member while staying faithful to their spirit. Overall, we reached out to 53 post authors in total, of which 10 responded positively. Commitment in online health communities often drops after a few months [104], thus, we suspect many of the people who did not respond were no longer active in the forum.

5 RESULTS

Our initial exploratory analysis and subsequent coding of threads suggest that the core members of the SA forum operate in habitual mode [63] in how they understand psychiatric drug withdrawal and tapering. This is emblematic of how communities build conceptual knowledge after years of collective sensemaking activities [46]. The fact that the forum's core members operate in habitual mode affects their interactions around informational and emotional support requested by OPs and delivered by the different members of the forum. Core members often leverage well-defined community-built protocols, particularly to deliver informational support. Core members also regularly share their concerns about the medical and pharmaceutical community, while newcomers question whom to trust. All members provide emotional support and regularly exchange advice on how to navigate the medical system.

5.1 Informational Support

In many OHCs, the process of sensemaking is ongoing and distributed among all members (e.g., [62, 110]). In SA, staff and veteran members have reached a shared understanding of discontinuation and have devised standardized protocols for how to safely stop the use of psychiatric drugs.

Informational support is typically administered in a top-down fashion by staff members (i.e., administrators and moderators). Staff members are recognized by regular members as the 'gatekeepers' of the collectively-built protocols. For example, we observed that when regular members were the first ones to respond in a newly-created thread, they would limit themselves to welcoming the OP and defer providing informational support to the staff. Comments like *"hopefully, a moderator will be here soon to help you with deciding the timing and dosage of your taper"* and *"we advise against changes in your drug regime that have not been suggested by moderators"* were common among veterans and even relatively new members. The distinction between different staff and regular members typically ceases to be relevant after the OP receives advice critical to tapering and withdrawal support and transitions to a phase of less pressing questions, for example, about practicing meditation to alleviate certain withdrawal symptoms. A hierarchy was also present among staff who deferred advice to different members of their team that had more experience with certain types of psychiatric drugs, e.g., *"We have to wait for [moderator]'s advice before proceeding."*

The subforum 'Tapering' contains 'pinned threads' that act as guides of how and why staff handle withdrawal in certain ways. Some examples are: 'Why taper 10% of my dosage?', 'Taking multiple psych drugs? Which drug to taper first?' and multiple guides on 'How to taper [psychiatric drug]'. According to the 'Why taper 10% of my dosage?' guide and a recent paper by the forum founder [33], the forum's approach was first inspired by research literature [12] and over the years was adjusted and vetted through collective sensemaking that took place both within SA and other peer-support groups (e.g., [39]). Staff members typically initiated the pinned threads, and the majority of interactions between staff and regular members within them involved general questions about the different protocols that the forum recommends. Staff members provided links to scientific papers and other peer-support resources to clarify their rationale. If members had questions about their specific discontinuation journey, they were directed by moderators to their individual threads.

Members come to the forum predominantly to seek informational support around planning new or adjusting ongoing tapers and occasionally with managing persistent post-withdrawal disorders, as we will later see in more detail. The reasons that OPs want to discontinue psychiatric drugs align with findings in the medical community, such as side-effects and lack of improvement of symptoms [13]. We document how OPs, while operating in active sensemaking mode, request and navigate the informational support they receive, and how staff members, who operate in habitual mode, deliver the protocols that the community has built over the years.

5.1.1 Planning a new or adjusting an ongoing taper. OPs' efforts to receive informational support typically occur when they join the forum to seek help with tapering one or more psychiatric drugs. OPs would find the forum either at the beginning of a new taper or in the midst of an ongoing one with signs of severe withdrawal. OPs would typically first ask for help on how to properly plan or adjust their drug regime, building up an understanding on how to approach tapering. In the absence of specific questions in the introductory post, staff members would explicitly ask the OP to clarify what they needed from the forum, with posts such as *"Q: Is there anything specifically that you are wanting assistance with?"*

In most threads we examined, the OPs had previously attempted to discontinue the drug(s) following the advice of their prescriber e.g., *"This will be the third time trying to stop Citalopram after being on it for two decades."* Some members reported that their prescribers recommended they abruptly stop taking them, e.g., *"my doctor told me to stop taking the drugs and everything will be normal in a few weeks".* More commonly, prescribers recommended that they taper over a few weeks, either by alternating days or by linearly reducing dosages, e.g., *"he recommended I take my current dosage every other day, then increasingly skip days".*

OPs often reported that their past attempts to discontinue use led to significant withdrawal symptoms, which brought them back to their provider's office. Prescribers often identified the withdrawal as relapse, and reinstated them to the original or higher dosages. Posts frequently mentioned, *"I have attempted to stop the drugs many times before but I had to reinstate because of severe withdrawal."* Some OPs even described being prescribed additional drugs: *"my psychiatrists prescribed a cocktail of antidepressants and antipsychotics, experimenting with introducing new ones while withdrawing me from others."*

The forum recommends a 10% tapering rule in the absence of adverse reactions. This method uses a 10% dosage reduction every 2–4 weeks, with the 10% reduction applied on the last dosage. To assist with the sensemaking process, the forum promotes digital tools that calculate the dosages on websites or with downloadable spreadsheets created by staff and veteran members. Figure 1 shows an example of such a tool, illustrating the exponential decay of the taper. If the taper is accompanied by severe withdrawal symptoms, members are recommended to reduce the reduction rate to more conservative variations (e.g., 5% or a 'slide method') and/or increase the pauses between reductions.

5.1.2 Addressing polypharmacy. In the presence of polypharmacy, the forum recommends *"tapering only one drug at a time so that you can identify the source of potential withdrawal symptoms and adverse reactions."* When OPs disclosed that they were on a cocktail of drugs, staff would try to identify whether there were any cross-interactions to determine which drug to recommend for taper first. Staff would typically ask OPs to *"add all the drugs you are taking on the Drug Interactions Checker on drugs.com and copy-paste in a new post the results you received."*

Identifying previously unknown cross-interactions was one of the first indications that OPs perceived a gap in their understanding of their health status. Many were often alarmed to see that *"I am on a drug cocktail with so many possible interactions, but not one of the multiple doctors I have seen has ever cautioned against them."* Typically, staff would recommend that 'activating' drugs, such as antidepressants, were to be tapered before 'sedating drugs', such as benzodiazepines, to ensure that the OP's sleep remains undisturbed.

The 10% method is typically applied to one drug at a time, and it can therefore take years for members to wean off a drug cocktail. This realization often lead to exasperation among newcomer OPs who had previously assumed that discontinuation is rapid, e.g., *"you're telling me that I would have to taper for years!"* Such posts suggest that OPs came in the forum with certain mental models of what discontinuation of psychiatric drugs is supposed to look and feel like based on their past and often repeated withdrawal experiences. Their subsequent interactions with the core members of the forum often challenged these models, thus continuously pushing them in an active sensemaking mode. Staff and core members would justify their recommendations drawing from the forum's past experiences, which have solidified their belief that tapers need to be exponential and thus long. For example, *"personal as well as countless experiences of other members have shown that this is the way to go to minimize withdrawal. Also tapering one drug at a time allows us to point to which drug creates issues during your taper".*

5.1.3 Monitoring symptoms. The process of withdrawal is often referred to as one of 'windows and waves' [5], where windows are periods of no or minimal symptoms and waves are periods when the symptoms are in full force and seem impossible to overcome. Minimal therapeutic dosages (e.g., 50mg for Sertraline) are often the hardest to taper, e.g., *"I am so discouraged that I no longer experience any windows ever since I dropped to 1mg."* Waves, especially for members who had been tapering successfully for a long time, created new gaps in understanding of withdrawal. This, in turn, led to opportunities for explicit, analytical, and effortful sensemaking that eventually led members to make new inferences and adjust their mental models. Staff would assist in these inferences by posing questions to determine whether the taper was too fast and to understand if

			cycle	dose	start date	% of start dose
Standard 10% taper			start	50.00	9/15/2020	100.00%
Enter data in green cells below						
starting date	9/15/2020		1	45.00	10/13/2020	90.00%
starting dose (see note)	50		2	40.50	11/10/2020	81.00%
reduction cycle (days)	28		3	36.45	12/8/2020	72.90%
% cut	10		4	32.81	1/5/2021	65.61%
			5	29.52	2/2/2021	59.05%
NOTES			6	26.57	3/2/2021	53.14%
(1) If your starting dose is less than 0.5 mg,			7	23.91	3/30/2021	47.83%
you may prefer using the "microdoses" tab.			8	21.52	4/27/2021	43.05%
(2) Use North American style for decimals,			9	19.37	5/25/2021	38.74%
Example: 5.6 or 112.7, not 5,6 or 112,7			10	17.43	6/22/2021	34.87%
			11	15.69	7/20/2021	31.38%
			12	14.12	8/17/2021	28.24%
			13	12.71	9/14/2021	25.42%
			14	11.44	10/12/2021	22.88%

≡ 🔒 standard ▾   🔒 microdoses ▾   🔒 brassmonkey slide ▾

Fig. 1. An example of a spreadsheet for calculating the 10% taper. Forum members insert the starting dosage of their drug (e.g., 50mg) and the first day of the taper (e.g., 9/15/2020) and the spreadsheet automatically calculates the exponential decay on the previous dosage. Additional tabs contain alternative tapering approaches SA recommends. Used with permission from the creators.

the OP needed to *"slow down or reinstate to a higher dosage or different drug and stabilize before reattempting tapering."*

The staff encouraged consistent regimes and the use of daily diaries, which they reviewed to identify triggers and patterns: *"You need to track changes in your symptom pattern throughout the process, to figure out if a dosage change is good or bad. You might get bad reactions hours later. Notes are essential to identify this."* Figure 2a shows an example diary posted by a moderator for other members to model. After OPs provide a few diary entries, staff would review them to identify triggers, e.g., *"From your last drug and symptoms journal, I see you eat breakfast in the morning but you are not consistent with your other meals. Please be mindful that a healthy and consistent diet is very important for your central nervous system."* Using the diaries, they would also make suggestions about when to take drugs to minimize symptoms, e.g., *"Perhaps taking these two doses further apart would help with your sleep."*

Although staff offered guides on how to structure diaries, the OPs often did not indicate that they made diaries, would not post their diaries, or did not structure them in the suggested manner. This was often a cause of confusion and frustration for staff members who had to sift through free-form and emotionally-loaded narratives to identify symptoms and patterns. For example, an administrator posted *"we've asked you many times for your symptom pattern. We can't tell anything from these isolated posts [...] To get anything out of peer support, you will need to take responsibility for tracking your symptoms, communicating them clearly and accurately, and not making yourself even worse through a habit of catastrophizing."* Such interactions, although relatively rare, indicate how the members' different sensemaking modes occasionally led to conflict. Core members who operated in habitual mode sometimes assumed habits and behavioral patterns that newcomers had not established or accepted yet.

6 a.m. Woke with anxiety
8 a.m. Took 2.5mg Lexapro
10 a.m. Stomach is upset
10:30 a.m. Ate breakfast
11:35 a.m. Got a headache, lasted one hour
12:35 p.m. Ate lunch
4 p.m. Feel a bit better
5 p.m. Took 2.5mg Lexapro
6 p.m. Ate dinner
9:20 p.m. Headache
10:00 p.m. Took 50mg Seroquel
10:20 p.m. Feeling dizzy
10:30 p.m. Fell asleep
2:30 a.m. Woke, took 3mg Ambien (NOT
"took 1/2 tablet Ambien")
2:45 a.m. Fell asleep
4:30 a.m. Woke but got back to sleep

Zoloft 150-200 mg- on and off between 1998 and 2004.

Lexapro 40 mg - 2004-2013 30 mg 2013 - August 2015 20 mg August 2015- September 2015 15 mg September 2015 - October 2015 10 mg October 2015 -Nov. 1 2015. Nov. 2015 increased dose to 12.5 mg to stabilize. Dec. 28 2015 11.25 mg March 29, 2016 10 mg. August 1, 2016 9 mg. October 23, 2016 8.1 mg. Nov. 29, 2016 7.5 mg. Feb. 25, 2017 7 mg. April 9, 2017 6.5 mg. June 2017 6 mg. Aug. 2018 5.75 mg March 2019 5.5 mg Apr. 2019 5.25 mg. June 2019 5 mg Sept. 2019 4.75 mg Nov. 2019 4.5 mg Dec. 2019 4.25 April 7 2020 4mg

Depakote 1000 mg 2008-2013 750 2013-Dec 2015 500 mg Dec 2015 to Feb 2, 2016. Sopped completely Feb 2 2016.

Adderall 40mg 2004-Feb 29, 2016. Feb 29,2016 - reduced Adderall to 20 mg based on pdoc's recommendations. March 29, 2016 - Reduced Adderall to 15 mg. April 30 reduced Adderall to 10 mgs. May 28, 2016 reduced Adderall to 5 mgs.June 8, 2016 stopped taking Adderall due to extreme agitation.

Amphetamine 20mg 2008 - 1/16. 1/16 - Stopped Amphetamine completely because pdoc did not renew script.

(a)   (b)

Fig. 2. (a) A drug and symptom diary offered by a moderator to help identify triggers and patterns. (b) A member's signature that contains their psychiatric drug and taper history. Used with permission from the creators.

In addition to diaries, staff would also use the forum's signature field to understand the medication history of the members. According to a guide, *"signatures are short summaries of all drugs, doses, and dates in the past 2 years."* Staff recommend that for legibility, they are written as *"lists of short lines".* Figure 2b shows an example of the signature of a member who has used a number of psychotropic drugs and has stopped or is in the process of tapering some of them. Signatures appear after every post a member writes, allowing others to immediately check and contextualize the member's drug history. Staff would often ask clarifying questions based on the content of the signature, such as, *"what is the current dosage?," "when did you start taking this drug?," "when was the last time you took it?,"* or *"you mentioned this drug but I do not see it in the signature."*

Despite the forum guidelines for signatures, we observed a variation in their form and specificity. This is another instance of how members operating in different sensemaking modes led to confusion, with staff members having to ask for clarification to form an accurate picture of the OP's drug and taper history, e.g., *"I am confused by your signature. Were you taking both Venlafaxine and Citalopram during the past 2 years? It also mentions that you tapered Venlafaxine over 3 months. When did you stop it? Please update your signature accordingly."*

Overall, in place of formal processes followed in doctor-patient settings (e.g., explicit collection of demographics, medical history, and clinical notes), staff built a partial medical picture of the members by reading their posts, signatures, and daily diaries. Members had the option of adding their gender and location in their profiles, but most did not use this feature and wished to maintain their anonymity.

5.1.4 Managing persistent post-withdrawal disorders. OPs also sought help with managing persistent post-withdrawal disorders, with prolonged symptoms lasting for months or even years. Threads often described people's continued symptoms, seeking advice on what action to take next: *"Eight months ago, following my doctor's advice, I tapered off Citalopram in a span of a month. Ever since, I feel like I am in hell, facing a number of physical, mental, and emotional symptoms. [...] I don't know if I should reinstate or suffer this withdrawal when I can barely function."* These threads revealed similar differences in understanding between newcomers and core members, but also led to different approaches that staff could take to assist OPs with their sensemaking. For

example, depending on the drug and the time elapsed since the last dosage, staff might recommend reinstatement to a small dosage to alleviate some symptoms followed by a taper.

Sometimes, the staff deemed that the risk of going back to medication was high and with uncertain results. For example, the staff recommended for the OP above, *"During the 8 months you have been off the drug, your brain has adapted to its absence. Reinstatement works dependably within 3 months from discontinuation; at 8 months, you are outside this window so we are not sure that a reinstatement would work. If you decide to do so, I would suggest the smallest possible dose and to monitor your response to it."*

If the OP chose not to reinstate, other members would transition to providing emotional support, for example, by posting *"Please don't forget that you are not alone in this journey and you can always talk to us. Hopefully this wave will be over soon."* In such cases, OPs underwent a different sensemaking process of learning to manage their symptoms rather than understanding how to conduct a taper. In general, threads on persistent post-withdrawal disorders were shorter, as the need for informational support was mostly limited to the first posts.

To summarize, we found that most OPs arrive in the forum with existing mental models of withdrawal based on their past tapering experiences that have been recommended by prescribers. The forum has built protocols that staff members deliver in a top-down hierarchical fashion, often challenging the preexisting mental models of OPs who transition to an active sensemaking mode. Core members have devised mechanisms to assist the sensemaking mode in the form of diaries and signatures but not all OPs make use of them. Finally, sensemaking can take place throughout the various steps of a taper, from its design, execution, all the way to the management of symptoms upon its completion.

5.2 Emotional Support

While the first few posts in a thread typically focused on informational questions and answers, the OPs' need for additional emotional support often arose as they continued to participate in the forum. Our findings around how members of SA requested and provided emotional support align closely with existing literature on OHCs (e.g., [10, 55, 101, 104]).

In contrast to informational support, emotional support was provided by all members. Non-staff members frequently drew from their own experiences to share coping mechanisms that supplemented the tapering plans recommended by staff members. Questions such as *"I want to ask whether it got worse before things turned around for you"* were followed by posts from members with similar experiences who would share that *"some of my symptoms get worse while others get better, sometimes new symptoms will appear while old ones will disappear. We've all been there."*

5.2.1 A community of people "in the same boat". Participants often expressed feelings of relief and hope after discovering they were not alone in experiencing withdrawal. As one member put it, *"it is amazing that SA creates purpose and camaraderie because it is a community of individuals at different points in their journeys but with shared goals."* Similar to OHCs that support complex and enigmatic medical problems, such as vulvodynia [110], members reported that *"in SA I found acceptance and validation that what I am going through is real. Both the medical community and my social support network fail to recognize withdrawal syndromes."*

Members, independent of how long they had been active in the forum, were comfortable offering emotional support by disclosing their own personal stories or offering simple words of encouragement, conveying that the difficulties will eventually pass: *"You are capable of surviving this misery. I was terrified during my own journey, not knowing whether I'd ever get better, just like you say."* Members often felt that sharing and hearing about similar experiences led to the forum to feel empathetic: *"No school can teach you how it feels, you have to go through it yourself to understand."*

We repeatedly saw requests from members who *"want to hear success stories, that I can do this, and that I am not alone in this."* or *"As I mentioned before, what I need most is reassurance that this will pass."* Such comments suggest that reading success stories can reinforce the actions that OPs take and provide some evidence for the utility of the community's informational advice. SA has a dedicated subforum on success stories and acknowledges when members are drug-free by adding visual indicators on their threads and profiles. Staff encouraged *"if you want to do some reading, check out: 'Success stories: Recovery from withdrawal'."* Members appreciated the stories of peers who successfully discontinued, as they illustrate how people in similar situations *"eventually made it to the other side."* Members would also see their own posts as testaments to the progress they achieved, which can positively reinforce the value of the community's sensemaking. For example, *"my daily updates will remind me of the good days during bad ones and document the recovery and coping mechanisms both for me and others."*

SA members would highlight the importance of coping with withdrawal and any environmental factors that might have contributed to the initial mental illness diagnosis that led them to psychiatric drugs. All members exchanged advice like, *"you need to eat healthy, exercise regularly, engage with therapy, meditation, and mindfulness, and in general build stable relationships of trust that will be a safe harbor during a storm."*, indicating that sensemaking around discontinuation went beyond drug dosage management, and considered overall well-being.

5.2.2 Potential detrimental effects. Similar to past work [21], we found that SA could have a detrimental effect on the emotional and mental state of some members, thus negatively affecting sensemaking. Some members disclosed spending hours on it, comparing themselves to others, and overanalyzing symptoms which increased their anxiety and created a vicious cycle. One OP expressed that *"I should admit that lately I was putting so much pressure on myself, was comparing my case and timeline with other people's cases, like they healed in 12 months and here I am still suffering at 20 months, oh did I damage my self beyond repair?"* Such posts were typically followed by periods where the OP disengaged from the forum. Members and moderators tended to encourage such breaks, e.g., *"Take as much time off as you need and come back to let us know how you're doing."*

To summarize, we found that all members participated in providing emotional support, drawing from their personal experiences regardless of their tapering status. Success stories were coveted and deemed to be motivational, thus having a positive impact on the sensemaking process. On the other hand, over-engagement with the forum could have an adverse effect on the progress of members and the management of their symptoms.

5.3 Medical Distrust

SA's primary goal as a forum is to help people who feel that they have not received adequate support from the medical community in their efforts to discontinue psychiatric drugs. The 'About' page of the forum describes, *"The personal stories on this site are documentation of an iatrogenic condition – suffering caused by medical treatment – that is almost always ignored, misdiagnosed, or denied by the medical establishment."* The term *iatrogenic* implies that the forum believes the withdrawal symptoms its members report are a direct result of the medical treatment and subsequent care they received. According to one OP, *"it is striking that the medical system fails to recognize and treat my severe condition that they caused."*

We observed that in many OPs posts, the perceived lack of support and clear guidance was documented to have began at their first interaction with their prescriber. One OP said, *"I was never informed about the potential to experience withdrawal syndromes or the need of a slower taper by my physician. When I expressed concerns about being on antidepressants for a long time, he claimed that unless there were major side effects there was no reason for me to stop them and that I'd be able to*

easily do so when I felt better." Another OP described their frustration for not being informed that *"I could experience sexual dysfunction because of Duloxetine. She said that she knew of this side effect but hadn't warned me because she didn't think that it would happen to me."*

Some members, after interacting with SA ended up questioning their original diagnoses and the need for having received psychiatric drugs in the first place and shifted to operating in sense-making mode: *"My doctor insists that my withdrawal symptoms are proof that I will always need antidepressants because I am wired differently. It's hard to believe this when I never had such symptoms before starting them."*

Distrust toward the medical community was pervasive and comments berating prescribers were common: *"Problem is at the beginning I went way too fast (On my idiot doctor's recommendation, of course). That's what put me where you are right now. Fortunately, I found SA before he got a chance to screw me up even worse."* Members also described negative feelings toward their prescribers. For example, *"I am feeling so much anger and resentment toward my doctor!"*

Overall, the posts revealed a breach of confidence that members experienced by trusting their prescribers. Expressions such as *"I have been betrayed"*, *"lied to"*, *"misled"*, and *"abused"* were common. For example, *"I can't help but feel extraordinary anger towards the prescribing doctor, and the thought of pursuing legal action crosses my mind frequently. In regards to earning potential and quality of living, I feel like these things have been robbed from me."*

In some rare cases, OPs were optimistic that they might have found an understanding prescriber who *"although she initially recommended to taper quickly, she listened to me, and she supported my plan to go at my own pace."* Other forum members had mixed reactions to such comments, challenging the OPs to align with the mental models of the core members, e.g., *"I don't think that your prescribing Dr. will have any understanding of withdrawal. Most don't. It's always good when a doctor says you are "normal"...kind of a rarity here in the U.S.A."*

Members also sometimes sought to alter pre-existing mental models by discussing a need to 'unpatient' and 'undiagnose' by removing the feeling of seeing oneself as a broken person that prior interactions with prescribers might have caused. For example, staff and veteran members commented that *"you need to stop thinking of yourself as someone that needs drugs to process normal emotions. You need to stop describing every feeling and event in your life with psychiatric terms."* Members often encouraged each other to find clinicians that do not see drugs as the first line of defense against mental health issues: *"I know you trust your doctor, but it sounds like you could use one who is not so chemistry dependant. The view that just getting the right chemicals/drugs in will "fix" your PTSD or Asperger's - is an outdated model."* The forum's language on drugs was emotionally-loaded, with members referring to them as *"poisons"* and *"evil"*, and likening them to *"nightmares"* and *"snakebites"*.

Many posts, mostly from staff and veteran members, argued that psychiatry lacks comprehensive and independent studies on the effects of psychiatric drugs and the withdrawal syndromes they cause. Instead, members believed that research and knowledge was influenced by the pharmaceutical industry, which they perceived as driven by profits rather than health outcomes. For example, one staff member described, *"Most research is conducted by pharmaceutical companies who do not acknowledge the difficulty of discontinuing the drugs they manufacture. Medical professionals receive training and reference materials from them and believe they are backed up by proper scientific studies. But they have a strong financial incentive to spend their resources in expanding the number of psychiatric conditions that can be resolved with their drugs."*

These views led some veteran members to urge for a collective voice mobilization, similar to other OHCs where peers have advocated for changes in health care services around different conditions [102]. For example, members would occasionally ask newcomers *"Given your symptoms, have you considered filling a report with the FDA and against your doctor?"* Some members were

hesitant to act, e.g., *"I have not filed the complaint yet, the timing has to be right."* Others reported the difficulties with having their complaints heard, e.g., *"I filed a complaint in my clinic but it took multiple iterations for them to listen."* We also observed movements to pressure local governments, for example, *"Please consider signing the following petition to be considered by the [European country] parliament."*

Many members were also cautious of alternative sources of support. For example, *"A naturopath may be helpful, or may be harmful - most naturopaths do not understand the nature of these drugs, and how they restructure your brain. If your naturopath says anything about "detoxing from the drugs," please run away as fast as your feet will carry you!".* Another member described that *"The only problem I ever had with seeing a psychologist was that she, like psychiatrists, liked to categorize and diagnose/label. And then overanalyze everything. It increased my anxiety and sense of not belonging. My preference has been for just plain therapists who teach coping techniques."*

Members highlighted the importance of being listened to, and finding understanding prescribers. For example, *"My doctor really listed to my experienced and confirmed that although withdrawal syndrome is rare, he has encountered it many times before. He even mentioned having 3 cases with persistent post-withdrawal disorder that lasted more than 2 years. I really appreciate his honestly."*

5.3.1 Navigating the Medical System. Despite the widespread distrust towards the medical and pharmaceutical communities, members were still in need of navigating the medical system. People frequently ask for advice on how to navigate the medical system in OHCs (e.g., [45, 55]), but engaging with the medical system becomes particularly important in the context of depending on long-term prescriptions to accomplish the exponential tapers recommended by the forum.

One member expressed this juxtaposition by saying that *"It is still hard to process the harm they did and get the help I do need from them. I have to play the system for my best interests."* We observed that members exchanged ideas on how to talk to their prescribers about tapering when prior interactions had only led to prescriptions of psychiatric drugs: *"my doctor has only been interested in asking me whether I am anxious and proceeding with another prescription. I am not sure how to talk to them about tapering when they only focus on if I am still anxious."*

Staff members typically recommended that *"When talking to the medical professionals, you need to be calm and assertive without coming across as a know it all. It's a good idea to write a script and practice what you want to say and how you are going to say it. It might also be helpful to take [a loved one] along with you. If they suggest a drug, ask what the drug would do, or is for (is it to cure or cover symptoms) and say that you would like to think about it. Make sure you get the details of the drug, better written down, so you don't forget or get it wrong. You can then do your research."*

Members also occasionally asked for advice on handling medical insurance claims and mental illness benefits because of severe withdrawal symptoms. For example, one member posted *"I would like a dr that can help me with the disability forms as I have been unable to work for a year [due to withdrawal] and it looks like I will not be well enough to work for a while."* Because advice often needed to be tailored to the member's locale, members would typically be directed to external directories of sympathetic providers and to threads where peers in the same geographic location could make such recommendations.

5.3.2 Tension. Although most OPs expressed gratitude for the forum support, we occasionally observed tension, typically between newcomers and staff or veteran members. This was a direct consequence of the gap in understanding of discontinuation between newcomers and core members. Some OPs were cautious to construct new inferences and adjustments to their existing mental models as the forum makes drastically different recommendations than their providers and current clinical guidelines. One OP expressed that *"I need time to read all this new information and form my own opinion. This is such a complicated topic, it's hard to know what to think."* This suggests that the

transition from perception of a gap to inference, and eventually action, took some time for OPs, or might not have occurred for others.

This hesitation is an indication that OPs were still actively sensemaking, but the core members of the forum were resistant to work with OPs who had not adopted their habitual understanding. The forum assumes that members will adopt its guides and adhere to a strict dosing schedule to minimize withdrawal effects, as shown in this administrator's comment: *"To go off drugs, you need to be in control of them, which means keeping to a dosing schedule. We cannot work with people who take their drugs on an irregular schedule."* Some members struggled to decide whether to trust the authority of their prescribers or the experience and advice of peers on the forum, indicating challenges starting the sensemaking process and different outcomes of the sensemaking process based on whose advice they would follow. For example, one OP wrote after receiving contradictory advice from the forum and their psychiatrist that, *"I have to say that I am so confused right now and I don't know whom to trust. I feel depressed and I know I could just take the Lexapro that he prescribed. But I am scared of its side effects and that it won't alleviate my withdrawal symptoms."* The response written by another member highlights how many of SA's members operate in habitual mode of sensemaking: *"You can trust this site because here you can find the wisdom of thousands of people who just like you suffered withdrawal when coming off antidepressants. Also, the moderators have gone or are going off the drugs themselves. On the other hand, what doctors know comes from drug companies."*

This attitude came in contrast to posts from some newcomers who were operating in active sensemaking mode. For example, one member wrote *"Also forgive me, but what credential or training do you have to counsel people? Very few people are able to come off these drugs, tapering by 10% or not. When someone has success with any method I would expect some support from my "team." If I am wrong about my assumptions, then explain why and provide your reasoning instead of just shutting it down. Is that too much to ask??"*

To summarize, we found that medical distrust among core members was wide-spread. All members exchanged advice on how to navigate a medical system that they did not necessarily trust. But, newcomers were challenged to choose between the advice of their prescribers and the recommendations of the forum.

6 DISCUSSION

Most OHCs studied before have explored assistance with the management of illnesses or chronic conditions (e.g., [57, 62, 72, 85]). More similar to OHCs which support substance abuse disorders (e.g., [90]), SA aims to provide support in managing drugs with the ultimate goal of discontinuation without withdrawal symptoms. While the medical community recognizes substance use disorders and has formalized approaches to help people stop using some kinds of substances, SA members routinely reported that their providers were unaware of and did not know how to support psychiatric drug withdrawal syndromes.

Our observations of SA reveal that the perceived gaps in care left by the medical system can create opportunities for OHCs to develop their own support mechanisms and act as independent or even sole sources of informational support. The collective experience of core members led to strict informational protocols that were collectively built over years and that are now delivered in a top-down fashion. At the same time, members can grow further apart from the medical system, which has consequences that extend beyond their psychiatric care. OHCs that disseminate advice without the research and institutional support of the medical system pose risks.

6.1 Emerging Hierarchical Organization in OHCs

SA staff routinely provided disclaimers that they are not medical doctors, but in practice, we observed that the OHC has created a rigid hierarchy and protocols which resembled medical advice that a clinician might provide. Although we did not identify how this came to be, core members trust staff to be the first line of response when it comes to informational support and have mostly assumed the role of providing emotional support. Trusting authoritative voices, such as administrators or moderators, is a common phenomenon in OHCs [72], but seeing OHCs as the primary source of informational support comes in contrast to prior work (e.g., [45]) which has observed how other OHCs encourage members to engage and trust the medical system rather than rely on peer advice.

Within staff, we observed that the personal experiences of moderators and administrators created 'specializations,' for example, based on the class of drugs the members asked for help. SA's members also consolidated their experience and opinions on what is the best course of action when it comes to psychiatric drug discontinuation in extensive guides that capture the results of years of collective sensemaking. Taken together, the protocols, their top-down delivery, and the hierarchy followed among members reveal that SA has transformed over the years in an OHC that acts similarly to an organized medical system. Medical professionals are trusted figures who leverage their specialized knowledge to develop and administer specific protocols when administering care, drawing from research and clinical experience. SA in that sense has created its own structures to compensate for the perceived lack of support in the traditional medical system.

As we will discuss in the next section, SA's rigid approach to providing support has direct and broad consequences on the relationship of the members with the medical community. It also affects how sensemaking processes manifest within its community. Given the longevity of the forum and the diverse set of discontinuation cases it has assisted with, sensemaking at a collective level can be seen as a process that has already happened and which is complete, with staff and veteran members operating primarily in habitual mode [63]. This can create barriers for newcomers who are operating in active sensemaking mode, having not yet accepted the protocols that SA follows and not knowing how to process the conflicting information received between the OHC and their providers. Additionally, because informational support is almost exclusively provided by staff members, information is more tightly controlled. We believe that this is intentional as members have only to choose between their prescribers' and SA's uniform recommendations; these two differing opinions are already enough to substantially confuse or concern some members. At the same time, competing viewpoints in OHCs have been shown to lead to a better understanding of medical conditions [64]. Finally, the extensive reliance on a small number of volunteering staff can be challenging to scale in OHCs [27]. In fact, during the COVID-19 outbreak, SA had to temporarily close the registration to new members as its staff could not handle the volume of new cases that sought help [3]. These challenges can have a negative effect on individuals who might not be able to access the resources that OHCs provide or engage in active sensemaking at an individual level.

6.2 Implications of Distrust toward Medical Community

In SA, we observed evidence that when OHCs fill a perceived gap left by the medical system, the relationship between members and the medical system can become highly strained and combative. Medical distrust was pervasive and perpetuated within SA. Dissatisfaction was magnified as members reported similar stories on how they were never informed that withdrawal syndromes would be a possibility and that their withdrawal symptoms were ignored or downplayed, often

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[3]The announcement on June 11, 2020 https://www.survivingantidepressants.org/topic/30-announcements/?do=findComment&comment=489848

leading to multiple failed attempts for discontinuation. Many members found validation in finding peers with similar symptoms and encouraging stories about a possible recovery. The structured environment of SA also provided more guidance on what members could do to discontinue their drugs and minimize their withdrawal symptoms. Eventually, though, many members expressed frustration about the way that they had been treated by their clinicians, even leading to collective mobilization and action. Although research has identified that other OHCs routinely question the integrity or knowledge of the medical profession (e.g., [35, 110]), medical distrust in SA was strong, as withdrawal syndromes were commonly seen as an iatrogenic problem that could have been prevented with proper education of the prescribers.

The medical distrust we observed in SA can have profound effects on the healthcare that the members would have sought to receive by a medical professional. Unsupervised medical advice by untrained individuals can lead to extremely dangerous consequences on the health of the individual. The protocols that OHC members suggest, and people may follow, may have been devised by members without any medical background and have not been validated through clinical trials. Even if the OHC has devised strict protocols, the information that staff are able to extract from the posts, signatures, and diaries is a subset of the medical history which would be recorded in a visit to a provider's office. Our observations of SA suggest that staff generally supported the wish of members to discontinue psychiatric drugs without a rigorous assessment of whether this was advisable. They also provided advice on how to navigate the medical system in order to receive the medication at the dosages that SA, not the medical provider, recommends. Finally, OHC members may also see staff members and peers within the OHCs as authoritative figures who are experts at creating and administering these protocols, and a substitute for their healthcare providers.

Liability becomes a challenging open question in cases where OHCs become a distributor of medical recommendations, even in light of disclaimers around the source of the recommendations. In SA, moderators and administrators made substantial efforts to ensure that OPs received advice which adhered to the forum's standards of care, frequently correcting or extending the informational advice that other members gave. However, thinking about how to hold individual members or OHCs at large accountable for the advice they give is an important direction for future work, particularly if OHCs become more widespread to fill gaps in medical care.

Another potential consequence is that OHCs can become a space for stigmatizing psychiatric treatment. There is already significant stigma associated with psychiatric drug therapy [95] despite the benefits to use of them for a wide variety of people in a wide variety of conditions [9, 19]. Increased ubiquity of OHCs like SA that describe a clear "right" and "wrong" around the use of psychiatric therapy and psychiatric drug treatments has the potential to reinforce that stigma and bring up tension between medical providers and patients around the use of psychiatric drugs for treatment. In practice, decision-making around whether, when, and how to prescribe psychiatric drugs and taper off of them requires individualized advice ("are psychiatric drugs right for this person?") and more scientific knowledge ("when and for whom are psychiatric drugs helpful?"). While further research on psychiatric drugs (e.g., validated taper protocols) and improved clinical practices (e.g., more clinical awareness of side-effects) are needed to provide this advice and knowledge, reading a hard negative stance towards psychiatric drugs on an OHC could lead a person who would otherwise benefit from it to avoid or not adhere to a prescription.

The organization of the forum and the fact that the core members operated in habitual mode of sensemaking left little room for other members to push back on or question the forum's stance or advice towards psychiatric drugs. Operating in habitual mode perhaps leads to a sentiment that new members either need to "get on board" or "get out," which also reinforces the stigma that pro-psychiatric (drug) treatments are not acceptable. This stance can be difficult for people who are still in the process of sensemaking for themselves. However, the labor of building up new members'

understanding of care also imposed burdens on forum members. This tension suggests that OHCs where members are operating at different stages of sensemaking may face conflict, even when goals and values are shared.

At the same time, OHCs can also help reduce stigmatized disclosures [3] and support patient advocacy. By bringing together people "in the same boat" and giving them space to be heard and get advice on navigating the medical system, it can lead to people taking ownership of their own healthcare and status. Like on other OHCs [110], we observed frequent discussions on SA on how to bridge care topics with providers. Particularly in light of many prescribers' limited understanding of the side effects of psychiatric drugs, such advocacy can help ensure OHC members receive the treatment and care they need.

Propagation of ideas around medical mistrust can further undermine the trust of OHC members toward the medical profession at large, having severe consequences, both at a psychological and physical level, for the members and their dependents [4]. Anti-vaccination offers a cautionary example of what happens when individuals turn to unfounded theories over the medical community's advice [68]. This holds true for OHCs like SA, even if recent literature provides early theoretical evidence [44] that SA's recommendation for exponential tapers minimizes withdrawal, and even if the advice was reported to be effective for at least some of its members.

We suspect that the development of OHCs centered around dissemination of advice is inevitable when people feel that the medical system does not understand or support their condition. In such cases, OHCs can offer a promising complement to the existing medical system and are known to want to accelerate the pace of medical research [53]. However, distrust of the medical system is also likely to permeate in OHCs whose core members operate in habitual mode of understanding how to support a condition and who see the traditional medical system as having not "caught up" to the advice they are disseminating.

In the remainder of the discussion, we suggest opportunities for OHCs to work with and within the medical system to promote changes, rather than operating independently. We also describe some guidelines for CSCW researchers looking to study online communities which have these inherent tensions.

6.3 Bridging the Gap

Informational support interactions in OHCs are primarily centered around logs that the members provide. In SA, we saw that these logs can take different forms: free-form narration in posts, drug history in signatures, and daily diaries. Our first suggestion in repairing the relationship between OHC members and the medical system is to harness these logs. Assuming that members continue visiting their providers, we can imagine that such logs could be brought to visits and inform treatment plans. Patients, instead of recalling their general impression of what has occurred since their past visit, could instead provide the logs as evidence of their experience [16] and of their adherence to the dosages recommended by their prescriber. Documenting the withdrawal symptoms, their frequency, and severity, can allow providers to distinguish between withdrawal and relapse, and thus adjust their prescriptions.

One of the major sources of grievance we saw in SA was not the symptoms themselves, but that members felt they were never informed about the possibility of withdrawal syndromes from their providers. Integrating logs in the patient-provider interaction can bring visibility to the frequency of withdrawal syndromes and may encourage providers to disclose this possibility when they first prescribe a psychiatric drug. Facilitating more supportive experiences within the medical system, even at an individual level, could help repair the breach of trust that we have observed among current SA members. We envision that technology could help close the loop by enabling people to objectively share their health status with their providers, with the goal of working together [65].

For such a change to take place, a consideration for OHCs like SA is how they can integrate tools that will allow their members to more easily create such logs in forms that providers can attend to during clinical consultations. We imagine this happening by imposing structure with forms, templates, or dedicated apps for specifying dates, dosages, and symptoms. Such tools could also provide data that could become part of the electronic health record of the patient and offer the advantage of streamlining communication with providers [17] and be used in collaboration with their doctors [18, 52]. In many OHCs, members share self-tracking data (e.g., blood glucose levels [94]) to construct individualized and collective insights about medical concerns [86]. In such OHCs, members reap the benefits of self-tracking by better understanding their own data while contributing to collective sensemaking by sharing insights on each other's data. Additionally, beyond facilitating interactions with providers, this approach has the advantage of linking a standardized quantified experience to the members' narratives [46] within the OHC. It also can help democratize the sensemaking process by allowing *all* the members to reflect both at an individual and collaborative level on the recorded data instead of relying on a small number of volunteers such as staff. SA also demonstrates the benefits of social support both for addressing informational and emotional needs, thus, new technology could incorporate social sharing features, similar to past work [79, 108].

One of the characteristics of OHCs is that the dedication of its members to better understand, manage, and treat their medical conditions and concerns, often leads them to push the boundaries of knowledge that has been produced by the medical system. This is especially true for OHCs that support members who feel that their conditions do not receive adequate support and as we saw with SA "take matters in their own hands." Beyond the dangers that we have already highlighted, we imagine that this innovative activity can be put to good use. For example, the protocols that OHCs like SA establish could provide candidates for potential treatments to evaluate in rigorous clinical trials to establish their efficacy. The lessons learned from these OHCs could potentially bootstrap the scientific process. Similar approaches have been used to integrate computational models into clinical care, taking genes that the models produce as candidates to be studied in clinical trials as drivers of certain types of cancer [26].

Even if the medical field is slow to notice and evaluate ideas generated in OHCs, OHCs themselves could seek ways to standardize how they assess the efficacy of the protocols that their members claim that have worked for them. For example, in addition to supporting collaborative reflection [30], cohort-produced data could be aggregated and shared with clinical experts to help build evidence towards the efficacy of the treatment plan. OHCs could adopt N-of-1 studies, which are gaining increased interest for personalizing medicine and allow for smaller samples [58], to introduce scientific rigor to the approaches they suggest. We also expect opportunities for OHCs, or at least core members, to collaborate more directly with research institutions to share their expertise.

At the same time, we acknowledge that bridging OHCs like SA with the medical system is a challenging sociotechnical problem, requiring buy-in that might not be desirable or possible. Many OHCs, SA included, aim for the broader medical community to adopt the ideas that the community is sensemaking around in order to improve care for everyone, not only members of the OHC. But formal integration could also exclude members who feel welcome in OHCs, for example, because they feel that the OHC provides better care than they have received through the medical system or do not have access to the medical system. Closely integrating OHCs with the medical system could make the OHC operate less autonomously, and reduce the trust that members have in the community. Medical professionals may also be hesitant to consider, validate, and eventually adopt advice that has been generated in OHCs given the source. The diverse nature of OHCs could also lead to advice which has the potential to cause harm if not thoroughly vetted. Value tensions are likely to occur in collaborations, with many OHCs recognizing and accommodating the experiences

of their members while the medical system seeks to build scientific evidence first. Further work is needed to develop strategies for mitigating these tensions.

Studying OHCs which largely operate outside the medical system also poses challenges for CSCW researchers. For many research questions, particularly around how communities facilitate sensemaking and advice, characterizing the practices and perspectives observed is a central goal. However, it is often out of the scope of our expertise to evaluate the clinical validity of the discussions the communities have, for example, in our case, the approaches that SA specifically recommends for tapering. Instead, we focused on highlighting the consequences, positive and negative, of OHCs developing protocols in place of the medical system. We further aimed to not promote or challenge a particular treatment strategy.

In the case of our study of SA, the medical research literature and best practices suggested rapidly evolved (e.g., NICE changing its patient guidelines for discontinuing antidepressants [32]) as we were understanding the forum's practices. We might expect OHCs to grow around topics where scientific understanding is unfolding, as OHCs often aim to make sense of care strategies or formulate understanding in light of minimal clinical support. We benefited from having a clinical collaborator interested in understanding and following the latest research, and frequently revisited our understanding of treatment strategies in light of this work. We found it valuable to summarize the current state of the medical literature alongside the practices recommended by SA.

A challenge in the space of studying OHCs is avoiding legitimizing the viewpoints or advice of harmful or otherwise problematic communities, such as anti-vaccination communities, by presenting the recommendations of those communities in scholarship. As relative newcomers to the topic of psychiatric drug discontinuation upon beginning this project, we again found it helpful to consult with and involve clinical collaborators to challenge and verify our own understanding of the space. There is still research utility in studying the practices of these communities, such as understanding how and why beliefs spread or studying the tactics members of these communities use to persuade or convince new members of their viewpoints. But we caution against reporting on or summarizing the advice disseminated by OHCs without first having a strong understanding of the clinical viewpoint(s) on the topic.

6.4   Limitations

Since our work focuses on one specific OHC, aspects of how advice is disseminated may not generalize to other OHCs. As a point of comparison, we did a cursory analysis of BenzoBuddies (BB), an OHC that specializes on benzodiazepines and that is also the largest public forum on (a specific class of) psychiatric drug discontinuation. BB also contains introduction threads but new members are then channelled by staff to specific subforums based on the starting point of their medical journey (e.g., tapering versus post-withdrawal, similar to the stages we saw in SA). There, OPs create new threads as questions arise, similar to what is typically done in most OHCs. Nevertheless, we believe that our following observations indicate that SA fundamentally operates similarly to related OHCs. In BB, we largely observed that staff members were again the first ones to respond to informational questions, recommending exponentially-decreasing tapers, while regular members provided emotional support. Despite focusing on benzodiazepines, BB contains a subforum that is dedicated to antidepressants and which offers the same protocols with SA and even links to its tapering guidelines. Finally, it also organizes knowledge in guides, uses signatures to track the members' medical and drug history, and highlights success stories to inspire members. Beyond SA and BB, a recent analysis of Facebook groups associated with antidepressant withdrawal [106] documented similar reasons for why patients turn to OHCs led by peers instead of relying on their prescribers. Finally, representatives from multiple OHCs that focus on psychiatric

drug discontinuation have expressed taking similar approaches when handling the informational and emotional needs of their members [4].

Despite these similarities, we speculate that OHCs that are integrated in social media platforms might foster different dynamics between its members. For example, in Facebook groups, we would expect the content to be primarily driven by posts with self-contained questions [110]. Such OHCs might also lead to a more peer-driven distribution of information, as 'leaders', either staff or veteran members, may not be as heavily emphasized and easily distinguished among peers. Finally, SA's anonymity might lead members to disclose more or different health-related information than they would in an eponymous OHC, e.g., a Facebook group, even if it were a private one.

Our analysis primarily focused on the content of the discussions occurring on SA and the kinds of advice given. Future research on how members longitudinally engaged with this advice, such as examining how often OPs adopted the advice recommended by other forum members or the trajectories of follow-up questions OPs often asked, would enable further understanding of how people ask for and give advice on OHCs. Other quantitative analyses, such as studying the dynamics and distribution of interactions among regular users and staff members throughout one's membership, could shed more light on our findings on the hierarchical nature of OHCs.

7 CONCLUSION

By qualitatively analyzing how an OHC around psychiatric drug discontinuation administers protocols developed through collective sensemaking, we find that OHCs whose core members primarily operate in habitual mode and which feel alienated by the medical community can introduce their own organizational structures to compensate for a perceived lack of support. Staff planned tapers and monitored the progress of members in an effort to minimize withdrawal symptoms, while all members provided emotional support and exchanged advice on how to navigate the medical system. We observed pervasive distrust toward the medical and pharmaceutical communities, with some members feeling confused about whether to trust the opinion of their prescribers versus that of the OHC. There is a strong need for healing the breach of trust between OHCs with the medical system where there is a perceived gap in healthcare. We see opportunities for technological solutions to empower individuals and doctors to better support healthcare and for OHCs to contribute the knowledge they have developed to clinical scientific discourse, but also see challenges in addressing the sociotechnical barriers between OHCs and the medical system.

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