





## Research Article

# Perceived Change in Quality of Life Related to Treatment of Hepatitis C Infection among People with Substance Use Disorder: A Qualitative Study

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**Background.** The hepatitis C virus (HCV) is often associated with people who inject drugs, and with a reduction in quality of life. While earlier forms of HCV treatment had low treatment uptake, newer HCV treatment integrated with opioid maintenance treatment appears to increase treatment uptake among those who inject drugs. The aim was to explore how people who inject drugs perceive changes in quality of life after treatment of HCV infection. **Methods.** Four focus group discussions, and 19 individual interviews were conducted with people who inject drugs or who had previously injected drugs and received opioid agonist therapy. All participants were successfully treated for and “cured” for HCV. Data were audio-recorded, transcribed verbatim, and analyzed using reflexive thematic analysis. **Results.** The HCV treatment helped participants to let go of negative thoughts and break destructive patterns of interaction. This facilitated the restoration of social relationships with family and others. Furthermore, some participants reported a general improvement in their health. Feeling healthy meant fewer worries such as infecting others. Also, interactions with health professionals were experienced as less stigmatizing. These physical, social, and psychological improvements led to a form of “awakening” and being treated for HCV gave participants hope for the future. **Conclusion.** HCV treatment improves the mental and physical health in addition to play an important social function. Successful HCV treatment was associated with a greater sense of hope for the future, reconnection with significant others, and reduced feeling of stigma. Overall, improved health and social relationships contributed to improved quality of life.

## 1. Introduction

The hepatitis C virus (HCV) is a bloodborne chronic infection, and 79% of HCV disease in high-income countries is associated with drug injection [1]. Among individuals exposed to HCV, approximately 80% develop chronic infections [2, 3]. HCV can develop over decades and lead to cirrhosis of the liver and complications such as hepatocellular carcinoma and liver failure, causing liver-related deaths and suffering [4, 5]. Transmission of HCV is high among people who inject drugs (PWID), people with

a history of injection drug use or a history of recent substance use receiving opioid maintenance treatment (OMT) [6, 7]. Among patients receiving OMT in Norway, about half had chronic HCV infection [8]. Liver disease and substance-related overdose are equally significant causes of death among people with opioid dependence under the age of 50 [9, 10].

Previously, the first-line therapy for HCV was interferon-based, which had moderate efficacy, considerable adverse effects and a low treatment uptake among PWID [11]. Over the last few years, efficient, direct-

acting antiviral treatments have become available for PWID [12]. Though HCV treatment coverage for PWID was initially low [13, 14], integrated treatment approaches focusing on interdisciplinary, decentralized clinics, availability, and accessibility have helped to increase HCV treatment uptake.

Health-related quality of life (HRQOL) is a concept referring to a person's subjective and dynamic perception of her/his state of health and how it affects their well-being, mental, physical, and social functioning [16, 17]. PWID and people with a substance use disorder (SUD) receiving OMT report a significantly reduced HRQOL compared to the population norm [18–21]. Furthermore, awareness of one's own HCV infection is associated with a significant reduction in quality of life (QOL) compared to those who are unaware of their HCV infection [14]. After being treated with interferon, improvement in HRQOL is reported in people achieving a sustained virologic response (SVR) compared to patients without SVR in physical health domains [22]. The HCV was, until 2014, treated with interferon, which generally had considerable side effects [11]. Today, a simplified, safe, and effective all-oral direct acting antivirals (DAA) therapy is offered to people who would receive treatment from professionals with specific knowledge related to their additional comorbidities, e.g., injection drug use [23]. Due to the shorter treatment length, low pill burden, fewer drug-drug interactions, and less side effects, the DAA treatment, compared to the interferon treatment, may influence patient's HRQOL differently, both during and after HCV treatment. Besides, stigmatization, understood as a sociocultural disapproval and discrimination of specific social groups [24], negatively impacts QOL. There is a correlation between higher levels of stigma and poorer health outcomes [25, 26]. However, few studies to date have examined how people with SUD experience HRQOL after successful HCV treatment with the new DAA and how they experience stigma. Against this background, the current study aims to explore how participants with a history of injection drug use perceive a change in quality of life from the successful treatment of HCV.

## 2. Materials and Methods

This qualitative study was linked to the INTRO-HCV study, comparing HCV treatment integrated with OMT treatment with standard treatments of HCV in the cities of Bergen and Stavanger in western Norway [27]. The INTRO-HCV study was conducted between the years 2017–2019. The target population was people receiving OMT or PWID in contact with municipal low-threshold health and care centers in one of these cities. Further details are available in the protocol and primary outcome articles [15, 27]. In order to reach a phenomenological and hermeneutical understanding of the participants' experiences, we used an adapted version of reflexive thematic analysis as described by Braun and Clarke [28].

**2.1. Recruitment.** Recruitment aimed to obtain a strategic range; in other words, participants were selected based on characteristics or qualifications that were strategic, relative to the research questions and the study's theoretical perspectives [29], such as having a history of injection drugs and carried out a successful treatment of HCV. All participants were recruited by research nurses, participating in INTRO-HCV study, who had substantial knowledge of the patient group through their daily work at OMT outpatient clinics or at a low-threshold municipality service. Inclusion criteria for this qualitative study were participants in the INTRO-HCV study who had completed HCV treatment and who had sustained virologic response (were "successfully" treated for HCV), living in one of the two cities and able to participate in focus group or individual interviews. The following exclusion criteria were used not being able to communicate orally.

**2.2. Population.** A total of 39 individuals participated in this study: 12 men and 7 women (age 32–65) were interviewed individually, and 17 men and 3 women (age 32–63) participated in 4 focus group discussions. The participants had a range of between 10 and 40 years of injection drug use. The majority of the participants were OMT patients, recruited from eight OMT clinics, and a smaller group of participants were recruited from the main low-threshold service in Bergen municipality. Some of the participants, especially those not in OMT, were currently injecting opioids. The participants had achieved sustained virologic response from three to 12 months before the interviews were conducted.

**2.3. Data Collection: Semistructured Individual Interviews and Focus Group Discussions.** Qualitative semistructured individual interviews and focus group discussions were used for data collection. Personal subjects, which can be perceived as sensitive, such as the participants' close relationships, sexuality, and changes in patterns of substance use, were only discussed in the individual interviews. It was deemed that general subjects, such as perception of the HCV treatment, were best addressed as part of group discussions. All interviews were conducted face to face, at an OMT clinic or at the municipality low-threshold service to which the participants belonged. The interviews were audio-recorded between October 2019 and May 2020 and transcribed verbatim.

The focus group interviews and the majority of individual interviews were conducted before the COVID-19 pandemic hit our country. However, due to the pandemic and government restrictions, i.e., distance and number of social contacts, as well as a general insecurity in the population, further recruitment for individual interviews became difficult. A couple of interviews were conducted with strict restrictions, e.g., participants were prescreening for symptoms of COVID-19, a distance of at least 2 meters was maintained between the participant and the interviewer, and face mask was used during the interviews. The participants in the individual interviews received compensation for their time (NOK 200) while the participants in the focus group discussions received food and drinks.

The interview templates for both the individual interviews and focus group discussions were co-constructed within the project group of the original research project. The project group was made up of 16 researchers with a broad range of interdisciplinary experience from research on substance use, welfare services and family therapy, and professionals (social scientists, medical doctors, psychiatric nurses, and social workers).

The individual interview guide focused on four main topics: (1) quality of life, (2) how they perceived themselves and (3) their relationships, and (4) substance use. The interviews lasted approximately 30 minutes. The individual interviews were conducted by research nurses who were trained in qualitative interviewing.

The focus group discussions focused on four main topics: (1) experiences of the treatment, (2) relationships, (3) stigma, and (4) physical and psychological problems. The discussions lasted between 52 and 93 minutes. The focus group discussions were conducted by a moderator, who led the discussions and maintained focus, and encouraged discussion among the participants. One person also served as assistant moderator, observing the group dynamic, providing a summary of discussion at regular intervals, and assisting in centering the discussion around the significant topics in the conversation. Both the moderator and the assistant moderator were trained in qualitative focus group interviewing. Of the 20 people who took part in the focus group discussions, one was visibly under the influence of a substance, while another slept through the majority of the discussion. Two participants left the discussion part way through the session. However, they had contributed little to the focus group discussions before leaving, and statements from them are not included in the analysis. All participants in the interviews had consented to study participation at the study initiation, and at that time, they were all competent to give consent. To ensure variation in informants, as some of the topics in the focus group and individual interview guides overlapped, people participating in the focus group discussions were excluded from individual interviews.

Willig [30] claims that ideally, the process of data collection continues until theoretical saturation has been achieved. However, based on the nature of qualitative research, saturation is difficult (if not impossible) to reach [31]. Therefore, the saturation of data in qualitative research functions more as a goal than a reality [30].

**2.4. Reflexive Thematic Analysis.** Our analysis proceeded as follows: Step 1: All the transcriptions were read by two of the authors (BUN and LL), and tentative ideas of topics were noted. Step 2: LL and BUN each coded the transcriptions separately, before swapping transcriptions for a new separate coding. Step 3: The codes were used to identify and name topics in the data material. Thematisation was performed first by LL and then discussed with BUN, before being shared with the article's other authors. The following topics were identified: (1) changed life situation results in hope and new opportunities, (2) physical and mental changes result in a new awareness of one's own health, and (3) changed interpersonal interactions. Step 4: Writing of the article, see Table 1 for an illustration of the analysis process.

**2.5. Research Ethics.** All procedures were conducted in accordance with the Declaration of Helsinki and were approved by the Norwegian Regional Committees for Medical and Health Research Ethics (REK (2017/51)). All participants signed a consent form and received copies of the ethics approvals for the research project. All participants were also informed of the option to withdraw from the research project at any stage with no explanation required. All transcripts were anonymized and stored on an encrypted server of the regional health authority.

### 3. Results

**3.1. Changed Life Situation Resulting in Hope and New Opportunities.** The participants had felt a sense of powerlessness and hopelessness associated with having a chronic hepatitis C infection and lack of opportunity to escape from this. A perception of hopelessness and the fact that they were already infected meant that for some, and it made no difference how they handled their injecting equipment. A lack of hope meant that little priority was placed on potential recovery from continued substance use and destructive lifestyle since participants did not believe they would live into old age. The disease had taken away their self-respect and made it difficult to imagine a future.

After completing treatment, many found that they had become rid of a considerable "inner demon," with the result that they did not stigmatize themselves in the same way as before. In this context, one said: "I no longer identify so much with the junkie scene" (Individual interview). This change led to improved self-perception, fewer concerns regarding the potential risk of infecting others, and reduced stigma to having HCV, and they were open to initiating changes. They regarded these changes as a step towards one day being drug-free. Former thoughts of an early death changed to hopes and dreams of a future with new opportunities. As one participant expressed it:

"Recovering from hepatitis C gives me hope for the future. If you have no hope of a future, you might just as well carry-on using drugs." (Individual interview.)

This hope for the future resulted in an increased awareness of the choices they were making. Although most participants were still dependent on substances, i.e., illegal or legal substances and medications used in an unprescribed manner, to varying degrees at the time of the interview, after the treatment, they were more aware of the importance of their choices:

"Once you recover from hepatitis C and start exercising, for example, you also become more aware of what you're eating. That's how I was when I recovered from the disease. I became more aware of my choices. I don't even drink water out of the same bottle if someone else has been using it, even if they've used a clean needle. I mean, you just never know." (Focus group interview.)

TABLE 1: Example of coding.

Example of transcription	Condensed meaning/codes	Topics
<p>“It was always in the back of my mind, it’s not something that you go and tell the average person, and if you meet someone new, like a new friend, girlfriend or whatever-it’s just amazing that you don’t have this hanging over you”</p>	<p>Great not to have to tell people about the disease</p>	<p>Changed interpersonal interactions</p>
<p>“It was great to tell the dentist: now you can get rid of that red X”</p> <p>“You constantly feel like it must be written on your forehead. But I’ve stopped telling myself that I’ve been branded this way”</p>	<p>Good that one can’t infect others</p> <p>Have stopped regarding oneself as branded</p>	<p>Changed life situation resulting in hope and new opportunities</p> <p>Physical and mental changes have resulted in a new awareness of one’s own health</p>

3.2. *Physical and Mental Changes Have Resulted in a New Awareness of One's Own Health.* The participants have suffered varying degrees of HCV-related afflictions, so their perception of subsequent change will therefore vary. Some felt that the treatment was a turning point in their life, while others had few or no perceptions of change. As sick, they tended to define themselves as victims of circumstances, with no means of influencing the situation. They felt that the people around them labelled them as dirty with a "self-inflicted disease," which in turn served to prolong and amplify a disease-related mental strain and sense of shame. However, for some, the HVC treatment aided a mental change:

"I don't know if I noticed so much [changes] physically, but mentally in relation to my own self-stigma (...) as long as you know you have hepatitis C the shame is often very latent. (...) facing GPs, those working in the laboratory, and if you are having surgery and things like that, then it does not take long, for me at least, before it didn't feel good. That feeling has disappeared, so it feels really good." (Focus group interview)."

The participants described HCV as an undetonated "disease bomb;" they did not know when it would explode or how much damage it might cause. This perception caused them considerable anxiety, as the previous quote also illustrated, regardless of the degree of specific physical or mental affliction. Thus, one benefit of the HCV treatment appears to be the absence of former worries associated with HCV, as one participant put it, "I don't need to be worried or think about the fact that I have a disease." (Individual interview).

The participants stated that they achieved a new awareness that there was a future over which they had control and thereby a new realization of their own health. This "awakening" meant that many felt an improved cognitive function and were more aware of what was happening in their own bodies and in their surroundings. Some participants felt that the HCV treatment reduced their physical health problems: e.g., pains they had felt in their body disappeared, and others had fewer hot flushes or sweats. Improved appetite and energy levels, in addition to better sleep hygiene also appeared to be associated with successful HCV treatment. In general, the participants expressed positive experiences and a sense of better health after successful HCV treatment:

"It [the HCV treatment] was like taking an internal shower and then becoming entirely clean once more." (Individual interview)."

Another participant conveyed:

"Well, firstly my urine used to be black, and it stank something awful. Moreover, I had pains, cramps in my kidneys and (...) I just was not well. After I recovered, I really noticed an improvement, both in my urine and the rest of my body. I no longer have those pains in my body." (Individual interview)."

Furthermore, participants health awareness led to a dramatically change of their substance use behavior after the HCV treatment. Many were more likely to stay away from the drug scene out of for fear of becoming reinfected, and several became more conscious of what they "were putting into their body":

"Me and my girlfriend have become extremely cautious about what we inject into our bodies and how we do it." (Focus group interview)."

Some even stopped injection substances because of their newfound desire to protect their health: "I don't want to take heroin anymore, because I don't want to affect my liver" (Individual interview). In addition, there was a big change in the participants' attitude to injection equipment where the majority no longer shared such equipment. Some participants even referred to the knowledge they gained during the HVC treatment and said, "Now that I know what it led to, I wouldn't share needles again (Individual interview)."

The general feeling of well-being also helped the participants to make better choices in their everyday life. This was expressed by a new awareness of how good routines improved their lives, and that this helped change their attitudes in several arenas:

"It's a question of attitude, it comes back to that. You have a better attitude on things when you're well. Something happens in your head, at least it did in mine. You wake up, you have a better attitude and a different view of why you do the things you do. It has a lot of knock-on effects." (Individual interview)."

3.3. *Changed Interpersonal Interactions.* Many participants had few or no close relationships, and their perception was that having HCV meant that they were different and stigmatized. After recovering, they felt "cleaner inside" and physically more like what they described as normal people.

"It might sound a bit strange, but I feel cleaner. I see hepatitis C as a dirty disease, a druggie's disease that you get through dirty needles. I felt like an outcast because I had something so dirty, something that no one wanted, and no one even wanted to talk about. Look, that's the dirty one." (Individual interview)."

According to the participants, a lack of knowledge about how HCV is transmitted meant that people kept their distance. The result of this was that the participants described how they often felt badly treated. Recovering from HCV was what enabled many of them to stay away from the illegal substance use market. Being regarded on the same level as "other people" made it possible to have relationships with people outside the drug scene, which tended to be the participants' preferred relationships. They also felt an increasing sense of separateness from those in the drug scene, and a reduced sense of being "branded." These changes were hugely important to their self-respect:

“Recovering makes a difference on how I will be remembered after I die, because I won’t have died from a drug-related disease.” (Individual interview).”

Relationships with close family were significantly improved once the participants recovered. In the same way as the participants described a change in their self-respect and hope for the future, their families often saw the change as a positive step towards a drug-free lifestyle. On this subject, the participants related that their own children were less worried that they (as parents) would die prematurely, and that they had made or resumed contact with their grandchildren, ex-partners, and other significant people:

“I often sit and think how incredibly lucky I am. I’m 51 and completely recovered after 30 years out there, and I can even be with my grandchildren without being afraid of infecting them.” (Individual interview).”

Their bodily functions and sense of happiness had been depressed while they were infected. Having to tell potential sexual partners about their disease was also associated with shame. With the virus-free status, both intimacy and the desire for sexual relationships gradually returned. Before, not using a condom had been inconceivable, but now they could be more relaxed and felt freedom in their intimate relationships. Reduced anxiety, shame, and fear of infecting others also resulted in the opportunity to form lasting intimate relationships.

Relationships with the support services and professionals also changed when the participants became virus-free. HCV was no longer relevant in appointments with doctors, dentists, and other medical personnel and support workers, and the participants noticed that the professionals were more relaxed: “It was great to tell the dentist: now you can get rid of that red warning flag” (Focus group interview). Without the “red warning flag,” they could be regarded as healthy and were treated like other people. New and improved relationships with support services also enabled the initiation of treatment for other conditions and/or challenges, such as assessments for ADHD.

#### 4. Discussion

Despite varying symptom burdens from HCV infection, our study shows that the participants noticed many social benefits from recovery from the virus. Many found that their quality of life was generally better. The transformation into better physical and mental health, the establishment and re-establishment of social relationships, and reduction in stigmatization were ascribed by the participants to the HCV treatment. This improvement process can be regarded in the light of different understandings of recovery. From a medical recovery perspective, a treatment of HCV that results in a reduction in symptoms or recovery from a disease will mean a virtually normal ability to function. A social recovery perspective understands recovery as a process of change, in which the person themselves is an active participant, and where the emphasis is on interaction between that person

and their surroundings [32, 33]. Structural factors, such as the stigmatization of people with SUD, may also play an important role, either impeding or facilitating recovery. Our results can be seen in the light of both understandings of recovery. The HCV treatment takes away a disease and thereby leads to improvement. Not all the participants experienced physical improvements, but the majority experienced clear changes at the social level. To understand our results and the transformation described by the participants, we can use the conceptual framework for personal recovery of Leamy et al. [34]. This framework identifies five different main categories in the recovery process: (1) connectedness, which concerns social support and being part of a wider social community, (2) hope and optimism about the future, which focuses on having a positive attitude, being motivated and positioned for change, (3) identity, which is about overcoming stigma and re-establishing a new identity, (4) meaning in life, which is about giving life new meaningful content and quality of life, and (5) empowerment, which is about one’s own strength, personal responsibility, and control over one’s life. Having a potentially fatal disease, such as HCV, imposes limitations on participants’ lives and future prospects [35, 36]. Those infected with HCV tend to have a fatalistic future perspective; since they are likely to have experienced HCV-related deaths among close friends and family members, they frequently believe that they themselves will suffer an early death because of the disease and therefore continue to engage in the risky practice of using substances [36]. This is also consistent with our study which, like earlier research [35–37], shows a transformation from pessimism to optimism in those who complete the HCV treatment. Recovery from the virus instilled participants with physical and mental vigor and consequently the opportunity to make more conscious choices and assume greater personal responsibility, such as in relation to substance use. This is also consistent with a study that found that HCV treatment in patients who were receiving OMT was perceived as an opportunity to “start anew” [35]. Furthermore, a study of 25 inmates treated with direct-acting antivirals found that pretreatment, they experienced physical and mental health issues as well as social concerns, while post-treatment, they experienced a “new beginning,” increased self-esteem and self-worth, and a positive change in lifestyle that also included a reduction in substance misuse [36]. In other words, HCV treatment brings hope, meaning in life and empowerment to many participants [38].

People with SUD experience harmful relationships and often adverse experiences and therefore they may isolate themselves and avoid establishing new relationships [39]. Those infected with HCV experience stigmatization from family members and/or staff in the health and social services [40–42], and the disease makes participation in social settings difficult, and social relationships are perceived as stressful [41]. HCV treatment can therefore be experienced as an existential transformation since it can repair a “broken self” [37]. Furthermore, Madden et al. [43] found that people who were virus-free after direct-acting antiviral treatment had established a new identity and improved their social relationships. This is consistent with our findings, since the

participants found that being virus-free gave them the opportunity to redefine their own identity, from sick to well, or from people with SUD to a person in the general population. Being virus-free removed the HCV-positive label and provided more freedom to establish new relationships, or more particularly to resume contact with family members. Stigmatization from various health professionals, social workers and other support agencies was also reduced. This provided a greater chance of experiencing “connectedness” [34], in which social relationships and being part of a larger whole are important factors.

The quality of life of people with SUD is lower than that of other patient groups with chronic disorders or people in the general population [44, 45]. In addition to age, factors such as comorbidities and mental disorders, including depression, also affect HRQOL [46]. The question is whether any change in quality of life can be attributed solely to HCV treatment itself, or whether change remains observable once the treatment has been completed. An Australian study found that change in HRQOL, identified as physical and mental HRQOL, was only associated with the period during which HCV treatment was administered [47]. The participants’ HRQOL was reduced while the treatment was ongoing, but after the follow-up period of 24 weeks after completion of treatment, their quality of life had returned to the original level (pretreatment). Disregarding the fact that our study has a different time dimension to the Australian study, our findings are nevertheless in contrast: the participants in our study perceived a generally improved quality of life both during and after the treatment. This is consistent with a study showing that those who achieved a virus-free status had a higher HRQOL than those who did not achieve this status [48]. One possible explanation of differences in HRQOL could be the use of different HCV treatment medication: some previous studies used interferon treatment, while most of the more recent studies, including ours, used direct-acting antivirals. Compared to interferon treatment, direct-acting antivirals are significantly more effective, administered over a shorter period and have fewer adverse effects [23, 49]. People treated with direct-acting antivirals achieve higher HRQOL scores compared to people treated with interferon [43].

*4.1. Strengths and Limitations.* One of the study’s strengths is the use of both focus group discussions and individual interviews. Focus group discussions provide a setting in which the participants talk to each other through an interactive process of group dynamics. This tends to ensure that the data is comprehensive and multifaceted. By also including individual interviews, we gained access to the informants’ own descriptions of subject areas of a more personal nature, such as self-perception and intimacy. The combination of the two different interview forms therefore gave us more comprehensive data.

One limitation is that this study took place at one specific time point. It is possible that the participants’ quality of life outcomes would change over time. Another limitation may be the inability of participants to speak freely; two research

nurses, who carried out clinical interviews and blood tests in the HCV study, also conveyed some of the individual and focus group interviews and participants might see them as part of the OMT system that controls their OMT and HCV treatment. However, since the design of the focus group was similar to a conversation it enabled the participants to speak openly, expressing their thoughts and feelings, which contributed to a possible higher validity. We assume that the important aspect was who answered the questions and how, and not the one who asked them.

Qualitative analysis draws heavily on the researcher’s ability to be critically aware of their own assumptions and choices in the process of analysis. Thus, we consider that transparency has been demonstrated by providing evidence in the analysis in the form of extensive quotations. However, as this study draws on the participants’ subjective accounts, it is difficult to replicate. Nevertheless, it would be an important task to carry out similar research to verify and refine the results.

## 5. Conclusion

An important implication of this study is that in addition to improving patients’ mental and physical health, HCV treatment also has an important social function, and that these improve patients’ QOL. Traditionally, treatment of people with SUD, and in particular among people with opioid dependence, has tended to have a strong focus on substance use during treatment. However, by facilitating and focusing on treatment of other diseases, such as HCV, SUD treatment can help people experience improved QOL and put patients in a position to be able to make other changes in their lives. Knowledge of how PWID and people with SUD experience and value HCV treatment could have an important spin-off effect that could be better utilised in clinical practice; achieving SVR can bring the health and social services closer to the person, who is then able to take advantage of services that may not previously have been relevant.

## Nomenclature

HCV:	Hepatitis C virus
HRQOL:	Health-related quality of life
OMT:	Opioid maintenance treatment
QOL:	Quality of life
PWID:	People who inject drugs
SUD:	Substance use disorder
SVR:	Sustained virologic response.

## Data Availability

The data supporting the current study are available from the corresponding author upon request.

## Disclosure

The funders had no role in the study design, data collection and analysis, decision to publish, or preparation of the manuscript.

## Conflicts of Interest

The authors declare that they have no conflicts of interest.

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