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Ethnic differences in nonverbal pain behaviors observed in older adults with dementia

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Background and Significance

Nonverbal older adults with dementia are at an increased risk for unidentified and undertreated pain. Prevalence reports estimate that 41% to 52% of older adults with dementia experience pain in the nursing home (Zwakhalen, Koopmans, Geels, Berger, & Hamers, 2009). With the chronic progressive decline of cognition and loss of function that occurs in dementia (Corbett et al., 2014), the expression of pain becomes more challenging (Corbett et al., 2014; Flo, Gulla, & Husebo, 2014; Shega et al., 2008). Consequently, as dementia progresses, these older adults tend to report fewer painful conditions (Burfield, Wan, Sole, & Cooper, 2012), even though they may suffer from the same painful diagnoses as cognitively intact older adults (Closs, Cash, Barr, & Briggs, 2005; Husebo et al., 2008; Reynolds, Hanson, DeVellis, Henderson, & Steinhauser, 2008). Burfield et al. (2012) found that 47.7% of cognitively intact older adults reported experiencing pain daily, while only 39.6% of those older adults with mild dementia, 29.4% of the moderately impaired, and 18.2% of older adults with severe dementia reported painful experiences despite similar painful diagnoses. These findings suggest that pain is less likely detected and treated in persons with dementia, particularly as the dementia worsens. Consequently, pain in residents with dementia often goes unnoticed, leaving these older adults to endure painful experiences without treatment interventions, which ultimately impacts quality of life and increases suffering (Herman, Johnson, Ritchie, & Parmelee, 2009).

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Pain Assessment in Persons with Dementia

To help alleviate pain in older adults with dementia, it is important that providers are proactive in screening and assessing for possible pain in this special population. Experts recommend using a hierarchy of pain assessment techniques where providers first attempt to obtain a verbal self-report of pain (the gold standard), followed by an identification of potential causes of pain, an observation of residents for nonverbal pain behaviors, a retrieval of proxy-reports of pain, and finally ends with the implementation of an analgesic trial (Bjoro & Herr, 2008; Hadjistavropoulos et al., 2007; Herr, Coyne, McCaffery, Manworren, & Merkel, 2011).

Established recommendations support the use of nonverbal pain behaviors to assess pain in nonverbal persons with dementia (Bjoro & Herr, 2008; Hadjistavropoulos et al., 2007; Herr et al., 2011). Six categories of nonverbal pain behaviors (facial expressions, vocalizations, body movements, changes in interpersonal interactions, changes in activities, and mental status change) were identified by an expert panel of the American Geriatric Society in 2002, providing the foundation on which tool development proceeded. These nonverbal pain behaviors are included in nonverbal pain assessment tools to guide providers in focusing on known pain-related indicators during pain assessment in this population. There are over 28 nonverbal pain assessment tools available for use in older adults with dementia (Husebo et al., 2012). The Non-communicative Patient Pain Assessment Instrument (NOPPAIN) is one pain assessment tool that was designed to be used by the certified nursing assistant (CNA) (a caregiver who spends the greatest amount of time with the resident) and was psychometrically evaluated for use in older adults with dementia (Horgas, Nichols, Schapson, & Vietes, 2007; Sheu, Versloot, Nader, Kerr, & Craig, 2011; Snow et al., 2004).

Ethnic Differences in Pain Expression

Mark Zborowski's work in the early 1950's was one of the first to report that pain is not only a neurological and physiological experience, but also a cultural one as well. Zborowski (1952) demonstrated that cultures vary in how they pattern pain attitudes as well as emotional, linguistic, and behavioral responses to pain. These pain related cultural norms are acculturated through modeling and are viewed with approval or disapproval by other members of the culture. In considering nonverbal expression of pain, Riley et al. (2002) noted increased expression of nonverbal pain behaviors in cognitively intact African American residents when compared to white counterparts (Riley et al., 2002).

Although few studies have explored ethnic differences in the expression of nonverbal pain behaviors, researchers have examined ethnic differences in the expression of emotions, which may provide additional detail regarding potential differences in the outward expression of pain behaviors (Marsh, Elfenbein, & Ambady, 2003; Mesquita & Walker, 2003; Stepanikova, Zhang, Wieland, Eleazer, & Stewart, 2012). Marsh et al. (2003) found subtle cultural variations in basic nonverbal facial expressions, suggesting that some differences do exist in the nonverbal expression of emotions (i.e. fear, disgust, sadness, surprise, happiness, and anger). However, we are not aware of any studies examining nonverbal pain behaviors in persons with dementia. The purpose of this study was to

examine ethnic differences in the presentation and intensity of nonverbal pain behaviors among African American, Caucasian, and Hispanic older adults with dementia when screened for pain by CNAs.

Methodology

The design of this study consisted of a secondary analysis of data from a primary study conducted by Snow et al. (2004) that examined the psychometric properties of the NOPPAIN. In the primary study, older adults were recruited from four nursing homes in Houston, Texas. Older adults with moderate to severe dementia (3 or greater on MDS-COGS) and a related diagnosis that could potentially cause dementia (e.g. organic brain disease, cardiovascular accident, head injury) were included in the study (Snow et al., 2004). All of the residents also had pain-related diagnoses, with the most common diagnoses being arthritis (41%), “pain” (39%), osteoporosis (28%), and fractures (28%). Informed consent was obtained from the family member or durable power of attorney and participant assent was also obtained. Since all of the patient-identifying information was removed from the data set after the primary study, the IRB determined this secondary data analysis was exempt from IRB approval.

A total of 83 older adults with dementia participated in the primary study. Residents were assisted by a CNA (hired from a temporary employment agency) while completing morning activities of daily living and were videotaped using a hand-held recorder for 5 to 15 minutes. A total of 78 videos of the older adults’ morning activities were created (5 of the elders declined videotaping). Of the available 78 videos, the primary study randomly selected a subset of 28 resident videos to be viewed and rated by a group of CNAs for the presence of nonverbal pain behaviors using the NOPPAIN (a smaller random sample of videos was use to reduce rater fatigue).

In the primary study, these 28 videos were scored by 6 CNAs for nonverbal pain behaviors using the NOPPAIN. CNAs were ethnically homogenous (African American). The CNAs were trained to use the NOPPAIN in a one-hour training session prior to data collection. Training consisted of an introduction to standardized assessments, orientation to the NOPPAIN assessment tool, and practice and feedback using the assessment tool on 6 training videos. The data collection for this study consisted of each CNA (n=6) reviewing the 28 video recordings and rating the presence (yes/no) and intensity of pain behaviors (0–10 scale) using the NOPPAIN, resulting in 168 completed assessments.

Secondary quantitative analyses of video ratings were completed using SPSS version 21.0. The purpose of this descriptive study was to examine ethnic differences in the presentation and intensity of nonverbal pain behaviors among African American, Caucasian, and Hispanic older adults with dementia when screened for pain by CNAs. Mean overall pain intensity scores as rated by CNAs, were calculated for the entire sample, for those residents identified as having pain, and across the three different ethnic groups. For all residents exhibiting pain behaviors, chi-square was used to compare ethnic differences in the presentation of nonverbal pain behaviors. Ethnic differences in overall pain intensity ratings were evaluated using ANOVA.

Measures

The NOPPAIN is a 17-item assessment tool that was designed for use by CNAs to screen for indicators of pain in persons with dementia. The tool includes an activity chart for pain assessment during different levels of activity, a body diagram, a pain response section for identification of nonverbal pain behaviors, and a reminder to ask the subject if he/she was in pain. The NOPPAIN includes 6 categories of nonverbal pain behaviors (pain words, pain noises, pain faces, rubbing, bracing, and restlessness), as well as descriptions of the types of nonverbal pain behaviors that could be included in each category. A 6-point Likert scale (0–5) is used for rating the intensity of each observed nonverbal pain behavior (Snow et al, 2004).

Good inter-rater reliability ($r = 0.72$ to $r = 1.0$), good internal consistency (Cronbach's alpha = 0.80 to 0.97), and acceptable test-retest reliability ($r = 0.68$ to $r = 0.95$) (Horgas et al., 2007; Snow et al., 2004) were established for the NOPPAIN. Testing of convergent validity showed moderate correlations between verbal reports of pain and nonverbal pain behaviors($r = 0.66$, $p < 0.001$) and moderate correlations between different nonverbal pain behaviors ($r = 0.63$ to 0.65, $p < 0.001$) (Horgas et al., 2007). Construct validity was established by comparing expert responses to CNA responses, showing 18.14 ($p < 0.05$) using a goodness of fit model (Curyto, Van Haitsma, & Vriesman, 2008; Snow et al., 2004). Construct validity of the tool in lab settings was strong (Horgas et al., 2007; Snow et al., 2004). Sheu et al. (2011) reported good distinction between moderate and severe states of pain, but also noted some issues distinguishing between mild and moderate intensities. The NOPPAIN is also good for distinguishing pain during movement and at rest (Lints-Martindale, Hadjistavropoulos, Lix, & Thorpe, 2012). The tool is one of the few that has been tested with racially diverse staff as raters (Snow et al., 2004) and the NOPPAIN also rates the intensity of pain behaviors (Horgas et al., 2007; Snow et al., 2004).

Results

The random sample of 28 older resident videos used in this secondary data analysis included 19 (69%) Caucasians, 4 (14%) African Americans, 2 (7%) Hispanic, and 3 (10%) other (where other includes those whose ethnic background was unknown or mixed). Five of the six CNAs in this secondary data analysis were women and all of the CNAs were African American with a mean age of 37 (S.D. 6.41). Additionally, five CNAs that rated the patient videos had received their high school diploma or GED and had spent an average of 9 months (S.D 4.08) working in the profession (see Table 1)

For the 168 completed assessments (six CNAs x 28 videos = 168), pain noises (29.8%), pain words (28%), and pain faces (28%) were identified most often. Of the six behaviors listed on the NOPPAIN, restlessness (2.4%), bracing (0.6%), and rubbing (0%) were rarely observed as indicators of pain. Examining the frequency of behaviors identified across ethnicities, pain noises and pain faces were frequently exhibited by all three ethnic groups, with pain noises ranging from 29.8%–50% and pain faces from 28.9%–41.7%. The behavior "pain words" showed the greatest variability between ethnic groups with 37.7% of Caucasians, 25% of Hispanics, and only 4.2% of African Americans exhibiting this pain behavior category. Of the six nonverbal behaviors included on the NOPPAIN, "pain words" is the

only behavior that was significantly different between the ethnic groups (X^2= 19.167, p < 0.001). Rubbing, bracing, and restlessness were rarely observed, and when endorsed these behaviors were only identified in the Caucasian residents (see Table 2).

In a total of 62 assessments (36.9%) CNAs marked “yes” in determining if the resident was in pain and rated the intensity of that pain on a 0–10 scale. Data for the 62 completed assessments that were recognized by CNAs as being indicative of pain were evaluated separately. For the elders that the CNAs classified as being in pain, of the six nonverbal pain behavior categories on the NOPPAIN, three behaviors were frequently identified by the CNAs: pain noises (67.7%), pain faces (66.1%), and pain words (64.5%). In all ethnic groups, pain noises and pain faces were the most common nonverbal signs of pain. Consistent with the entire sample, rubbing, bracing, and restlessness were rarely observed across ethnic groups in this sub-sample of persons identified as “in pain”, and when endorsed were only identified in Caucasian residents.

In the assessments where residents were rated as “pain present”, only 2.4% of the 62 completed assessments had a CNA-identified pain NRS score of 3 or higher. The reported pain intensity by CNAs was low with the mean pain score of 0.68 (S.D. 0.91), as rated on a 0–10 scale. Mean pain reports by the CNA across ethnicities were also low with Hispanics mean pain rating of 0.83 (S.D. 0.94), Caucasians having a mean pain rating of 0.76 (S.D. 0.95), and African Americans mean pain rating of 0.58 (S.D. 0.83) (see Table 3). Significant differences were not noted in the overall pain intensity ratings across ethnicities (F=2.078, p=0.105).

Discussion

In this study, key nonverbal behaviors were identified by CNAs as most prevalent indicators of pain in persons with dementia, with differences noted between ethnic groups. For the entire sample (168 completed assessments), three nonverbal pain behavior categories were frequently identified by CNAs as being expressed by residents with dementia: pain words, pain faces, and pain noises. Lints-Martindale et al. (2012) evaluated the psychometric properties of 6 nonverbal pain assessment tools and also found that pain faces and pain words/vocalizations were important pain behaviors when detecting pain and can be easier to identify than other nonverbal pain behaviors. Other research in cognitively intact older adults has found that facial expressions are often used to indicate pain (Closs et al., 2005; Mentes, Teer, & Cadogan, 2004). While the parent study did not explore the CNA’s perceptions of pain behaviors, findings in this secondary data analysis suggest that pain faces, pain noises, and pain words were identified most often in each ethnic group.

Rubbing, bracing, and restlessness were rarely noted in residents in this study. Shega et al. (2008) also found that persons with mild to moderate cognitive impairment presented low frequencies of bracing when compared to cognitively intact counterparts. Interestingly, all of the residents who displayed bracing or rubbing in this study were Caucasian and the majority of the residents presenting these behaviors were not identified as having pain by CNA raters (n = 98%). This may suggest that CNAs do not recognize rubbing, bracing, or restlessness as nonverbal pain behaviors that are indicative of pain. Contrary to the findings

of this study, some research suggests that the most common nonverbal pain behaviors seen in residents experiencing pain are rubbing and bracing (Closs et al., 2005; Cohen-Mansfield & Creedon, 2002; Mentes et al., 2004; Shega et al., 2008), but are based primarily on providers' perceptions. Instead, Tsai et al. (2011) suggest that guarding, a nonverbal pain behavior that is not included on the NOPPAIN, may be a better indicator of pain than rubbing or bracing; as cognitively impaired elders may display more guarding than any other nonverbal behavior. Guarding results in stiff and rigid movements that often worsen as dementia progresses (Shega et al., 2008), which may account for the increased likelihood that this behavior will be present in older adults with dementia. In the end, the findings of this study suggest that rubbing, bracing, and restlessness may not be good indicators of pain in older adults with dementia who are unable to communicate their pain experiences. Future research is needed, in samples of persons with dementia experiencing greater levels of pain severity, to explore possible ethnic differences in the expression of the nonverbal pain behaviors rubbing and bracing.

Potential differences in pain behavior between ethnic groups in this study provide impetus for further investigation. In looking at the completed NOPPAIN assessments for African American residents experiencing pain, African Americans frequently exhibited pain faces and pain noises in the presence of pain, thus it is interesting that CNAs did not identify more African American residents as having pain in their dichotomous ratings. Wandner et al. (2011) found discrepancies in pain assessments based on the resident's ethnicity with raters assuming white residents were more sensitive to pain than their African American and Hispanic counterparts. Furthermore, raters have been found to unknowingly use the resident's ethnicity to make pain assessment decisions (Hirsch et al., 2010). Trawalter, Hoffman, and Waytz (2012) support these findings, but suggest that ethnic differences in pain assessment tendencies may be more related to perceptions of status and perceived ability to cope with hardship resulting in lower pain scores for diverse residents. Additionally, Peeters and Vlaeyen (2011) show that an increase in catastrophizing behaviors, common in African Americans (Fabian, McGuire, Goodin, & Edwards, 2011), led to a decrease in the expression of nonverbal pain behaviors in cognitively intact residents. Future research is needed that explores the impact of ethnic background on pain assessment decisions and experiences.

African Americans were also significantly less likely to express pain words when compared to Caucasian counterparts. Little is known about the maintenance of ethnic perceptions of pain and tendencies, especially in older adults with dementia who have impaired cognitive function, acknowledging a need for future research. Contrarily, work of Riley et al. (2002), found that African Americans presented higher pain behaviors. These differences in findings may be due to the cognitive status of the subjects in this study and/or the relatively large sample size used by Riley et al. (2002) (N=1557) increased ability to recognize racial differences in pain expression. Additionally, all of the CNA raters in this study were African American, which may also account for some of the discrepancy this study and previous work.

CNA's dichotomous pain intensity ratings for the residents were low as were the intensities of pain behaviors. It is also interesting that higher pain intensity ratings were not noted in

this sample since the majority of CNAs (83%) in this study were women and women are typically more sensitive to the pain experiences of others and more likely to infer higher pain intensities (Davoudi, Afsharzadeh, Mohammadalizadeh, & Haghdoost, 2008). However, it is also possible that the CNAs underestimated the pain experiences, as commonly cited in the literature (Prkachin, Solomon, & Ross, 2007). Prkachin et al. (2007) explored the inferences of pain in others by observing for nonverbal pain behaviors, recognizing that healthcare providers have a tendency to underestimate pain when inferring pain in others using nonverbal pain behaviors. The lower pain rating may also be dependent upon the rater's personal biases of what behaviors are indicative of pain and/or lack of knowledge on current recommendations regarding pain behaviors identified in persons with dementia. Although all subjects had painful diagnoses as part of the inclusion criteria, the low pain scores may be related to lack of pain experienced by the subjects with dementia. In the end, had the ratings of pain been higher in the patient videos, it is possible that the CNAs would have noticed more pain behaviors during the screenings for pain, resulting in a better understanding of the role of ethnicity in the outward expression of nonverbal pain behaviors.

The presence of healthcare disparities for minority residents emphasizes the importance and need of research in this area (Campbell & Edwards, 2012). Minorities are less likely to receive adequate pain assessment and management, partially due to provider cultural incompetency, but also as the result of possible unknown differences in pain needs (Trawalter et al., 2012). Weech-Maldonado et al. (2012) found that greater cultural competency and awareness resulted in improved pain control for minority persons and examining this relationship in persons with dementia is a necessary step in improving pain identification in this vulnerable population.

Limitations

Secondary analysis of an existing data set designed to establish psychometrics of a new pain behavior assessment tool limits the design and methods to answer the research questions proposed for this study. Although, the small sample size leads to several limitations in interpreting findings, it does provide impetus for future research including the use of larger samples of ethnically diverse persons with dementia. Little is known about the maintenance of ethnic perceptions of pain with the onset of dementia. Due to the progressive and destructive nature of dementia on cognition, the patient's ability to recall culturally-influenced preferences in pain expression is questionable. Future work should also focus on the provider's inference of pain in this population. Additionally, the behaviors that were recognized in the resident videos could be indication of other unmet needs (i.e. agitation, hunger, depression, etc.) and not the expression of pain, thus additional research is needed in this area.

The low pain intensities that were identified by CNAs suggest the sample is limited in representation of different levels of pain severity. Consequently, judgments of behavior prevalence and intensity need to be evaluated in larger studies with broader pain ranges. Additionally, the NOPPAIN assessment tool has several components, but only includes a limited number of the possible nonverbal pain behaviors and the body diagram and activity chart were excluded from the analyses in this study. The NOPPAIN also has some reported

issues with distinguishing between mild and moderate pain intensities (Sheu et al., 2011). While there are limitations to the findings of this study, this work is the first to address possible ethnic differences in the expression of nonverbal pain behaviors in persons with dementia.

Conclusion

This study is the first to examine potential difference in the expression of nonverbal pain behaviors across ethnicities in persons with dementia. Findings suggest a need for more research to guide staff education and development of different approaches to tailor care to ethnically diverse older persons. Although limitations exist, this study advances the current research by highlighting the importance of observing for pain words, pain faces, and pain noises during pain assessments and addressing potential ethnic differences in nonverbal expression of pain. However, since pain is typically inferred by the provider for older adults with dementia using observation of nonverbal pain behaviors, future work should evaluate ethnic differences in the provider's pain assessment decisions.

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Table 1

Resident and CNA Demographics

Demographics	All Residents (N=28) N(%)	CNAs (N=6) N(%)
Age	N/A	36. 5 (S.D. 6.41)
Sex N(%)		
Male	N/A	1(17%)
Female		5(83%)
Race N(%)		
Caucasian	19(67.9%)	0(0%)
African American	4(14.3%)	6(100%)
Hispanic	2(7.1%)	0(0%)
Other	3(10.7%)	0(0%)
Education N(%)		
No High School Diploma	N/A	1(16.7%)
High School Diploma		5(83.3%)
Work Experience (months)	N/A	8.67 (S.D. 4.08)

Table 2

Display of Nonverbal Pain Behaviors

	Completed Assessments		Caucasian Assessments		African American Assessments		Hispanic Assessments		Other Assessments	
	All	In Pain	All	In Pain	All	In Pain	All	In Pain	All	In Pain
	n(%)		n(%)		n(%)		n(%)		n(%)	
	N = 168 (100%)	n = 62 (36.9%)	n = 114 (67.9%)	n = 51 (82.3%)	n = 24 (14.3%)	n = 4 (6.5%)	n = 12 (7.1%)	n = 5 (8.1%)	n = 18 (10.7%)	n = 2 (3.2%)
*Pain Words	47(28%)	40(64.5%)	43(37.7%)	37(72.5%)	1(4.2%)	1(25%)	3(25%)	2(40%)	0(0%)	0(0%)
Pain Noises	50(29.8%)	42(67.7%)	34(29.8%)	32(62.7%)	7(29.2%)	4(100%)	6(50%)	5(100%)	3(16.7%)	1(50%)
Pain Faces	47(28%)	41(66.1%)	33(28.9%)	32(62.7%)	7(29.2%)	4(100%)	5(41.7%)	4(80%)	2 (11.1%)	1(50%)
Rubbing	0(0%)	0(0%)	0(0%)	0(0%)	0(0%)	0(0%)	0(0%)	0(0%)	0(0%)	0(0%)
Bracing	1(0.6%)	1(1.6%)	1(0.9%)	1(2%)	0(0%)	0 (0%)	0(0%)	0(0%)	0(0%)	0(0%)
Restlessness	4(2.4%)	1(1.6%)	4(3.5%)	1(2%)	0(0%)	0(0%)	0(0%)	0(0%)	0(0%)	0(0%)

*Significant difference noted between ethnic groups, p<0.05

Table 3

Mean Intensities of Pai

	Overall Pain Intensity		Pain Words Intensity		Pain Noises Intensity		Pain Faces Intensity		Rubbing Intensity		Bracing Intensity		Restlessness Intensity	
	All	**In Pain**	**All**	**In Pain**	**All**	**In Pain**	**All**	**In Pain**	**All**	**In Pain**	**All**	**In Pain**	**All**	**In Pain**
	N= 168 (100%)	**n = 62 (36.9%)**	**N = 168 (100%)**	**n = 62 (36.9%)**	**N = 168 (100%)**	**n = 62 (36.9%)**	**N = 168 (100%)**	**n = 62 (36.9%)**	**N = 168 (100%)**	**n = 62 (36.9%)**	**N = 168 (100%)**	**n = 62 (36.9%)**	**N = 168 (100%)**	**n = 62 (36.9%)**
	X (SD)	**X (SD)**	**X (SD)**	**X (SD)**	**X (SD)**	**X (SD)**	**X (SD)**	**X (SD)**	**X (SD)**	**X (SD)**	**X (SD)**	**X (SD)**	**X (SD)**	**X (SD)**
Caucasian	0.76 (0.95)	1.65 (0.74)	0.67 (1.11)	1.41 (1.30)	0.56 (1.03)	1.20 (1.25)	0.55 (1.09)	1.22 (1.36)	0.00 (0.00)	0.00 (0.00)	0.02 (0.19)	0.04 (0.28)	0.02 (0.19)	0.04 (0.28)
African American	0.58 (0.83)	1.75 (0.50)	0.08 (0.41)	0.50 (1.00)	0.67 (1.13)	2.25 (0.50)	0.67 (1.09)	2.25 (0.50)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)
Hispanic	0.83 (0.94)	1.60 (0.55)	0.50 (1.00)	0.60 (0.89)	1.25 (1.42)	2.40 (0.89)	0.92 (1.24)	1.80 (1.30)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)
Others	0.22 (0.55)	1.50 (0.71)	0.00 (0.00)	0.00 (0.00)	0.22 (0.65	1.00 (1.41)	0.22 (0.65)	1.00 (1.41)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)
Total	0.68 (0.91)	1.65 (0.70)	0.50 (1.00)	1.24 (1.28)	0.59 (1.06)	1.35 (1.33)	0.56 (1.06)	1.32 (1.33)	0.00 (0.00)	0.00 (0.00)	0.01 (0.15)	0.00 (0.25)	0.01 (0.15)	0.00 (0.25)

No Significant Difference noted between ethnic groups, p<0.05

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