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Consumers' Experiences in Dual Focus Mutual Aid for Co-occurring Substance Use and Mental Health Disorders

Harlan Matusow¹, Honoria Guarino¹, Andrew Rosenblum¹, Howard Vogel², Thomas Uttaro³, Sadiqua Khabir⁴, Martin Rini⁵, Thomas Moore⁵ and Stephen Magura⁶

¹National Development and Research Institutes, New York, NY. ²Double Trouble in Recovery, Inc. West Palm Beach, FL.

³New York eHealth Collaborative, New York, NY. ⁴Bowery Residents' Committee, New York, NY. ⁵Cherry St. Health Services, Grand Rapids, MI. ⁶The Evaluation Center, Western Michigan University, Kalamazoo, MI.

Corresponding author email: stephen.magura@wmich.edu

Abstract: Mutual aid fellowships have been shown to improve outcomes for those with co-occurring substance use and mental illness disorders. Processes associated with usefulness include helper therapy (the assumption of a helping role to foster commitment) and reciprocal learning (the sharing of problems and solutions among members). The present qualitative investigation used focus groups comprised a subset of participants in Double Trouble in Recovery (DTR), a 12-step mutual aid group for those with co-occurring disorders, to gather their subjective perceptions of the groups. Participants emphasized that in linking them to others with similar problems, the DTR groups played a vital emotional role in their lives and provided a needed venue for information sharing that might have been otherwise unavailable.

Keywords: mutual-Aid, co-occurring disorders, dual-diagnosis, focus groups, Double Trouble in Recovery, DTR, 12-step

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Introduction

Co-occurring psychiatric and substance use disorders are common; in the United States, 8.9 million people have both past year mental illness and dependence on or abuse of illicit drugs or alcohol.¹ Co-occurring disorders are generally more severe, chronic, and less likely to result in positive treatment outcomes than single disorders.²⁻⁵ Compounding these issues, people with co-occurring disorders are less likely to seek and avail themselves of treatment.⁶ The severity of co-occurring illnesses and the stigma with which this population is regarded combine to severely diminish treatment access, resulting in low utilization of services. Substance Abuse and Mental Health Services Administration's (SAMHSA's) National Survey on Drug Use and Health estimated that in the United States in 2010, there were 8.9 million adults with a mental illness and a substance use disorder and in the past year, 44% of these individuals received substance use treatment or mental health treatment, 13.5% received both these types of treatment, and 37.6% did not receive any treatment.¹

Mutual aid refers to nonclinical, nonprofessional peer-to-peer support for the purpose of overcoming a shared problem, typically addiction. Twelve-step fellowships are one example of mutual aid. In the substance abuse community, 12-step groups have a long history. Alcoholics Anonymous (AA), the most prevalent mutual aid organization in the United States, was created in 1935, and its 12-step program of recovery became the template for numerous other "anonymous" groups seeking to offer support, guidance, and fellowship for a range of addictions.⁷ These groups share core precepts of anonymity, spirituality, and singleness of purpose, based on the principle that substance abuse must remain "relentlessly in the foreground" in order to sustain attention and avoid denial.⁸ Affiliation with 12-step groups both during and after formal treatment has been identified as a beneficial and cost-effective way to improve substance use outcomes, and ongoing 12-step participation has been linked to reduced risk of relapse and better family, social, and vocational functioning across age groups.⁹⁻¹² Despite the documented benefits of single-focus 12-step groups such as AA and Narcotics Anonymous (NA), there is a small but growing body of research and narrative accounts suggesting that single-focus 12-step groups may be underutilized by

persons with dual disorders and that dually diagnosed persons may feel stigmatized when attending single-focus groups, for example, by not being able to discuss their mental illness or issues such as challenges in adhering to psychiatric medication regimens.¹³⁻¹⁷ Moreover, while studies evaluating 12-step groups for persons with co-occurring disorders have reported benefits associated with 12-step participation,^{18,19} clinicians are less likely to refer their dually diagnosed patients to mutual aid groups as compared with their singly diagnosed patients, that is, those with substance use disorders only.^{9,20,21}

Double Trouble in Recovery (DTR)

Double Trouble in Recovery (DTR) is a mutual aid program adapted from the 12 steps of AA. It was created in New York in 1989 to meet the needs of individuals dually diagnosed with substance use and a mental illness. In addition to speaking about substance use issues, DTR encourages its members to talk about mental health symptoms and the medication regimens that many members use to help alleviate them, topics that they may be reluctant to or discouraged from discussing in single-focus 12-step groups. Previous and ongoing research suggests that participation in DTR results in reduced substance use, better adherence to psychiatric medication regimens, and better coping skills and quality of life.²² Specific processes associated with outcome improvements have been linked to the reciprocal nature of group interactions and subsequent improvements in self-image and self-efficacy derived from seeing oneself as both receiving and giving advice.²³ In the helper therapy process, one comes to see oneself as more competent based on having exchanged one's role from being helped to being a helper.²⁴ Sharing skills, coping mechanisms, or guidance are examples of reciprocal learning processes. In reciprocal learning, a peer identifies with others in a group who are seen as similar yet, because of better coping, worthy of emulation.^{25,26}

Purpose

The current qualitative study was undertaken to (1) investigate DTR attendees' perceptions of the effects of DTR participation on their lives and (2) to better understand the specific self-help processes underlying DTR group dynamics.



Methods

This study reports findings from three focus groups conducted among a sample of patients ($n = 31$) with co-occurring mental and substance abuse disorders who attended DTR groups as part of a randomized clinical trial (RCT) to determine outcomes associated with DTR.

Setting

Two focus groups took place in New York City, one in Manhattan, the other in Staten Island. The Manhattan group took place in the community room of a 24-bed residential facility for people with co-occurring substance use and mental illness disorders. Residents are woken at 6:00 AM for medications and after breakfast leave the facility from 8:00 AM to approximately 3:30 PM to attend support groups (eg, recovery wellness) in various outpatient programs in the community. DTR groups are held on-site once weekly on Thursday evenings at 6:00 PM. The setting for the Staten Island focus group was a psychiatric facility with both outpatient and residential programs. This facility provides treatment for people with psychiatric disorders or co-occurring substance abuse and psychiatric disorders; most are characterized by the latter. Almost three-quarters of the patients live in supported housing nearby; one quarter live on the grounds of the facility in dorm-style housing, and a small percentage live independently. Patients typically arrive at the facility between 9 and 10:30 AM and spend 4 to 7 hours in various groups (eg, relapse prevention), projects, discussions, and meals. DTR groups are held once weekly at 10:00 AM Friday mornings in a large community room where light refreshments were provided by the study. At the time the focus groups in NYC were conducted, the chairpersons of both DTR groups were dually diagnosed individuals in recovery with prior experience conducting DTR groups in the New York metropolitan area.

One focus group took place in Grand Rapids, Michigan, at a large, comprehensive mental health and substance abuse treatment agency. The agency provides primarily group counseling and education for people with either single psychiatric disorders or co-occurring psychiatric and substance abuse disorders. Patients referred to DTR had completed some form of outpatient counseling such as the intensive outpatient program, individual counseling, and/or weekly

therapy groups such as depression, anxiety, bipolar, post-traumatic stress disorder, and early recovery/relapse prevention groups. Patients are enrolled in such outpatient counseling for periods of 3 to 8 weeks. Thus, DTR served as an “aftercare” modality at this agency. Two weekday DTR groups were conducted each week during most of the intervention period, each meeting for one hour in a group room at the facility (at 4:30 PM and 6:00 PM). DTR-assigned study subjects were scheduled to attend one DTR group a week. Each DTR meeting was chaired (led) by a peer member of the group, who was selected to do so by the group members at the start of each meeting. Light refreshments were provided by the study, and each subject attending received \$5 for transportation expenses (most members needed to drive to the site).

As part of the RCT, DTR groups have been conducted at the Staten Island facility since April 2009 at the Manhattan site since June 2009 and at the Grand Rapids, Michigan, site since January 2010. At the study's inception, all interested patients who had histories of both mental disorders and substance abuse (alcohol and/or drugs) were screened for suitability for the study. In order to be eligible to participate in the RCT, patients were required to have a mental illness diagnosis and a history of problematic substance use. Eligible patients who consented to participate in the RCT were randomly assigned to one of two conditions: immediate participation in a DTR group or delayed DTR participation. The project was approved by the Institutional Review Boards of Western Michigan University and the Michigan Department of Community Health. Signed informed consent was required and obtained from participants.

Participants

In all, 352 subjects took part in the RCT during 2009–2012, of whom 235 were inducted at the three clinical sites where the focus groups were held (48 at the Staten Island site, 40 at the Manhattan site, and 147 at the Grand Rapids, Michigan, site). The DTR chairpersons in New York City and a DTR coordinator in Michigan invited current DTR group participants to a voluntary focus group where they could discuss their opinions about DTR. The focus group participants were thus a convenience sample of volunteers. Those who attended the three focus groups were 16 of the average of 20 to 25 people



who attended the Grand Rapids DTR group regularly or intermittently, 9 of the average of 7 to 10 people who attended the Staten Island DTR group, and 6 of the average of 5 to 7 people who attended the Manhattan DTR group. Thus, the focus group participants were most of the subjects who were attending DTR groups at those sites at the time of recruitment.

The anonymous format precluded the collection of demographic data from focus group participants. In general, however, as determined by data collected in conjunction with the RCT, New York DTR participants were more likely to have a serious mental illness and to live in supported housing, while Michigan DTR participants were more likely to have just completed treatment, live independently, and exhibit higher levels of substance use. According to their self-report, focus group participants' duration of exposure to DTR ranged from 2 weeks to 2.5 years.

Focus group procedures

The focus groups were conducted 21, 29, and 31 months after the initiation of the RCT in Michigan, Manhattan, and Staten Island respectively. In New York, the groups were conducted by the project director (HM) and a PhD ethnographer (HG). In Michigan, the group was conducted by the principal investigator (SM) and a doctoral candidate in behavioral science. DTR participants were informed that the focus group would be an informal, confidential 1 to 2 hour discussion about their experiences in DTR, that there was no obligation to attend, and that each person who participated would be compensated for their time. Participants in the New York groups were compensated \$30 for participating. In Michigan, participants were compensated \$50 to cover higher transportation expenses.

The focus group facilitators timed their arrival to coincide with the conclusion of the regularly scheduled DTR group and were introduced to the participants by the DTR chairperson. The groups were reminded that they could speak freely and that the focus group was intended to obtain information about their opinions of DTR and how DTR participation has affected them. Participant identifying information was not collected; the participants were anonymous to the focus group facilitators. Questions were posed to the group, and participants who chose to respond were encouraged to do so. Although participants were encouraged to

respond to all questions posed, not all participants answered all questions. The facilitators managed response time in a manner that insured opportunities for all participants to speak. In New York, the ethnographer posed the questions and coordinated the responses among the group while the project director recorded verbatim notes. In Michigan, the principal investigator (SM) coordinated the discussion while the doctoral candidate took notes. Discussion among members and follow-up responses were encouraged; no member was permitted to dominate the discussion.

Focus group format

The focus groups were intended to enrich our understanding of RCT participants' DTR experiences by eliciting qualitative data regarding the perceived usefulness of and engagement in DTR. Thus, the goal of each session was to provide a conversational platform in which members could speak freely about their experiences in DTR. The following questions were posed in each focus group: (1) What have been the impacts of the DTR group on your life? (2) How has DTR been different from other 12-step groups you may have attended in the past? and (3) If there were no DTR group, but you still had the same problems, what do you think would have happened in the time you've been coming to the group? Once the focus group participants had addressed these questions, the floor was opened to a general discussion about DTR. We also asked participants to tell us how they believed the DTR group could be improved.

Although all three research questions were posed in a structured manner, the responses were conversational; themes were frequently revisited several times within a session. The facilitators attempted to keep the discussion on topic but were not overly rigid about directing participants to stay with any particular question at any point in the discussion.

Data analysis

Verbatim notes from focus group sessions were thematically analyzed by means of an iterative, comparative process influenced by grounded theory.^{27,28} Preliminary coding and analysis of data from each focus group was first conducted independently by each city's team. Subsequently, the first two authors combined data from all three focus groups to develop

overarching code lists and thematic categories. (Because of the small size of the dataset, no qualitative data analysis software was used.) Taking into consideration both themes related to project aims and emergent themes (ie, themes not specifically anticipated prior to the conduct of the research but salient to the focus group investigation), verbatim notes were repeatedly reviewed and compared, with particular attention paid to the most common themes (ie, those that emerged repeatedly and were voiced by multiple participants). All thematic coding was reviewed by the co-principal investigator (AR), who was not involved with facilitation of the groups.

Results

Themes common to all focus groups

As seen in Figure 1, six themes emerged as common to all three focus groups/sites. Across sites, we identified two broad thematic categories, one related to internal mechanisms such as emotional support and cognition, the other associated with practical concerns such as skills building and finding medical help. A sentiment explicitly voiced by 16 participants (52%) and endorsed by broad consensus in both New York City and Michigan was the emotional experience of feeling a shared sense of community in DTR and feeling respected and supported, as summed up by a Staten Island participant who said, “My mental illness is part of my character, and here I can be me. I have learned both to take control and to receive help from others. I have learned about patience and respect.”

Developing a degree of insight into the relationship between mental health symptoms and substance use issues emerged as an important topic for 12 participants (39%): “It wasn’t until this group that I realized that my substance use didn’t cause my mental illness, though it might contribute to it. I used to think my drug use caused it, like it was my fault.” Ten participants (32%) expressed gratitude for the opportunity to discuss symptoms, “We can talk about symptoms here.” A Manhattan participant offered that “I never even connected mental illness with using; here I learned that drinking and using can make it worse.” A refrain that flowed from the discussion of mental health symptoms and received broad endorsement from 13 participants (42%) across all sites was an appreciation of the fact that the DTR format encourages members to focus on the importance of medication adherence and learning methods for achieving it: “I learned how to use my meds without also picking up.” One Michigan member highlighted the contrast between DTR and 12-step meetings she had attended in the past: “In AA and NA you are judged for taking mental health medications; they told me I was still an addict who is using. In the DTR group, I can talk about my medications without being judged.” “My mental illness is part of my character. Imagine me out on the streets without my meds!”

Themes specific to New York city

There were also some differences among the groups. Spontaneously elicited reports of giving oneself over to a higher power, a cornerstone of traditional 12-step ideology, did not emerge in the focus group

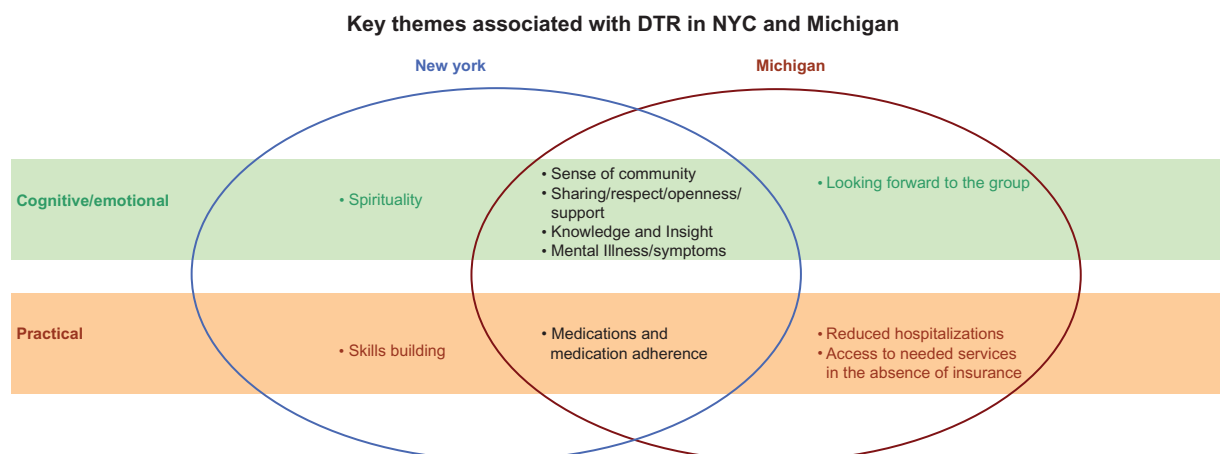


Figure 1



discussion in Michigan or in Manhattan. In contrast, in Staten Island, several members acknowledged the importance of believing in God and were eager to share their spiritual journeys. A quote from one member, “When I found a power greater than myself, I redeemed myself and found a place of serenity. God brought me back my sanity,” typified this sentiment among participants in the Staten Island focus group. Another member characterized the role of his higher power this way: “I thought I was going to suffer in hell, but God told me I still have control over my life. ‘Go to the group, and make amends.’” Among practical concerns, New Yorkers concurred that DTR helped equip them for certain challenging situations they might find themselves in: “Getting to know people like me, I learned how to deal with situations that would put me—if I was out on the street—under someone else’s control.” Developing the tools and the motivation to transcend mere survival skills was a theme that resonated among New Yorkers as well, “I helped a lady across the street the other day, like you see on TV. It felt so good, it felt so ... respectful, and that’s what we do here in this group; this is where I learned to respect myself.”

Themes specific to Michigan

Among Michigan participants, there was strong agreement about the central importance of having a group every week, affiliation, and the emotional comfort associated with looking forward to the group and having “a schedule, a ritual. We’re all links in a chain, and we all need to be here every week.” Another member explained that the communal, welcoming, low-pressure environment of DTR made her less reticent about attending other 12-step groups, something she had never considered before: “Going to DTR has made me want to go to other groups as well. It also helped me understand the relationship between my anxiety and my drug use.” Michigan participants emphasized the differences between single- and dual-focus 12-step groups. Several members lamented the regimentation they had sensed in single-focus 12-step meetings that they had attended in the past: “NA was too rigid and repetitive to meet my needs.” “AA and NA are too rigid. It’s their way or the highway.” “AA? They’re all preachy ... a bunch of prehistoric gurus who want you to sit your ass down and listen.” Important practical impacts of DTR participation

voiced by Michigan participants included reduced hospitalizations and gaining access to therapy in the absence of insurance: “When I couldn’t get funding for going to counseling, this place gave me the space to talk about my mental health. Without it, I would have had nowhere to go.” “If it weren’t for this group I would be in jail, using ... or in a mental hospital. Instead, I haven’t used since last July, and I have less mental issues as well.” “The programs I used to be in never addressed the real problems I had. Because of this group I haven’t smoked crack or gone to the hospital in over a year!”

Discussion

Research has shown that mutual aid is associated with improved substance use outcomes, both for singly diagnosed and dually diagnosed individuals.^{19,29} The present findings suggest reasons, from participants’ perspectives, why DTR attendance has been associated with reduced substance use and anxiety and improved medication adherence.^{30,31} For both the Michigan and New York City groups, developing a sense of affiliation in a safe, supportive environment—the essence of mutual aid fellowships—was a predominant theme. Participants appreciated the opportunity to gain knowledge and insight about their mental health symptoms, medications, and their relationship to substance use; the groups provide an environment in which such discussion is not only allowed but encouraged. Also, participants received affirmation for who they are, that is, individuals with substance use histories and also individuals with mental illness. Affirmation, that is, recognition/acceptance of being mentally ill rarely occurs in single-focus 12-step groups.^{16,32} These results distinguish dual-focus 12-step groups from groups with a single-focus orientation in that, rather than keeping substance use “relentlessly in the foreground,” the more inclusionary framework encourages members to express their concerns about both mental illness and substance use. Our findings are consistent with earlier research in which support from dually diagnosed peers emerged as a key ingredient of DTR participation.¹⁵ The sharing of ideas and the reciprocal exchange of information about mental illness, medication, and medication adherence are themes that echo earlier findings in which reciprocal learning was associated with improvements in self-efficacy, substance use



outcomes, and attendance at DTR meetings.²³ The importance of a spiritual orientation (eg, surrender to a higher power) has also been documented in empirical research on mutual aid groups.^{33–35} Spirituality, a theme that emerged in Staten Island, was not a topic of discussion among Michigan or Manhattan members. This may represent a study artifact since the Staten Island DTR chairperson had substantial experience with a variety of 12-step groups, including DTR, and repeatedly acknowledged in DTR meetings that he had benefited from reliance on a higher power.

Learning about and gaining access to needed services, a benefit cited by Michigan attendees but not those in New York, may stem from differences in living situations between these two samples in that New York participants lived primarily in supported housing, where medical and mental health services—a formal part of their treatment—are easily accessible and ongoing. In contrast, Michigan participants were far more likely to be in aftercare and living independently. In this situation, services are more challenging to access and can represent a substantial out-of-pocket expense.

Limitations

The focus groups in this study were conducted in separate clinical locations with self-selected participants. Subjects had been participating in DTR for various lengths of time, had disparate backgrounds, and had different degrees of experience with 12-step programs. However, a more homogenous sample would likely limit external validity of the results since most 12-step groups, whether single-focus or dual-focus, include a diverse mix of participants. The most important feature of such groups, which includes DTR, is that all participants have a similar problem (mental illness and/or substance abuse).

It is unknown what effect, if any, differential time of DTR exposure had on participants' perceptions of DTR benefits. A future research direction could be to examine factors that sustain participation in DTR groups. Such research would require individual interviews with subject identification (whereas the present study was conducted with subject anonymity) and a considerably larger sample wherein differences between newer and long-time DTR participants could be compared.

The present study is also limited by small sample size; a follow-up study should recruit more participants in more focus groups. The data presented here are more in line with a pilot study, intended to initiate procedures and determine whether a more extensive qualitative study of this kind would be of value.

Finally, different investigators conducted the focus groups in New York City and Michigan, and, thus, it is possible that questions were framed and responses elicited in ways influenced by their possibly different perspectives. This was necessary because the present study was conducted in two widely separated states. However, a follow-up study would be better advised to have the same facilitators conduct all focus groups.

Conclusion and Implications

Considerable research supports the effectiveness of 12-step fellowships for those in recovery from substance use disorders and those diagnosed with co-occurring disorders. This qualitative study suggests that the specific 12-step processes that have been embraced by traditional mutual aid fellowships—and are associated with improved outcomes—apply to those 12-step participants with co-occurring disorders and support the perceived efficacy of dual-focus mutual aid. With the advent of health care reform, as greater numbers of Americans are expected to be referred to or to seek mental health treatment, dual focus mutual aid groups such as DTR can provide a low-threshold treatment option that is effective from both a clinical and cost perspective. In this context, mutual aid groups may serve a critical function by helping to increase access to mental health services for particularly vulnerable populations such as those with co-occurring disorders.

A main conduit through which clients first reach 12-step groups is clinician referrals.^{20,36} For example, one-half of AA members report being first referred to 12-step by a health care professional.³⁷ It is, therefore, of paramount importance that mental health clinicians encourage their dually diagnosed patients to begin or continue to participate in 12-step fellowships that, like DTR, are inclusionary, nonstigmatizing, and send a message that is supportive rather than, as one member put it, “judgmental.” In the evolving health care reform environment, the Affordable Care



Act is likely to simultaneously (1) integrate services (bringing both providers and consumers of mental health and substance abuse services together) and (2) encourage greater numbers of people to accept services for substance abuse, even if they have already sought services for other problems such as psychiatric symptoms. Providing information to mental health providers about consumers' perceived benefits of DTR may help ensure that consumers with co-occurring disorders are referred to needed services such as 12-step fellowships consistently and reliably.

Previous research indicates that a belief that 12-step participation can boost recovery, recognition of the severity of the client's substance abuse, and interest in learning about 12-step groups predict clinician referral of dually diagnosed people to 12-step groups.^{21,36} Future efforts to spur referrals to 12-step groups among mental health clinicians must, therefore, include strong educational initiatives that focus on the (1) efficacy, value, and ongoing support afforded by 12-step fellowships; (2) nature and prevalence of dual-diagnosis; (3) severity of substance abuse and its impact upon the client's quality of life; and (4) challenges and opportunities associated with providing 12-step support for dually diagnosed people. There is evidence of improved outcomes for individuals who participate in 12-step groups geared to their dual diagnoses.^{18,19} The current study suggests that providing a sense of community, openness, affirmation, and mutual understanding, the foundation of traditional (single focus) 12-step fellowships, also applies to those participating in 12-step groups for dually diagnosed people. In a health care system that increasingly integrates substance abuse and mental health services, this would likely lead to increased referrals to 12-step groups for mental health patients with co-occurring substance abuse, a population that has had limited opportunity to benefit from this modality.

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Author Contributions

Conceived and designed the experiments: SM. Analysed the data: HG, HM. Wrote the first draft of the manuscript: HM. Contributed to the writing of the manuscript: AR, HG, SM. Agree with manuscript results and conclusions: TU, SK, MR, TM. Jointly developed the structure and arguments for the paper: HM, HG, SM, AR. Made critical revisions and approved final version: AR. All authors reviewed and approved of the final manuscript.

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Competing Interests

Author(s) disclose no potential conflicts of interest.

Disclosures and Ethics

As a requirement of publication author(s) have provided to the publisher signed confirmation of compliance with legal and ethical obligations including but not limited to the following: authorship and contributorship, conflicts of interest, privacy and confidentiality and (where applicable) protection of human and animal research subjects. The authors have read and confirmed their agreement with the ICMJE authorship and conflict of interest criteria. The authors have also confirmed that this article is unique and not under consideration or published in any other publication, and that they have permission from rights holders to reproduce any copyrighted material. Any disclosures are made in this section. The external blind peer reviewers report no conflicts of interest.

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