

## **Applying KDQOL™-36 Form to CKD Patients**

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### **Abstract:**

Treatments of Chronic Kidney Diseases (CKD) are analyzed in Bingöl city and at regional level. CKD is a major problem in Bingöl and Turkey. Increasing numbers of CKDs cause dissatisfaction and extra load on healthcare staffs and families in Bingöl city. Two main hospitals in Bingöl giving dialysis services are controlled and responsible staffs were interviewed. Later, two surveys with 96 and 78 respondents at different times in 2015 were carried out of 160 patients. Having a high health-related quality of life (HRQoL) is an important performance indicator for dialysis centers at the treatment of End Stage Renal Disease (ESRD). KDQOL™-36 Scoring Program (v 2.0) and SPSS 20 versions are used to find the life quality of patients and compare respondents according to education, gender and hospital by One-way ANOVA test. Just Hemodialysis (HD) treatment is suggested at Bingöl city center and life qualities of private hospital patients were found better than government hospital when both surveys are compared. Symptom/problem list with  $50.84 \pm 18.40$ ; Effects of kidney disease with  $49.29 \pm 20.85$ ; and Burden of kidney disease with  $21.55 \pm 22.63$  values have been found from first survey of 96 CKD patients in Bingöl city in 2015. The burden and effects of CKD are found the most effective factors on life quality of patients.

### **Key Words:**

Chronic Kidney Failure, Quality of Life Years, Bingöl City, Haemodialysis

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## Introduction

Kidneys are one of the most important parts of body by cleaning blood from urea and balancing the blood pressure and minerals level. It is found that numbers of Chronic Kidney Diseases(CKD) have been increasing dramatically from Aslan & Üstün (2013) study and life years of CKD patients is low with few treatment options in Turkey.( Aslan & Değer, 2015) Each kind of treatment methods has pros and cons and the treatment types depend on the individual requirements of patients and life style. Increasing life quality of patients can be a success parameter for a hospital or a country. Increasing the life years and quality of treatment has a cost which can be shared by patients and governments. Taking 2-3 times 4 hours treatment each week is a tiring task depriving patients from works and many daily life tasks. To provide an improved treatment to each patient, the individual illness and symptoms, information needs, diet requirements, daily activities, physiological situation, emotional supports, taking medicines on times, critical body signs are to be known.

The probability of living 5 years is 60,3% in Turkey by taking the HD treatment and HD provides about 5-10% functions of original kidneys. Each CKD patients has 160,933.04 TL/life average cost covered by Turkish governments. 9,988,750,207 TL in 2022 is the expected average of all HD patients in Turkey. Hence, hypertension, diabetics, kidney injures and cardiovascular illnesses are to be checked regularly to prevent the development of CKD to ESRD. 5.691 years is the average of living after ESRD in Turkey with maximum 20 years living with a CHD from beginning. (Aslan, 2015) Healthy people are the core for development of regions by providing better healthcare services with high quality. Treatments of kidneys are analyzed in Bingöl city and at regional level in Turkey. Chronic Kidney Diseases (CKD) is a major problem in Bingöl as in Turkey. Increasing numbers of CKFs cause dissatisfaction and extra load on healthcare staff in Bingöl city. Two main hospitals in Bingöl one main government hospital and one private hospital giving dialysis services are controlled and responsible staff s were interviewed and later patients were surveyed two times at different dates with 96 and 78 patients respectively in 2015.

The best way to treat CKD is to find a new kidney from suitable donors to increase life years and life quality. However, it is not possible to find enough living or cadaveric kidney in Turkey due to cultural and economical reasons. Çoban (2014) found that Renal Transplantation (TX) rejections can be decreased by successful treatments and controls. However, chronic rejection risk, infections, diabetes mellitus, hypertension, cardiovascular diseases and secondary malignancy are to be considered during treatment and cancer risks are also to be taken into account separately. (Aslan, 2015) Just few patients in last two years could be able to make TX in Bingöl city and their kidneys were accepted by their bodies without need of coming HD centers regularly but just for controls. Patients in Bingöl city have low or middle level salary or incomes to find reluctant donor and buy their kidneys.

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### Literature Background

Having a high Health-Related Quality of Life (HRQoL) is an important performance indicator for dialysis centers at the treatment of End Stage Renal Disease(ESRD). Self administrated HRQoL measurements are done by patients according to their health situation. Well-being and functions of patients are evaluated by scores given to the questionnaire. Functional, social status, health status, wellbeing, patient satisfaction, patient preferences, role limitations, pain, mental health and general health conditions are main concepts of HRQoL. With help of these concepts, HD, PD, and transplantation types of kidney treatments are compared according to their effectiveness. (Yıldırım et al., 2007) KDQOL-36 scoring system consisting Physical Component summary(PCS) and of Mental Component Summary(MCS)-(1-12) related health, activity limits, ability to accomplish desired tasks, depression and anxiety, energy level, and social activities, burden of CKD subscale (13-16) related daily life, takes up time, causes frustration of CKD patient, symptoms and problems subscale (17-28b) like sore muscles, chest pain, cramps, itchy or dry skin, shortness of breath, faintness/dizziness, lack of appetite, feeling washed out or drained, numbness in the hands or feet, nausea, effects of kidney disease on daily life subscale (29-36) related to diet restrictions, ability to work around the house or travel, feeling dependent on doctors and other medical staff, stress or worries, sex life, and personal appearance is used to evaluate the situation and life quality of patients. (Hays et al., 1994) Clinical performance measures for ESRD are adequacy of dialysis, access to blood, anemia, blood pressure and electrolytes in blood. (Heidenheim et al., 2003) Sensitivity, reliability, validity and cultural differences are to be considered in the KDQOL-36 scoring system and its scales and many studies were carried out in past show that KDQOL-36 has high reliability and validity with some adjustments to different cultures. (Porter et al., 2010) It was found that Disease Quality of Life-Short Form (KDQOL-SF) questionnaire is a suitable tool to measure the life quality kidney transplant patients by applying it to a single center 418 kidney transplant patients in Hungary. (Barotfi et al., 2006) HRQOL patient-perceived physical & mental functioning is the most powerful independent predictor of hospitalization and death as serum albumin. (Lowrie et al., 2003) The needed degree of lifestyle change, adherence to diet and medications and the symptom burden in particular affects patients' HRQOL. With 1000 patients, it is found that 5 point increase in PCS score reduces 6 % of hospital days and increase a 10% improvement in the chance of survival. (**KDQOL-36 , 2016**) One point increase in PCS reduce Renal Replacement (RR) mortality and RR hospitality by 2%. One point increase in MCS decreases relative risk of mortality by 2% and relative risk of hospitalization by 1%. (Lowrie et al., 2003) Interventions, staff support and elements in life causing low scores are need to be analyzed to increase life years of patients.( Mapes et al., 2003)

In a study done in Konya Research and Training center hospital in Turkey, it was found that 293 patients out of 420 patients were still on HD and 127 patients having higher mean age, lower mean values of serum creatine and albumin, higher prevalence of DM, received twice weekly for less than 4 h in all HD sessions and lower HRQOL than living patients died during five years control.( Güney et al., 2012) Moreover, There is a positive correlation among PMCS and age, gender, education level, working, albumin, and Hb. It is found that PMCS has 47.2 ±23.1 mean physical scores and 53.2 ±21.1 mean mental scores from 511 HD patients in Konya in 2005.( Güney et al., 2005) Sertraline

treatment improves the PCS by 13 points and MCS scores by 12 points for PD patients with about 7 points decrease in BDI by comparing control group and experiment groups. (Atalay et al., 2010)

**SUBJECTS AND METHODS**

Two surveys with 96 patients and 78 patients were carried out in 2015 at a government and a main private hospital in Bingöl city, Turkey. Observations and interviews were also carried out to find major problems and make suggestions for improvements. KDQOL-36 form was used for carrying out surveys and KDQOL™-36 Scoring Program (v 2.0) is used to find means and standard errors for each group of survey. Descriptive statistics, One-Way ANOVA and correlations are used to compare Private and government hospital according to surveys, age, education level, gender and seeing a psychiatry doctor regularly.

By Yıldırım et al. (2007), it was found that the Turkish version of the KDQOL-SF-36 carried out in randomly selected 82 patients has high reliability with 0.84 Cronbach Alfa in Istanbul with ESRD. By Whitney U test, with a 25% increased risk of death can occur with 10 points in the Physical Composite Score (PCS) in the Kidney Disease Quality of Life – short form (KDQOL-SF) discriminate validity of the KDQOL-36 questionnaire at Siriraj Hospital between April and August 2011 in Thailand was carried out from 167 HD patients and 62 peritoneal dialysis patients and it was found that it is significantly valid .( Thaweethamcharoen et al., 2009)

**RESULTS OF SURVEYS AND OBSERVATIONS**

Symptom/ problem list having the mean of 50.84 with the least mean score of 6.25 from 50<sup>th</sup> patient of government hospital and the highest mean score 89.58 from 30<sup>th</sup> of government hospital , effects of kidney disease having the mean of 49.29 and max 93.75 value of 53<sup>th</sup> patient from GH and 9.38 min value of 46<sup>th</sup> patient from government hospital , burden of kidney disease having mean of 21.54 and 100 max value from 71<sup>th</sup> patient of PH value and 6.25 minimum value 5<sup>th</sup> patient of PH, SF-12 Physical Composite having 33.84 mean with 50.5 max value and SF-12 Mental Composite groups having 36.71 mean with max 63.01 are used to find a score for each patient and categorize each hospital from 96 respondents out of about 170 patients at city center. Effects of CKD has higher score at GH as 52.29 while it is 44.74 at PH. However, patients of PH have better results for burden of CKD, mental health composite and physical health composite groups. There are not any significant differences between hospitals at Symptom/problem list group as shown below.

**Table 1:** Results of first survey from 96 respondents

| Scale (number of items in scale) | Hosp. | Mean  | Median | Stan. Dev. | n  |
|----------------------------------|-------|-------|--------|------------|----|
| Symptom/problem list (12)        | GH    | 50,95 | 52,08  | 21,02      | 59 |
|                                  | PH    | 50,06 | 52,08  | 13,60      | 37 |
|                                  | Total | 50,84 | 52,08  | 18,40      | 95 |

|                                 |       |       |       |       |    |
|---------------------------------|-------|-------|-------|-------|----|
| Effects of kidney disease (8)   | GH    | 52,29 | 50,00 | 22,73 | 59 |
|                                 | PH    | 44,74 | 42,19 | 16,63 | 38 |
|                                 | Total | 49,29 | 46,88 | 20,85 | 96 |
| Burden of kidney disease (4)    | GH    | 19,92 | 12,50 | 21,10 | 59 |
|                                 | PH    | 23,36 | 12,50 | 25,07 | 38 |
|                                 | Total | 21,55 | 12,50 | 22,63 | 96 |
| SF-12 Mental Health Composite   | GH    | 36,40 | 35,56 | 10,19 | 54 |
|                                 | PH    | 36,99 | 37,48 | 13,92 | 35 |
|                                 | Total | 36,72 | 36,18 | 11,77 | 88 |
| SF-12 Physical Health Composite | GH    | 33,31 | 32,05 | 8,61  | 56 |
|                                 | PH    | 34,76 | 35,53 | 7,43  | 33 |
|                                 | Total | 33,84 | 32,98 | 8,23  | 88 |

Private hospital patients have a higher mean of seeing a psychiatry doctor while there are no significant differences for education, age, satisfaction level and gender. SY11 item with 3.6 and 3.2 means of PH and GH respectively, Effect6 item with 3.5 and 3.1 means of PH and GH respectively and Effect7 item with 3.7 and 3.05 means of PH and GH respectively items show significant differences between hospitals by One-Way ANOVA test with 95% significance level. Scales are developed from 1-low score (positive score on patient) to 5-high score (Negative effects on patient). Each item is categorized to find the negative and positive effects on patients for 96 respondents. Middle points are accepted as the threshold in each scale and it is found that moderate activities, climbing several stairs, worried and unhappy, pain of muscles, cramps, itchy skin, dry skin and access isles problems items do not affect the patients negatively while other items have negative effects on patients as shown in Table below. Negative items are to be improved to increase the life quality of CKD patients living at Bingöl city center.

**Table 2:** Results from SF(Physical Composite) and SY group items from first survey

| Item   | Mean | Effect                          | Scale        | Item                        | Mean | Effect   | Scale |
|--|------|---------------------------------|--------------|-----------------------------|------|----------|-------|
| SF1: General health rating                             | 4.00 | Negative                        | 1-5          | SY1: Pain of Muscles        | 2.35 | Positive | 1-5   |
| SF2: Moderate activities                               | 1.73 | Positive                        | 1-3          | SY2: Pain of Chest          | 3.48 | Negative | 1-5   |
| SF3: Climbing several stairs                           | 1.67 | Positive (Restricted limitedly) | 1-3          | SY3: Cramps                 | 2.77 | Positive | 1-5   |
| SF4: Accomplishing less                                | 1.30 | Negative                        | Yes(1)-No(2) | SY4: Itchy skin             | 2.32 | Positive | 1-5   |
| SF5: Limiting work and other activities                | 1.29 | Negative                        | Yes(1)-No(2) | SY5: Dry Skin               | 2.32 | Positive | 1-5   |
| SF6: Doing less work than expecting (Emotional causes) | 1.36 | Negative                        | Yes(1)-No(2) | SY6: Breathing difficulties | 3.49 | Negative | 1-5   |

|                              |      |          |                  |   |      |          |     |
|------------------------------|------|----------|------------------|---|------|----------|-----|
| SF7: Work as carefully       | 1.35 | Negative | Yes(1)-<br>No(2) | SY7: Faintness or<br>dizziness                      | 3.36 | Negative | 1-5 |
| SF8: Pain                    | 3.42 | Negative | 1-5              | SY8: Lack of<br>appetite                            | 3.34 | Negative | 1-5 |
| SF9: Calm and peaceful       | 4.02 | Negative | 1-5              | SY9: Washed out<br>and drained                      | 3.38 | Negative | 1-5 |
| SF10: Energy                 | 4.41 | Negative | 1-5              | SY10: Uyuşukluk<br>in hands and<br>feet             | 3.22 | Negative | 1-5 |
| SF11: Worried and<br>unhappy | 3.21 | Positive | 1-5              | SY11: Nausea or<br>upset stomach                    | 3.42 | Negative | 1-5 |
| SF12: Social life            | 2.75 | Negative | 1-5              | SY12a: Access<br>issues/entering<br>places problems | 2.12 | Positive | 1-5 |

Burden items have low scores and burden2 item has 2.02 max score. Fluid restriction found by Aslan & Değer (2015) that they do not care fluid consumptions and this item has positive effect on patients with 2.58 mean. However, drinking too much water affects blood pressure and some other body functions negatively. Patients are mainly satisfied from both center and just 12% of them selected no option while CKD have high burden and effects on the life of CKD patients as shown in Table 3 with negative decision from survey.

**Table 3:** Results of SY group from first survey

| Item   | Mean | Decision | Scale |
|--|------|----------|-------|
| Effect1: Fluid restriction                         | 2,58 | Positive | 1-5   |
| Effect2: Dietary restrictions                      | 3,04 | Negative | 1-5   |
| Effect3: Ability to work at home                   | 3,21 | Negative | 1-5   |
| Effect4: Ability to travel                         | 3,24 | Negative | 1-5   |
| Effect5: Depending on medical staff                | 3,25 | Negative | 1-5   |
| Effect6: Stress and worries                        | 3,29 | Negative | 1-5   |
| Effect7: Sexual life                               | 3,05 | Negative | 1-5   |
| Effect8: Personal appearance                       | 2,56 | Negative | 1-5   |
| Satisfaction from centers                          | 1,12 | Positive | 1-2   |
| Burden1: Affecting my life significantly           | 1,66 | Negative | 1-5   |
| Burden2: Spending most of my time dealing with CKD | 2,02 | Negative | 1-5   |
| Burden3: Feeling stressed due to CKD/Frustration   | 1,92 | Negative | 1-5   |
| Burden4: Burden on family                          | 1,82 | Negative | 1-5   |

There are no differences according to Gender with ANOVA test. SF3-8, SF11-12, Burden 2-4, SY2-3, SY-7-10, SY12a, effect2, effect3, effect6 and effect8 items show differences and other 15 items show no differences through ANOVA tests according to education level. Respondents have mainly primary education level. Thus with total of 76 respondents, they are the main group of patients. The total mean is generally close to this group mean due to central tendency theory and 12 of respondents do not have any

kind of education in their life. SY1, SY5, SY12a, effect1 show differences according to seeing a psychiatry doctor regularly or not. In all items, “yes” satisfaction option according to ANOVA test and differences has a higher mean and the biggest difference is 0.83 coming from effect1 item.

### *Second Survey*

Firstly, 96 patients were surveyed at the first quarter of 2015 and about 5-6 months later after first survey, 78 patients : 27 patients from PH and rests from GH were surveyed at the same hospitals. Findings and suggestions were shared with both hospital main responsible doctors after first survey. Changes such as improving sport activities, caring their eating habits, checking by a psychiatry doctor regularly etc. were suggested to the doctors of both hospitals. Specialized kidney doctor responsible from both hospitals worked at GH and gave part-time services to PH. PH hospital has one doctor as the manager of center. Symptom/ problem list group has max 98 mean from 8<sup>th</sup> PH patient and 8.33 mean from 48<sup>th</sup> GH patient. Effects of kidney disease group have the highest mean of 100 from 8<sup>th</sup> PH patient and min 6.25 mean from 31<sup>th</sup> GH patient. Burden of kidney disease has the max mean of 68 from 25<sup>th</sup> PH patients and other 6.25 mean from 75<sup>th</sup>, 36<sup>th</sup>, 39<sup>th</sup> and 40<sup>th</sup> GH patients. SF-12 Physical Composite group has max mean value of 47 from 75<sup>th</sup> GH patient and min 19.38 mean value from 41<sup>th</sup> GH patient. Moreover, SF-12 Mental Composite has max mean of 53 from 28<sup>th</sup> GH patient and 17.81 min mean value from 67<sup>th</sup> GH patient. From overall analyzing, Burden of kidney disease has the lowest mean from both hospitals as shown in Table 4. GH patients has 13.85 score than 19.8 PH patients score. Symptom/problem list group has the 50.93 highest mean with 57.41 PH score. When first survey (S1) and second survey(S2) results are compared. Effects of kidney disease by 6.82%, burden of kidney disease by 5.68%, mental health composite by 4.77% and physical health composite by 2.61% have decreased while there are 7.35% increase, 7.46% increase, 3.68% decrease, 4.65% decrease for first four groups as shown below in Table 4 for PH patients. There are dramatic decreases in effects of kidney disease and burden of kidney disease groups for GH. Changes in climates especially in summer have increased the load of CKD on patients and this factor is to included in further studies. In general, PH management improved the life quality of its patients while life quality has decreased in GH.

According Lowrie et al. (2003), there is a 10% decrease living chances at GH and there are not significant differences at PH after five months. Relative risk of mortality have increased totally by 10% for CKD patients with lower relative risk of mortality at PH with 2 % less than GH in Bingöl city. However, Symptom of patients have decreased about 14% and effects of CKD on live improved by 27% at PH, showing that suggestions were helpful at PH while suggestions were not applied well at GH due to high circulations of staffs and CKD patients. The results of Bingöl city with 33.84 mean of physical scores from S2 and 31.23 mean of physical scores from S2 are lower than 47.2 ±23.1 mean of CKD patients in Konya city from Atalay et al. ( 2010) study.. Mental score is 53.2 ±21.1 higher about 30% from Bingöl city results

**Table 4:** Results from second survey (S2)-78 patients

| Scale (number of items in scale) | Hospital | Mean of S2 | Mean of S1 | Median | Stan. Dev. | n  |
|----------------------------------|----------|------------|------------|--------|------------|----|
| Symptom/problem list (12)        | GH       | 47.51      | 50.95      | 50.00  | 21.32      | 51 |
|                                  | PH       | 57.41      | 50.06      | 52.08  | 21.90      | 27 |
|                                  | Total    | 50.93      | 50.84      | 50.00  | 21.90      | 78 |
| Effects of kidney disease (8)    | GH       | 37.32      | 52.29      | 37.50  | 17.85      | 51 |
|                                  | PH       | 52.20      | 44.74      | 46.88  | 17.29      | 27 |
|                                  | Total    | 42.47      | 49.29      | 40.63  | 18.93      | 78 |
| Burden of kidney disease (4)     | GH       | 13.85      | 19.92      | 12.50  | 13.19      | 51 |
|                                  | PH       | 19.68      | 23.36      | 18.75  | 18.40      | 27 |
|                                  | Total    | 15.87      | 21.55      | 12.50  | 15.33      | 78 |
| SF-12 Mental Health Composite    | GH       | 31.75      | 36.40      | 31.79  | 9.18       | 51 |
|                                  | PH       | 32.34      | 36.99      | 32.54  | 9.49       | 27 |
|                                  | Total    | 31.95      | 36.72      | 32.16  | 9.23       | 78 |
| SF-12 Physical Health Composite  | GH       | 29.55      | 33.31      | 28.59  | 6.66       | 51 |
|                                  | PH       | 34.40      | 34.76      | 33.32  | 7.24       | 27 |
|                                  | Total    | 31.23      | 33.84      | 29.64  | 7.20       | 78 |

SY1 and Effect1 items has become negative as shown in Table 5 while SY2 ,SY6, SY1, SY12a and Effect5 have become positive from negative. In general, the results of S2 are better than first survey and there are remarkable improvements in results and life quality.

**Table 5:** Item results from second survey

| Item  | Mean   | Decision | Item    | Mean   | Decision |
|---|--------|----------|---------|--------|----------|
| SF1   | 3.7949 | Negative | SY1     | 3.5513 | Negative |
| SF2   | 1.4744 | Negative | SY2     | 2.6538 | Positive |
| SF3   | 1.6154 | Positive | SY3     | 3.4487 | Negative |
| SF4   | 1.0769 | Negative | SY4     | 2.5897 | Positive |
| SF5   | 1.0385 | Negative | SY5     | 2.5641 | Positive |
| SF6   | 1.1154 | Negative | SY6     | 2.7308 | Positive |
| SF7   | 1.2179 | Negative | SY7     | 3.3462 | Negative |
| SF8   | 3.9487 | Negative | SY8     | 3.4103 | Negative |
| SF9   | 4.1026 | Negative | SY9     | 3.8974 | Negative |
| SF10  | 4.8590 | Negative | SY10    | 3.2179 | Negative |
| SF11  | 2.8205 | Positive | SY11    | 2.6538 | Positive |
| SF12  | 1.9103 | Negative | SY12a   | 1.4872 | Positive |
| Burden1                                       | 1.1948 | Negative | Effect1 | 4.4359 | Negative |
| Burden2                                       | 1.3077 | Negative | Effect2 | 4.3205 | Negative |
| Burden3                                       | 1.7051 | Negative | Effect3 | 4.0256 | Negative |
| Burden4                                       | 2.3333 | Negative | Effect4 | 3.2564 | Negative |
| Satisfaction                                  | 1.1154 | Positive | Effect5 | 1.8052 | Positive |
| More patients are satisfied in second survey. |        |          | Effect6 | 3.9103 | Negative |
|   |        |          | Effect7 | 2.0256 | Positive |
|   |        |          | Effect8 | 2.6282 | Positive |

### **Conclusion**

Private hospital provides higher life quality CKD patients since PH has less patients and can treat patients individually controlling their diet, sport activities, social life, taking medicines, etc. Government hospital have narrow rooms and cannot have specialized kidney doctors always due to being in a disadvantaged place due to security, lack of social life possibilities etc. Bingöl University have been opened in 2008 however there is not any medicine faculty to educate specialized doctors and make researches about CKDs. CKDs cannot be separately considered from other patients and there are needs of being checked by psychiatry doctors, inner specialist, skin doctors etc. To decrease effects created due to lack of functions of ESRD.

The living chance of CKD patients has decreased by 10% at Bingöl city after five months. However, suggestions and changes have been successful at PH and symptom of patients have decreased about 14% increasing life quality and effects of CKD patients on live improved by 27% at PH. Mean scores at Bingöl city for CKD patients is lower than Konya city CKD patients. However, the second survey was carried out in September 2015 and patients have to consume more water and be active. Thus, results of groups have decreased

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### **Compliance with Ethical Standards**

All procedures performed in this study involving human participants were in accordance with the ethical standards of the Bingöl Health committee through getting written necessary permissions from both hospitals management and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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