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COMMUNITY DISCLOSURE BY PEOPLE LIVING WITH HIV IN RURAL CHINA

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Abstract

The decision to disclose HIV serostatus is a complex and a challenging task because of potential stigma, blame, and fear associated with HIV infection. Despite continued research on HIV disclosure, literature on HIV disclosure to community is still scarce. The purpose of the study is to describe patterns of HIV status disclosure to community members in a sample of HIV-infected men and women in rural China. This study used the baseline data of a randomized controlled intervention trial for HIV-affected families in China. The data was collected between late 2011 to early 2013. In addition to demographic and HIV-related clinical characteristics, we collected the extent of HIV disclosure to members within the community. We first calculated descriptive statistics and frequencies to describe the demographics of the sample. We then compared the extents of HIV disclosure to different community members. We performed chi-square tests to determine whether the demographic and socioeconomic variables were associated with the extent of HIV disclosure to community. A total of 522 PLH were included in the study. The results show that age and family income are associated with the extent of disclosure of HIV status to members within the community, including neighbor, village leaders, people in the village, and coworkers. More disclosures were found among older age groups. People with less family income tend to disclose more to the community than those with higher family income. There is a need to explore the association of HIV disclosure to the community to help realize the public health and personal implications of disclosure. Our results underscore the potential benefits of age and socioeconomic status–specific interventions in the efforts to dispel barriers to HIV status disclosure to the community.

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HIV disclosure is a critical component of HIV/AIDS prevention and the treatment efforts for both individual and public health outcomes (Chaudoir, Fisher, & Simoni, 2011; Dageid, Govender, & Gordon, 2012; Hult, Wrubel, Bränström, Acree, & Moskowitz, 2012). Disclosure may have lifelong implications because the health and longevity of people living with HIV (PLH) have improved due to medical science advances (Shacham, Small, Onen, Stamm, & Overton, 2012). The disclosure of HIV status to sex partners, family, and friends has been of interest to researchers since the early days of the HIV epidemic, and disclosure is generally associated with benefits in terms of physical health, psychological well-being, health behaviors, and medication adherence (Biadgilign, Deribew, Amberbir, & Deribe, 2009; Bingham, Harawa, & Williams, 2013; Strachan, Bennett, Russo, & Roy-Byrne, 2007; Zea, Reisen, Poppen, Bianchi, & Echeverry, 2005). Despite continued research on HIV disclosure, the majority of studies have focused on the issues of maternal disclosure and disclosure to spouses or sexual partners and family members (Letteney & LaPorte, 2004; Murphy, Austin, & Greenwell, 2007; Ostrom Delaney, Serovich, & Lim, 2008). A recent meta-analysis examining the factors influencing HIV disclosure among PLH in Nigeria found only two studies reported disclosure to work colleagues or persons outside family (Adeoye-Agboola, Evans, Hewson, & Pappas, 2016). Literature on HIV disclosure to the community remains limited as there is a paucity of data on the patterns of or factors impacting disclosure to nonsexual relationships, including neighbors and members in the community (Chaudoir et al., 2011).

The decision to disclose HIV serostatus is a complex and challenging task due to the potential stigma, blame, shame, and fear associated with HIV infection (Przybyla et al., 2013; Tsai et al., 2013). A recent study demonstrated that HIV-infected parents who had disclosed their statuses to their children reported worse mental health conditions and experienced stigma and discrimination from others (Qiao et al., 2015). The scope of disclosure varies from non-disclosure to partial disclosure to full disclosure (Wiener, Mellins, Marhefka, & Battles, 2007). Previous studies have reported that factors, such as time since diagnosis, age, education, gender and marital status, are correlated with HIV disclosure (Akani & Erhabor, 2006; Antelman et al., 2001; Bouillon et al., 2007; Simon Rosser et al., 2008). Previous studies have reported that male sex was associated with the nondisclosure of HIV status (Ndiaye et al., 2006; Olley, Seedat, & Stein, 2004; Simbayi et al., 2007). Researchers have also identified a number of motivations that affect disclosure likelihood, including fear of rejection and self-blame (Derlega, Winstead, & Folk-Barron, & Petronio, 2000; Derlega, Winstead, Greene, Serovich, & Elwood, 2002). Although numerous empirical studies have explored the role of personal and interpersonal factors in HIV disclosure, most of the existing studies are conducted in North America or African and limited literature has focused on HIV disclosure in other culture context (Qiao, Li, Zhou, Shen, & Tang, 2016). For example, a previous study found that in a family-oriented society like China that is profoundly impacted by the collectivistic nature of Confucianism (Ko et al., 2007), the decision to disclose is made together as a family (Li et al., 2007).

The epidemic of HIV/AIDS has spread dramatically in China since the first AIDS case was identified in 1985 (Wu, Rou, & Cui, 2004). There are currently 437,000 PLH in China (United Nations Program on HIV/AIDS, 2014), yet the HIV epidemic in China is predominantly a rural epidemic as a large number of rural villagers were infected through

unsafe plasma collection practices in the early to mid-1990s (Li et al., 2010). Since the collapse of China's cooperative medical schemes, which were the pillars for prevention and health care delivery in the pre-market-reform era, there has been limited effort to rebuild community-based health schemes (Yip et al., 2007). As a result, people living in rural villages need to rely on other members in the community for support or to pay for medical expenses (Yip et al., 2007). In addition, previous studies also suggested that HIV disclosure is an essential part of access to treatment programs in resource-limited settings (Medley, Garcia-Moreno, McGill, & Maman, 2004; Norman, Chopra, & Kadiyala, 2007). A previous study found that PLH living in rural China with higher levels of disclosure to members within the community reported a higher level of access to care and the use of antiretroviral treatment (ART) (Ding, Li, & Ji, 2011). Therefore, HIV disclosure to community may play a critical part in HIV prevention and care effort in rural China.

The current study describes the patterns of HIV status disclosure to members within the community of a sample of HIV-infected men and women in rural China. In particular, this study fills the gap of the literature by identifying the differences of HIV disclosure between various types of community members (e.g., neighbors, village leaders, people in the village, and coworkers) in rural China. In addition to describing the patterns of disclosure, we explore the factors associated with the extent of HIV disclosure to community by analyzing the associations of disclosure with individual characteristics (e.g., age and gender). To facilitate the wellbeing of PLH, it is highly important to examine the factors that contribute to disclosure patterns. This study aims to fill the existing gap of literature on HIV disclosure to community members and provides information that can help inform the development of tailored interventions to support disclosure.

METHODS

PARTICIPANTS

This study used the baseline data of a randomized controlled intervention trial for HIV-affected families in Anhui Province, China. A detailed description of the intervention pilot has been previously reported (Li et al., 2011). Most existing HIV infections in Anhui were caused by commercial plasma donations and blood transfusion during the early 1990s (Ji, Detels, Wu, & Yin, 2006). During that late 1980s and early 1990s, thousands of illegal commercial plasma collection centers were established in rural China (Wu, Rou, & Detels, 2001). The practice of pooling blood and re-infusing red blood cells into donors of the same blood types caused a rapid spread of HIV infections since HIV-1 antibody testing was not required prior to 1995 (He & Detels, 2005). Although these practices ended more than two decades ago, the history of this HIV outbreak continues to impact many rural areas in the country, including Anhui province.

Four counties in Anhui Province (Lixin, Funan, Yinzhou, and Linquan) were selected because they have large numbers of HIV-affected families, similar demographics, and HIV epidemiological data. Within each county, the villages with heavy HIV caseloads were identified and selected, resulting in a total of 32 villages in this study. A total of 522 PLH were recruited based on the following criteria: (1) participants must be aged 18 or over, (2) participants must be residents of one of the selected villages, (3) participants must have a

sero-negative family member and children in the family who were willing to participate in the study, and (4) participants must provide signed informed consent. The data were collected between October 2011 and March 2013.

DATA COLLECTION

The recruitment process began at village clinics where PLH receive routine check-ups and treatment services. Village health workers verbally communicated with the PLH about the study and distributed printed flyers to potential participants. The PLH who demonstrated interest in the study were referred to a study recruiter who met with them individually to assess their eligibility for the study. Following a standardized script, project recruiters explained the study's purpose, procedures, confidentiality issues, and potential risks and benefits to the prospective participants. All participants provided written informed consent prior to data collection. The refusal rate was approximately 5% ($n = 26$).

The participants were surveyed in a private room at the village clinic or at their preferred venue. Each assessment lasted approximately 45 to 60 minutes. The participants received 50 yuan ($8.3 US) for their participation. The assessment was conducted using the computer-assisted personal interviewing (CAPI) method as an interviewer asked the participants questions that were displayed on a screen and input the responses directly into a laptop computer. Approval for this study was obtained from institutional review boards of the University of California, Los Angeles, and the Anhui Provincial Center for Disease Control and Prevention.

MEASURES

Gender, age, marital status, level of education, and annual family income were collected from all participants. The level of education was assessed by asking the participants how many years of school they had completed. Marital status was measured by asking the participants the following question: "What is the current status of your marriage?" The response items included: married/living as married, separated/divorced/widowed, and never married. Only three participants had never been married; therefore, marital status was dichotomized into currently married or living as married and not married for the statistical analyses. The HIV-related clinical information obtained from the participants included their partner's HIV status and how they thought they had acquired the HIV infection based on the following question: "In your opinion, how did you become infected with HIV?" The response categories included: heterosexual intercourse, homosexual intercourse, injection/needle sharing, blood donation, blood transfusion, mother-to-child transmission, and other.

The participants were asked to whom, other than health workers, they had disclosed their HIV status to first and then asked how long they waited after learning of their HIV diagnosis to disclose their HIV status. Based on Derlega et al.'s HIV disclosure measurement, the extent to which the PLH disclosed their HIV serostatuses to members of their community was measured by asking the participants the question "how widely is your HIV status known to the following people?" with reference to four different groups, including (a) neighbors, (b) village leaders, (c) people in their village, and (d) coworkers (Derlega et al., 2002). A composite disclosure to the community score was derived by summing across the PLH's

levels of disclosure (0 = none of them, 1 = some of them, and 2 = all of them) to each of the potential recipients (score range = 0 to 8). A score of 8 indicated full disclosure to all members of the community.

DATA ANALYSIS

All analyses were performed using the SAS statistical software version 9.4 (SAS Institute Inc., Cary, NC, USA). First, we calculated descriptive statistics and frequencies to describe the demographics of the PLH, including the level of education, annual family income, HIV-related clinical characteristics, and HIV disclosure variables, including the first person they disclosed to and the time required to disclose their status. We then compared the extents of HIV disclosure to neighbors, village leaders, people in the village, and coworkers among the participants. We performed chisquare tests to determine whether the demographic and socioeconomic variables, including gender, age, marital status, level of education, and annual family income, were associated with the extent of HIV disclosure to members of the community.

RESULTS

The participant demographics and characteristics are summarized in Table 1. A total of 522 PLH were included in the study. Approximately 45% of the participants were male, and 43% of the participants were between the ages of 41 and 50 years with a mean age of 49 years (SD = 8.83). The majority (81.4%) of the participants were married or living as married. The average individual annual income was 4, 213 yuan (SD = 8,572; approximately $648 US). Approximately 40% of the sample had not received any formal education, and the average number of years of education received was three (SD = 2.98). According to their self-report, 86.7% of participants were infected with HIV through paid plasma blood donation, and 5.4% were infected through heterosexual intercourse. Approximately 27.0% of the PLH had a spouse who was infected with HIV.

The majority (73%) of the sample disclosed their status to someone in less than one month, 18% disclosed within twelve months, and 8% disclosed more than one year after learning of their HIV status. Excluding health workers, 66% of the PLH first disclosed their HIV status to their spouses/partners, 13% to their sons or daughters, 10% to their parents, and 6% to their brothers or sisters. In sum, 19 respondents (4%) did not disclose to any of the community members, 1 person disclosed to some of the community members (0.1%), and 152 people (29%) disclose to all four types of the community members. In particular, 91% (n = 475) had disclosed to all their village leaders, and 86% (n = 450) of the PLH disclosed their HIV statuses to all their neighbors. In contrast, the participants were less likely to disclose to people in their village and their coworkers. Sixty-three percent (n = 331) of the participants fully disclosed their HIV statuses to people in the village, and 60% (n = 174) fully disclosed their status to coworkers, while 21% (n = 60) did not disclose to any of their coworkers and 9% (n = 46) did not disclose to any person in the village.

The differences of demographic and socioeconomic variables with the extents of HIV disclosure to various networks are presented in Table 2. There were statistically significant differences in the disclosure of HIV status to members of the community, including

neighbors, village leaders, people in the village, and coworkers by age and family income ($p < 0.05$). The older people tended to disclose more to the community, and the people with lower annual family incomes tended to disclose more to the community than those with higher family incomes. Additionally, there were statistically significant differences in HIV disclosure to people in the village by gender, and females tended to disclose their statuses to the people in the village to a greater extent than males. Furthermore, there were statistically significant differences in HIV disclosure to neighbors, village leaders, and people in the village but not coworkers by educational level. People with no formal education and lower levels of education were more likely to disclose their statuses than those who had received more years of education. There were statistically significant differences in HIV disclosure to the community with the exception of coworkers ($p = 0.025$) by marital status. Married people tended to disclose their statuses to coworkers to a greater extent than those who were not married.

DISCUSSION

The study explored the patterns of community disclosure of HIV status among a sample of people living with HIV in China. This study found that the extent of HIV status disclosure to different members of the community varied. HIV disclosure to village leaders occurred with the highest frequency, and a lower level of disclosure to coworkers was observed. Additionally, the results implied that several demographic variables might influence the decision to disclose, including annual family income, education level, and age. These findings imply that greater levels of disclosure are associated with lower family income, lower levels of education, and increased age. One possible explanation for these findings is that the people with greater levels of education and higher family incomes were less likely to disclose because they did not want to ruin their reputations or social statuses by disclosing their statuses to the community. A previous study conducted in China revealed that more educated individuals experience greater levels of HIV-related stigma in China (Lee et al., 2005), which could be a possible explanation to the present study. Another potential explanation is that the people with less education and less income were less likely to be able to afford the cost of HIV/AIDS treatment and required more financial support, and HIV status disclosure to the community was an inevitable result of seeking treatment and financial support.

Previous studies that have examined disclosure patterns according to age have presented different results. In a national sample of 713 HIV-infected individuals, Nokes and colleagues (2000), found that persons aged 50 and older were significantly less likely to disclose their statuses than their younger counterparts. In two other studies, Serovich and Mosack (2003), found that age did not influence whether HIV-positive men disclosed their HIV statuses to their sexual partners, and Abera, Gedif, Engidawork, and Gebre-Mariam (2010), observed no significant differences in the proportions of men and women who had disclosed their HIV statuses according to age. In contrast to these studies, a study conducted in Cape Town, South Africa demonstrated that individuals older than 25 years were more likely to disclose their HIV statuses to their sexual partners than individuals aged between 18 and 24 years (Vu et al., 2012). The literature concerning age and community disclosure remains limited. The findings of the present study imply that increased age is associated with increased HIV

status disclosure to members of the community. One possible explanation for this finding is that older participants were less concerned about the potential negative consequences of disclosure. A previous study found that younger patients reported perceiving greater stigma than older patients (Sirey et al., 2001). Another potential explanation is that the passage of time might inevitably be associated with the disclosure of serostatus. The results from the present study indicate that future interventions that seek to support HIV status disclosure to the community should be tailored according to age.

In addition to the relation between HIV disclosure to the community and socioeconomic status as measured by education and annual family income, gender also played a role in HIV status disclosure to the community. The literature examining the association between gender and disclosure is mixed. Previous studies conducted in South Africa and Burkina Faso demonstrated that men were less likely to disclose their HIV statuses than women (Ndiaye et al., 2006; Olley et al., 2004). However, in studies conducted in Mali (Ndiaye et al., 2006) and Central Ethiopia (Lemma & Habte, 2008), no variations in HIV status disclosure according to gender were observed. Our study indicated that women were more likely to disclose to the people in the village than men. One possible explanation for this finding is that women are more liberal in their attitudes toward HIV/AIDS and experience less HIV-related stigma in China (Lee et al., 2005). In the light of the inconsistent findings regarding the relationship between gender and HIV status disclosure, continued scientific efforts are needed to better understand the factors that might further influence the relationship between gender and HIV status disclosure.

The results from the present study may inform the future development of interventions that seek to support HIV status disclosure to communities. There are potential negative consequences of HIV status disclosure, but potential benefits are also noted. Our findings suggest that HIV service providers should engage in targeted outreach to younger people living with HIV, especially those with higher family incomes given that this population is less likely to disclose their statuses. We need to understand more about the value of support from the community following disclosure to foster the sustained health and wellness of PLH and others in their lives.

Several limitations should be noted when interpreting the results of the present study. First, this study used a cross-sectional study design to examine the factors associated with disclosure. Therefore, it is not possible to draw causal inferences, and we cannot determine whether other unmeasured factors may have accounted for our results, such as perception of social support (Derlega, Winstead, Greene, Serovich, & Elwood, 2004; Serovich, Brucker & Kimberly, 2000) and perceived communal stigma related to HIV (Derlega et al., 2002). Additionally, this study was conducted among PLH who were mostly infected via plasma donation in rural China in the 1990s and faced less societal stigma compared to people infected through other transmission routes associated with immoral or illegal behaviors such as sex work and drug us (Valdiserri, 2002). These people sold their blood for profit as a means of supporting their families, though not socially desirable, many people sympathize with these former commercial plasma donors and do not view their behaviors as immoral (Gao et al., 2004). Thus, their process of HIV status disclosure might also be different, and the results cannot necessarily be generalized to other PLH. One of the inclusion criteria for

this study was that at least one family member had to know of the HIV status of each enrolled PLH. Thus, the findings may not be generalized to PLH who have not disclosed to any of their family members. Finally, this study was also limited in that it relied on self-reports, which can be subject to reporting bias.

Despite the potential weaknesses, the results from this current study emphasize that the extent of HIV disclosure to the community remains an important issue. Previous literature conducted in resource-limited settings showed that HIV serostatus disclosure to community members may have potential public and personal health benefits (Akani & Erhabor, 2006; Medley et al., 2004). Compared to the level of disclosure to community members in a previous study conducted in South Africa that reported 43.1% of nondisclosure (Wouters, Meulemans, & Van Rensburg, 2009), the findings from this study reveal that there were high levels of full disclosure to neighbors and village leaders among the respondents. In rural China, land remains as an important factor in the local political economy for which the village leaders still have control over regarding the farming input (Kennedy et al., 2004). In addition, in a highly social society like China where neighbors often know each other well and have a sense of community (Li et al., 2009), disclosure to community members, especially village leaders and neighbors in the context of rural China could bring social and material support, leading to both physical and mental health gains (Kalichman et al., 2003; Waddell & Messeri, 2006). These findings have policy implications, albeit tentative, with respect to the types of interventions that should be targeted for PLH and families affected by HIV in the rural Chinese context.

CONCLUSION

Exploration of the factors associated with HIV disclosure to the community is needed to help realize the public health and personal implications of disclosure. This study described the patterns of HIV status disclosure and their correlates in rural China. Our results underscore the potential benefits of age- and socioeconomic status-specific interventions that aim to remove barriers to HIV status disclosure to the community.

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TABLE 1

Demographic and Background Characteristics ($N = 522$)

Characteristic	Number	%
Gender		
Male	234	44.8
Female	288	55.2
Age (years)		
20–40	104	19.9
41–50	222	42.5
51–60	144	27.6
61 and older	52	10.0
Marital status		
Married or living as married	425	81.4
Not married	97	18.6
Education (years)		
None	210	40.2
1–6	241	46.2
More than 6	71	13.6
Individual income (yuan)		
≤ 500	165	31.6
501–2,500	95	18.2
2,501–5,000	144	27.6
> 5,000	118	22.6
HIV-positive partner	141	27.0
HIV transmission[a]		
Heterosexual intercourse	28	5.4
Homosexual intercourse	1	0.2
Drug injection	3	0.6
Blood donation	30	5.8
Blood transfusion	451	86.7
Mother to child	1	0.2
Other	6	1.2
To whom did you disclose your status first[a]		
Spouse/partner	343	65.8
Parent	52	10.0
Sibling	31	6.0
Child	68	13.1
Friend	3	0.6
Other	24	4.0
Length it took to disclose after diagnosis (months)[a]		
0	357	73.5
1–12	88	18.1

Characteristic	Number	%
> 12	41	8.4

[a]Two people did not provide an answer to the HIV transmission question, one person did not answer the disclosure question, and 36 did not complete the “length it took to disclose” item.

TABLE 2

The Extent of HIV Disclosure to Members in the Community by Demographic and Socioeconomic Variables (N = 522)

	How widely is your HIV status known to the following people?															
	Neighbor *n* (%)				Village Leader *n* (%)				People in the Village *n* (%)				Coworkers[a] *n* (%)			
	None	Some	All	*p*	None	Some	All	*p*	None	Some	All	*p*	None	Some	All	*p*
	(*n* = 42, 8%)	(*n* = 30, 6%)	(*n* = 450, 86%)		(*n* = 31, 6%)	(*n* = 16, 3%)	(*n* = 475, 91%)		(*n* = 46, 9%)	(*n* = 145, 28%)	(*n* = 331, 63%)		(*n* = 60, 21%)	(*n* = 54, 19%)	(*n* = 174, 60%)	
Gender				0.866				0.474				0.017				0.131
Male	21 (9)	8 (3)	205(88)		17 (7)	5 (2)	212 (91)		23 (10)	78 (33)	133 (57)		33 (21)	38 (25)	84 (54)	
Female	21 (7)	22 (8)	245 (85)		14 (5)	11 (4)	263 (91)		23 (8)	67 (23)	198 (69)		27 (20)	16 (12)	90 (68)	
Age				**< 0.001** **				**0.004** **				**0.0005** **				**0.0002** **
20–40	21 (20)	8 (8)	75 (72)		16 (15)	3 (3)	85 (82)		20 (19)	34 (33)	50 (48)		20 (29)	19 (28)	30 (43)	
41–50	11 (5)	15 (7)	196 (88)		8 (4)	7 (3)	207 (93)		14 (6)	62 (28)	146 (66)		31 (22)	26 (18)	84 (60)	
51–60	7 (5)	5 (3)	132 (92)		4 (3)	5 (3)	135 (92)		8 (6)	37 (26)	99 (69)		7 (11)	8 (13)	46 (75)	
> 60	3 (6)	2 (4)	47 (90)		3 (6)	1 (2)	48 (92)		4 (8)	12 (23)	36 (69)		2 (12)	1 (6)	14 (82)	
Marital Status								0.428				0.119				**0.025** *
Married	35 (8)	27 (6)	363 (85)		26 (6)	15 (4)	384 (90)		37 (9)	128 (30)	260 (61)		55 (22)	49 (20)	141 (58)	
Not married	7 (7)	3 (3)	87 (90)		5 (5)	1 (1)	91 (94)		9 (9)	17 (18)	71 (73)		5 (12)	5 (12)	33 (77)	
Education (years)				**0.032** *				**0.005** **				**0.0004** **				0.055
None	11 (5)	14 (7)	185 (88)		6 (3)	8 (4)	196 (93)		12 (6)	48 (23)	150 (71)		18 (19)	9 (9)	70 (72)	
1–6	19 (8)	15 (6)	207 (86)		15 (6)	7 (3)	219 (91)		22 (9)	76 (32)	143 (59)		33 (22)	35 (23)	83 (55)	
> 6	12 (17)	1 (1)	58 (82)		10 (14)	1 (1)	60 (85)		12 (17)	21 (30)	38 (54)		9 (23)	10 (25)	21 (53)	
Income (yuan)				**0.015** *				**0.002** **				**0.0007** **				**< 0.0001** **
≤ 500	8 (5)	12 (7)	145 (88)		6 (4)	5 (3)	154 (93)		9 (5)	41 (25)	115 (70)		4 (10)	5 (13)	31 (78)	
501–2500	3 (3)	8 (8)	84 (88)		1 (1)	2 (2)	92 (970		5 (5)	26 (27)	64 (67)		7 (13)	7 (13)	42 (75)	
2501–5000	13 (9)	6 (4)	125 (87)		10 (7)	5 (3)	129 (90)		15 (10)	39 (27)	90 (63)		18 (19)	23 (24)	54 (57)	
> 5000	18 (15)	4 (3)	96 (81)		14 (12)	4 (3)	100 (85)		17 (14)	39 (33)	62 (53)		31 (32)	19 (20)	47 (48)	

Note.

[a]288 respondents completed this question. Numbers in bold indicate that the differences are statistically significant;

*significant at the 0.05 probability level, $p < 0.05$;

**significant at the 0.01 probability level, $p < 0.01$.