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Internalized stigma and sterile syringe use among people who inject drugs in New York City, 2010-2012

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Abstract

Background—Little is known on the effect of stigma on the health and behavior of people who inject drugs (PWID). PWID may internalize these negative attitudes and experiences and stigmatize themselves (internalized stigma). With previous research suggesting a harmful effect of internalized stigma on health behaviors, we aimed to determine socio-demographic characteristics and injection risk behaviors associated with internalized PWID-related stigma in New York City (NYC).

Methods—Three NYC pharmacies assisted in recruiting PWID. Pharmacy-recruited PWID syringe customers received training in recruiting up to three of their peers. Participants completed a survey on injection behaviors and PWID-related stigma. Among HIV-negative PWID (n=132),

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Contributors

Alexis Rivera analyzed and interpreted the data, supervised data collection and wrote the draft of the manuscript. Jennifer DeCuir assisted in data analysis. Natalie Crawford, Silvia Amesty, and Crystal Fuller Lewis supervised data collection and contributed to the analysis. Crystal Fuller and Natalie Crawford designed the study. All authors contributed to subsequent drafts and approved the final manuscript.

Conflicts of Interest

The authors declare no conflicts of interest.

multiple linear regression with GEE (to account for peer network clustering) was used to examine associations with internalized PWID-related stigma.

Results—Latinos were more likely to have higher internalized stigma, as were those with lower educational attainment. Those with higher internalized stigma were more likely to not use a syringe exchange program (SEP) recently, although no association was found with the recent use of pharmacies for syringes. Lastly, higher internalized stigma was related to less than 100% use of pharmacies or SEPs for syringe needs.

Conclusions—These data suggest that PWID with higher internalized stigma are less likely to consistently use sterile syringe sources in urban settings with multiple sterile syringe access points. These results support the need for individual-and structural-level interventions that address PWID-related stigma. Future research is needed to examine why PWID with higher internalized stigma have less consistent use of public syringe access venues.

Keywords

stigma; injection drug use; HIV risk behaviors; syringe sources

1. INTRODUCTION

The US war on drugs, initiated in the 1970s as a way to aggressively reduce drug use in the US, has promoted a negative and stigmatizing environment towards drug users (Bluthenthal et al., 1999; Inciardi, 1986). Although the dissemination of stigmatizing messages has been successful in reducing cigarette smoking in the US (Bayer and Stuber, 2006), rates of illicit drug use from 2002 to 2012 have increased across the country (SAMSHA, 2013). The institutionalization of anti-drug messages and harsh criminal sentences for drug use can have a harmful effect by labeling drug users as people who are not wanted in society. To avoid stigmatization from others, drug users may hide their use (Luoma et al., 2007; Mateu-Gelabert et al., 2005), which might prevent them from seeking needed medical and social services and social support. Experiencing drug use discrimination has been associated with depression (Latkin et al., 2012) and having a greater number of sexual and injecting partners, possibly because the shared discriminatory experience connects drug users together (Crawford et al., 2013b, 2012a). Black and Latino drug users have reported drug use discrimination as the most prevalent form of discrimination experienced in their lifetimes (Minior et al., 2003; Young et al., 2005), as well as the type of discrimination that has most impacted their lives (Minior et al., 2003). Since the effects of drug use discrimination can be compounded by other forms of discrimination that blacks and Latinos face (i.e., racial discrimination), it is important to study the effects of drug use discrimination in these populations in order to be able to intervene.

Although there has been research on drug use discrimination and stigma among illicit drug users overall in the US, discrimination and stigma specifically due to injection drug use has been less understood. Nevertheless, people who inject drugs (PWID) have been more likely to report perceived stigma (Luoma et al., 2007; Semple et al., 2012). This may be because injection is usually seen as a more undesirable behavior compared to snorting or smoking, and because injection has a direct link to HIV transmission. Stigma towards PWID has been

associated with stigma towards HIV-positive people in a national sample (Capitano and Herek, 1999). Similarly, those who use ‘harder’ drugs (i.e., heroin) are more likely to report discrimination (Crawford et al., 2012b). In a review of global barriers to implementing HIV prevention efforts, negative views towards PWID have been identified as a major deterrent to HIV prevention coverage and treatment access (Strathdee et al., 2012).

Experiencing stigma and discrimination can lead to the internalization of these feelings, also known as internalized stigma and includes feeling ashamed of yourself or blaming yourself for having a certain characteristic (Corrigan, 1998). Luoma et al. (2007) found that PWID who reported internalized drug use stigma were more likely to hide their drug use as a method for coping with stigma. Experiencing stigma due to injection drug use has also been linked to riskier injection behaviors, with perceived drug use stigma being found to be associated with syringe sharing among PWID in India (Latkin et al., 2010). However, less is known about the relationship between injection drug use-specific stigma and health behaviors, specifically injection risk behaviors of PWID in the US. This analysis will be one of the first to describe internalized PWID-related stigma and injection risk behaviors related to internalized PWID-related stigma among a U.S. heavy drug-involved urban population to our knowledge. Data for this analysis were drawn from a sample of predominately black and Latino PWID who were recruited from high drug-activity neighborhoods in NYC. The purpose of this analysis was to determine socio-demographic characteristics and injection risk behaviors associated with internalized PWID-related stigma.

2. METHODS

2.1. Study design

This analysis utilizes data from the Pharmacists as Resources Making Links to Comprehensive Testing Services “PHARM-Link Services” study, an intervention using pharmacies participating in New York State's (NYS) Expanded Syringe Access Program (ESAP) which allows pharmacies to sell non-prescription syringes to PWID. The PHARM-Link Services study was a three-armed nonrandomized pharmacy-based intervention with the overall objective of increasing HIV testing by de-stigmatizing HIV and offering HIV testing as a comprehensive part of chronic disease prevention. Pharmacies were assigned to offer HIV testing only (Control Arm), HIV testing in conjunction with other chronic disease screenings after viewing video aimed at decreasing HIV stigma (Intervention-1 arm), or HIV testing only, after viewing the video (Intervention-2 arm).

2.2. Recruitment of study pharmacies and participants

We targeted ESAP-registered pharmacies in neighborhoods with high drug activity in Upper Manhattan and the Bronx, which had previously been ethnographically mapped as part of a randomized, pharmacy-based intervention (Crawford et al., 2013a). A list of ESAP-registered pharmacies was obtained from the New York State (NYS) Department of Health and pharmacies in these neighborhoods were identified and contacted for an eligibility screener (either in-person or on the phone). Pharmacies were eligible to participate in the study if they reported: 1) at least five new non-prescription syringe-purchasing customers a month; 2) no requirements of additional documentation from customers during syringe

transactions; and 3) willingness to sell syringes to PWID. A total of four pharmacies were screened for eligibility, of which all were eligible. Three pharmacies were chosen to participate based on having ample space to conduct private HIV testing as part of the study. Individuals were eligible for the parent study if they were: 1) a PWID syringe pharmacy customer; 2) an under/un-insured pharmacy customer; or 3) a recruited peer of a PWID syringe customer study participant. This analysis was restricted to those who reported injection drug use in the past three months and reported a HIV-negative status. Pharmacy staff were trained on how to discretely describe the study, offer participation, and provide an appointment card at the point of a syringe sale for their PWID syringe customers and at the point of sale or during communication about other pharmacy services for their under/un-insured customers. There were no additional eligibility criteria for under/un-insured customers, and pharmacy staff were told to use their judgment in recruiting these customers (e.g., to recruit Medicaid customers). These customers were included in the study in order to attempt to increase HIV testing among a low SES population that may not have regular access to HIV testing and to minimize stigma among PWID by not singling them out for participation. All pharmacy customer participants who reported injection drug use in the past 6 months during the survey were invited to recruit up to 3 of their peers and were given 3 study coupons that contained an individual identification number (in order to track peer referrals) and the study phone number to make an appointment.

At the scheduled appointment, which occurred within private partitions in the pharmacy, research assistants obtained informed consent and participants completed a 45-minute Audio Computer Assisted Self Interview on laptops. The survey, available in both English and Spanish, assessed socio-demographic characteristics, injection risk behaviors, syringe sources, self-report HIV status, and PWID-related stigma. Participants were compensated \$30 for completion of the survey. Participants who were eligible to refer peers were compensated \$10 for each peer recruited and a \$10 bonus if they recruited three peers. Data were collected between October 2010 and March 2012. The PHARM-Services study was approved by the institutional review boards of Columbia University Medical Center and the New York Academy of Medicine.

2.3 Measures

2.3.1. Dependent variable – PWID-related stigma—PWID-related stigma was measured using the Attitudes Toward Injection Drug Users (IDUs) Scale (Brenner and Von Hippel, 2008), a 10-item scale field-tested and validated among graduate students and healthcare workers in Australia (reliability = 0.72). The items assess participants' level of agreement with a series of positive and negative attitudes toward PWID with responses on a 5-point Likert scale with options including “Strongly Disagree”, “Disagree”, “Not sure”, “Agree”, and “Strongly Agree.” The scale included 5 negative items (“I won't associate with known IDUs if I can help it”, “IDUs should be locked up to protect society”, “Injecting drug use is just plain wrong”, “Injecting drug use is immoral”, “I avoid IDUs whenever possible”) and 5 positive items (“IDUs have a perfect right to their lifestyle, if that's the way they want to live”, “Injecting drug use is merely a different kind of lifestyle that should not be condemned”, “IDUs are mistreated in our society”, “People should feel sympathetic and understanding of IDUs”, and “IDUs should be accepted completely into our society”).

Positive attitude items were reverse-coded so that reporting “Agree” or “Strongly Agree” indicated stigmatizing attitudes. Due to differences between the population where the scale was developed and our study population, exploratory factor analyses were conducted to determine the number of dimensions underlying the scale.

Exploratory factor analyses revealed that the items loaded on two factors – one for the negative attitude items (Cronbach's alpha = 0.72) and another for the positive attitude items (Cronbach's alpha = 0.55). Because the reliability of the positive attitude items was poor, this sub-scale was not used. In accordance with the original scale, the mean of all negative attitude item responses was calculated to obtain a PWID-related stigma score ranging from 1 (no stigma) to 5 (high stigma). Factor analyses were conducted using Mplus 6.1 (Muthen and Muthen, 2010).

2.3.2. Independent variables

2.3.2.1 Injection risk behaviors: Years since injection initiation (continuous) was assessed. Injection risk behaviors in the past three months included the number of injection partners (continuous), borrowing a syringe that had previously been used (yes vs. no), 100% sterile syringe use (yes vs. no) and frequency of injection (daily vs. less than daily). Participants were also asked about their syringe source(s) in the past three months which included using a pharmacy (yes vs. no), a SEP (yes vs. no), or both pharmacy and SEP (yes vs. no) at least once.

2.3.2.2 Study characteristics and socio-demographic characteristics: We included recruitment method (non-syringe pharmacy customer, PWID syringe customer, PWID peer) and pharmacy neighborhood (Central Harlem, South Bronx, Washington Heights). Socio-demographic characteristics collected included sex (male, female), age (continuous), race/ethnicity (black, Latino, White/Other), education level (high school graduate or equivalent vs. less than a high school level education), homelessness in past three months (yes vs. no), and regular full or part-time employment in the past three months (yes vs. no).

2.4. Statistical analysis

This analysis was restricted to those who reported injection drug use in the past three months (n=144). In order to examine individuals' risk for HIV, we excluded those who self-reported HIV positive status in the survey (n=12) for a final analytic sample of 132 participants. Index PWID participants and their recruited peers were defined as a network cluster. Those that were not index PWID participants or did not recruit peers were defined as their own individual network cluster. Descriptive statistics for socio-demographic characteristics and risk behaviors were calculated; *t* tests, ANOVA, and simple linear regression (for continuous predictors) were used to determine significant differences by PWID-related stigma scores. For the 3-level independent variables, post hoc pairwise comparisons were conducted. Injection risk and syringe source variables significant at the 0.05 level or less were included in separate multiple linear regression using generalized estimating equations (GEE) to account for clustering of participants within a network cluster. All data cleaning and statistical analyses were performed using SAS version 9.3.

3. RESULTS

Characteristics of the analytical sample and mean PWID-related stigma score by characteristic are shown in Table 1. The sample was mostly Latino (55.3%), male (80.2%) with a mean age of 42.7 years. In terms of injection risk behaviors in the past three months, a quarter of the sample were daily injectors, 9.0% reported syringe borrowing, 95.4% reported always using a pharmacy or SEP, 69.5% used a pharmacy as a syringe source at least once, and 68.7% used a SEP at least once. The mean PWID-related stigma score was 2.2 with a standard deviation of 0.76 (range: 1.0-4.2); about a quarter of the sample agreed to at least two stigmatizing attitudes (data not shown). In bivariate analyses (Table 1), there were differences by race/ethnicity, education level, SEP use, pharmacy use, and 100% SEP or pharmacy use by PWID-related stigma score.

There were two separate final multivariable models due to high correlation between using an SEP and always using a pharmacy or SEP. In both models (Table 2), those who used a SEP in the past three months had lower mean PWID-related stigma scores, compared to those who did not use a SEP ($b = -0.31$; 95% CI: $-0.57, -0.18$) and those who always used pharmacies/SEPs all the time ($b = -0.75$; 95% CI: $-1.49, -0.01$) had lower mean PWID-related stigma scores compared to those who did not use pharmacies/SEPs all the time. In both models, Latinos had higher mean PWID-related stigma scores than Whites and those with higher education levels had lower mean PWID-related stigma scores than those with lower education levels.

4. DISCUSSION

This report of internalized PWID-related stigma and its associated risk behaviors among a vulnerable, predominately black and Latino study sample in the US contribute to a highly underrepresented research area of critical importance. Using a novel scale that we were able to validate among our sample, these data highlight that Latinos and those with lower educational attainment had higher mean stigma scores. Additionally, inconsistent use of pharmacies or SEPs was independently associated with internalized PWID-related stigma. These data provide reasonable evidence of the relationship between high-risk behavior and internalized stigma given that this was study sample of PWID who had negative feelings about PWID, and in turn, were less likely to safely and legally access sterile syringes.

Prior findings among a NYC street-recruited black and Latino drug user sample revealed that Latino drug users exhibited a higher likelihood of drug use-related shame when exposed to drug use discrimination compared to black drug users (Minior et al., 2003). Shame has been identified as a component of internalized stigma (Corrigan, 1998). Although our results compared Latinos to whites, it is consistent with finding an association between race/ethnicity and internalized drug use stigma. Our finding of higher internalized PWID-related stigma may be partially explained by Latinos being more likely to perceive and report more experiences of drug use discrimination in general and as the most significant type of social discrimination that impacts their life. It is possible that experiencing discrimination due to drug use affect Latinos differently compared to other racial groups which in turn may aide in developing a higher prevalence of internalized drug use stigma (Minior et al., 2003). The

Latinos in our PWID sample were mostly Puerto Rican (72%) and it is unknown if our results are consistent with other PWID studies that have Latino samples of varying heterogeneity. Since Latino PWID are heavily burdened with both HCV and HIV compared to other US racial groups of PWID, more research is needed on how culture and social norms influence PWID-related stigma which in turn may help explain racial disparities in HIV/HCV.

One explanation for the association between lower educational levels and higher internalized PWID-related stigma may be that those with lower education may be more likely to self-endorse misconceptions, myths, and stereotypes regarding PWID (Herek et al., 2009; West et al., 2011). However, the specific relation between drug use stigma and educational level has not been fully explored and this report adds to this critically needed area of study (Magdalena, 2013). For example, in a national sample of people with alcohol use disorders, lower educational level was associated with perceiving alcohol use stigma from others (Keyes et al., 2010). More research is needed on what inaccurate beliefs regarding injection drug use are being held by those with lower educational levels in order to design interventions that provide appropriate information and education on injection drug use.

Finally, the relation between sterile syringe source access and lower mean stigma scores may be explained by PWID perceiving discrimination due to their drug use or feeling ashamed of their use which in turn has been associated with feeling as though they should “hide” their drug use.⁵ Thus, those who have internalized stigma related to drug use may not feel comfortable accessing sterile syringes from public venues such as pharmacies or SEPs. In their qualitative study of PWID in Brooklyn, NY, Mateu-Gelabert et al. (2005) found that it was common for PWID to hide signs of drug use in order to avoid discrimination from family, romantic partners, and neighbors. In NYS, identification is needed in order to use a SEP and this process forces someone to identify as a PWID. This is supported by previous research that has found that fear of public exposure of PWID status was a primary barrier for SEP use (Murphy et al., 2004). SEP use has been documented as a significant factor in decreasing syringe sharing (Bluthenthal et al., 2000), and accessing drug treatment (Brooner et al., 1998), health care, and other services specialized for PWID (Cronquist et al., 2001), and targeting internalized PWID-related stigma may assist in these outcomes. Policy changes or syringe access strategies that promote more private syringe acquisition such that individuals are not identified as drug users may assist in this regard since dismantling stigmatizing attitudes at individual and community levels may be a more difficult challenge to overcome.

In terms of pharmacy syringe access, always using a pharmacy or SEP compared with less than 100% use was associated with a lower mean PWID-related stigma score, while accessing sterile syringes from pharmacies alone demonstrated no association with PWID-related stigma. Since being seen at a pharmacy does not automatically label someone as a PWID, pharmacies may be a more feasible syringe source for those who want to hide their use. Furthermore, structural-level interventions can make pharmacies more inviting environments for PWID and increase repeat use among those who may still feel discomfort in making a pharmacy syringe purchase. In our Pharmacies As Making Links to Community Services (PHARM-Link) study, a randomized pharmacy-intervention, we trained NYC

ESAP-registered pharmacists and pharmacy staff on harm reduction principles and how to engage and provide HIV prevention information to their PWID syringe customers (Crawford et al., 2013a). PWID syringe customers who utilized these pharmacies were more likely to report 100% sterile syringe use and no pharmacy syringe purchase barrier at three-month follow-up compared those who utilized control pharmacies (unpublished results). These results highlight the importance of creating a more supportive and less stigmatizing environment at a service delivery level, which can enhance sterile syringe access.

It is interesting that internalized PWID-related stigma was associated with not always obtaining syringes at pharmacies or SEPs yet was not associated with 100% sterile syringe use. It is possible that those with higher internalized PWID-related stigma are obtaining syringes that they believe are sterile from other sources. All six participants who reported less than 100% pharmacy/SEP use reported that they received their syringes from someone who got them from a pharmacy or SEP (secondary exchange), five also reported obtaining their syringes from a drug dealer. Since these individuals did not obtain the syringe themselves, it is not completely possible to tell if the syringes are sterile. This is also indication that these participants may have not felt comfortable going to a sterile syringe access venue because of PWID-related stigma and sent someone they knew instead.

Our results are subject to some limitations; our data are cross-sectional and temporality and causation cannot be inferred. While we do not know the direction of the association between internalized PWID-related stigma and sterile syringe venue access, either direction is of public health concern. Second, our results have limited generalizability. The sample consisted of either pharmacy syringe customers or their peers from NYC; pharmacy syringe customers have been shown to practice safer injection risk behaviors than other PWIDs (Rudolph et al., 2010). However, although our sample may have had lower injection risk than other PWIDs, an association between risk behavior, namely inconsistent use of safe syringe sources, and internalized stigma was still found. Third, the original PWID-related stigma scale was not originally designed to measure internalized stigma, yet by examining this measure among PWID we believe it is a viable measure of how PWID feel about their own injection drug use. Since positive items of the original scale were dropped, construct validity of the scale was less than ideal. However, we used one of the few validated measures that exists in the literature. The development of instruments to measure PWID-related stigma, especially among PWID, is still in its early stages and further studies are needed to explore the domains underlying this construct. Fourth, given the small sample size, we may not have been able to see true associations with variables with limited variability (i.e., gender, employment). Fifth, since this scale has not been used among other samples, we are not able to assess whether PWID-related stigma was high or low in our sample. The mode of recruitment used in the study (through pharmacies or a PWID peer) may have led to sample with lower internalized PWID-related stigma than the general PWID population. In spite of limitations, we were able to validate a novel scale and contribute to the scarce literature on PWID-related stigma. Our analysis is one of the few to examine factors associated with internalized PWID-related stigma among a marginalized, hard-to-reach population.

In this community study sample of PWID, internalized PWID-related stigma was higher, among Latinos and those with low educational attainment. The relation between decreased use of public syringe access venues and internalized PWID-related stigma highlights a clear example of how access to a public health prevention service can be dampened when use of this service identifies a socially stigmatizing individual or behavior (e.g., drug use). Given the lack of drug use-related stigma reduction interventions in the US, there is clear need for stigma-reducing interventions targeting both individuals and the structural environment to help increase access to available prevention services.

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Highlights

- Little is known on the effects of internalized PWID-related stigma
- We determined correlates associated with internalized PWID-related stigma
- Higher internalized stigma was associated with lesser use of sterile syringe source
- Results support the need for interventions that address PWID-related stigma

Table 1

Characteristics of people who inject drugs (PWIDs) and mean PWID-related stigma score by characteristic (n=132); PHARM-Link Services Study, New York City, 2010-2012.

	Total sample n (%)	PWID-related stigma score (mean, SD)	p value
Study characteristics			
Recruitment method			0.2391
Non-syringe pharmacy customer	3 (2.3)	2.5 (1.1)	
Pharmacy syringe customer	78 (59.1)	2.3 (0.7)	
PWID peer	51 (38.6)	2.1 (0.7)	
Pharmacy neighborhood			0.8285
Washington Heights	44 (33.3)	2.2 (0.9)	
South Bronx	20 (15.2)	2.2 (0.8)	
Central Harlem	68 (51.5)	2.3 (0.7)	
Socio-demographic characteristics			
Age (mean, SD)	42.7 (9.7)		0.8673
Gender			0.2135
Male	105 (80.2)	2.3 (0.76)	
Female	26 (19.9)	2.1 (0.75)	
Race/ethnicity			0.0033
Latino	73 (55.3)	2.4 (0.8)	
Black	18 (13.6)	2.2 (0.7)	
White/Other	41 (31.1)	1.9 (0.6)	
Education level			0.0001
< High school	38 (28.8)	2.6 (0.8)	
High school	94 (71.2)	2.1 (0.7)	
Homeless^a			0.8225
No	78 (59.1)	2.2 (0.8)	
Yes	54 (40.9)	2.2 (0.6)	
Employment^a			0.7384
Not employed	113 (86.3)	2.2 (0.7)	
Employed	18 (13.7)	2.2 (0.9)	
Injection risk behaviors			
Years since injection initiation (mean, SD)	16.7 (11.1)		0.9792
Number of injection partners^a (mean, SD)	0.64 (1.0)		0.5682
Frequency of injection^a			0.6598
Less than daily	98 (74.2)	2.2 (0.8)	
At least daily	34 (25.8)	2.2 (0.7)	
Syringe borrowing^a			0.2913
No	120 (91.6)	2.3 (0.8)	
Yes	12 (8.4)	2.0 (0.5)	

	Total sample n (%)	PWID-related stigma score (mean, SD)	p value
100% sterile syringe use^a			0.0918
No	59 (45.0)	2.1 (0.7)	
Yes	72 (55.0)	2.3 (0.8)	
Pharmacy^a			0.9448
No	40 (30.5)	2.2 (0.9)	
Yes	91 (69.5)	2.2 (0.7)	
SEP^a			0.0034
No	41 (31.3)	2.5 (0.7)	
Yes	90 (68.7)	2.1 (0.7)	
100% pharmacy or SEP use^a			0.0125
No	6 (4.6)	3.0 (1.0)	
Yes	124 (95.4)	2.2 (0.7)	20

^b past 30 days

^c past 2 months

^a past 3 months

Table 2

Adjusted associations between characteristics of PWIDs and PWID-related stigma score (n=132); PHARM-Link Services Study, 2010-2012^a.

	Model 1	Model 2
Adjusted β (95% CI)		
Race/ethnicity		
Latino	0.34 (0.08, 0.59)**	0.34 (0.07, 0.60)*
Black	0.02 (-0.31, 0.35)	0.15 (-0.20, 0.38)
White/Other	<i>ref.</i>	<i>ref.</i>
Education level		
High school	-0.46 (-0.75, -0.18)**	-0.51 (-0.78, -0.24)***
< High school	<i>ref.</i>	<i>ref.</i>
SEP use		
Yes	-0.31 (-0.57, -0.06)*	
No	<i>ref.</i>	
100% pharmacy or SEP use		
Yes		-0.75 (-1.49, -0.01)*
No		<i>ref.</i>

^a All models account for the clustering of 132 participants over 84 networks

* p<0.05

** p<0.01

*** p<.0001