

COMBATTING STIGMA AND BIAS IN ADDICTION RESEARCH BY WORKING WITH PATIENTS AS RESEARCH-TEAM PARTNERS

PRZEZWYCIĘŻANIE STYGMATYZACJI I UPRZEDZEŃ W BADANIACH NAD UZALEŻNIENIAMI PRZEZ PRACĘ Z PACJENTAMI JAKO PARTNERAMI ZESPOŁU BADAWCZEGO

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Abstract

Addiction to illicit substances continues to be a persistent and growing public health crisis, resulting in an increasing need for effective research and subsequent implementation in addiction research. Currently, research and treatment opinions and perspectives are limited to those of providers and professionals while failing to include patients as partners. The lived experiences of patient research partners who have experienced addictions are not well incorporated into research and interventions. Stigma and biases influence addiction research by excluding patients as partners, resulting in less robust solutions and potential biases. Related patient as partners challenges may be mitigated by maintaining open communication, inclusive recruitment, appropriate training and assessment of researcher-partner

Streszczenie

Nielegalne substancje psychoaktywne są nadal źródłem trwałego i narastającego kryzysu zdrowia publicznego, co narzuca potrzebę podejmowania efektywnych badań naukowych i wdrażania ich wyników. Obecnie w badaniach i perspektywach rozwoju leczenia bierze się pod uwagę opinie profesjonalistów, podczas gdy pacjenci nie są włączani w ten proces jako partnerzy. Ich życiowe doświadczenia nie są właściwie wykorzystywane w prowadzonych badaniach i interwencjach medycznych. Piętno i uprzedzenia mają wpływ na badania przez wykluczenie pacjentów jako partnerów i tym samym przyjmowanie mniej skutecznych oraz potencjalnie błędnych rozwiązań. Wyzwania z tym związane da się przezwyciężyć przez przyjęcie takich strategii, jak otwarta komunikacja, partycypacyjna rekrutacja, odpowiednie szkolenie i ewa-

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collaboration. The implementation of these strategies may allow for meaningful partnerships. As drug-involved overdoses and/or deaths continue to climb, using patients as partners in addiction research is crucial to improving research. Thus, patients as partners who have experienced addiction are needed to combat stigma and bias, and create impactful and translational research outcomes.

Keywords: Patients as partners, Stigma, Bias, Addiction research, Psychoactive substance use disorder.

luacja współpracy badacz-partner. Ich wdrożenie może doprowadzić do prawdziwego partnerstwa. W kontekście stale rosnącej liczby przedawkowań i/lub zgonów partnerstwo pacjentów w badaniach ma kluczowe znaczenie dla poprawy ich jakości. Pacjenci z przeżytymi doświadczeniami zaburzeń używania substancji psychoaktywnych są niezbędni jako partnerzy do przezwyciężania stygmatyzacji i uprzedzeń oraz uzyskania wartościowych, dających się zastosować w praktyce wyników badań.

Słowa kluczowe: pacjenci jako partnerzy, piętno, uprzedzenia, badania nad uzależnieniami, zaburzenia używania substancji psychoaktywnych.

Addiction to illicit substances continues to be a persistent public health crisis [1, 2], particularly with the rise in accessibility to illicit drugs [2, 3]. Drug overdose deaths increased 30% from 2019 to 2020 and 15% in 2021 in the United States; as a result, an estimated 108,000 overdose deaths occurred in 2021 [4]. As the prevalence and number of overdoses continue to rise [1-3], effective research and subsequent implementation are crucial in addressing the needs of those with addiction. Current opinions and perspectives are limited to those of providers and professionals and fail to utilize patients as partners and their lived experiences and perspectives. The lack of narrative experiences of people with addictions in research and interventions results in less robust solutions and potential biases. Paired with the rise in drug-involved overdoses and deaths, there is a growing need for patient research partnerships in addiction research. Yet, stigma and bias are powerful in influencing addiction research and can result in the exclusion of patients as partners.

In many ways, people are experts in their lived experiences. This is particularly true in settings where topics and situations are socially taboo or stigmatised like in the case of addiction. Patients as partners can provide valuable insights into their lived experiences of addiction, enabling a richer and more relevant scientific discovery process [5, 6]. Some report that patients as partners provide meaningful feedback [5, 7]. Input from patients as partners is likely to improve patients' experience with care [6] as they intimately understand patient perspectives and preferences. This provides a valuable proposition in research as patients as partners

can positively impact the resulting research and health outcomes [5]. Patient partners are those from a patient population who are involved as collaborators [8] and are equal members of research teams [9-11]. Patient partners can provide input during various steps of a research study [9, 12], including the design of the study, priority setting, collecting and analysing data, and aiding in the distribution or implementation of research results [9, 12, 13].

Addiction is widely misunderstood and stigmatised by the public; as a result, researchers and healthcare providers are not free from these biases. The associated public stigma of people with addiction or substance use disorder [14] falls within the three broad stereotypes, prejudices, and discrimination themes [15]. The public often views people with substance-use disorder as reckless, unreliable, inadequate (e.g., they do not meet social expectations) and a threat (e.g., criminals) [15]. This kind of stereotyping can and does unconsciously translate into research by influencing interactions with participants and creating biased methods.

There have been efforts to include community partners in addiction studies who will represent the interests, needs and concerns [16] of those with addiction. While community partners know about and are empowered to represent their respective communities [16], patients as partners pose a more intimate view of health systems. One can surmise that patient research partnerships are not well incorporated within addiction research due to the addiction-related stigma [15, 16], particularly with the perception that those with

addictions are “unreliable” and “inadequate”. These attitudes can dissuade researchers from forming patient research partnerships with those who have experienced addiction, however, this is not an ethical reason to exclude patients as partners who have experienced addiction from research opportunities.

Patients as partners can act as a bridge into the reality of addiction and as a protective measure against stigma and bias. In research, patients as partners can also provide unique and valuable perspectives on the collected research data [17]. The perspectives of patients as partners in addiction science can be especially valuable when analysing the nuances of qualitative data [17]. For patients as partners to be effectively included, they must be accepted and respected from the start of the partnership.

There have been a few efforts in support of the use of patient partnerships in research. The National Institutes of Health launched the Helping to End Addiction Long-term (HEAL) initiative in the United States, which aims to develop partnership with researchers, clinicians, patients, caregivers and communities for opioid-use disorder [18]. Further, patients as partners, clinicians, and researchers continue to advocate for “person-first” language, in so far as those with addiction are addressed as “a person with substance-use disorder” as opposed to the stigmatising term “addict” [19].

In the past, patients as partners have been recruited into careers grounded in advocacy. For instance, Alcoholics Anonymous fills service positions for those who had experienced alcohol use disorder (AUD) [20]. The expertise of those who have experienced substance addiction have become privileged-access interviewers and are recruited by research institutes [20]. This has been exemplified through the employment of people who inject drugs to conduct outreach related to human immunodeficiency virus (HIV) in an effort to prevent or reduce its occurrence early in the opioid epidemic [21-24].

There have been attempts to recruit hard-to-reach populations via patients as partners for treatment, prevention, and research. A study conducted by Colón *et al.* 2010, engaged both patients who were drug-free and those currently using illegal substances for peer outreach and HIV education. As a result, it was discovered that there were potential positive benefits in training these patients as outreach workers [22]. Patients as partners who were actively using illegal substances were able to have a positive effect through the training for outreach activities; patients as partners may reduce their own drug use and risk behaviours, and their active usage of illegal substances may grant them improved access to current users or others at high risk in the hard-to-reach populations [22].

There are challenges for people with addiction to participate in a meaningful way, as a result of being members of a vulnerable and hard-to-reach population. Additionally, there is variability in recovery and the severity of substance addiction that can potentially complicate partnerships. These challenges can be mitigated by maintaining open communication, inclusive recruitment, appropriate training and assessing researcher-partner collaboration [25]. Researchers should be cognizant of potential power imbalances [25] between themselves and the patient partner. Implementing these strategies can allow people with addiction to participate in meaningful partnerships. Furthermore, connecting with potential patients’ partners within addiction science may be challenging due to strained relationships between healthcare providers and patients with addiction [26]. Some clinicians are concerned that participation in research or other outreach may put the patient partner at risk of relapse [22]. However, this concern may be addressed when patient research partnerships are framed as an opportunity rather than a threat to sobriety.

Due to the limited research into the topic of patient research partnership in addiction research, more research into the implementation and exploration of patients as partners in addiction research is urgently needed.

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Conflict of interest/Konflikt interesów

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Ethics/Etyka

The work described in this article has been carried out in accordance with the Code of Ethics of the World Medical Association (Declaration of Helsinki) on medical research involving human subjects, Uniform Requirements for manuscripts submitted to biomedical journals and the ethical principles defined in the Farmington Consensus of 1997.

Treści przedstawione w pracy są zgodne z zasadami Deklaracji Helsińskiej odnoszącymi się do badań z udziałem ludzi, ujednoliconymi wymaganiami dla czasopism biomedycznych oraz z zasadami etycznymi określonymi w Porozumieniu z Farmington w 1997 roku.

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