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# Frequency and Correlates of Financial Distress in Patients with Advanced Cancer

Jacqueline Tschanz, MD,* Rida Khan, MD,* Maxine De La Cruz, MD, Minxing Chen, and Eduardo Bruera, MD

## Abstract

***Introduction:*** Financial distress, a term used to encompass the negative consequences of the cost of medical treatment, can lead to delay of care, psychological distress, or even bankruptcy for patients and/or their families. Cancer is an expensive medical condition, and this distress is not routinely assessed.

***Methods:*** The primary objective of this study was to determine the frequency of high financial distress in patients with advanced cancer. Secondary objectives include determining the association between high financial distress with clinical and demographic characteristics. Primary outcome was based on the result of the InCharge Financial Distress/Financial Well-Being Scale (IFDFW), an eight-question survey with each question rated from 1 (overwhelming stress) to 10 (no stress at all). High financial distress was defined as a mean score of ≤4.0. Quality of life was assessed with Edmonton Symptom Assessment Scale-Financial and Spiritual Distress (ESAS-FS), Comprehensive Score for Financial Toxicity—Functional Assessment of Chronic Illness Therapy, and FACT-G surveys. Demographic data was collected from questionnaire and chart review.

***Results:*** One hundred and forty adult patients with advanced cancer were enrolled. The average patient age was in 50s, 67% were White, 12% Hispanic, 14% African American, and 4% Asian. Of the participants, 35/140 patients (25%) reported high financial distress. Patients with high financial distress were younger (55.1 vs. 59.3 years old, $p = 0.04$), less likely to be married (51.4% vs. 82.9%, $p = 0.002$), less likely to be working full time (23% vs. 31%, $p = 0.001$), and had lower annual household income (49% making less than $40,000 a year vs. 13%, $p < 0.001$). There was a significant association between financial distress, symptom burden, and decreased quality of life. There was a strong correlation between the IFDFW score and single item 0–10 financial distress ESAS (0.6, $p < 0.001$).

***Discussion:*** High financial distress is frequent among patients with advanced cancer. It was associated with younger age, nonmarried status, symptom severity, and decreased quality of life. Our findings suggest that financial distress should be monitored in supportive cancer care.

**Keywords:** financial toxicity; financial distress; palliative care; supportive care; advanced cancer

## Key Message

Financial distress is frequent among patients with advanced cancer, and it was associated with younger age, nonmarried status, symptom severity, and decreased quality of life. Our findings suggest that financial distress should be monitored in supportive cancer care.

## Introduction

Patients and families may experience significant distress due to the burden of cost of their cancer care, a concept called financial distress. This can lead to delay of care, psychological distress, or even bankruptcy.[1] Prior studies have shown that over half of cancer patients experience one of these three consequences, or toxicities, of the cost of care. Cancer is one of the most expensive medical conditions, second only to heart disease.[2] According to recent data, treatment of cancer leads to over $16 billion in out-of-pocket costs to patients and almost $5 billion in patient time costs.[3] Even with insurance, the cost of health care has been shifted to the patient, through higher premiums, deductibles, copayments, and coinsurance.[4] These financial strains can come from high out of pocket costs, decrease in income due to loss, and other

Department of Palliative Care, Rehabilitation, and Integrative Medicine, The University of Texas MD Anderson Cancer Center, Houston, Texas, USA.
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nonmedical costs.[5] Medicare beneficiaries who received a new cancer diagnosis incurred out of pocket expenditures that were a mean of 23.7% of household income.[6]

Financial distress in cancer care has been evaluated in prior studies with many different tools. Delgado-Guay et al., used self-scoring of financial distress on scale of 0–10 and found some level of financial distress was reported by 86% of patients at a comprehensive cancer center and in 90% of patients at a public hospital.[7] Using the InCharge Financial Distress/Financial Well-Being Scale (IFDFW), Meeker noted greater financial distress in the youngest age group and progressive lesser financial distress with age.[8] Another study noted higher financial distress as measured by the Comprehensive Score for Financial Toxicity-Functional Assessment of Chronic Illness Therapy (COST-FACIT) tool to be associated with younger age, nonmarried status, longer duration since diagnosis, and lower household income.[9]

Financial distress from the burdens of high costs and debt may also interfere with a patient's physical symptoms and quality of life.[10] In one study, financial distress correlated with worse quality of life, higher anxiety, and depression.[7] In another study, self-reported quality of life was inversely correlated with the degree to which cancer caused financial problems independent of other sociodemographic variables.[11]

This study was performed in a palliative and supportive care clinic by palliative care physicians. The primary objective of this study was to determine the frequency of high financial distress in patients with advanced cancer at an outpatient supportive care center at a tertiary cancer care center. Secondary objectives include determining the association between high financial distress with clinical and demographic characteristics.

## Methods

This was a cross-sectional survey of patients in the outpatient Supportive Care Center at MD Anderson Cancer Center located in Houston, Texas. This study protocol was reviewed and approved by the Institutional Review Board at MD Anderson Cancer Center. All participants provided written informed consent.

### *Patient population*

Patients seen at Supportive Care Clinic and older than 18 years old with diagnosis of advanced cancer, as defined by recurrent disease, locally advanced disease, metastatic disease, or refractory disease were eligible as noted from an electronic medical record chart review. Patients were excluded if they could not communicate in English or if they had impaired cognition. Patients who were potentially eligible were contacted at the time of their consultation.

### *Data collection*

Patient demographics, including age, gender, ethnicity, marital status, caregiving, cancer type, date of cancer diagnosis, treatment, ECOG, time of diagnosis to first SCC consult, educational level, insurance, place of residence, home ownership status, annual household income, Edmonton Symptom Assessment Scale-Financial and Spiritual Distress (ESAS-FS), and memorial delirium symptom assessment were collected and recorded. Enrolled patients received a packet with the following assessment tools:

IFDFW Scale is a validated survey designed to measure a person's financial state. This is designed for the general population and not specific to any group. The survey consists of eight questions and each of them is rated from 1 (overwhelming stress) to 10 (no stress at all). A mean score of the eight questions will be used to interpret the financial distress: a mean score of 1.0–4.0 = high financial distress/low financial well-being, a mean score of 4.1–6.9 = average financial distress/average financial well-being, and a mean score of 7.0–10.0 = low financial distress/high financial well-being.[12]

The COST-FACIT survey was developed as part of a series of questionnaires aimed at measuring different symptom indexes of health-related quality of life in patients with advanced diseases such as cancer. The survey contains 12 questions and each of them is rated from 0 (not at all) to 4 (very much). This survey focuses on financial distress caused by illness in patients with cancer.[13]

The FACT-G is an instrument validated in cancer patients to measure quality of life. It comprises of 27 questions that assess well-being in four domains: physical symptoms, participation in and enjoyment of normal daily activities, social support and communication, and mood and emotional response to illness.[14]

The ESAS-FS is an updated version of the Edmonton Symptom Assessment System (ESAS) tool including financial and spiritual distress, and it consists of 12 symptom items to measure severity of patient's symptoms.[15] Twelve symptoms are rated on a scale of 0–10 and higher total scores correlate with higher symptom burden. This is collected as standard of care and was not administered to participants as part of the research study.

Government institutions use the terms financial distress and financial toxicity interchangeably.[16,17] The scoring assessments above use different terms with IFDFW using the term financial distress and COST-FACIT uses the term financial toxicity. For purposes of this study, we used "financial distress" throughout for clarity.

### *Statistical analysis*

We planned to reach approximately 200 patients and expected 140 (70%) to participate. High financial distress is defined as a mean score of IFDFW survey is ≤4.0. With the sample size of 140, a two-sided 95% confidence interval extends a maximum of 0.083 from the proportion of high financial distress. The mean score of the IFDFW survey was used to interpret financial distress in advanced cancer patients. Descriptive statistics, such as mean, standard deviation, median, interquartile range (IQR) and range were used to summarize the mean scores of IFDFW. Patients with mean scores of IFDFW survey ≤4.0 were classified as having high financial distress, while others with scores ranging from 4.1 to 10.0 were classified as average/low financial distress. The primary endpoint of the study was the frequency of high financial distress, which was estimated with a 95% confidence interval.

The first secondary endpoint was the association between high financial distress with clinical and demographic characteristics in advanced cancer patients. The second secondary endpoint was the correlation between mean scores of IFDFW and scores from other financial distress instruments, such as

Cost-FACIT and ESAS-FS financial distress rating. The third secondary endpoint was the association between high financial distress with patient symptoms in ESAS and quality of life assessed by FACT-G.

Characteristics of the study sample were described using summary statistics such as mean and standard deviation for continuous measures, and frequency and proportion for categorical measures. Patients were summarized based on their financial distress status (high financial distress vs. average or low financial distress), and two sample *t-test* or Chi-squared test (or Fisher's exact test if frequency of any cells is smaller than 5) was used to assess the clinical and demographic factors difference between the two financial distress statuses. In addition, univariate ordinary least squares regression and logistic regression were used to determine the associations listed in secondary objectives 2 and 3. For OLS regression, robust standard error estimation was reported due to non-normal distribution of the IFDFW score.

## Results

One hundred and forty patients completed the survey out of 509 patients eligible who were approach with a response rate of 28%. Once this goal recruitment of 140 was met the study was concluded. The process of patient recruitment is summarized in Figure 1. Table 1 shows the patient characteristics. The average age of patients was 58 years old with a standard deviation of 10.5. Of our patients surveyed, 67% were white, 12% were Hispanic, 14% were African American, and 4% were Asian. 48% of patients completed bachelor's degrees or advanced degrees.

Of the participants, 35/140 (25%) reported high financial distress as defined as an IFDFW score of less than or equal to 4.0, while the other 105 patients reported either average or low financial distress as defined as IFDFW average of 4.1 or higher.

Compared to the patients with average or low financial status, the patients with high financial distress were on average younger (55.1 vs. 59.3), less likely to be married (51.4% vs. 82.9%), less likely to be working full time, and had lower annual household income as seen in Table 1. Education level and homeowner status were not significantly associated with higher financial distress. As seen in Table 2, there was no significant association with cancer type, treatment modality, or type of health insurance.

There is a significant correlation between the three tools for assessing financial distress. Table 3 reports the univariate ordinary least squares regression results, with continuous primary outcome of the mean score of IFDFW as the dependent variable, and the COST-FACIT and ESAS-FS as independent variables. Results in Table 3 indicated that the financial well-being scale is significantly associated with both these scores. For each one unit increase in the score of COST-FACIT average, there is a 0.18-unit increase (b = 0.18, S.E. = 0.01, $p$ value <0.001), and ESAS-financial distress rating average there is a 0.6-unit reduction (b = –0.6, S.E. = 0.05, $p$ value <0.001).

As shown in Table 3, there is a significant correlation between high financial distress and both increasing symptom burden and decreasing quality of life. The univariate ordinary least squares regression results, with continuous primary outcome of mean score of IFDFW as dependent variable, and other factors ESAS total score and quality of life (FACT-G) as independent variables. For each one unit increase in total ESAS there is a 0.06 unit reduction (b = –0.06, S.E. = 0.01, $p$-value <0.001), and for each one unit increase in FACT-G there

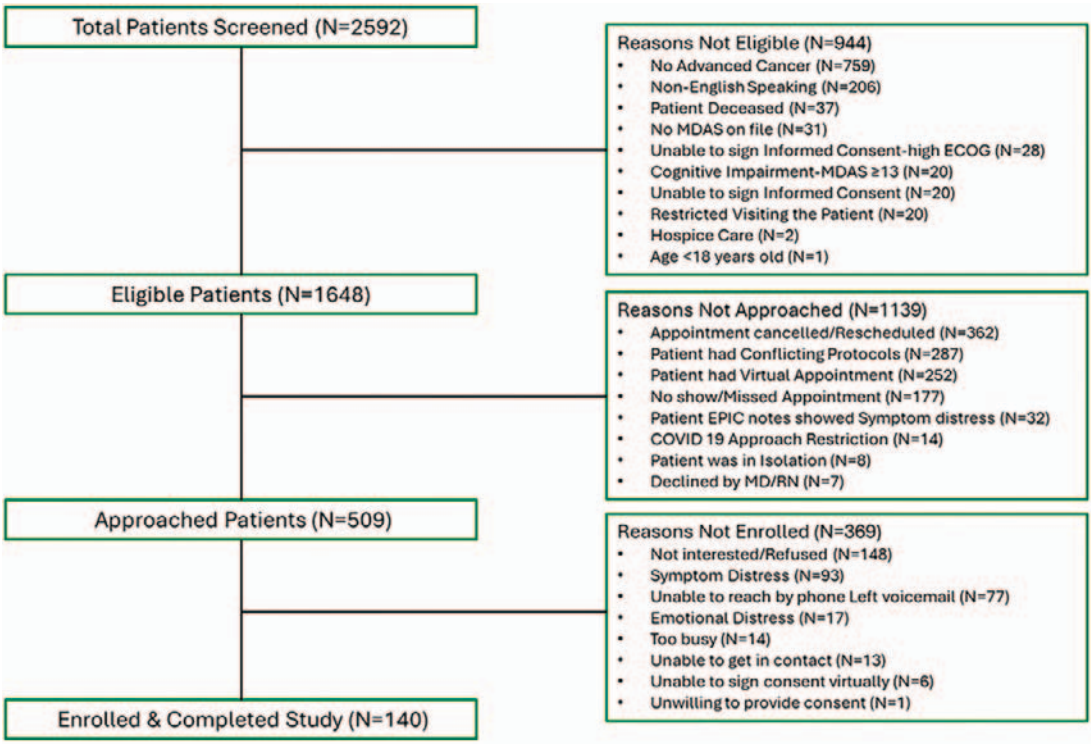


**FIG. 1.** Patient enrollment. Categories for exclusion on right side are not mutually exclusive and patients may have had multiple reasons to not be eligible.

Table 1. Patient Demographics[a]

| Characteristic | *High financial distress*[b] (n = *35*) Mean (SD) | N (%) | *Average/low financial distress* (n = *105*) Mean (SD) | N (%) | p-*value* |
|---|---|---|---|---|---|
| Age | 55.1 (9.4) | | 59.3 (10.7) | | ***0.040*** |
| Gender | | | | | 0.316 |
| Female | | 24 (68.6) | | 62 (59.1) | |
| Male | | 11 (31.4) | | 43 (41.0) | |
| Ethnicity | | | | | 0.086 |
| White | | 19 (54.3) | | 77 (73.3) | |
| Hispanic | | 8 (22.9) | | 9 (8.6) | |
| African American | | 7 (20.0) | | 12 (11.4) | |
| Asian | | 1 (2.9) | | 5 (4.8) | |
| Other | | 0 (0.0) | | 2 (1.9) | |
| Marital status | | | | | ***0.002*** |
| Single/Never married | | 7 (20.0) | | 8 (7.6) | |
| Married | | 18 (51.4) | | 87 (82.9) | |
| Divorced | | 8 (22.9) | | 6 (5.7) | |
| Widowed | | 2 (5.7) | | 3 (2.9) | |
| Separated | | 0 (0.0) | | 1 (1.0) | |
| Involved in caregiving | | | | | 0.180 |
| No | | 23 (65.7) | | 81 (77.1) | |
| Yes | | 12 (34.3) | | 24 (22.9) | |
| Education level | | | | | 0.433 |
| Up to high school | | 10 (28.6) | | 22 (21.0) | |
| Vocational/technical school | | 1 (2.9) | | 3 (2.9) | |
| Associate degree/some college | | 12 (34.3) | | 25 (23.8) | |
| Bachelor's degree | | 7 (20.0) | | 33 (31.4) | |
| Advanced degree | | 5 (14.3) | | 22 (21) | |
| Place of residence | | | | | 0.992 |
| Local | | 9 (25.7) | | 27 (25.7) | |
| Out of town | | 18 (51.4) | | 55 (52.4) | |
| Out of state | | 8 (22.9) | | 23 (21.9) | |
| Homeowner status | | | | | 0.238 |
| Homeowner with mortgage | | 15 (42.9) | | 55 (52.9) | |
| Homeowner without mortgage | | 10 (28.6) | | 34 (32.7) | |
| Renter | | 9 (25.7) | | 14 (13.5) | |
| Prefer not to answer | | 1 (2.9) | | 1 (1.0) | |
| Employment status | | | | | ***0.001*** |
| Full time | | 8 (22.9) | | 33 (31.4) | |
| Part-time | | 2 (5.7) | | 4 (3.8) | |
| Unemployed | | 2 (5.7) | | 17 (16.2) | |
| Retired | | 10 (28.6) | | 43 (41.0) | |
| Other | | 13 (37.1) | | 8 (7.6) | |
| Annual household income | | | | | ***<0.001*** |
| <$40,000 | | 17 (48.6) | | 14 (13.3) | |
| $40,000–$80,000 | | 9 (25.7) | | 23 (21.9) | |
| >$80,000 | | 4 (11.4) | | 47 (44.8) | |
| Prefer not to say | | 5 (14.3) | | 21 (20.0) | |

[a]All values rounded up to nearest tenth decimal place.
[b]As defined by IFDFW score.
IFDFW, InCharge Financial Distress/Financial Well-Being Scale.

is a 0.09 unit increase (b = 0.09, S.E. = 0.01, *p*-value <0.001) in the primary outcome of IFDF W scoring.

## Discussion

Financial distress in medical care is a growing source of stress for patients with cancer. Our study found 25% of patients expressed high financial distress, which is consistent with prior studies on incidence of financial distress in cancer patients.[7,18,19] Financial distress was associated with age, marital status, income, and employment status. We found no association with other clinical factors such as type of treatment, type of cancer, type of insurance coverage, or time since diagnosis.

Our study found an association between high financial distress, higher symptom burden and worse quality of life. It is unclear from our study if this financial distress worsens

Table 2. Financial Distress and Medical Characteristics[a]

| *Characteristic* | *High financial distress*[b] *(n = 35)* | | *Average/low financial distress (n = 105)* | | p-*value* |
|---|---|---|---|---|---|
| | *Mean (SD)* | N *(%)* | *Mean (SD)* | N *(%)* | |
| Average time since initial cancer diagnosis in months | 77.6 (114.8) | | 54.7 (64.1) | | 0.200 |
| Average time from diagnosis to first consult to supportive care measured in months | 62.9 (112.6) | | 43.1 (62.1) | | 0.424 |
| Average ECOG score | 1.5 (0.85) | | 1.5 (0.8) | | 1.000 |
| Advanced cancer diagnosis | | | | | 0.502 |
| Head and neck | | 4 (11.4) | | 5 (4.8) | |
| Thoracic | | 8 (22.9) | | 22 (21.0) | |
| Gastrointestinal | | 6 (17.1) | | 16 (15.2) | |
| Gynecological | | 2 (5.7) | | 14 (13.3) | |
| Breast | | 7 (20.0) | | 18 (17.1) | |
| Genitourinary | | 5 (14.3) | | 25 (23.8) | |
| Other | | 3 (8.6) | | 5 (4.8) | |
| Treatment modalities | | | | | 0.164 |
| Surgery | | 6 (17.1) | | 6 (5.7) | |
| Chemo | | 24 (68.6) | | 82 (78.1) | |
| XRT | | 5 (14.3) | | 13 (12.4) | |
| Targeted therapy | | 0 (0.0) | | 4 (3.8) | |
| Insurance type | | | | | 0.340 |
| Medicare | | 24 (68.6) | | 53 (50.5) | |
| Medicaid | | 1 (2.9) | | 4 (3.8) | |
| Private | | 9 (25.7) | | 43 (41.0) | |
| Military | | 0 (0.0) | | 3 (2.9) | |
| None/Self Pay | | 1 (2.9) | | 2 (1.9) | |

[a]All values rounded up to nearest tenth decimal place.
[b]As defined by IFDFW score.

symptoms and quality of life or if the poor quality of life leads to higher feelings of financial distress. Our findings suggest that financial distress should be evaluated in patients who report high symptom burden or poor quality of life, especially when these findings are persistent.

It is important to have simple ways to assess and regularly monitor financial distress in advanced cancer patients receiving palliative care. These patients frequently have other physical and emotional symptoms.[20–23] It is therefore important to measure these while also minimizing the burden of multiple assessments. Our study found a strong association of the 20-question IFDFW with the rating of 0–10 financial distress in the ESAS questionnaire given routinely prior to clinic visits (Table 3). More analysis and data are needed to characterize the specificity and sensitivity of the ESAS scale as compared to more comprehensive and time-demanding tools.

Studies have shown an association of higher financial distress with lack of insurance,[24,25] lower income,[26] and lower educational level.[27] Previous studies by our team have found that there is an association between these objective measures of patients' financial situation.[7] Our current study supports these findings. Our data also suggest that demographics or other objective measures of financial status should not be assumed to be enough to rule out the presence of financial distress. Our study supports prior research showing an association between age and financial distress in cancer care. This distress is theorized to be associated with education level, insurance, children to care for, and access to paid sick leave.[8] Our study found less financial distress in married versus single participants. Singles tend to have fewer savings, are less likely to own a home, and have a lower net worth than their age-related, married counterparts,[28] signs of less financial stability, which can lead to distress after the financial strain of cancer treatment.

Medical costs and debt have continued to affect millions of Americans.[29] Though these have been normalized in our

Table 3. Association Between Financial Well-Being Scale (IFDFW), COST-FACIT, Edmonton Symptom Assessment Scale-Financial Distress (ESAS-FS), Total ESAS Score, and Quality of Life (FACT-G)

| *Predictors* | *Ordinary least squares results* | | | |
|---|---|---|---|---|
| | *Coefficient* | *Robust SE* | *95% CI* | p-*value* |
| Cost-FACIT | 0.18 | 0.01 | (0.16, 0.19) | *<0.001* |
| Financial distress rating in ESAS-FS | –0.60 | 0.05 | (–0.70, –0.50) | *<0.001* |
| FACT-G | 0.09 | 0.01 | (–0.08, –0.03) | *<0.001* |
| ESAS-Total | –0.06 | 0.01 | (–0.08, –0.03) | *<0.001* |

CI, confidence interval; COST-FACIT, Comprehensive Score for Financial Toxicity-Functional Assessment of Chronic Illness Therapy; SE, standard error.

society, can we be doing something to combat this? Recent ethical studies are asking providers to consider a patient's financial status prior to offering certain therapies. ASCO has recently released guidelines and advice for clinicians that encourage patient–physician discussion about the cost of cancer care.[30] Important potential barriers to this include the impression that doctors are willing to compromise on quality of care based on a patients' financial means and doctors being unaware of costs associated with treatment options.[31,32] One qualitative study found both oncologists that have conversations about cost and those that do not cite the same justifications for doing so, notably that both felt their decision was based on maintaining therapeutic relationship and to not undermine care decisions.[33] Studies have shown that even when oncologists believe they should have cost-of-care discussions, only a minority do as they are unsure when or how to have them.[32,34] Nonmedical support has also been shown to decrease financial distress with early intervention from support staff such as social workers.[35] Our study identifies that 25% would have been great candidates for this conversation with their oncology teams and involvement of support staff, independent of primary cancer or even insurance status.

Limitations of this study include a small sample size of 140, with a response rate of 28% of the subjects approached, and setting, as the patient population at a large tertiary cancer center may not be representative of the general population. Our patient population is generally more educated, 48% of participants have bachelor's degree or higher compared with 38% of U.S. population.[36] This sample is also younger than the average cancer patient (58 years vs. 66 years in general population[37]). Patients who have access to a large tertiary cancer center may express different levels of financial distress, as seen in our data's 98% insurance coverage rate. A study by Delgado et al. showed that patients seen in a county hospital in the area had a higher level of financial distress as compared with patients seen at a cancer center.[7]

In conclusion, we found that high financial distress is reported by one quarter of all patients receiving supportive cancer care. This is higher among patients with higher symptom burden, lower quality of life, younger age, and nonmarried status. This study highlights the importance of assessing financial distress in patients with cancer and how it relates to symptomatology. In clinical practice, it may be feasible to use the ESAS-FS to assess financial distress and overall well-being, which will then allow providers an opportunity to address the physical and emotional burden inflicted by the financial distress. Future research should focus on how providers and institutions can best address or even prevent financial distress for cancer patients, and how common it is for oncology teams to discuss the cost of therapeutic options for patients.

### Author Disclosure Statement

The authors have no conflicts of interests to disclose.

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Address correspondence to:
*Jacqueline Tschanz, MD*
*Department of Palliative Care*
*Rehabilitation, and Integrative Medicine*
*The University of Texas MD Anderson Cancer Center*
*1515 Holcombe Blvd*
*Unit 1414*
*Houston, TX 77030*
*USA*

*E-mail:* jmtschanz@mdanderson.org