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Peer Knowledge and Roles in Supporting Access to Care and Treatment

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Abstract People living with HIV (PLWHIV) have been involved in the continuum of HIV care since the early days of the epidemic providing education and prevention services. There is a growing interest in utilizing HIV positive peers to support access to care and treatment, but little is known about the range of roles these peers perform and what they need to know to do this work. This study of 186 HIV-positive peers currently providing community health services in eight states found that peers perform a wide range of roles, including assistance with care and treatment, emotional support, and service referrals. Over 80% discussed medications with clients. On average, experienced peers provided correct responses to 73% of questions about HIV and AIDS, and 65% of questions about the appropriate role of a peer. Peers living with HIV for more than 5 years, in paid employment with more than a high school education had higher HIV knowledge scores than volunteers. Higher education, length of time living with HIV, age and speaking English as the primary language were associated with higher peer knowledge scores. This

study suggests that we cannot assume that peers already working in the field are fully knowledgeable about HIV care and treatment or peer roles. It is important to address gaps in knowledge through continuing education and to create common standards for the training and skills that peers who work in community health settings need to have.

Keywords HIV · AIDS · Peers · Training · Treatment adherence · Community health worker

Introduction

People living with HIV (PLWHIV) have been involved in the continuum of HIV care as community health workers since the 1980's, providing outreach, HIV education and buddy services [1–4]. Over the years we have learned a great deal about the roles that PLWHIV perform as peers in prevention work [5, 6]; what they need to know to do this work [7–9] and models that appear to work [7, 10–12]. The evidence suggests that peer interventions can decrease HIV transmission risk behaviors, provide HIV-related education and promote healthier behaviors [1, 2, 12–15]. Based, in part, upon the success of peer interventions to reduce transmission, there is a growing interest in utilizing HIV positive peers to improve access to HIV primary care and adherence to treatment [12, 16–21].

The interest in using HIV positive peers to support care and treatment also stems from the search to find community health interventions that effectively help PLWHIV overcome some of the barriers to health care. As many as 30% of those who know their HIV status in the United States are not receiving appropriate medical care [22–24] for a variety of reasons, including financial barriers, logistical problems in accessing care, and patient-specific

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B. S. Loscher-Hudson Kansas City Free Health Clinic, Kansas City, MO, USA concerns [25, 26]. Even when financial barriers are removed, however, untreated depression, homelessness, health beliefs, negative experiences with health care providers, stigma and distrust of the health care system have a significant impact on the receipt of appropriate HIV care [26–28]. A recent study of people who were not receiving regular HIV medical care found that several health beliefs influenced their care-seeking behavior. People reported that they did not want to be reminded of their illness, did not feel sick enough to seek care or felt that medications did more harm than good [29]. In light of these beliefs and the stigma that still surrounds the diagnosis of HIV disease, there is a growing interest in strategies that employ HIV positive peers who may be uniquely positioned to address these concerns and can serve as role models [9, 16].

Most of the existing literature on peer work to support HIV care and treatment describes experimental interventions such as support groups, directly observed therapy or risk reduction interventions with HIV positive individuals (prevention with positives). In order for this research to be applied successfully in routine clinical settings, a better understanding is needed of the range of roles performed by HIV-positive peers currently working in community health settings. We also need to learn more about the skills and knowledge required to be effective in this work. While there is some overlap with the knowledge and skills required to work in HIV prevention, peers who work in care and treatment settings may need a more thorough understanding of the HIV life cycle, medications and side effects, drug resistance and adherence. In addition to HIV knowledge, peers need to learn about the appropriate role for peers working as part of a clinical team, when to make referrals, how to handle boundary and confidentiality issues and how to take care of themselves in the workplace setting. The published literature is remarkably silent in all of these areas, even when outcomes of experimental interventions are described.

This article describes the results of a survey on peer roles and knowledge that was administered to HIV-positive peers as part of a series of peer training programs in eight states from 2006 to 2008. The Health Resources and Services Administration (HRSA) HIV/AIDS Bureau, through funding from the Minority AIDS Initiative, supported organizations in Oakland, CA, St. Louis and Kansas City, MO, and New York, NY to provide training to HIV-positive peers to engage other people living with HIV/AIDS in care and treatment. A fourth organization in Boston, MA served as a multi-site evaluation and support center to conduct an evaluation of the initiative. The results described below provide insight into the range of roles performed by HIV-positive peers in the United States who are currently working to help HIV-positive clients access the health care system and medical treatment. The article also describes peers' knowledge about HIV treatment and essential peer roles.

Methods

Sample

A total of 423 peers, defined as people living with HIV and non-clinician members of the affected community, participated in the peer training programs. The results reported below come from 186 of the peers (44%) who responded "yes" to the question: "Are you currently working or volunteering as a peer?," and also reported working or volunteering for 6 months or more. This group of experienced peers was selected because we were interested in the knowledge strengths and gaps of those already working in the field, as well as the roles they performed during the previous 6 months. Both inquiries required peers to have current work experience.

Design and Instruments

A baseline survey was administered to training participants prior to the first training session. The survey instrument consisted of four parts: Socio-demographic information (age, race/ethnicity, gender, education and prior peer work experience); Knowledge questions (15 questions about HIV and peer roles); Peer roles (13 items that describe activities peers perform in their work); and HIV self-care (health care utilization, medication adherence, and risk reduction practices). At the time of study implementation, there were no validated instruments to measure HIV knowledge, other than knowledge of transmission and prevention [8, 30], and no instruments that measured knowledge of peer roles. The knowledge and peer role portions of the survey were developed through a literature review of existing measures for HIV knowledge and peer skills, a review of instruments used by peer training organizations and in consultation with the program and training directors to confirm that the survey reflected the core competencies that would be addressed through the training programs. These competencies were originally identified by HRSA in the project design [31] and later through discussion and analysis among peer program and training directors, peer trainers, and evaluators from the participating organizations. The core competencies include HIV/ AIDS: the viral life cycle, medications and resistance, risk and harm reduction, and treatment adherence; Peer roles: workplace expectations, boundaries, confidentiality, counseling, navigating the health care system, working as part of a clinical team, communicating with providers, readiness to be a peer, self-care; and Communication skills:



stages of change, listening skills, open-ended questions, cultural awareness, and non-judgmental behaviors. The instruments were field tested in both English and Spanish to check for comprehension and appropriate literacy levels. All sites obtained Institutional Review Board approval for this study.

Measures

Composite measures were created to categorize the different peer roles and knowledge items. Peer roles were grouped into 5 categories: Provide emotional support (1 item), HIV care and treatment support (4 items), Harm reduction and behavior change (3 items), Care referrals (2 items) and Other peer roles (3 items). Participants were asked how often they performed these roles with clients in the past 6 months with response options of never, 1 or 2 times, 3–10 times or more than 10 times.

The knowledge questions were grouped into 2 categories: HIV knowledge and peer role knowledge. HIV knowledge consisted of 11 items (7 true/false, 4 multiple choice) related to HIV transmission, the viral life cycle, treatment adherence and managing side effects. Peer role knowledge consisted of 4 multiple choice items about knowledge of specific activities related to peer work.

Data Analysis

Basic descriptive analyses were used to describe peer characteristics, evaluate individual items in the knowledge scores, and describe the roles performed by peers. To avoid ceiling effects for the knowledge score, two items that were answered correctly by 95% of participants were removed. Items answered "don't know" or "missing" were considered incorrect answers. Items answered correctly were summed to create the mean knowledge scores. Mean scores were calculated for HIV knowledge based on 9 items and for peer role knowledge based on 4 items.

We used an iterative model building procedure based on linear regression models to identify factors associated with the knowledge scores. The following factors of interest were evaluated: gender, race, age, education, language, employment status as a peer, years working as a peer, place of work, and time HIV-infected. We first fit unadjusted analysis for each factor of interest. The normality assumption was tested and verified for the two knowledge scores and Tukey's Test was used to control for type 1 experiment wise error rate. Factors significantly associated with knowledge scores at a significance level of 0.15 were included together in a single multivariable model. Factors that were no longer significant at the 0.15 level in the multivariable model were removed one at a time. Finally, factors not significant in unadjusted analyses were included

one at a time in the multivariable model to assess their significance in the presence of other variables. The final model was determined using this iterative approach. Prior to regression modeling, we assessed bivariate correlations between all independent variables. To avoid potential collinearity, no pair of variables with a Spearman correlation coefficient greater than 0.40 was included in the same model. Although a significance level criterion of 0.15 was used for entry and retention in the model building process, a two-sided alpha level of 0.05 was used to test whether a factor was significantly associated with the HIV knowledge score and the peer role knowledge score. Data analysis was performed using SAS version 9.1 (SAS Institute Inc., Cary, NC).

Results

Table 1 provides descriptive information about these experienced peers. Two-thirds of the peers were female, 56% were Black and 20% identified as Hispanic or Latino. More than 95% of the peers were over the age of 30 and 60% had more than a high school education. Eleven percent reported that their primary language was a language other than English, and half of this group completed the survey in Spanish. Most of the peers were volunteers (61%) rather than paid staff (39%), and the median time working or volunteering was 4.75 years. Most of the peers (85%) reported that they had received other training in the past 2 years. They worked for a broad range of organizations, most commonly AIDS Service Organizations or Community Based Organizations (62%). Over 85% of peers knew their HIV status for at least 5 years and 86% reported taking HIV medications at the time of the survey.

Table 2 shows the different roles performed by peers in the prior 6 months and the frequency with which these roles were performed. Nearly all of the peers (92%) reported that they provided emotional support to a client at least once. Peers also reported a broad range of other activities, with over 80% reporting that they helped clients understand how HIV medications can improve their health, discussed safer sex with a client, talked with a client about behavior change, helped a client understand what confidentiality means and helped a client find or choose social services. Over three-quarters of the peers helped clients talk openly with their doctor (80%), set boundaries with clients (78%) or helped a client find or choose HIV services (81%). Fewer peers reported performing activities more than ten times in the past 6 months. The most common activity was the provision of emotional support.

Overall, the peers provided correct responses to 73% of the HIV knowledge questions and 65% of the peer role knowledge questions. As shown in Table 3, more than 90%

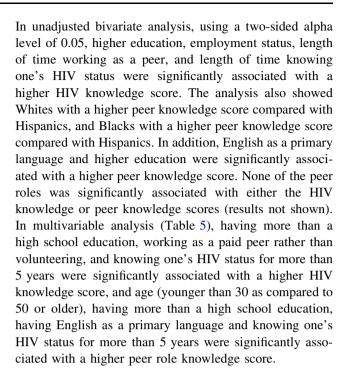


Table 1 Characteristics of experienced peers (n = 186)

Characteristic		n (%)
Gender	Female	126 (67.7)
	Male	57 (30.7)
Race/Ethnicity	Black	101 (55.5)
	White	33 (18.1)
	Hispanic or latino/a	36 (19.8)
	Other	12 (6.6)
Age	<30	6 (3.3)
	30-49	112 (61.5)
	50 and older	64 (35.2)
Education	High school or less	73 (39.7)
	>High school	111 (60.3)
Primary language	English	165 (88.7)
	Spanish/other	21 (11.3)
Other training in the last 2 years	Yes	157 (84.9)
	No	28 (15.1)
Employment status as a peer	Volunteer	114 (61.3)
	Work	72 (38.7)
Years working as a peer	<5 years	94 (50.5)
	5 years or more	92 (49.5)
Place of work	None	7 (3.8)
	Hospital or clinic	47 (25.4)
	ASO/CBO	115 (62.2)
	Other	16 (8.6)
Years HIV positive	5 years or less	27 (14.8)
	>5 years	155 (85.2)
Taking HIV meds	Yes	160 (86.0)
	No	26 (14.0)

of the peers understood that opportunistic infections occur because HIV weakens the immune system, that having an undetectable viral load does not eliminate the risk of transmission and that HIV medications do not cure HIV. Approximately 80% of the peers answered correctly that people do not necessarily need to start taking medications as soon as they are diagnosed, that it is not better to take half of your medications than none at all, that HIV medications reduce your viral load and which problems should generate a referral to a mental health counselor. Fewer than 80% of the peers responded correctly to questions that asked what the HIV antibody test looks for, what a person should do if they have diarrhea, what harm reduction means, and what activity is not appropriate for a peer. The two questions that were least likely to generate a correct response include "A viral load less than 200 means you have AIDS" (38.2% correct) and "Which of the following is an open-ended question?" (29.6% correct).

Table 4 shows the peer characteristics and roles associated with differences in HIV and peer knowledge scores.



Discussion

The purpose of this study was to identify the activities HIV positive peers perform to support access to HIV care and treatment and to better understanding the level of peer knowledge in order to inform the development of peer training and supervision programs. In the literature, peer roles are often defined by the specific intervention being studied, such as modified directly observed therapy [17–20, 25, 32–34], social support [25, 35] or prevention for positives [9, 12, 14, 15, 33]. In this sample of peers working in eight states it appears that HIV positive peers conduct a wide range of activities in natural (non-study) settings that encompass the roles described above, as well as helping clients find HIV and social support services, coaching clients in communications with their providers, helping clients make choices about disclosure, and helping clients understand confidentiality and boundaries. Although peers are likely to spend more time providing emotional support or encouraging risk reduction than engaging in direct discussions of medications or provider interactions, most peers in this study were engaged in both types of activities.

Given the diverse roles for peers, it is important to think broadly about the skills and knowledge people living with HIV need in order to support other people in HIV care and treatment. Several studies of peer interventions emphasize the importance of working with peers who have a solid knowledge of HIV and demonstrate the ability to manage their own HIV disease [21, 27, 32, 36], including an understanding of the HIV viral life cycle, medications and



Table 2 Experienced peers who performed specific roles and the frequency of performance in the previous 6 months (n = 186)

	Frequency of performance n (%)			
	Never	One or two times	Three-ten times	More than ten times
Provide emotional support	13 (7.1)	29 (15.8)	49 (26.6)	93 (50.5)
HIV care and treatment support				
Help a client talk openly with his or her doctor	36 (19.7)	50 (27.3)	38 (20.8)	59 (32.2)
Help a client understand how HIV medications can improve their health	30 (16.3)	26 (14.1)	49 (26.6)	79 (42.9)
Help a client to take HIV medications correctly	58 (33.1)	42 (24.0)	40 (22.9)	35 (20.0)
Go with a client to health care or social service appointment	82 (45.1)	46 (25.3)	32 (17.6)	22 (12.1)
Harm reduction and behavior change				
Help a client decide to reduce their drug use	55 (30.6)	45 (25.0)	37 (20.6)	43 (23.9)
Discuss with a client how to have safer sex	25 (13.6)	27 (14.7)	44 (23.9)	88 (47.8)
Talk with a client about a behavior change that impacts their health	26 (14.1)	40 (21.7)	43 (23.4)	75 (40.8)
Care referrals				
Help a client find or choose HIV services	34 (18.8)	42 (23.2)	54 (29.8)	51 (28.2)
Help a client find or choose social or support services	26 (14.4)	38 (21.0)	58 (32.0)	59 (32.6)
Other peer roles				
Help a client make choices about disclosing HIV status	52 (28.7)	57 (31.5)	41 (22.7)	31 (17.1)
Set clear boundaries with clients	41 (22.5)	38 (20.9)	47 (25.8)	56 (30.8)
Help a client understand what confidentiality means	25 (13.7)	37 (20.2)	53 (29.0)	68 (37.2)

side effects, and adherence. This knowledge is important in helping clients to talk openly with providers or understanding how and why to take their medications. Other important peer skills include strong communication skills, the ability to be a role model, empathy and the ability to establish strong relationships, and the ability to maintain confidentiality [32, 36, 37].

Although tests of HIV knowledge regarding care and treatment are fairly new, they are important if we want peers involved in this work to impart accurate information to their clients. When this study was initially designed, the published literature on HIV knowledge focused on transmission rather than care and treatment [8, 38]. There was only one published HIV knowledge test at the time, a fiveitem test conducted among HIV positive patients in New York, which was associated with self-reported adherence. Since then, two scales have been published, one by Nachega [39] and one by Balfour [30]. While the Nachega scale still focuses heavily on transmission, Balfour's HIV Treatment Knowledge Scale was designed to identify gaps in treatment knowledge, particularly among HIV-positive individuals. Both our scale and Balfour's scale contain items that are very important for peers to know in order to educate other clients. For example, both scales include a true/false question "It is better to take half of your medications than none at all." In the Balfour sample, 63% of HIV-positive patients answered this question correctly, while in our peer sample 80% answered correctly. While it is encouraging that HIV-positive individuals working as peers are more likely to answer this question correctly than patients in general, it is also reasonable to ask the question: "Shouldn't all peers working to support HIV care and treatment know the answer to this question?" It is also concerning that only 38% of experienced peers in this study answered "false" to the statement that "a viral load less than 200 means you have AIDS." Understanding the difference between viral load and CD4 count values is essential for peers who help clients interpret their own lab values and discuss the implications with their providers. While we can expect that experienced peers may answer an occasional HIV care and treatment question incorrectly on a test, it is reasonable for peers to demonstrate a floor of knowledge before talking with clients about the HIV viral life cycle, medications, side effects and adherence. These results highlight knowledge gaps among peers which indicate a need for continuing education and a strong peer/ supervisor relationship to support ongoing peer learning and to help peers apply this learning in their work.

Progress is being made in the testing of HIV treatment knowledge, but the HIV peer literature contains no mention of measures that test knowledge or awareness of other peer skills. Most descriptions of training for peer interventions are brief, when they exist at all. A few descriptions mention training topics such as communication skills, non-judgmental approaches, stages of change, disclosure, boundaries, codes of conduct and motivational interviewing [6, 9,



Table 3 Correct responses of experienced peers to HIV and peer knowledge questions (n = 186)

HIV knowledge questions	n (%) Correct
Average correct response rate across nine questions below	73%
People who have AIDS get opportunistic infections because HIV weakens the immune system	168 (90.3)
If you have an undetectable viral load, you cannot give HIV to your partner (T/F)	167 (89.8)
Taking HIV medications does not cure HIV (T/F)	167 (89.8)
HIV medications help to reduce your viral load	152 (81.7)
Everyone should start taking HIV medications as soon as they are diagnosed (T/F)	149 (80.1)
It is better to take half of your HIV medications than to take none at all (T/F)	148 (79.6)
The HIV test looks for HIV antibodies	130 (69.9)
If a person with HIV has diarrhea, they should drink a lot of water	120 (64.5)
A viral load less than 200 means you have AIDS (T/F)	71 (38.2)
Peer knowledge questions	
Average correct response rate across four questions below	65%
If a person with HIV has the following problem, you should refer him or her to a mental health counselor: All of the above (throws up after eating, feels down or depressed for a long time, thinking everyone is out to get him or her)	152 (81.7)
Harm reduction means: All of the above (reducing the amount of alcohol you drink, entering a drug treatment program, wearing condoms when you have sex)	144 (77.4)
Which activity is not appropriate for a peer? Letting a client know which medications to stop taking	134 (72.0)
Which of the following is an open-ended question? How do you feel about telling your partner about your HIV	55 (29.6)

19, 21, 32]. However, we found nothing that formally evaluates peer knowledge or understanding of these skills. The four peer role knowledge items included in this study are not a validated peer role knowledge test, but rather represent an initial effort to measure the understanding of communication skills and peer roles. The fact that fewer than 75% of peers correctly answered the question "What is *not* an appropriate role for a peer?" suggests that peer training programs need to provide more coverage of appropriate peer roles, including boundaries and the roles of other team members. It is also concerning that only 30% of experienced peers could correctly identify an openended question, suggesting a need for more training and skills practice in communication skills. Measures that assess the understanding of peer roles are as important in

evaluating peer functions as the health information contained in the HIV knowledge tests.

Peers in paid employment with higher education had higher HIV knowledge scores than volunteers. This finding is not surprising and may reflect employer recruitment and hiring practices when hiring individuals for paid positions and greater attention to the continuing education and supervision of peers in paid employment. However, peers in both paid employment and volunteer settings need regular supervision with a strong peer development component. Primarily English-speaking and younger peers had higher peer role knowledge scores. This highlights the importance of effectively translating, adapting and teaching peer skills to peers whose primary language is not English, and ensuring the opportunity to understand and practice these skills.

There are several limitations to this study. First, the study draws upon the experiences and knowledge of a convenience sample of active experienced peers who were recruited to participate in peer training programs through a variety of different recruitment methods. Thus the results do not necessarily reflect the general experiences of all peers in the United States. However, to our knowledge there are no other studies of peer roles and peer knowledge that include such a robust sample of peers and peer experiences across organizational settings and geographic locations. Second, the survey instrument was offered only in English and Spanish. Peers whose primary language was neither Spanish nor English may have been at a disadvantage when answering some of the peer knowledge questions, thus contributing to their lower scores. However, there were only eleven people in the sample whose primary language was neither Spanish nor English. Third, the questions asked are not part of a validated HIV or peer knowledge scale. More research is needed to develop a validated scale to measure peer knowledge of appropriate peer roles and behavior.

Conclusion

As this study demonstrates, we cannot assume that peers working in the field are fully knowledgeable about HIV care and treatment or peer roles. Gaps in knowledge or skills can be addressed in peer training programs, but are also important to address subsequent to initial training in peer supervision, continuing education and professional development. This study also highlights the breadth of roles that HIV-positive peers perform. In light of this finding, it is important to create common standards for the training and skills that peers who work in community health settings need to have. Although some important peer skills cannot be measured by a true/false or multiple choice



Table 4 Experienced peer characteristics and associated knowledge scores (n = 186)

Characteristic		HIV knowledge score (0–9) mean (SD)	P value	Peer role Score (0–4) mean (SD)	P value
All respondents		6.8 (1.7)		2.6 (1.0)	
Gender ^b	Female	6.8 (1.7)	0.67	2.6 (1.0)	0.55
	Male	6.9 (1.7)		2.5 (1.0)	
Race/Ethnicity ^a	Black	6.8 (1.8)	0.41	2.7 (1.0)	<.001
	White	7.3 (1.6)		3.1 (1.0)	
	Hispanic/Latino	6.7 (1.5)		2.1 (1.0)	
	Other	6.9 (0.8)		2.4 (0.8)	
Black versus Hispanic/Latino					0.001
White versus Hispanic/Latino					<.001
Age ^a	<30	7.5 (1.9)	0.29	3.5 (0.5)	0.07
	30-49	6.9 (1.3)		2.6 (1.0)	
	50+	6.6 (2.1)		2.5 (1.1)	
Education ^b	High school or less	6.3 (1.9)	<.001	2.2 (1.0)	<.001
	>High school	7.2 (1.3)		2.9 (0.9)	
Primary language ^b	English	6.9(1.6)	0.14	2.7 (0.9)	<.001
	Spanish/other	6.3 (1.7)		1.6 (1.1)	
Employment status as a peer ^b	Volunteer	6.6 (1.7)	.03	2.6 (1.)	0.54
	Work	7.2 (1.6)		2.7 (1.0)	
Years working as a peer ^b	<5 years	7.1 (1.4)	.01	2.7 (0.9)	0.18
	5 years or more	6.5 (1.8)		2.5 (1.1)	
Place of work ^a	None	7.4 (1.0)	0.10	2.6 (1.3)	0.68
	Hospital or clinic	7.0 (1.5)		2.7 (1.0)	
	ASO/CBO	6.8 (1.7)		2.5 (1.0)	
	Other	5.9 (1.9)		2.8 (1.0)	
Years HIV positive ^b	5 years or less	6.1 (1.7)	.008	2.3 (1.1)	0.09
	>5 years	7.0 (1.5)		2.7 (1.0)	

Table 5 Multivariable analysis of characteristics associated with higher knowledge scores among experienced peers (*n*=186)

	HIV knowledge score (0-9)		Peer role score (0–4)		
Characteristic	β (Standardized β) P -value		β (Standardized β)	P-value	
Age					
<30	N/A ^a		0.82 (0.14)	0.03	
30–49			0.17 (0.08)	0.25	
50+			Referent	_	
Education					
>High school	0.77 (0.25)	<.001	0.62 (0.29)	<.001	
Primary language					
English versus other	N/A ^a		0.95 (0.29)	<.001	
Employment status as peer					
Working versus volunteer	0.50 (0.16)	0.03	N/A ^a		
Years HIV positive					
>5 years	0.69 (0.16)	0.03	0.41 (0.14)	0.04	

^a Items marked "N/A" did not meet criteria for inclusion into the final multivariable model (see "Methods")

test, such as the ability to be an active listener or empathy, other concepts can be tested. These include identifying examples of when confidentiality is breached or when to refer clients to other members of the clinical team. Peer training programs could be improved by regular evaluation of trainee knowledge and implementation of continuing



^a ANOVA used

^b Independent samples *t*-tests used

education programs based on the results of these evaluations.

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