

A Patient-Centered Approach:
Applicability of Harm Reduction Principles in Various Healthcare Settings

by
Katherine Bodner

A THESIS

submitted to

Oregon State University

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the requirements for the
degree of

Honors Baccalaureate of Science in BioHealth Sciences
(Honors Scholar)

Presented May 20, 2020
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Viktor Bovbjerg

The public health framework of harm reduction was evaluated in one care setting to determine its potential for use in other fields of healthcare. Qualitative interviews were conducted with 11 clients of the HIV Alliance's needle exchange program. Analysis of client responses revealed three themes: 1) harm reduction methods work well for the HIV Alliance's clientele, 2) conventional methods of healthcare outside of the HIV Alliance are not as constructive as they could be, and 3) the patient-provider relationship is critical in all healthcare settings. It was determined that harm reduction methods would be suitable for healthcare settings because of its patient-centered, non-coercive approach and view of patients as capable of deciding their health-related behaviors and care.

Key Words: Harm reduction, needle exchange program, healthcare, qualitative research

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I understand that my project will become part of the permanent collection of Oregon State University, Honors College. My signature below authorizes release of my project to any reader upon request.

Katherine Bodner, Author

Table of Contents

	Page
Abstract.....	3
Purpose.....	8
Acknowledgements.....	9
Introduction.....	10
Background.....	11
Bloodborne Infections.....	11
History of Harm Reduction.....	12
Needle Exchange Services.....	13
Current Study.....	14
Methods.....	15
Setting.....	15
Participants.....	15
Recruitment.....	15
Consent Process.....	16
Protocol.....	16
Participant Privacy and Confidentiality.....	18
Data Analysis.....	18
Positionality.....	19
Results.....	20
Content Analysis.....	20
Thematic Analysis.....	23
Discussion.....	26
Significance of Findings.....	26
Comparison to Previous Research.....	27
Applicability to Other Healthcare Settings.....	28
Potential Extensions of Research.....	29
Conclusion.....	31
References.....	32
Appendix.....	34
Table 1.....	34
Figure 1: Recruitment Poster.....	35
Figure 2: Verbal Consent Script.....	36
Figure 3: Interview Script.....	37
Figure 4: Word Cloud for HIV Alliance.....	39
Figure 5: Word Cloud for Other Settings.....	40

Purpose

I have volunteered at a needle exchange program in Eugene, Oregon for two years. Run by an organization called the HIV Alliance, it embodies a progressive public health principle known as “harm reduction,” which is defined on the HIV Alliance website as “a public health philosophy that seeks to empower individuals, remove barriers to accessing the support that they need, and supply pragmatic approaches to risk reduction in a non-judgmental/non-coercive way that is compassionate and accepting of any positive change” (HIV Alliance, 2019). This Honors thesis provides evidence in favor of encouraging other branches of healthcare, including dentistry, dietary planning, and fitness training, to integrate harm reduction principles into patient care and practice.

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I would like to first thank the HIV Alliance for allowing me to interview their extraordinary clients and for welcoming my desire to get involved with open arms two years ago; the staff, fellow volunteers, and clients at this organization have greatly impacted me and shaped my beliefs in what it means to be a healthcare provider. I wish everyone at the Alliance the best in the years to come!

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Introduction

Harm reduction is defined on the Harm Reduction Coalition website as “a set of practical strategies and ideas aimed at reducing negative consequences associated with drug use” (Harm Reduction Coalition, n.d.) and on the HIV Alliance website as “a public health philosophy that seeks to empower individuals, remove barriers to accessing the support that they need, and supply pragmatic approaches to risk reduction in a non-judgmental/non-coercive way that is compassionate and accepting of any positive change” (HIV Alliance, 2019). It is a form of primary prevention, which is when measures are taken to reduce damage or injury as a result of a behavior before the behavior is performed. While largely associated with illicit drug use, harm reduction can be presented in a myriad of ways, including wearing seatbelts in a car or applying sunscreen on a sunny day.

Because of the innate broadness and flexibility of harm reduction, it is possible that its range of applicability may be expanded to other fields beyond drug use alone. There are a wide array of risky human behaviors that harm reduction can be applied to, such as unhealthy eating habits, sedentary lifestyles, failure to maintain proper personal hygiene, and more.

This thesis suggests that harm reduction may prove to be successful at empowering patients and effectively causing behavioral changes when incorporated into fields involving healthcare and personal wellness. Traditional methods of encouraging patients to adjust their lifestyles may not be the most effective method for catalyzing long-term positive changes, and harm reduction may offer a different approach that empowers rather than shames patients. In this study, we conducted qualitative interviews with people who have received care using harm reduction principles.

Background

Bloodborne Infections

There are a number of infections that can be accumulated through cross-contamination between the blood of two individuals. This can occur when people who use injection drugs share used needles with one or more other users, causing infections from one person to be transmitted to another. Examples of diseases that exist in the blood and are susceptible to bloodborne transmission include HIV, hepatitis B, and hepatitis C.

Human immunodeficiency virus (HIV.gov, n.d.) is a virus that resides in the blood. The virus attacks the body's immune system by invading specific white blood cells called "CD4 cells" (also known as T cells), making copies of itself, and spreading to invade and destroy more cells, effectively lowering the body's ability to fight infection (Chapter 1, 2003). HIV can be spread through mixing of various body fluids such as blood, semen, breast milk, and vaginal secretions (CDC, 2019b), and transmission through the use of injection drugs contributed to 6% of new HIV diagnoses in the United States in 2017, which is about 2,324 people (HIV.gov, n.d.). Left untreated, HIV will progress to acquired immunodeficiency syndrome (AIDS), which means that the immune system is so depreciated that opportunistic infections that are less threatening to healthy individuals such as pneumonia can easily kill the person (CDC, 2019a). Although there is no cure for HIV/AIDS, antiretroviral therapy is a very effective form of pharmaceutical treatment that can make the amount of HIV in the blood undetectable, allowing victims to live long and healthy lives despite their HIV infection (CDC, 2019a).

Hepatitis is broadly defined as inflammation of the liver that can be caused by alcohol use, use of certain medications, or a viral infection (CDC, 2020). Hepatitis B is caused by the hepatitis B virus and can either be a short-lasting (acute) or a lifelong (chronic) condition that can lead to other severe illnesses and even death (CDC, 2020). Like HIV, hepatitis B can be transmitted through shared bodily fluids like blood and semen, and is commonly transmitted through sexual activity, use of injection drugs, and from

mother to child during childbirth (CDC, 2020). Because this infection has a 90% chance of becoming chronic when it infects infants and a 5% chance when it infects adults, it is highly recommended that people at risk, including infants, children, sexually active people who are not in a monogamous relationship, and people who use injection drugs, are vaccinated with the hepatitis B vaccine (CDC, 2020).

Hepatitis C is caused by the hepatitis C virus and is spread through the blood (Mayo Clinic, 2019). People at heightened risk of getting infected with the virus include people who use injection drugs, health workers exposed to infected blood, people who engage in sexual activity with people of unknown health status, people living with HIV, and others (Mayo Clinic, 2019). While chronic hepatitis C can lead to serious conditions such as cirrhosis, liver cancer, or liver failure, several treatment options, such as antiviral medication that can cause undetectable viral levels in the body, are available for consideration (Mayo Clinic, 2019). There are currently no vaccines that can protect people from contracting hepatitis C, so people must use caution when participating in behaviors that put them at risk (Mayo Clinic, 2019).

History of Harm Reduction

Principles of harm reduction have been utilized for thousands of years, and in the specific context of injection drug use have been used for several centuries (Pates & Riley, 2012). Perhaps the first instance of substance injection with a “syringe” occurred in 1665 by Christopher Wren when he filled a bladder with various substances, injected them into his dog with a quill, and observed the outcomes on the dog’s behavior as a result of directly injecting substances into the bloodstream (Pates & Riley, 2012). The need for reduction of harm due to substances arose with the widespread use and abuse of morphine injections in the 1800s, which was commented on by Allbutt in 1870 when he said “Patients are injecting themselves daily or more than daily during long periods of time, for neuralgia, which as far from cured as they were at the outset” (Pates & Riley, 2012, p. 6). This led to many suggestions from concerned

physicians and scientists, such as cleansing needles used on sick patients and avoiding the use of rusty or broken equipment (Pates & Riley, 2012).

When HIV/AIDS began spreading at a rapid rate in 1985 in part due to injection drug use, the collective mindset in the United States began to shift from maintaining a negative attitude toward drug users and their “unhealthy habits” to an attitude of gradually accepting drug use as a lifestyle choice that is less of a threat to the American public than the spread of HIV/AIDS (Steenholt et al., n.d.). From this point forward, policy began to change in favor of implementing programs and regulations existing to combat HIV/AIDS transmission from a harm reduction perspective, namely through providing sterile equipment to users through needle exchange programs, making condoms more accessible, and increasing funding to prevention and treatment facilities (Steenholt et al., n.d.). These techniques, rather than asking people to stop using drugs, provided means of preventing disease transmission while allowing them to continue to participate in the same behaviors as before.

Needle Exchange Services

The first needle exchange program was established in 1984 in Amsterdam to help prevent the spread of Hepatitis B, and the first legal needle exchange program in America was implemented four years later in Tacoma, Washington (The Center, n.d.). The first illegal needle exchange program in the United States was started by Jon Parker, a previous injection drug user himself, in Connecticut in 1986 after someone brought sterile needles for distribution at a HIV/AIDS prevention meeting for current users (PBS Frontline, 2006).

The Centers for Disease Control and Prevention estimates that there are currently over 200 needle exchange programs in over 36 states across the U.S. (PBS Frontline, 2006), and while federal funding of these programs has been banned since 1988, they continue to exist primarily with financial support of their communities and local governments. Injection drug users are estimated to inject themselves an

average of 1,000 times per year (PBS Frontline, 2006), providing about 1,000 opportunities for users to become infected in a given year when clean needles are not available to them.

The HIV Alliance is a nonprofit organization in Oregon that was founded in 1994 to provide resources and support to people living with HIV/AIDS and to help prevent the spread of bloodborne infections (HIV Alliance, 2017). As of 2017, they conduct over 1,300 free HIV tests each year to those at risk of infection and provide various care services to 13 counties in Oregon (HIV Alliance, 2017). Their needle exchange program was established in 1999 and was founded on the principles of harm reduction (HIV Alliance, 2017). In 2019 alone, the HIV Alliance had 169 active volunteers that collectively served over 9,000 hours to help the organization reach its goals through needle exchange and various other services (HIV Alliance, 2017).

Current Study

The aim of this study was to investigate, from the perspective of HIV Alliance clients, the use of harm reduction principles at the HIV Alliance, a nonprofit organization that provides services to those living with HIV/AIDS and people who use injection drugs. By conducting qualitative interviews with clients that use their needle exchange program, insight was gained about client perceptions regarding their patient-centered treatment by HIV Alliance staff in comparison with their experiences at other settings of healthcare that do not embody harm reduction principles.

Methods

Setting

Interviews were conducted at sites of the HIV Alliance's needle exchange program throughout the winter of 2020. This service is offered in several locations throughout Eugene, including at the HIV Alliance office on City View Street (Tuesdays and Fridays from 1:00-3:00pm), 2nd and Van Buren Street (Mondays and Wednesdays from 6:00-7:30pm), in Springfield on South 18th Street (Thursday from 6:00-7:30pm), and The Center for Recovery in Cottage Grove (Tuesdays from 5:30-7:00pm).

Participants

All clients of the HIV Alliance needle exchange program were eligible to participate. Clients were required to be at least 18 years of age to receive services, and were not asked about their purpose for receiving syringes. While some transgender clients utilized this program to obtain sterile syringes for hormone injections and other clients used the sterile syringes for insulin injections for diabetes, it is likely that most clients utilized the program for safer methods of injection drug use for themselves or for those in their interpersonal relationships. According to the HIV Alliance's program director, Amanda McClusky, approximately 60% of needle exchange clients were homeless at the time. The amount of time that each participant had been receiving care from the HIV Alliance was not explicitly asked of each person, but from the 7 participants who volunteered this information, 5 of them had utilized the needle exchange program for at least 12 months.

Recruitment

A large sign was posted at the needle exchange site refreshments table, inviting clients to participate in a research study (see Figure 1). It offered a brief description of the project and an approximate duration for the interviews. Signage specified that participation in the study was optional, strict client confidentiality would be maintained, and refusal to participate would not affect the client's ability to receive services from the HIV Alliance in the future. Needle exchange clients were also

informed by staff that there was a student conducting on-site interviews for an optional research study and to read the poster or ask the student for more information if they were interested; HIV Alliance staff did not actively recruit clients for the study.

There was great potential for selection bias and selection effects in the recruitment process of this study. I was unable to be present at all eleven needle exchange events each week over the course of this study and I volunteered at some locations more than others, so the more established relationships with certain clients in these locations likely impacted their willingness to participate. There were also individual differences between clients that undoubtedly influenced their participation, including their ability to trust other people, the duration they had been receiving care from the HIV Alliance, and even personality characteristics like openness to experience or extroversion. These aspects are likely also related to their experiences with receiving healthcare, so our findings are most likely skewed by the types of people that participated. It should also be considered that I was a young college student, a white female, and had been a volunteer with the HIV Alliance for an extended period of time, and these factors very likely impacted the recruitment process as well.

Consent Process

This study utilized a verbal consent process because requiring signatures would have involved unnecessary collection of identifiable data and would put participants at unnecessary risk for breaches in privacy and confidentiality if these documents were lost or stolen. The verbal consent script is included in the Appendix.

Protocol

Because this study involved working with human subjects, it was reviewed and approved by the Oregon State University Institutional Review Board (IRB). The data collected was categorized as requiring Level 3 data security, meaning that participants were under greater than minimal risk with the

use of identifiable data, so we took appropriate measures and precautions according to the IRB's recommendations.

Data were collected during needle exchange hours. The recruitment poster indicated to potential participants that if they were interested in being interviewed, they should notify Katie, the needle exchange volunteer conducting the interviews who was wearing a name tag. The name tag said "KATIE" in large letters. When potential participants notified the student researcher that they would like to be interviewed, she asked them to follow her into the RV where she would begin the verbal consent process with the verbal consent script (see Figure 2) before beginning the interview. During the interview, RV doors and windows were closed to prevent other people from overhearing the private conversations.

Following previous research with this population in this setting (e.g., Rochester, 2018), interviews were held inside the needle exchange RV, a recreational vehicle that stores supplies for the event. This vehicle was always parked next to the tables where needle exchange was held, and experienced supervisors were seated nearby in the event that assistance was needed. Conducting interviews in the vehicle allowed for privacy and provided a comfortable setting for interviews to take place.

The duration of interviews varied greatly, ranging from 5-25 minutes. The interviews had an average duration of about 11 minutes.

Audio recordings of the interviews were collected using Audacity, a computer recording program, on an OSU-distributed, password-encrypted laptop provided by Dr. Kelly Chandler. Once collected, files were stored in a password-protected file folder until they could be transcribed onto the on-campus laboratory computer in a timely manner. Interviews were transcribed onto Word documents on an OSU computer in Dr. Chandler's on-campus FLOW Lab with the help of ExpressScribe, a computer program that aids in the transcription process. Once transcribed, audio recordings were deleted and transcriptions were stored in Box behind the OSU firewall where only study investigators had access to them.

After personal identifiers were removed and replaced by pseudonyms, the transcripts were printed. Pseudonyms and original identifying sources of information were stored together in a spreadsheet in Box where only those involved in the study could access them. Printed transcripts were stored and coded only in appropriate settings where they were only accessible to those involved in the study, which was primarily Dr. Chandler's locked FLOW Lab.

Participant Privacy and Confidentiality

Data were recorded on a password-protected laptop computer as audio recordings and stored in a password-protected folder. Names, date of birth, gender, address, or any other identifying characteristics of each interviewee were not collected to ensure client confidentiality and protection. If a participant inadvertently mentioned an identifiable person (including details about themselves), those statements were de-identified during transcription (e.g. "neighborhood" replaced "Oak Street"). Audio recordings were downloaded weekly to a research computer on the OSU campus, behind the OSU firewall, in password-protected folders restricted to the project investigators. Once audio files were transcribed and verified, the original audio files were deleted and the laptop folder previously holding audio files was destroyed. In addition to these measures, research results do not directly quote any individual transcription, but rather describe the themes which emerged from the aggregate data.

Data Analysis

After removal of any direct and indirect identifiers, anonymized transcripts were printed for the purpose of coding them by hand with pen and paper. Coding is the first step in drawing themes from large texts of qualitative data, and in this study, it involved defining the main ideas of the participants' responses to each of the questions asked. For example, if somebody described their feelings towards a care setting with statements like "I felt comfortable telling them anything I wanted" and "I felt like I could be myself with the providers," these statements would be given the code "safe space." *The Coding*

Manual for Qualitative Researchers by Johnny Saldana was utilized as a resource for reference, and codes were reviewed by Dr. Chandler before moving forward.

Next, all codes were compiled into an Excel spreadsheet. Each of the seven questions had columns for all the responses, which were entered into the spreadsheet along with their related codes. Each response entry also included the unique interview number to facilitate keeping track of them and to enable the frequency of each response to be calculated. Finally, codes were organized into categories and eventually grouped into overarching themes.

Positionality

As someone who has volunteered with the HIV Alliance for two years and who thinks highly of the progressive work their staff are executing, this may have influenced interpretation of findings. This qualitative research study, like any other, was influenced by the biases held by its researchers. No human researcher can be without bias, and this must be considered when making conclusions about the validity of this project, especially with its subject matter being rooted in social justice.

Results

To answer the research question of why principles of harm reduction should be utilized instead of traditional healthcare methods in the realm of patient care, participant responses and codes were compiled. Next, the results were summarized in the “Content Analysis” section below, followed by the descriptions of the overarching themes of significance in the section titled “Thematic Analysis.”

Content Analysis

The first interview question investigated participants’ feelings whenever they attended needle exchange at the HIV Alliance. Nine out of eleven participants expressed positive responses, including descriptions of feeling secure, pleasant, and welcome. Most of the negative feelings reported were in regards to other clients, such as that the participants were often suspicious of them stealing their belongings or that they created a chaotic environment at times. All participants reported that being at

Participants reported feeling comfortable, welcome, and safe at needle exchange.

needle exchange makes them feel comfortable, and only one person said that attending makes them feel vulnerable. Some people said that a significant benefit of attending needle exchange was their ability to help others by exchanging needles for them or collecting resources such as condoms and supplies needed to inject drugs safely. While five participants reported feeling empowered when using the needle exchange program, five others reported that it does not make them feel empowered. Two participants specifically mentioned how needle exchange used to make them feel when they first started attending: they mentioned that it used to be “nerve-wracking” or that they were ashamed of going, and one person even reported feeling belittled in once instance. However, each of these participants added that their current feelings toward going to needle exchange were nothing but positive.

When clients come to needle exchange, they are offered a wide variety of resources, including naloxone kits, fentanyl test strips, information about rehabilitation programs, and more. The second question of each interview investigated whether or not participants felt comfortable deciding to utilize

these resources. All participants indicated that they were comfortable using these resources on their own,

All participants indicated that they felt comfortable determining whether to use the HIV Alliance's services.

without pressure from those working at needle exchange. One participant mentioned that they were hesitant at first because they felt ashamed, but they eventually decided to take advantage of the available resources in an effort to keep those close to them healthy and safe.

Question three investigated whether those working at needle exchange had ever been judgmental towards the participants, and all participants reported that the HIV Alliance staff were nonjudgmental. One participant reported that one of the needle exchange workers had been slightly judgmental one time, yet several mentioned that they had been receiving care from them for years and that they have always been nonjudgmental towards them. Two people said that other clients or observers had been judgmental before and two others reported feeling judgment from police officers when at needle exchange, but seven of the eleven participants reported never feeling judged by anybody at needle exchange.

Next, participants were probed about their general opinion of whether they think individualized care, such as what is currently given at the HIV Alliance, is better than the equal treatment that is traditionally given in healthcare settings. Ten of eleven participants reported that individualized care is better than equal treatment, and one participant was unsure. The most common reasons people preferred individualized treatment were that clients are all different and have different needs, it makes clients more comfortable, it enables providers to be "true" to the patient, and that it generally feels better to the clients. One participant even said that the method of individualized treatment allows people to feel like they're more than "just a number." One argument in favor of equal treatment and care is that it helps prevent patients and providers from inappropriately crossing professional boundaries, but some people brought up that equal treatment allows more people to "fall through the cracks" and leads to healthcare providers going through the motions of their care routines without really making an impact on their patients.

Individualized treatment makes clients feel like more than "just a number."

Participants were asked whether those working at needle exchange had ever criticized them for their past or current behaviors. Ten out of eleven people said the staff had not criticized them and

Many participants voiced that they felt that they could talk to needle exchange staff about anything.

provided several instances of them listening to their “sob stories,” mentioning the staff members’ good listening skills and the clients’ ability to talk to them about anything they wanted. The one instance that a participant mentioned that someone at needle exchange criticized them was because the participant was in an unhealthy relationship and the worker was playfully encouraging them that they deserved someone better and was only looking out for the client’s best interest.

The next set of questions asked participants about their experiences with healthcare providers in conventional care settings, and this provoked some emotional responses.

When asked whether providers in other settings had judged them before, ten out of eleven people reported that they had, and six people indicated that they felt judged every time. One person reported having never received judgment

Six out of eleven participants have felt judged every time they receive healthcare from providers outside of the HIV Alliance.

from providers, but was encouraged by them to stop using drugs. Two people admitted that not all healthcare providers were bad or judgmental. Participants reported a number of ways providers had treated them judgmentally, which included being denied care, being asked to leave, providers not being physically gentle with them, making them wait much longer to receive care (which was often justified by providers assuming that the patient was making it up or only seeking a bed for the night), giving clients generic or less effective medications, and drug testing them without their consent or knowledge.

Participants have been treated so poorly by providers outside of the HIV Alliance that many have forgone necessary appointments or avoided receiving healthcare altogether.

Participants reported that these negative experiences often made them feel angry, sad, worthless, unwelcome, and hopeless, and even led them to forgo necessary medical care, distrust doctors and providers, and believe that they are better off without their help.

When asked how these experiences affected their progress in working toward a healthier lifestyle, most

people said that it negatively impacted their progress by making them want to take more drugs, worsening their mental health, or inspiring a sense of shame and hopelessness.

Lastly, people were asked if there was anything else that they would like to share about their experiences in seeking help at the HIV Alliance, and the responses were overwhelmingly positive and grateful for their dedicated, kind, and reliable staff. Different anecdotes included reports of being healthier and getting fewer infections, that the Alliance does not make them feel like they have

The majority of participants expressed appreciation for the HIV Alliance's services and staff.

barriers to jump over, that their community was “cleaner” overall, and that if they were to get infected that they would feel safe knowing that they were in the care of the Alliance. All of the constructive criticism provided involved old programs that participants wished the organization would bring back; one respondent, however, essentially said “If it ain’t broke, don’t fix it.” The HIV Alliance is hailed as one of the best programs available for the Eugene community, and participants often credited the program for saving their lives and enabling them to feel more empowered, safe, and helpful to others.

Thematic Analysis

Three overarching themes emerged that remained consistent throughout most of the eleven interviews.

Theme 1: Harm reduction methods work well for this community

Harm reduction, with its core pillars of empowerment, no judgment, compassion, and individualized care, has served the clients of this needle exchange program well. The individualized care methods used at the HIV Alliance don’t categorize all people who inject drugs into a “box” or treat them all like they are the same, which has been regularly reported for other providers and was regarded in the interviews as more harmful than helpful. Participants in this study reported that it is important to make patients feel comfortable and not like “just another number.” They also implied that the individualized and genuine care provided at the HIV Alliance prevents people from “falling through the cracks” and increases rates of client retention.

Theme 2: Methods of healthcare outside of the HIV Alliance are not as constructive as they could be

Ten out of eleven participants reported a sharp decrease in the quality of treatment received from healthcare providers once they realized that they used injection drugs. As previously described, participants in this study have been asked to leave, not had their medical emergencies taken seriously, and treated less gently than was warranted in conventional care settings. This universally discriminatory medical environment has led many injection drug users to stop seeking necessary medical care out of fear of judgment or unethical treatment, and has overall created general feelings of distrust in injection drug users toward healthcare providers.

One suggested method of improving the quality of care that people who use injection drugs receive is to implement mandatory addiction education programs in all healthcare-related certification and training regimens. Additionally, requiring community service hours in settings like the HIV Alliance where medical professionals would regularly come in contact with homeless people and people who use drugs could also help tremendously. The goal of these assignments is to better educate providers about the challenges of those facing addiction, homelessness, and poverty because many providers pass judgment on people in these communities and treat them poorly out of ignorance about the challenges they face. If providers can begin to think of these people as more relatable and less different than the patients they are more used to, perhaps they can start to treat them with the same high quality care that they provide to those who do not use injection drugs.

Theme 3: The patient-provider relationship is critical in all healthcare settings

Regardless of whether participants were discussing care from the HIV Alliance or not, participants believe that the relationships between patients and their providers are critical for effective care and patient satisfaction. Participants unanimously applauded the needle exchange staff for their genuineness, relatability, dedication to their work, and their ability to be themselves in a way that builds trust with their clients. By working hard to please their patients and making an obvious effort to meet their

needs, the staff at the HIV Alliance fulfill one of the core principles of harm reduction of removing a major barrier to accessing the support that they need, by building trusting relationships with each of their patients. Doing so not only allows the HIV Alliance providers to get to know the needs of their patients better, but it likely has a profound impact on their client retention rates.

In contrast, healthcare providers outside of the HIV Alliance must make a stronger effort to strengthen their provider-patient relationships. People who use injection drugs have been treated poorly by medical professionals for a long time, and many of the personal anecdotes provided by participants included opportunities for providers to build trust that were not taken. For example, one participant brought up an instance where they asked a question about a health concern, and rather than patiently and respectfully educating their patient about the matter, their provider was rude and belittled them for not knowing the answer already. Statements from several participants implied that although most of them had unsupportive relationships with their providers, many of them care what their providers think of them and their judgments towards them often have a large impact on their self-esteem and self-worth. If providers can work to nonjudgmentally support their patients, educate them respectfully, and work hard to rebuild broken trust, perhaps they can become better providers and increase patient satisfaction and retention as the HIV Alliance has for years.

Discussion

Significance of Findings

The discoveries found through this research have the potential to greatly influence current methods of healthcare. Harm reduction has shown great promise through the HIV Alliance, an organization that serves many of society's most stigmatized individuals and has managed to not only meet their needs, but also exceed their expectations and make them feel secure, welcome, and safe. Because of the pillars of harm reduction, the HIV Alliance does not impose rigid rules on its patients, expect abstinence to be their goal, or provide a stressful environment of care by employing providers with beliefs that may negatively impact the care experience of their clients. The staff at the HIV Alliance exhibit a level of dignity and respect for their clients that is unusual for this population, and participants in this study indicated that their methods create a comfortable place to receive care that encourages client retention in ways that other healthcare settings have not compared. With one of the research findings indicating that it is critical for providers to be actively building trust with their patients in order to have an effective relationship, it has been shown through our participants' testimonies that conventional care settings have not effectively done this for them and their quality of care has suffered because of it. If healthcare providers truly value the health and wellbeing of their patients, they must embody a more patient-centered approach that honors the dignity, individuality, and humanity of each of their patients in the very way that the principles of harm reduction advise.

Findings were presented to the Harm Reduction Coalition (HRC) meeting on May 6th, 2020, at which several HIV Alliance staff representatives were present. The study aim, methods, and results were described, along with specific client feedback for the HIV Alliance and word clouds (see Figure 4 and Figure 5) created from words and phrases used by participants to describe their experiences with the HIV Alliance and with other care settings. HRC members expressed during the meeting that they had fallen into a routine as an organization and were lacking in purpose, but the findings of this study effectively

inspired them to start new projects involving decreasing the stigma against people who inject drugs held by providers and helping them to build more trusting patient-provider relationships. One person at the meeting shared that they were often asked by clients of their organization to accompany them to doctor's appointments to advocate for them because they had such traumatizing experiences with judgment from providers in the past. Overall, the HIV Alliance and other organizations that advocate for use of harm reduction-based care in stigmatized groups were inspired by our results and were excited to begin to make positive changes in this realm of outreach programming.

Comparison to Previous Research

A similar study to this had similar conclusions: published in the *Harm Reduction Journal*, Hawk et al. interviewed patients and staff at an HIV clinic to determine principles of harm reduction that should be emulated in healthcare settings, including the need for providers to treat patients with “humanism” and “individualism” by treating them with dignity and respect, in addition to treating them as individuals (Hawk et al., 2017). This conclusion closely follows responses to the fourth interview question of the current study, which indicated that clients at needle exchange prefer individualized care when they are treated as “more than a number.” The HIV clinic study also concluded that the principle of patient autonomy must be upheld (Hawk et al., 2017), which can also be seen in the affirmative client responses to the second question of whether they felt comfortable deciding which resources and directions of care they chose for themselves. Other meaningful principles that Hawk et al. shared that healthcare providers should adopt included pragmatism (meaning that they should recognize that no patient's behavior will ever be perfect), incrementalism (any positive change bring patients closer to health and negative changes can be expected), and accountability without termination (patients have the right to make poor health choices and to choose their health behaviors without punishment for not accomplishing their goals) (Hawk et al., 2017). Overall, the HIV Alliance, according to its clients, has successfully implemented

many of the harm reduction principles in their practice while other healthcare settings should consider doing the same because of the reported patient satisfaction in the aforementioned settings.

A study done at the University of Washington's Alcohol and Drug Abuse Institute that interviewed patients at a local needle exchange found that some patients would like to be offered medical services at the needle exchange program due to stigma they faced at other care facilities and settings (Newman et al., 2019). They expressed sentiments similar to those in this study in regards to how providers have treated them in the past, including being judged, not treated with privacy or respect, and overall preferring the comfortable, safe atmosphere present at needle exchange (Newman et al., 2019). The University of Washington study concluded that a more holistic approach is critical when providing treatment for individuals at needle exchange programs that addresses not only their different social determinants of health, but the stigma that they regularly face (Newman et al., 2019).

Applicability to Other Healthcare Settings

There are many healthcare settings in which implementing harm reduction principles may prove useful. A study performed at the University of Texas successfully implemented a program based on harm reduction that was designed to reduce the harm associated with drinking in college students rather than eliminate this behavior entirely (Fromme & Orrick, 2004). In the context of addressing tobacco addiction, an article published in *The New England Journal of Medicine* evaluated FDA policies regarding e-cigarettes and determined that this approach, if put forth correctly and not just in the name of harm reduction, could effectively help those suffering from tobacco addiction (Fairchild et al., 2018). One study sought to investigate the applicability of harm reduction principles in those struggling with destructive gambling behaviors through limiting continuous or excessive opportunity to gamble, but their results were inconclusive (McMahon et al., 2019). Other suggested settings that harm reduction may prove to be helpful and effective include exercise programs for people with sedentary lifestyles, those that struggle with maintaining adequate personal hygiene, and many types of addictions.

Harm reduction principles have proven to be largely successful with clients of the HIV Alliance, but they may not be universally effective for all settings. For instance, people who impose extraordinary risk onto others should not be treated according to harm reduction such as with empowerment, increased access to supportive resources, or compassionate acceptance of any positive changes. Many settings, primarily criminal law, must use methods which attempt rehabilitation in the larger context of assuring public safety.

Potential Extensions of Research

There are several opportunities for further extension of this research. Within the HIV Alliance, there are hundreds of clients who were not interviewed, and the staff likely have new and interesting perspectives as providers who embody harm reduction principles in their procedures. However, this research at the HIV Alliance was not meant to be representative of all care settings, and there would be great benefit from conducting similar interviews in other care settings that embody or do not embody harm reduction in their practices. Because harm reduction is a relatively new framework, the more settings and participants that can be investigated, the more informed that the world of public health and healthcare can become about the benefits and limitations of this method. Offering longer, more extensive interviews may also provide greater insight than the ones conducted in this study and introducing new research methods may be of benefit as well. Gaining perspectives from current providers outside of the HIV Alliance may also be helpful to identify hidden weaknesses in modern healthcare systems that may be mitigated through more comprehensive education and that include harm reduction principle training implemented in their programs.

As previously mentioned in the Methods section, these results were almost certainly influenced by the biases of the researchers. For instance, when the interview questions were created, several questions inquired about the participants' experiences with the HIV Alliance, but only a few questions investigated their experiences with other healthcare settings, and these questions were framed in a way

that prompted participants to discuss adverse events. If this project were to be continued, it is strongly advised that the interviewer asks participants about their experiences with receiving care outside of the HIV Alliance with a neutral approach before inquiring about their negative experiences, which would help investigators to understand their authentic opinions without influence from the way the question is framed. In addition to this, during the coding and data analysis process, it would be wise to have another investigator examine the data and codes to determine potential biases contributed by the person who was coding and then adjust findings accordingly; while Dr. Chandler evaluated my codes in this study, having an additional investigator do the same would help to further prevent the influence of bias on our results.

Conclusion

Harm reduction is a novel public health framework that is worth implementing into common practices for healthcare settings. Its pillars of being non-coercive, patient-centered, and empowering people to make their own decisions regarding their health have proven through this study to be very successful for the highly stigmatized injection-drug-using population that the HIV Alliance has served since 1999 through its needle exchange program. The critical importance of the patient-provider relationship was highlighted in this research as well; employing harm reduction practices has greatly contributed to the trusting relationships maintained between staff and clients at the HIV Alliance, and doing so in other settings would undoubtedly enable patients to trust their providers more and for providers to serve their patients more effectively. Overall, if healthcare providers desire to better meet the needs of their patients, exercising the patient-centered approach of harm reduction and working to build trust must be considered if they are to do this, especially for the populations that have been cast aside not only by society, but particularly by those working in healthcare.

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Appendix

Table 1: Participants’ reported feelings about needle exchange and healthcare providers

	Positive	Neutral	Negative
Feelings about the needle exchange program	<ol style="list-style-type: none"> 1. Comfortable 2. Secure/safe 3. Nonjudgmental 4. Pleasant/good 5. Enables clients to help others 6. Don’t need to hide it 7. Welcomed 	<ol style="list-style-type: none"> 1. No issues 2. Usually just pass through 	<ol style="list-style-type: none"> 1. Suspicious of other clients and theft 2. Chaotic environment 3. Long wait times
How health care providers have made them feel			<ol style="list-style-type: none"> 1. Worthless/ belittled 2. Hopeless 3. Angry 4. Sad or crazy 5. Unwelcome 6. Better off without them 7. Distrust 8. Providers are incompetent

Figure 1: Recruitment poster

Research Opportunity:

Tell us about your experiences with needle exchange!

What: Katie, a student at OSU, is conducting research on harm reduction, a patient-centered principle that the HIV Alliance embodies. She is interested in interviewing you and hearing about your experiences with the Alliance and its needle exchange services. Interviews will take no more than 20 minutes.

Where: At needle exchange several days per week.

Who: All needle exchange clients are welcome and encouraged to participate.

Why: Participation will 1) allow you to contribute valuable data to a student's thesis research project, 2) help the Alliance improve their services, and 3) inform the field of public health research about the utility of harm reduction. There is no financial reward for participation.

Note: Whether or not you participate in this study will not impact your ability to receive services from the HIV Alliance.

Interviews will be audio recorded, but no identifiable data (i.e. name, date of birth) will be collected. Although the HIV Alliance staff will know whether or not you participate, the information you provide in the interview is private.

Interested?

Please tell Katie, the student researcher. She is a needle exchange volunteer and is wearing a name tag.

Study Title: A Patient-Centered Approach: Applicability of Harm Reduction in Various Healthcare Settings

Student Researcher: Katie Bodner, Oregon State University, bodnerk@oregonstate.edu

Principal Investigator: Dr. Viktor Bovbjerg, Oregon State University, viktor.bovbjerg@oregonstate.edu

Figure 2: Verbal consent script

Verbal Consent Script Document

Purpose. I am an Oregon State University student researcher interested in the public health principle of harm reduction, which is used by the HIV Alliance at needle exchange. Harm reduction is defined on the HIV Alliance’s website as “a public health philosophy that seeks to empower individuals, remove barriers to accessing the support that they need, and supply pragmatic approaches to risk reduction in a non-judgmental/non-coercive way that is compassionate and accepting of any positive change.” This project forms the core of my Honors thesis, which is called “A Patient-Centered Approach: Applicability of Harm Reduction Principles in Various Healthcare Settings.” The main goals of my project are to:

1. Gain insight about the pros and cons of the Alliance’s harm reduction approach to care by interviewing Alliance clients
2. Use your answers to figure out whether other fields of healthcare could effectively use a “harm reduction” approach to providing care

This project will not:

1. Keep or use your name or any personal information
2. Give your specific responses to these questions to the HIV Alliance or its staff
3. Change how you get care or whether you can receive care from the Alliance

Activities. If you are at least 18 years of age and are a client at needle exchange, I am offering the chance for you to participate in this study. This interview asks about your experiences at needle exchange and for your opinions about the care you have received here. Interviews will be audio recorded because this is required for this study. After listening to this form, if you would like to volunteer, you will say out loud “I consent”.

Time. The interview will take about 20 minutes.

Risks. This study poses no risk to your health. There is some risk for loss of privacy; we will have audio recordings of your answers which may contain identifiable or private information, but they will be stored on a password-protected laptop in a password-protected folder and will be completely destroyed shortly after we have written out your responses on a secure, password-protected computer on the OSU campus. Your information will not be used or distributed for future studies. You may find some of the questions I ask to be upsetting, but you can skip any questions that you wish not to answer.

Benefits. This survey will help healthcare providers and myself better understand the method of harm reduction and its ability to help patients in other settings.

Payment. There is no payment for participating in this study.

Confidentiality. The information you provide during this study will be kept confidential. To help ensure confidentiality, I will not collect your name or any identifying information. Your responses will be kept confidential and all information collected will be stored in a locked file in a password-protected computer. At no point will your information be available to the Alliance or its staff, or to anyone not immediately involved in this project.

Mandatory Reporting. Under Oregon law, we are required to report to the appropriate authorities any information concerning child abuse or neglect. We may also report threats of harm to self or to others or incidents of sexual harassment or sexual violence.

Voluntariness. Your participation is voluntary. You can stop at any time, or skip certain questions. Whether or not you decide to participate does not affect your ability to get services from the Alliance, or the care you receive from the Alliance staff. I, as the student researcher and interviewer, can also stop the interview at any time.

Figure 3: Interview script

Interview Script

Thank you for taking the time to participate in my research study. I'm going to ask you a few questions involving your experiences at needle exchange; these are your stories and your opinions, so there is no "right" or "wrong" answer to any of these, I am only trying to understand your experience with the needle exchange program. As I mentioned earlier, we are very serious about reassuring your privacy and the privacy of your family, friends, and other needle exchange clients, so please remember to avoid using names or any identifiable information about you or other people. At the end, you will have the opportunity to ask me any questions you have that pertain to this project. Let's begin!

- 1) When you come to needle exchange, how does being here make you feel?
 - a) [Prompt] Comfortable or vulnerable? Empowered or belittled?
- 2) When you are at needle exchange and different resources are offered to you, do you feel comfortable deciding for yourself whether or not to use them?
- 3) This needle exchange program uses a principle called "harm reduction" in its approach to offering services. Harm reduction is defined as "a public health philosophy that seeks to empower individuals, remove barriers to accessing the support that they need, and supply pragmatic approaches to risk reduction in a non-judgmental/non-coercive way that is compassionate and accepting of any positive change." One of the core principles of harm reduction means that those working for the Alliance at needle exchange are non-judgmental.
 - a) Can you think of a time where this held true for you? Please describe that experience.
 - b) Can you tell me about a time when you felt judged when using the needle exchange program?
- 4) Do you believe that meeting clients where they are at in their individual journeys at needle exchange is more beneficial than treating every client the same? Can you explain?

- 5) The Alliance emphasizes not criticizing clients for their past and current behaviors. Has this been your experience with the Alliance staff? Can you tell me about your experience?
- 6) Have there been any instances of healthcare providers in hospitals, clinics, dentist offices, or similar settings judging you for using injection drugs and/or participating in other risky behaviors?
 - a) How did this make you feel?
 - b) How did this affect your progress in working toward a healthier lifestyle?
- 7) Is there anything else you would like to share about your experiences with seeking help at the HIV Alliance?

Those are all the questions I have today. Do you have any questions for me about this project?

Thank you again for taking the time to share your experiences with me; your stories and opinions are the most important part of my research and I am grateful for your willingness to contribute. Have a good afternoon/evening!

Figure 5: Word cloud of words and phrases used by participants to describe their experiences in receiving conventional care from care settings outside of the HIV Alliance.



