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Overcoming medication stigma in peer recovery: A new paradigm

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Abstract

Background—Treatment for opioid use disorder involving opioid-based pharmacotherapies is considered most effective when accompanied by psychosocial interventions. Peer-led support groups are widely available and have been described by many as fundamental to the recovery process. However, some individuals using medications face stigma in these settings, which can be contradictory and counterproductive to their recovery.

Methods—This paper describes the development of the "Ability, Inspiration and Motivation" or "AIM" group, an alternative peer support group that aims to remove medication stigma from peer recovery. Qualitative interviews with staff, peers, and clients of a community-based buprenorphine treatment program were used to establish the core components of the curriculum to support client needs.

Results—Staff, peers, and clients of the buprenorphine program indicated a need and desire to establish a peer recovery group that recognizes persons on medication as being in recovery and destigmatizes use of medication to treat opioid addiction. A respectful environment, holistic perspective on health, spirituality, sharing, and celebration were all established as necessary pillars of the AIM group curriculum.

Conclusions—The community-based effort to establish and develop the AIM group demonstrates that combining the strengths of a peer support with evidence-based medication treatment is both possible and desirable. Shifting the culture of peer recovery groups to support the use of medications may have implications for improving treatment retention and should be considered as a potential strategy to reduce the burden of the opioid epidemic.

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Author contributions

N.K. analyzed results of the participant surveys and drafted the manuscript. T.N. and M.N. participated in process of developing the AIM model, designed and carried out the participant survey, and contributed to the manuscript. D.A. and M.F. contributed to the planning process and design of the AIM paradigm and edited the manuscript. All authors reviewed and approved of the final contents of the manuscript.

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Keywords

Buprenorphine; medication treatment; opioid use disorders; overdose prevention; peer support; self-help; stigma; 12-step

Introduction

Opioid use disorder (OUD) is a serious public health problem in the United States. In 2015 alone, over 33,091 overdose deaths involved some type of opioid.[1,2] OUD is a chronic illness, but it can be managed successfully if treated appropriately. Medication treatment involving opioid agonist or antagonist pharmacotherapy in conjunction with psychosocial interventions has been repeatedly recommended for the treatment of OUD and has been associated with reduced rates of overdose as compared with no treatment or treatments that do not involve medication.[3–5] In addition, maintenance using such medications has proved to be effective in retaining patients in treatment, reducing opioid use, and improving social function.[6] Current treatment guidelines recommend that use of these medications be combined with psychosocial treatment for best outcomes.[7] However, substantial knowledge gaps remain regarding the types of psychosocial interventions that are most effective as a complement to medication, as well as how to make these interventions widely available and accessible.[8]

Although not recognized by the American Society of Addiction Medicine as psychosocial treatment per se,[9] some of the most widely available and utilized ancillary psychosocial services are mutual aid or self-help peer support groups.[10] Within such groups, consisting mostly of Narcotics Anonymous (NA) and other 12-step programs, peers with a history of substance use disorders routinely meet and support each other throughout the process of recovery.[11] A recent editorial by Galanter and colleagues suggested that medication treatment could potentially enhance treatment outcomes and improve retention in 12-step–oriented rehabilitation settings.[12] Although peer groups in conjunction with medication may indeed have potential to help persons remain in recovery and prevent relapse and risk of overdose, a significant obstacle remains: There is persistent cultural stigma within the substance use treatment community resting on the belief that using opioid-based medications involves a means of substituting one drug for another, and that those who take such medications are not truly abstinent.[13] This stigma has particularly been expressed as an issue among NA groups. NA states in its official literature that although all individuals should be welcomed to attend meetings, those who use medications are not yet considered “clean” and groups may choose to prevent individuals on medication from sharing experiences or leading meetings.[14]

Although not a universal philosophy of all peer recovery groups or 12-step programs, in several circumstances, stigma against medication may create an atmosphere that can be intimidating and antagonizing for people who are taking medications.[15] Qualitative research has found that many persons with OUD express disinterest in using buprenorphine treatment to sustain their recovery because they consider taking medication to be “cheating,” or not genuinely “drug-free.”[16] Persons who take medication and also participate in 12-step

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meetings have expressed that they often struggle with the abstinence-only philosophy that encourages them to reduce their dose or come off of their medication completely, and as a result they sometimes hide their medication treatment status from their peers.[17] Notions that being on medication is not considered true abstinence may be internalized by participants, leading to self-stigma[18] and reluctance to engage in long-term medication maintenance. As the risk of relapse and opioid overdose increases exponentially after the cessation of medication treatment,[19] such pressures to terminate medication may actually increase the prevalence of overdose.

The rate of opioid use and overdose deaths in Baltimore City, like many other American cities, is disturbingly high, creating a significant challenge to public health.[20] The increasing availability of opioid agonist therapy over the past decade has been associated with reduced numbers of heroin overdose deaths,[3] but a recent increase in overdoses has occurred[20] and access to medication treatment remains limited relative to need among the population. In 2010, the Behavioral Health Leadership Institute, a nonprofit organization dedicated to filling gaps in behavioral health services, established a buprenorphine treatment program in partnership with a community-based recovery center in Baltimore, in which buprenorphine engagement and stabilization services are offered to community members who participate in 12-step and other peer recovery groups at the center. Indeed, the program showed initial success and promise for increasing access to medication treatment and improving outcomes among underserved communities with high rates of OUD.[21] However, stigma associated with medication treatment within the center's 12-step recovery groups was identified by several staff members and clients as a significant barrier to recovery, a phenomenon that has also been expressed by others who take buprenorphine in Baltimore.[17]

To learn how to better support those who take buprenorphine and are simultaneously engaged in community support that involves peer recovery groups, this study sought to better understand the nature of medication stigma and explore alternate methods of providing both peer support and a positive atmosphere for medication adherence. To this end, the authors conducted qualitative interviews and focus groups with staff, peers, and clients participating in the existing buprenorphine program to explore their experiences with medication stigma within the peer recovery groups they attend. Participant feedback was used to design and establish an alternative peer recovery paradigm and curriculum, which aims to combine the constructive components of existing peer support groups with a positive approach to medication treatment and validate unique and multimodal paths to recovery. In this paper, we describe the process of developing the curriculum for this new peer recovery paradigm called "Ability, Inspiration and Motivation," or "AIM." Following this, the authors discuss the potential for adapting this paradigm within other settings that use medication treatment.

Methods

Setting

The AIM group was developed at Dee's Place, a grassroots recovery center located in East Baltimore that partners with the Behavioral Health Leadership Institute to provide low-threshold buprenorphine treatment to community members who are engaged in 12-step and

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other peer recovery groups. A team of clinicians, which includes a physician, a nurse, and a social worker, works together with peer recovery advocates and leaders from the local community to deliver buprenorphine engagement and stabilization services, before linking clients with a long-term primary care physician who can continue to prescribe their medication. As a complement to taking buprenorphine, clients also participate in peer recovery groups and other activities that take place at the recovery center. Since its initiation in 2010, this program has engaged over 300 clients in buprenorphine treatment, the majority of which are African American adults (87%) between the ages of 45 and 64 (71%). At initiation, most clients were unemployed (71%), lived in unstable housing conditions (75%), had a history of criminal justice involvement (84%), experienced co-occurring physical (59%) and mental health (51%) conditions, and had high rates of recent emergency care use (40%). Most clients entered the program after many years of opioid use (average 28 years).[22]

Development of the AIM curriculum

Review of existent peer support groups—A preliminary planning phase took place through which authors gathered information about existent peer recovery models. To learn about the format and customs of NA and other 12-step groups, 2 public health master's degree students who had gone through didactic training in qualitative research methods engaged in participant observation at several meetings held at Dee's Place over a period of 2 months. They recorded observations about the environment, including peer interactions, and talked with leaders conducting the meetings. In addition, authors reviewed information about the goals, philosophies, and practices of NA as well as of other existing programs, including Maintenance and Recovery Services (MARS),[23] Self-Management and Recovery Training (SMART),[24] and Methadone Anonymous,[25,26] by reviewing program materials, curriculums, and literature published through public online sources. This phase was considered accomplished when authors were no longer able to find additional official literature on these major peer recovery groups.

Interviews with buprenorphine program staff and peers—Once the authors became familiar with practices of NA and other support groups, individual interviews were conducted with staff and peers at Dee's Place (including the physician, the nurse, and 2 peer recovery coaches), in addition to 2 former clients of the program who were to serve as leaders of the new peer recovery group. Interviews were carried out by the same 2 public health master's degree students utilizing semistructure questionnaires. Questions were asked regarding how participants believed different components of NA and other 12-step groups benefited and/or impeded clients' recovery, and the questions also inquired about medication-stigma experiences and the impact of these experiences on buprenorphine engagement and retention. Interviews also asked staff and peers about which components of peer support groups they would like to keep, remove, or add in the creation of a new peer support curriculum.

Focus group with buprenorphine program clients—Next, a focus group was formed with 2 female and 8 male active clients in the buprenorphine program who were simultaneously engaged in peer recovery groups and voluntarily agreed to participate in the

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study. The same interviewers inquired about the role of 12-step groups in clients' recovery and how it impacted their experience with buprenorphine treatment. A similar semistructured questionnaire was used to inquire about topics regarding both positive and negative experiences of 12-step and other peer support groups and which components of these groups they believed were helpful and/or detrimental to their recovery. Questions asked specifically whether clients believed medication stigma was a problem and whether it played a role in their buprenorphine-based recovery. In addition, clients were asked to make suggestions regarding which components of existent peer recovery groups should be kept and what additional topics and activities should be included in the alternative peer support group curriculum.

Thematic analysis—Qualitative data from interviews and focus groups were gathered, and thematic analysis using a directed content analysis approach[27] was conducted to extract information relevant to the development of the AIM curriculum. This qualitative methodology was useful for extracting interview content and helping to develop a curriculum that reflected the needs and perceptions of buprenorphine clients as well as clinical and peer recovery staff. Areas of interest for curriculum development for which content was gathered and organized included the following: (a) which goals clients and staff hoped the group would accomplish; (b) which components of existent peer support groups were found to benefit clients in their recovery process and should be maintained in the curriculum; (c) which components of existent peer support groups were found to be stigmatizing and/or potentially harmful for clients who were taking buprenorphine and should be changed in the curriculum; and (d) what new information and/or activities would benefit the recovery process and should be added to the curriculum.

Finalizing curriculum—Main themes were extracted based on the experiences of clients and staff at Dee's Place, notes from initial observations of NA and other 12-step groups, materials from other support groups, and information from the experiences of other medication treatment clients reported in the literature.[15–17,28] Findings were then used to establish a curriculum designed to maintain the strengths of helpful peer support groups and simultaneously reduce medication sigma. The curriculum was reviewed and revised by the former clients who were to become peer recovery coaches and lead the new group at Dee's Place, and a name was selected for the group based on input from those involved in the planning process. The final mission and components of the AIM curriculum are presented in detail below. This study was approved by the Johns Hopkins School of Public Health Institutional Review Board (IRB 00006855).

Results

Using input from staff, peers, and clients at Dee's Place, the mission of the AIM group was articulated: "To promote respect, wellness and recovery through peer support and education by allowing participants to share their unique paths to recovery." This judgment-free mission ensures that all members have the opportunity to share their stories, voice their opinions, and assume leadership positions and allows those on medication to celebrate their engagement in recovery. AIM meetings are open to all interested participants, regardless of medication status. Meetings are led by peer recovery coaches who follow a curriculum that incorporates

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strategies to conceptualize addiction as a treatable disease, address stigma related to both drug use and medication treatment, and encourage wellness among all participants. The AIM paradigm incorporates 3 important themes that emerged from the qualitative research process as essential elements and have become the pillars of the AIM curriculum: respectful environment; holistic perspective on health; and spirituality, sharing, and celebration.

Respectful environment

Facilitating a respectful environment emerged as a central theme. Clients on medication treatment expressed feeling judged or excluded by peers and leaders in NA and other groups for taking medication, and in certain cases they were not permitted to participate or contribute to meetings. Clients indicated feeling ashamed for taking medication and that at times they felt they had to keep their medication status secret as to avoid judgment by others. Moreover, existent support groups were often found to use terminology that promoted self-stigma (e.g., addict). A respectful environment is therefore intended to reduce participant shame and secrecy related to medication treatment and set a progressive tone, including thoughtful use of language. As part of this effort, OUD is recognized as a disorder that affects the brain and relapse is recognized as a common symptom that medication can help prevent. Through this framework and by removing the negative language that surrounds drug use such as “clean” and “dirty,” the AIM group moves away from the notion that a person can only achieve recovery through abstinence and will power alone. The AIM group is built on the premise that affirming language that supports the disease model of addiction can instill confidence and self-esteem and improve the recovery process.[29] The AIM model works to improve the use of language within its own group meetings as well as provide members with tools to combat stigmatizing language regarding addiction and medication treatment in other peer recovery settings and the greater community.

Holistic perspective on health

Another theme that emerged was promoting holistic health and well-being. Clients experienced several comorbid physical and mental health problems and expressed a desire to learn health tips and receive more general information about healthy habits and tools for emotional health that they could adapt to their own lives. Indeed, persons with substance use disorders are at higher risk for a range of chronic illnesses and infectious diseases,[30,31] and staff agreed that encouraging healthy behaviors and basing the group on a holistic perspective of health could aid the recovery process. More specifically, the AIM group incorporates health tips related to nutrition and includes a brief exercise period with stretches and other light physical activities to encourage healthy behaviors that can be incorporated into all areas of participants’ lives, beyond only substance use. Different materials with health information and a variety of light exercises are reviewed during sessions and distributed to clients to take home with them.

Spirituality, sharing, and celebration

A third theme that emerged was the importance of spirituality, story sharing, and celebration of recovery milestones. Interviews with clients and peers highlighted that these 3 aspects of existing peer recovery models were worthwhile and should be retained in the new AIM curriculum. Participants expressed that moments of spirituality invoke a sense of unity and

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purpose among group members. Therefore, the AIM curriculum incorporates beginning and ending each session with a shared moment of spirituality that welcomes any faith or belief.

Story sharing was also expressed as a vital part of successful self-help recovery, and clients expressed interest in incorporating this component, especially given they were often barred from sharing in other groups due to their medication status. Participants indicated wanting to have time to share their stories with a smaller subset of the larger group. A “Think, Pair, Share” exercise was incorporated into the curriculum and involves participants pairing up and sharing weekly successes and/or struggles with another person at every meeting. This was designed to help build stronger bonds between participants and also to allow clients the opportunity to share their story with the larger group.

Lastly, celebration of recovery milestones was also identified as an essential part of the recovery process, especially as many participants were unable to celebrate recovery while on medication in traditional peer recovery groups. Thus, recovery milestones of those who actively engage in treatment and recovery groups receive recognition and celebration in the AIM group. Celebrating milestones in the AIM group addresses self-stigma by empowering clients who are engaged in recovery, including taking prescribed medication, to receive acknowledgement for their recovery progress beyond the traditional “time clean.” This element assures that recovery progress be celebrated for all individuals irrespective of the role of medication in their treatment. This process may also introduce clients to a network of persons who may be similarly taking medications as part of their recovery process.

Piloting of AIM group and next steps

The first AIM meeting was hosted in February of 2016 and was led by the 2 recovery coaches who were former clients of the buprenorphine program and had been involved throughout the entire planning process. Meetings are open to the community and not limited to participants of the buprenorphine program at Dee’s Place or people who use medication treatment. In the first 6 months of the program, the AIM group received over 70 participants and continues to function successfully on a weekly basis. Ongoing evaluation of participant impressions and AIM group outcome evaluation is in progress.

Discussion

The current paper describes the development and implementation of an alternative peer support group designed to counter the cultural stigma associated with taking medication treatment for OUD. This stigma is common in certain 12-step programs and can, at times, be harmful to the process of recovery of those seeking evidence-based care for OUD. The qualitative data gathered from staff, peers, and clients in the planning and design of the AIM group curriculum illustrate that there is indeed a need and desire for peer support groups that are more inclusive of those in medication treatment. Findings also show that many existent aspects of support groups can be adapted to deliver necessary support in a manner that does not stigmatize persons who take medications. The AIM group curriculum established that despite the long-standing abstinence-only culture in many peer support groups, there is no inherent contradiction in a recovery group that embraces people on medication as being in recovery. Thus, it was possible to combine essential elements of peer recovery with

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evidence-based and clinically recommended use of medications to establish a recovery group that embraces and destigmatizes persons on medication treatment.

Calls have been made across the substance use field to promote more progressive treatment models that expand availability of medications and address the pervasive stigma in substance use treatment.[32] In the recently released report “Facing Addiction in America,” the former Surgeon General called for a cultural shift in how we think about addiction. This report addressed the need to expand use of evidence-based medications and resolve internal controversies in the recovery community, including stigma against medication in peer recovery groups.[33] Thus, expanding medication treatment to include peer support paradigms such as the AIM group—which accepts people on medications—may be a fundamental component of retaining clients in long-term treatment and preventing incessant relapse and overdose among the multitude of people currently experiencing OUD. Creating a positive and welcoming environment and encouraging the use of less stigmatizing language may be especially essential to support clients who already experience stigma, vulnerability, and trauma in many other aspects of their lives.

This study is subject to important limitations. First, the process of developing the curriculum was based on qualitative interviews with a small number of persons, including staff, peers, or clients of one buprenorphine treatment program in Baltimore City that serves a very specific and sociodemographically homogenous population with long-term opioid use. Therefore, the experiences and perceptions expressed and which were used to design the curriculum are not necessarily generalizable or representative of other clients with OUD who attend peer support groups. Second, participants of the qualitative interviews have frequent contact with authors, who are also involved in the other activities of the treatment program and may therefore have been influenced somewhat by their goals and perceptions. Despite these limitations, our study established that it was possible and beneficial to engage communities and persons who are affected by substance use in the process of designing interventions that are culturally appropriate and meet community needs. Through the use of active participant observation, qualitative interviews, and focus groups, the authors were able to engage and incorporate the desires of the persons for whom the intervention is essentially designed to impact.

Currently, efforts are underway to expand and adapt the AIM model to other treatment and community settings and meet the needs of the persons involved. This is being done through multiple paths: For one, new peer recovery leaders will be trained across different community treatment sites to start new peer support groups and adapt the AIM paradigm and curriculum to meet the needs of the communities they serve. Trainings include education regarding the use of holistic health techniques, the use of nonstigmatizing language, and knowledge of opioid-based pharmacology and its role in the recovery process. Having more AIM leaders will allow for the creation of additional groups at various sites, facilitating improved ease of access for greater numbers of people. Moreover, the AIM group, and its mission of antistigma, is being promoted through educational materials, media, and trainings at different recovery sites. Information about the group is also being circulated throughout substance use treatment networks, including medication treatment providers, so they can refer clients or start their own AIM group. Lastly, ongoing evaluation of the AIM group is in

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process to better understand the needs of participants and empirically assess what elements of such groups are most beneficial to the recovery process. Based on these efforts, future programs can be adapted to maximize benefits to participants and retain them in effective recovery.

Anticipated challenges implementing the AIM group will surely be encountered while working to expand such a paradigm to new settings. AIM group locations may initially be limited, and changing the perspective of existent groups, such as NA, regarding medication treatment will likely be a slow process. Nonetheless, this study highlights the need for and potential success of alternative peer support paradigms for persons seeking support in recovery from OUD. This is especially relevant given the urgent need to expand recovery supports in communities across the nation suffering from the opioid epidemic. Thus, rigorous efforts by the health care and recovery communities should be made to remove medication stigma from both existent and new treatment programs. Reducing stigma may not only assist those struggling with OUD but will also help shift our conversation about substance use disorder in general from one that dismisses persons for their moral failings to one that understands addiction as a chronic disease that can be managed and treated effectively through dedicated and evidence-based interventions that promote health and long-term recovery.

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