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Quality of Life and Functional Impairment in Compulsive Hoarding

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Abstract

Compulsive hoarding patients have been found in previous studies to have substantial disability and functional impairment. However, no prior study has examined subjective and objective quality of life (QOL) in patients with compulsive hoarding. This present study compared compulsive hoarders and non-hoarding OCD patients across a variety of QOL domains. Subjects were 171 consecutive adult patients (34 compulsive hoarders, 137 non-hoarding patients with DSM-IV OCD) treated openly between 1998 and 2004 in the UCLA OCD Partial Hospitalization Program (OCD PHP), a specialized, intensive, multi-modal treatment program for treatment-refractory patients. Scores on the Quality of Life Scale and other symptom severity measures on admission were compared between compulsive hoarders and non-hoarding OCD patients. Compulsive hoarders were older and had lower global functioning than non-hoarding OCD patients. Both groups had low overall QOL scores across multiple domains. Compulsive hoarders had significantly lower levels of satisfaction with their safety than non-hoarding OCD patients, were more often the victims of both violent and non-violent crime, felt less safe in their neighborhoods, and felt less protected against attack. Compulsive hoarders were also much less satisfied with their living arrangements than non-hoarding OCD patients. No differences were found on financial variables, but the vast majority of patients in both groups were unemployed. Compulsive hoarders have lower QOL than non-hoarding OCD patients in the domains of safety and living situation. Psychosocial rehabilitation that focuses on problems with victimization, safety, employment, and financial areas may be a beneficial augmentation to treatment for compulsive hoarding.

Introduction

Obsessive-compulsive disorder (OCD) is a common and often debilitating disorder that can cause severe distress and functional impairment. OCD adversely impacts many facets of patients' daily lives, including subjective quality of life (QOL), social functioning, physical health, and occupational functioning (Akdede et al 2005; Antony et al 1998; Bobes et al 2001; Bystritsky et al 1999; Bystritsky et al 2001; Eisen et al 2006; Koran et al 1996; Masellis et al 2003; Moritz et al 2005; Rapaport et al 2005; Rodriguez-Salgado et al 2006;

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Stengler-Wenzke et al 2006). QOL in patients with OCD has been assessed by several prior studies, using a variety of instruments (Akdede et al 2005; Antony et al 1998; Bobes et al 2001; Bystritsky et al 1999; Bystritsky et al 2001; Eisen et al 2006; Koran et al 1996; Masellis et al 2003; Moritz et al 2005; Rapaport et al 2005; Rodriguez-Salgado et al 2006; Stengler-Wenzke et al 2006). All of these studies found that patients with OCD had significant impairment in QOL, and several found that QOL in OCD patients was comparable or even lower than in patients with schizophrenia or depression (Bobes et al 2001; Bystritsky et al 2001; Koran et al 1996; Stengler-Wenzke et al 2006). The severity of comorbid depressive symptoms has consistently proven to be the strongest predictor of QOL in patients with OCD (Eisen et al 2006; Koran et al 1996; Masellis et al 2003; Moritz et al 2005; Rapaport et al 2005; Rodriguez-Salgado et al 2006).

OCD also produces significant occupational impairment and socio-economic consequences. OCD patients have been found to have low levels of education, high unemployment, low average income, and high dependence on social security or other disability payments (Kouzis & Eaton 2000; Leon et al 1995). In one large sample, 34% of OCD patients were unable to work because of their psychopathology (Eisen et al 2006). Rates of unemployment in OCD patients vary from 22% to 55% (Koran et al 1996; Kouzis & Eaton 2000; Stengler-Wenzke et al 2006). While QOL usually improves with treatment of OCD, changes in QOL are not strongly correlated with changes in OCD symptom severity (Bystritsky et al 1999; Lochner et al 2003; Mancebo et al 2008). Substantial QOL impairment appears to persist in OCD patients even after successful amelioration of symptoms with treatment (Bystritsky et al 1999; Mancebo et al 2008; Moritz et al 2005). These findings suggest that QOL impairment may be a relatively independent domain that should be assessed and targeted specifically in OCD patients (Bystritsky et al 2001; Rapaport et al 2005).

Hoarding is defined as the acquisition of, and inability to discard items even though they appear (to others) to have no value (Frost & Gross 1993). Hoarding and saving behaviors have been observed in several neuropsychiatric disorders, including schizophrenia, dementia, eating disorders, autism, and mental retardation, as well as in non-clinical populations, but they have been most commonly associated with OCD (Steketee & Frost 2003). However, several lines of evidence suggest that compulsive hoarding is clinically (An et al 2008; Fontenelle et al 2004; Grisham et al 2005; Lochner et al 2005; Samuels et al 2002; Saxena et al 2002), neurobiologically (An et al 2008; Saxena et al 2004; Tolin et al 2009), and genetically (An et al 2008; Grisham et al 2005; Lochner et al 2005; Saxena et al 2004; Tolin et al 2009; Zhang et al 2002) distinct from OCD. Compulsive hoarding is driven by obsessional fears of losing important items that the patient believes might be needed later and excessive emotional attachments to possessions (Frost & Gross 1993). Living spaces become sufficiently cluttered so as to preclude the activities for which they were designed, causing significant impairment in social and/or occupational functioning (Frost et al 2000a; Saxena et al 2002). In severe cases, hoarding can produce health risks from infestations, falls, fires, and inability to eat in the home (Steketee & Frost 2003). Compulsive hoarding and saving symptoms are part of a discrete clinical syndrome. The core symptoms are urges to save, difficulty discarding, excessive acquisition and clutter, but the syndrome also includes indecisiveness, perfectionism, procrastination, difficulty organizing tasks, and avoidance (Frost & Hartl 1996). Patients who have hoarding and saving as their most prominent and distressing symptom dimension and show the other associated symptoms listed above are thus considered to have the “compulsive hoarding syndrome” (Saxena et al 2002; Steketee & Frost 2003). Clinically significant compulsive hoarding is quite common, with a population prevalence estimated at 3–5% (Iervolino et al 2009; Mueller et al 2009; Samuels et al 2008).

Compulsive hoarding is associated with considerable disability and poor global functioning. Frost et al (2000a) found that OCD patients with significant hoarding symptoms had significantly higher levels of social, family, and work-related disability than non-hoarding OCD patients, patients with other anxiety disorders, and community controls. Hoarding OCD patients in that study also had significantly more anxiety and depressive symptoms than the non-hoarding OCD patients, which could have independently accounted for their greater disability. Our group (Saxena et al 2002) found significantly lower global functioning, as measured by the Global Assessment of Functioning Scale (GAF) (Endicott et al 1976), in compulsive hoarders than non-hoarding OCD patients along with more severe anxiety. However, OCD symptoms were not more severe in compulsive hoarders than non-hoarding OCD patients, indicating that the differences in functioning did not simply reflect differences in symptom severity. OCD patients with hoarding symptoms showed significantly greater levels of disability in multiple domains of functioning, including work, family, romantic relationships, friendships, activities of daily life, and other interests, compared to non-hoarding OCD patients (Lochner et al 2005). However, hoarding patients in that study had significantly more severe overall OCD symptoms and greater comorbidity with depressive and anxiety disorders than non-hoarding OCD patients, so it was not clear whether their greater disability was due to overall symptom severity, comorbidity, or an independent effect of hoarding. In contrast, two studies (Fontenelle et al 2004; Grisham et al 2005) found no difference in GAF scores between hoarders and non-hoarding OCD patients. Taken together, these studies suggest that disability and functional impairment seen in many compulsive hoarders may be related to comorbid anxiety and depressive symptoms.

Self-identified hoarders have been found to have a greater number of chronic medical conditions, higher rates of health care utilization, and a greater number of work impairment days than their non-hoarding family members (Tolin et al 2008). Severity of hoarding predicted work impairment, and 38% of the hoarders reported annual incomes below the U.S. poverty line (Tolin et al 2008). However, no prior study has examined QOL in domains such as safety, victimization, daily activities, family contact, and general life satisfaction in compulsive hoarders. This information is necessary for the development of more specific social, occupational, and vocational rehabilitation programs that could target QOL and other functional deficits that may persist despite symptom improvement after standard treatment (Bystritsky et al 2001).

The objectives of the present study were to quantify and compare both subjective and objective measures of QOL and functional impairment in patients with compulsive hoarding versus non-hoarding OCD patients in an intensive treatment program setting. We hypothesized that hoarders would be older and have lower GAF scores than non-hoarding OCD patients, given previous findings (Frost et al 2000b; Frost et al 2000a; Grisham et al 2006; Kim et al 2001; Lochner et al 2005; Samuels et al 2008; Saxena et al 2002). We predicted that hoarders would be less satisfied with their living situations, given their amount of clutter, and that hoarders would have greater victimization/safety concerns. These predictions were based upon prior reports of theft by threat or force (Hartl et al 2005) and feelings of insecurity from break-ins (Samuels et al 2008) in compulsive hoarders. Finally, we hypothesized that hoarders would have greater financial problems and receive more social service assistance than non-hoarding OCD patients (Frost et al 2000a).

Methods

Subjects

Subjects were 171 consecutive adult patients (84 males and 87 females, aged 18–72, of several different ethnicities) with DSM-IV OCD (if compulsive hoarding symptoms were counted) treated openly between 1998 and 2005 in the UCLA OCD Partial Hospitalization

Program (OCD PHP), a specialized, six-week treatment program for severely ill patients with OCD and related disorders that provides intensive, multi-modal treatment (Bystritsky et al 1996). Diagnoses were made by semi-structured clinical interview, along with the Anxiety Disorders Interview Schedule-Revised (ADIS-R) (DiNardo & Barlow 1989). The Yale-Brown Obsessive-Compulsive Scale (YBOCS) and Symptom Checklist (Goodman et al 1989) provided a listing of the specific OCD symptom factors present in each patient, including the following categories of obsessions and compulsions: harm and aggression, contamination and cleaning, sexual, hoarding/saving, religious/scrupulosity, symmetry/order, somatic, and miscellaneous.

Subjects were classified as having compulsive hoarding syndrome if they: 1) reported compulsive hoarding/saving obsessions and/or compulsions symptoms as prominent, distressing, and impairing symptoms on the YBOCS Symptom Checklist and clinical interview; 2) met the clinical criteria for compulsive hoarding developed by Frost & Hartl (1996), which require: a) the acquisition of, and failure to discard a large number of possessions that appear (to others) to be useless or of limited value, b) living or work spaces sufficiently cluttered so as to preclude activities for which those spaces were designed, and c) significant distress or impairment in functioning caused by the hoarding behavior or clutter; and 3) had associated symptoms of indecisiveness, disorganization, procrastination, and avoidance on clinical interview and the YBOCS.

Of the 171 patients, 34 met these criteria and were classified as having the compulsive hoarding syndrome (Steketee & Frost 2003; Saxena et al 2002). Of these, 29 reported that compulsive hoarding/saving was their primary symptom factor, while five patients reported hoarding as their second most prominent OCD-related symptom domain. The other 137 patients did not report any hoarding/saving symptoms on the YBOCS checklist or on clinical interview. Other OCD symptoms were identified in 17 of the 34 compulsive hoarding patients by the YBOCS Symptom Checklist.

Patients presented with a wide range of comorbid diagnoses, including major depression, bipolar disorder, psychotic disorders, other anxiety disorders, and substance abuse disorders, which were addressed with medication but not symptom-specific behavioral therapy. Patients with active psychosis, mania, dementia, mental retardation, or other cognitive impairments were excluded. For all patients included in the analysis, compulsive hoarding or OCD was the primary disorder that caused the most distress and impairment, compared to their comorbid conditions. The majority of the patients had failed to respond to previous outpatient trials of serotonin reuptake inhibitor medication and at least one previous outpatient trial of exposure and response prevention.

This study was approved by the UCLA Medical Institutional Review Board. After complete description of the study to the participants, written informed consent was obtained.

Assessment Methods

Symptom severity and level of functioning were assessed for each subject at entry into the program, using standardized rating scales. Although inter-rater reliabilities were not obtained, raters went through a standardized training process to ensure rater proficiency and consistency. OCD symptom severity was measured by the YBOCS. The severity of depressive and anxiety symptoms was measured by the 28-item Hamilton Depression Rating Scale (HDRS-28) (Hamilton 1960a) and Hamilton Anxiety Scale (Ham-A) (Hamilton 1960b). Overall psychosocial functioning was measured with the GAF.

QOL was assessed with the Lehman Quality of Life Interview–Short (Lehman 1988), an instrument used mostly in patients with schizophrenia (Lehman 1996). This instrument has

rarely been used in the assessment of QOL in patients with anxiety disorders but has been found to be sensitive to impairment and changes in both subjective and objective QOL in OCD patients (Bystritsky et al 1999; Bystritsky et al 2001). The short form of this scale can be administered as a clinician-rated interview within thirty minutes. It measures several parameters of QOL, including a) general life satisfaction, b) living situation, c) daily activities and occupational functioning, d) family, e) social relations, f) finances, g) work and school, h) legal and safety issues, and i) health. These dimensions are measured both by collecting objective data (i.e. number of social meetings, amount of support from the family, etc.) and by subjective ratings of patient satisfaction with each of the dimensions using a simple eight point scale that rates a patient's experience from Terrible (1) to Delightful (8) (Lehman 1988). In addition, the QOL instrument obtains information on objective indices of occupational and socioeconomic status, such as monthly income, welfare and unemployment benefits.

Data Analysis

The data were first statistically tested for distributional properties, outliers, and missing values. Items were summed for each of the eight subjective and eight objective QOL factors, according to the method of Lehman (1988). QOL summed scores were compared between the two groups: compulsive hoarders (n = 34) and non-hoarding OCD patients (n = 137), using Analysis of Variance procedures. Demographic variables such as age and gender, and symptom severity measures were explored as possible covariates. ANCOVA were then performed with covariates. Secondary analyses (ANCOVA) were conducted on the individual items. Data were analyzed using SPSS statistical software. All statistical tests were two-tailed, with significance levels set at .05.

Results

Compulsive hoarders were significantly older than non-hoarding OCD patients, $F(1, 171) = 30.37$; $p = .000$ (see Table 1). Therefore, age was used as a covariate for all subsequent analyses. Groups did not differ with respect to gender. Hoarders and non-hoarding OCD patients did not differ in symptom severity; YBOCS, HDRS-28, or Ham-A scores. However, compulsive hoarders had significantly lower pre-treatment GAF scores than non-hoarding patients, $F(1, 171) = 7.55$; $p = .007$.

QOL scores in virtually all subjective and objective domains were considerably lower for both patient groups (see Table 2) than published community norms (Lehman 1988), indicating pervasive life dissatisfaction and severe social and functional impairment. QOL scores on the victimization and safety factor differed significantly between non-hoarding OCD and hoarding groups. Compulsive hoarders had significantly lower scores on the subjective "satisfaction with safety" factor, $F(1, 169) = 6.99$; $p = .009$ (Table 2). Individual item analysis revealed that hoarders felt less safe in the streets of their neighborhood, $F(1, 169) = 5.17$; $p = .024$, and less satisfied with the protection they had against being robbed or attacked, $F(1, 169) = 7.52$; $p = .007$, than non-hoarding OCD patients. In addition, hoarders scored higher on the objective "victim" scale, $F(1, 169) = 6.64$; $p = 0.01$. Approximately 9% of hoarders had been the victims of violent crime, and 23% had been victims of non-violent crime, compared to 4% and 15% in the non-hoarding group. Compulsive hoarders also showed a trend toward lower scores than non-hoarding OCD patients on the subjective "satisfaction with living situation" $F(1, 169) = 3.49$; $p = .06$, factor. Hoarders were significantly less satisfied with their living arrangements than non-hoarding OCD patients, $F(1, 169) = 6.17$; $p = .014$.

The two groups did not show significant differences on most occupational and financial factors. However, only 15% of hoarders and 14% of non-hoarding OCD patients were

currently employed, and QOL ratings for occupational and work functioning included only those who were currently working. Thus, both groups had significant occupational impairment, unemployment, and disability. Compulsive hoarders did not have significantly higher scores than non-hoarding OCD patients on any QOL factors. GAF scores and QOL objective and subjective social variables for OCD subjects were correlated, $r = .19$, $p < .05$; $r = .24$, $p < .05$, respectively. Results did not indicate any other QOL and GAF score correlations for either group. When the OCD group was matched for age and gender to the hoarding group (34 in both groups), results for all analyses were no longer significant.

Discussion

This study was the first to conduct a comprehensive assessment of subjective and objective QOL across multiple life domains in compulsive hoarders. Overall, many of our hypotheses were supported. As predicted, we found that compulsive hoarders had lower global functioning than non-hoarding OCD patients. Compulsive hoarders have consistently been found to be more globally impaired than non-hoarding OCD patients, but the findings of several previous studies were confounded by higher levels of anxiety, depression, and global illness severity in the hoarding patient samples (Frost et al 2000a; Lochner et al 2005; Saxena et al 2002). However, in our sample, anxiety and depression scores did not differ between groups and did not account for the lower GAF scores in compulsive hoarders. Our results are consistent with other reports demonstrating a lower level of overall functioning in hoarders and demonstrate that their functional impairment is independent of depression and anxiety severity.

Both compulsive hoarders and non-hoarding patients in this sample had low overall QOL scores across multiple domains, much lower than published norms for community residents (Lehman 1988; Lehman 1996), and comparable to those found previously for state hospitals and patients with schizophrenia (Bystritsky et al 2001; Lehman 1988; Lehman 1996). These results indicate that compulsive hoarding is associated with low subjective and objective QOL, just as has been found in previous studies of OCD (Moritz 2008; Norberg et al 2008). Overall, QOL and GAF scores were not correlated in this sample with the exception of GAF scores and QOL objective and subjective social variables for OCD subjects. This is not surprising given that both groups had relatively low GAF scores. Additionally, there is mixed evidence of a direct translation of low GAF to QOL scores in OCD and schizophrenia samples (e.g., Calvocoressi et al 1998; Woon et al 2010).

As we had hypothesized, compulsive hoarders had significantly lower scores than non-hoarding OCD patients in two major domains of QOL: safety and living situation. Hoarders felt less safe in their own neighborhoods, were less satisfied with their protection against attack or robbery, and were more often the victims of crime. Hoarders were also much less satisfied with their living arrangements than were non-hoarding OCD patients. Financial and occupational variables did not differ significantly between groups. However, the majority of both groups were unemployed.

Compulsive hoarders differed most from non-hoarding patients in the safety and victimization domains of QOL. Hoarders felt much less satisfied with their personal safety than did non-hoarding OCD patients. Interestingly, these safety concerns may be accurate. Our results suggest that hoarders are more often the victims of crime, both violent and non-violent, than non-hoarding OCD patients. The exact cause of the higher rate of victimization is uncertain. We can only speculate that it may be due to living in a chaotic environment and/or living in lower income areas. Higher rates of victimization have also found in other psychiatric populations with low GAF scores, such as patients with schizophrenia spectrum disorders (Fitzgerald et al 2005). However, when GAF scores were controlled, compulsive

hoarders still had greater safety and victimization difficulties than non-hoarding OCD patients in our sample. Other investigations have highlighted high rates of victimization in hoarders. Compulsive hoarders reported feeling less secure from home break-ins in childhood than non-hoarders (Samuels et al 2008) and higher rates of theft by threat or force than normal controls (Hartl et al 2005). Some compulsive hoarders report that their hoarding initially developed as a result of a break-in (Steketee and Frost, 2007). A history of history of victimization or involuntary home clearing may contribute to paranoid beliefs often seen in hoarders. Thus, personal safety and victimization by crime are critical issues that must be addressed in the assessment and treatment of compulsive hoarders.

Compulsive hoarders also reported significantly lower satisfaction with their living arrangements than non-hoarding OCD patients, and had a trend toward significantly lower satisfaction with their overall living situation. This result is perhaps not surprising, given the marked effect of clutter, hoarding, and saving on compulsive hoarders' home sanitation, livability, and ability to use rooms, objects, surfaces, and living space. In severe cases, clutter prevents the normal use of space to accomplish basic activities, such as cooking, cleaning, or even sleeping. Interference with these functions can make hoarding a dangerous problem, putting people at risk for fire, falling (especially elderly people), and infections (Kim et al 2001; Steketee & Frost 2003).

Occupational impairment was not found to differ significantly between groups in this study. This was likely due to the fact that only a small percentage of the patients were employed (15% of hoarders; 14% of non-hoarding OCD patients). Most patients had lost their jobs or were unable to work due to their symptom severity, which may account for similar findings across groups in economic and employment variables. Typically, patients come to an intensive treatment program only after other treatments have failed and have significant impairment across a wide range of life domains. (Bystritsky et al, 1996)

As seen in several previous studies (Frost et al 2000a; Frost et al 2000b; Grisham et al 2006; Kim et al 2001; Saxena et al 2002), compulsive hoarders were older than non-hoarding OCD patients in this sample. Compulsive hoarding is more often found in older than younger age groups (Samuels et al 2008), and hoarding severity tends to increase with age (Grisham et al 2006; Ayers et al 2010). However, all analyses of QOL and symptom severity data covaried for age, so age could not account for the significant between-groups differences found in this study.

Limitations of this study included a discrepancy in sample size between the two patient groups. Studying a larger sample of compulsive hoarders group might elucidate impairment in other QOL domains than found in this study. Additionally, this study was conducted in an intensive outpatient setting, so the results may not be reflective of standard outpatients, who would likely be less severely impaired. The high unemployment rate and overall disability level of both compulsive hoarders and non-hoarding OCD patients may have decreased the likelihood of detecting significant differences in occupational functioning between the two groups.

Another potential limitation was the fact that no specific rating of hoarding symptom severity was done on patients in this study. When the data were collected (1998–2004), no hoarding-specific symptom severity scale was available. At that time, hoarding was considered to be one of the symptom domains of OCD. The YBOCS Symptom Checklist was used to identify each patient's current symptoms, including hoarding-related obsessions and compulsions, as well as other OCD symptoms. For the few patients who had both prominent compulsive hoarding and prominent non-hoarding OCD, their YBOCS scores would have reflected the severity of both types of symptoms. Future studies using specific

rating scales for compulsive hoarding symptom severity, such as the Saving Inventory-Revised (Frost et al, 2004) and the UCLA Hoarding Severity Scale (Saxena et al, 2007) will be needed to investigate the specific relationship of compulsive hoarding symptom severity to quality of life and functional impairment.

Nevertheless, our findings reveal significant impairment in QOL and multiple domains of functioning in compulsive hoarders, even exceeding that of patients with severe, treatment-refractory OCD. These chronically disabled patients require extensive education, psychosocial rehabilitation, and support in order to obtain a higher level of functioning. Many of these QOL issues are not typically addressed in traditional psychotherapy and pharmacotherapy. Implications for treatment of compulsive hoarding may include behavioral and educational components to protect hoarders against crime, as well as occupational and vocational rehabilitation services devoted to helping them find or maintain steady employment.

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Table 1

Clinical Variables of Study Population

CLINICAL VARIABLE	Compulsive Hoarding (n = 34)	Non-Hoarding OCD (n = 137)	ANOVA or Chi-squared	
			F or χ^2	p
Female	64%	47%	3.25	.07
Age (years)	44.5 (11.5)	32.8 (11.0)	30.37	<.001
YBOCS	29.4 (4.0)	30.2 (4.1)	1.41	.24
HDRS-28	20.6 (8.2)	20.6 (8.2)	.26	.61
HAM-A	34.9 (10.0)	34.73 (8.2)	.004	.95
GAF	39.7 (7.2)	44.2 (9.5)	7.55	.007

p <.05

Table 2

Quality of Life Factor Scores

Quality of Life Factor	Compulsive Hoarding (n = 34)	Non-Hoarding OCD (n = 137)	ANOVA	
			F	p
Objective				
Daily Activities	0.05(.19)	0.55(.20)	.75	.37
Family Contact	3.46(1.08)	3.98(.87)	2.66	.11
Social Contact	3.25(.90)	3.28(.95)	.18	.67
Financial Adequacy	0.34(.20)	0.28(.18)	.06	.81
Victimization	0.16(.29)	0.09(.20)	6.64	.01
Arrests	0.00(.00)	0.08(.42)	.45	.50
Amount Spent	\$333 (369)	\$258 (329)	.54	.46
Subjective				
Daily Activities	3.18(1.38)	2.95(1.16)	.82	.37
Family Contact	4.47(1.48)	4.63(1.35)	.24	.63
Social Relations	4.22(1.12)	4.20(1.30)	.39	.54
Finances	3.60(1.51)	4.10(1.66)	.43	.51
Safety	4.84(1.18)	5.42(.96)	6.99	.009
Life Satisfaction	3.60(1.34)	3.46(1.32)	.24	.63
Living Situation	4.37(1.35)	4.59(1.23)	3.49	.06
Health	3.50(1.13)	3.73(1.04)	1.92	.17

p <.05