

## THE ASSESSMENT OF THE PERCEIVED EMOTIONAL DISTRESS: THE NEGLECTED SIDE OF CANCER CARE

### LA EVALUACIÓN DEL MALESTAR EMOCIONAL PERCIBIDO: LA FACETA DESATENDIDA DE LA ATENCIÓN DEL CÁNCER

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#### Abstract

The purpose of this research was to present the latest development of the The Perceived Emotional Distress Inventory (PEDI) as a brief 15-item self-report measure intended to be used for the assessment of psychological distress in cancer patients. Factor Analyses of Principal Components with promax rotations were performed with a combined male and female sample of 481 cancer patients at St. Joseph's hospital Cancer Institute in Tampa, Florida, to provide further evidence of construct validity. The factor structure, internal consistency, and Pearson correlation coefficients of the PEDI are presented in this report. The factor analysis identified three factors comparable to those found in previous samples in USA: The first factor, anxiety/depression; second factor, hopelessness; and third factor, anger expression. Global alpha coefficient of 0.92 for the inventory indicates strong internal consistency. Pearson correlations between the subscales of the instrument is impressive for such a brief measure. This study emphasizes the need for a brief, self-report instrument to assess anger expression, anxiety, depression and hopelessness as components of perceived emotional distress in cancer patients, while explicitly excluding the potentially confounding effects of somatic symptoms commonly associated with cancer treatments. Further

#### Resumen

El propósito de este estudio fue evaluar la estructura factorial del Inventario de Malestar Emocional Percibido (IDEP), un instrumento de medición del malestar emocional de 15 ítems, en una muestra de 481 pacientes con cáncer que iniciaron sus tratamientos con radioterapia y/o quimioterapia en el Instituto de cancer del hospital St. Joseph's en la ciudad de Tampa, Florida, USA. Se llevó a cabo un análisis factorial de componentes principales y método de rotación promax con autovalores superiores a 1. El primer factor contiene seven ítems correspondientes a síntomas de ansiedad y depresión. El segundo factor está agrupado por cuatro ítems relacionados con sentimientos de desesperanza, mientras un tercer factor presenta cuatro ítems que manifiestan la expresión de ira. Los resultados obtenidos nos indican que el Inventario de malestar emocional presenta una estructura factorial consistente con el marco conceptual en el cual se basó la construcción del instrumento, El coeficiente alpha de Cronbach para el instrumento total del IDEP es de 0,92, lo cual es significativamente elevado, como también los coeficientes alpha para sus cuatro sub-escalas. Los resultados observados demuestran evidencia empírica acerca de la validez de constructo y la consistencia interna del IDEP. Es necesario

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research will be needed to provide information about the PEDI's use in populations other than cancer patients including attempts to replicate these findings in more heterogeneous populations.

**Keywords:** Cancer, emotional distress, anxiety, anger, hopelessness, depression.

un mayor esfuerzo con el propósito de replicar estos mismos resultados en pacientes con otros tipos de diagnóstico y en culturas diferentes.

**Palabras Clave:** Cáncer, malestar emocional, ansiedad, ira, desesperanza, depresión.

## INTRODUCTION

The diagnosis of cancer and the aggressive treatments currently available to cure the disease are traumatic events that have a major impact upon patients and their family members. The occurrence of significantly elevated levels of anxiety as compared to a normal population has been reported to be as high as 85% for newly diagnosed cancer patients. In addition, the incidence of depression in cancer patients varies from 20% to 25% in United States<sup>(1)</sup>, and 72% to 89% in Sweden<sup>(2)</sup>, with the prevalence increasing to 77% for those with advanced illness<sup>(3)</sup>. Despite this increased attention to control these troublesome symptoms in patients with cancer, there have been no concerted efforts to address the assessment of emotional distress based on psychometric measures particularly developed for cancer patients.

High emotional distress cancer patients experience coping difficulties evidenced by a negative and pessimistic attitude toward the treatments, and a dismal view regarding recovery. More information needs to be given to the primary oncologist and his/her staff about the recognition of significantly high levels of emotional distress; how to query the patient to elicit adequate information about their feelings, and how to identify appropriate resources to which the oncological patients could be referred for psychological counseling and support. In this sense, the recognition of perceived emotional distress in cancer patients needs to be a top priority within

psychosocial oncology programs across the world<sup>(4-7)</sup>.

Approximately 50% of all the individuals diagnosed with cancer in the United States experience significant levels of emotional distress, and many of these symptoms are unrecognized and untreated<sup>(8)</sup>. The diagnosis of cancer and the strain caused by the overwhelming side effects of its treatments are a perfect example of a potential stressors events capable of evoking emotional distress<sup>(9)</sup>. There is accumulating evidence in the literature indicating that cancer patients experience significant levels of emotional distress at initial diagnosis, at recurrence or progression of the disease, and at terminal stage<sup>(1,10)</sup>.

## CLINICAL SCREENING OF PERCEIVED EMOTIONAL DISTRESS

The standardized assessment of perceived emotional distress is at least as problematic as its own definition. A survey of cancer centers in United States reports relying only on interviews for the assessments of emotional distress for cancer patients, as opposed to the utilization of screening instruments<sup>(8)</sup>. Unfortunately, there has been relatively little systematic and methodological effort to evaluate or improve existing measures. Cancer programs could clearly benefit from a brief, easy to administer, yet comprehensive form of evaluation that identifies emotionally distressed cancer patients, who are experiencing not only anxiety and depression, but also anger and

hopelessness. The need for a standardized measure of perceived emotional distress designed to eliminate the potentially confounding effects of somatic symptoms frequently associated with therapeutic treatments in cancer patients has become increasingly important.

Perceived emotional distress is an important construct in the field of psychooncology, and remains a legitimate topic of study<sup>(11)</sup>. Although this concept is not comparable to clinical depression or major psychiatric illnesses, individuals with such diffuse types of complaints are in serious need of psychological and behavioral interventions in the medical field<sup>(12,13)</sup>. We define this state of perceived emotional distress as marked by *“subjective feelings that vary in intensity from sadness, uncertainty, confusion and worry to more significant symptoms such as anxiety, the expression of anger, social isolation and hopelessness”*. Our conceptual framework of the perceived emotional distress construct in patients with cancer includes the expression of anger, hopelessness, and a significant degree of underlying multidimensionality, and should be clearly distinguished from clinical depression<sup>(14)</sup>.

The clinical screening of perceived emotional distress as part of an initial psychosocial assessment, may offer an opportunity to identify high-risk patients before they receive their diagnosis of cancer<sup>(15)</sup>. Subsequent assessments of perceived emotional distress taken after a diagnosis of cancer, following surgery, or upon beginning chemotherapy or radiation treatments could provide invaluable evidence of the need for psychological intervention to treat or manage these debilitating symptoms<sup>(16)</sup>. Despite the negative impact of perceived emotional distress on cancer patients and its effects on quality of life, the screening for such emotional states has not been a consistent part of routine procedures in cancer programs.

## MEASURING PERCEIVED EMOTIONAL DISTRESS IN CANCER PATIENTS

It is critically important to recognize that conceptual clarity is essential to empirical progress. Therefore, in order to develop a valid and reliable screening measure, we must distinguish perceived emotional distress, conceptually and empirically, from those factors which are only indirectly related to the construct. The distinction between somatic distress and emotional distress is of critical concern. Somatic distress is regarded in the literature as a preoccupation with physical symptoms<sup>(17)</sup>. However, somatic distress, such as lack of appetite, difficulty with sleep, and a lack of energy, are not exclusively related to the emotional distress construct. Furthermore, in the case of cancer patients, somatic symptoms are more likely to be due to the side effects of cancer treatments than to the emotional state of the patient. Consequently, in the development of screening measures, we should be careful not to include somatic symptom items to ensure a valid and reliable measurement of perceived emotional distress in patients with cancer<sup>(18)</sup>.

The Perceived Emotional Distress Inventory (PEDI) is a 15-item, brief self-report screening inventory designed to measure the presence and severity of emotional distress as a multi-factor, general mood disorder defined as subjective feelings that vary in intensity from sadness, uncertainty, confusion and worry to more significant symptoms such as anxiety, the expression of anger, social isolation and hopelessness in cancer patients (see Appendix). The PEDI carefully discriminates the confounding effects of somatic symptoms more commonly associated with cancer treatment. The inventory evaluates three distinct dimensions of perceived emotional distress, which include anxiety/depression, hopelessness, and anger expression<sup>(19)</sup>.

Items describing somatic symptoms commonly associated with the treatment

of cancer patients were carefully not taken into consideration. This is consistent with previous studies that report confounding issues with those items that assess somatic symptoms of emotional distress because they overlap with somatic symptoms caused by cancer-related treatments<sup>(20)</sup>. In addition, the instrument provides clinical decision-making support at intake and during the course of treatment. In responding to each PEDI item, patients reported to “what extent they had experienced each emotional distress-related symptom during the past month, including today” by rating themselves on a 3-point scale: (0) not at all; (1) sometimes; (2) often; (3) very much so.

The major purpose of this article is to report the latest data of the PEDI with a larger sample of male and female cancer patients and provide further evidence of construct validity. The driving force of our research has been to counteract the neglected responsibility to identify patients with cancer, who are at high risk of experiencing elevated levels of psychological distress during all phases of diagnosis and treatments. Given the prevalence of perceived emotional distress in the field of oncology, clinical screening of this sort provides the opportunity to identify vulnerable patients as they attend their appointments.

## METHOD

Factor analysis is the most important method of construct validity and, in this case, is central to the measurement of the perceived emotional distress construct. Exploratory factor analyses rather than confirmatory factor analysis were carried out, because such analyses were judged to be more conservative<sup>(21)</sup>.

## Participants

The PEDI was administered to 481 cancer patients, 312 females (65%)

and 169 males (35%), who received either radiation and/or chemotherapy treatment in the outpatient services at St Joseph’s Cancer Institute and hospitals in Tampa, Florida. A sample size of at least 150 participants was determined to be necessary to satisfy the *subjects-to-variable* (STV) ratio based on the number of variables<sup>(21,22)</sup>. They ranged in age from 22 to 79 years old (median age= 46). Minimal inclusion criteria for subjects were: (1) 18 years of age or greater; (2) no history of psychiatric illness or substance abuse; (3) completion of the informed consent form. Psychiatric illness or substance abuse were considered to be potentially confounding factors for the evaluation of perceived emotional distress. Consequently, 19 patients (4%) were ruled out because they had a previous history of psychiatric illness or were undergoing psychological treatment. 96 patients (20%) from the total sample were Hispanic. The sample consisted of patients diagnosed with lung cancer 76 (16%), breast cancer 178 (37%), prostate cancer 156 (32%), colorectal cancer 41 (9%), and ovarian cancer 30 (6%).

## Instruments

The Perceived Emotional Distress Inventory (PEDI) is a 15-item, brief self-report screening inventory designed to measure the presence and severity of emotional distress. The PEDI was elaborated to provide a simple yet reliable instrument for use with cancer patients, and identify individuals at high-risk of emotional distress when they are first diagnosed with cancer or upon receiving treatment<sup>(23)</sup>.

## Procedure

Patients receiving treatment at St Joseph’s Cancer Institute and Hospitals were informed about the study by the research coordinator.

Those who met inclusion criteria to participate in the study were provided a written informed consent statement. The consent form clearly emphasized that participation in the study was voluntary, and that all information would be strictly confidential. The questionnaire packet, consisting of demographic data queries and the PEDI, were administered during the course of their intake for radiation treatment sessions at St Joseph's Center for Radiation Therapy and/or chemotherapy treatment sessions. Each patient, having been given standardized oral and written instructions in English completed the demographic

data information section and assessment inventory. The study was approved by the St Joseph's Hospital Institutional Review Board.

## RESULTS

The means, standard deviations, alpha coefficients, and item-remainder correlations for the PEDI, the Anxiety, Depression, Hopelessness, Expression of Anger subscales, and the 15 individual items are reported in Table 1. The alpha for the total PEDI scale is significantly high at .92 as well as the alphas for the brief four item subscales, ranging from .79 to .88. The item remainder correlations

**Table 1. Means, standard deviations, and alpha coefficients/item remainder correlations of the Perceived Emotional Distress Inventory (PEDI) for a combined sample of male and female cancer patients.**

MEASURE/ITEM	Mean	Std Dev	Alpha/I.R.
EDI (Emotional Distress Inventory)	28.62	9.24	.92
EDI: Anxiety	8.12	2.42	0.86
I feel strained (2)	2.41	0.83	0.69
I feel nervous (5)	2.61	0.87	0.68
I feel confused and restless (6)	1.97	0.86	0.74
I feel overwhelmed by "simple difficulties" (7)	1.98	0.91	0.66
EDI: Depression	7.94	3.02	0.88
I worry that my condition will get worse (8)	2.48	0.91	0.67
I feel sad (14)	2.14	0.93	0.78
I am not enjoying the things I usually do for fun (9)	2.08	1.01	0.59
EDI: Hopelessness	6.24	2.01	0.79
I feel distant from my friends (3)	1.87	0.87	0.59
I am losing hope in the fight against my illness (10)	1.48	0.72	0.58
I feel like a failure (15)	1.62	0.71	0.56
I am losing faith in my medical treatment (12)	1.47	0.51	0.43
EDI: ANGER	7.14	2.56	0.81
I get easily irritated (1)	2.09	0.85	0.56
I am angrier than I am willing to admit (4)	1.93	0.84	0.69
I feel angry (13)	1.86	0.71	0.68
I "boil inside". but I try not to show it (11)	1.62	0.71	0.49

The number in parentheses refer to the number of the items in the instrument.

Table 2. **Factorial analysis of the Perceived Emotional Distress Inventory (PEDI) items for a sample of male and female cancer patients**

Emotional	Factor 1	Factor 2	Factor 3
Distress Inventory	Dep/Anx	Hopeless	Anger
EDI: Anxiety			
I feel strained (2)	0.76		
I feel nervous (5)	0.74		
I feel confused and restless (6)	0.61		
I feel overwhelmed by "simple difficulties" (7)	0.73		
EDI: Depression			
I worry that my condition will get worse (8)	0.48		
I feel sad (14)	0.79		
I am not enjoying the things I usually do for fun (9)	0.68		
EDI: Demoralization			
I feel distant from my friends (3)		0.56	
I am losing hope in the fight against my illness (10)		0.72	
I feel like a failure (15)		0.74	
I am losing faith in my medical treatment (12)		0.66	
EDI: Anger			
I get easily irritated (1)			0.45
I am angrier than I am willing to admit (4)			0.79
I feel angry (13)			0.47
I "boil inside", but I try not to show it (11)			0.62
Eigenvalue	7.54	1.57	2.34
Inter-factor Correlations Factor 1 - Factor 2 = 0.64			
Factor 1 - Factor 3 = 0.58			
Factor 2 - Factor 3 = 0.54			

The number in parentheses refer to the number of the items in the instrument.

of .43 or greater provides further evidence of strong internal consistency for each of the brief 4 item subscales.

The responses to the 15 items comprising the Perceived Emotional Distress Inventory (PEDI) were subjected to principle components factor analyses with

promax rotations, for a combined sample of male and female cancer patients. Our sample was appropriate for the purpose of performing this type of factor analysis as indicated by Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy  $>0.634$ , and the Bartlett's test of sphericity ( $p < 0.001$ ) was

**Table 3: Pearson correlation coefficients analysis for a sample of male and female cancer patients for the Perceived Emotional Distress Inventory (PEDI), its Anxiety (ANX), Depression (DEP), Hopelessness (HOP), and Anger (ANG) subscales.**

	PEDI	ANX	DEP	HOP	ANG
PEDI		0.88	0.81	0.84	0.89
ANX	0.88		0.71	0.60	0.65
DEP	0.81	0.71		0.59	0.44
HOP	0.84	0.60	0.59		0.53
ANG	0.89	0.65	0.44	0.53	

All correlations were significant at the  $p < .001$  level.

significant, therefore suitable. Well defined anxiety/depression as a main factor, and hopelessness and anger expression as two small factors, with Eigen values greater than 1.0 were found. The scree test and breaks criterion suggested that three factors should be extracted. The three factor promax solution for the combined sample provided a clear simple structure. The strong inter-factor correlations among these factors, .54 or greater, provide the statistical rationale for using the promax rotation solutions. The salient factor loadings, equal to or greater than .45, are reported in Table 2 for the 15 items. Factor 1 consisted of seven items with dominant salient item loadings ranging from 0.48 to 0.79 reflect symptoms of anxiety and depression, whereas Factor 2 was comprised of four items with strong dominant loadings ranging from .56 to .74. The content of the items comprising this factor reflected losing hope, losing faith, feeling like a failure, and social isolation. Factor 3 was composed of four items with content relating to anger expression. This factor also presented with strong and dominant loadings ranging from .45 to .79 (see Table 2). These results

are consistent with previous findings with different sample of cancer patients reported on the development of the PEDI<sup>(19)</sup>.

Pearson correlation coefficients analysis was used to evaluate the relationship among the PEDI scale, its Anxiety, Depression, Hopelessness, and Anger scales. The correlations for the cancer patients who completed the measure are reported in Table 3. As might be expected, each of the scales of the PEDI were very strongly correlated ( $p < .001$ ). The greatest correlation was among the Anxiety and Depression scales, which is consistent with our previous study at Morton Plant Hospital Cancer Center in Clearwater, Florida.

## DISCUSSION AND SUMMARY

The purpose of this research was to present the latest development of the PEDI as a brief and psychometrically sound screening inventory for the assessment of the perceived emotional distress in cancer patients by providing further evidence of construct validity. This empirical report does not present any data related to

concurrent validity of the PEDI because it was previously reported somewhere else<sup>(19)</sup>. The underlying reasoning for our ongoing research efforts has been the need to efficiently identify patients at high-risk of experiencing significant levels of emotional distress when they receive their diagnosis of cancer, undergo surgery, or when they begin chemotherapy or radiation treatment. The PEDI was designed to provide clinical decision-making support at intake and during the course of their oncological treatments by concisely evaluating four major dimensions of perceived emotional distress: anxiety, depression, anger and hopelessness.

In examining the factor structure of the PEDI, a three-factor solution had the best simple structure and was most meaningful, providing valuable information on the component dimensions of perceived emotional distress. A factor solution was considered to have good simple structure when each item loaded unambiguously on one factor<sup>(24)</sup>. Salient items were identified as possessing factor loadings equal to or greater than 0.45. In this sense, the assessment of perceived emotional distress in cancer patients offers a coherent theoretical framework that includes anxiety, depression as well as the expression of anger and hopelessness related constructs<sup>(25)</sup>. In previous studies of psychological distress, anger has been underestimated because of the belief that anger is a normal and logical emotional reaction to a life threatening illnesses, particularly within a cross-cultural context<sup>(26)</sup>.

We found a very strong first factor comprised of seven items with loadings ranging from 0.48 to 0.79, assessing anxiety and depression. Although depression and anxiety have been viewed as independent and conceptually distinct syndromes, the ability to differentiate between depression and anxiety on self-report measures has proven to be very difficult<sup>(27)</sup>. This is particularly true in self-report instruments that have not taken into consideration

items reflecting symptoms of somatic anxiety and somatic depression.

A second factor was comprised of four items with strong dominant loadings ranging from 0.56 to 0.74. The pessimistic-oriented nature of the items in this particular factor may indicate that *hopelessness* has both, a negative affectivity and a cognitive component, or perhaps that these items tap social isolation and "a sense of giving up" in cancer patients. Since the experience of these feelings is commonly reported by cancer patients after being informed of recurrence, or that the condition has become terminal, the emergence of this factor as an independent dimension for this sample of cancer patients is not at all surprising.

Consistent with our previous studies on the PEDI, we report a third factor with items that relate to anger expression. We had initially expected a one-dimensional, bipolar factor of anger expression given the small number of items, which the data clearly supported in this third factor. Thus, rather than assessing two relatively independent dimensions of anger expression as in the preliminary study by Moscoso et al.<sup>(14)</sup>, the items seemed to suggest a single bipolar factor. Our previous factor analyses of the anger expression subscale in patients with cancer have identified a comparable factor.

The results of the factor analysis for the 15-item PEDI clearly indicate that this measure provides a valid and reliable description of the experience of emotional distress in patients with cancer. The factor structure of the inventory confirmed the assumed structural properties and provided empirical support for conceptualizing emotional distress as a multi-dimensional construct. The strong correlation between the PEDI scale and its Anxiety, Depression, Anger and Hopelessness subscales were expected. The 0.92 coefficient alpha for the 15-item instrument indicated



significant internal consistency. This is impressive when considering that three psychometrically discrete and significantly correlated dimensions were identified.

In summary, the results reported in this study offer strong empirical evidence of good internal consistency and construct validity for the measure. The factor analyses are suggesting that the PEDI provides significant information about the multidimensional aspects of perceived emotional distress in cancer patients. However, these findings should be taken cautiously. The current study presents limitations related to the oncology population's specific characteristics. Further research will be needed to provide information about the PEDI's use in populations other than cancer patients including attempts to replicate these findings in more heterogeneous populations. This study emphasizes the need for a brief, self-report instrument to assess anger expression, anxiety, depression and hopelessness as components of perceived emotional distress in cancer patients, while explicitly excluding the potentially confounding effects of somatic symptoms commonly associated with cancer treatments. In addition, future studies in this field should distinguish the negative affectivity and mood from somatic aspects of anxiety and depression, and recognize conceptually and empirically the differences between the experience, expression, and control of anger<sup>(28)</sup>.

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APPENDIX  
PERCEIVED EMOTIONAL DISTRESS INVENTORY

Developed by Manolete S. Moscoso, Ph.D.

Name: \_\_\_\_\_ Age: \_\_\_\_\_ Sex: \_\_\_\_\_ Date: \_\_\_\_\_

**Directions:** Please read each statement and circle the number (0-1-2-3 ) which best describes the way you have been feeling during the past week, including today. Do not spend too much time on any one statement but give the answer which describes your **present feelings**.

**During the past month, including today....**

	<u>Not at all</u>	<u>Sometimes</u>	<u>Often</u>	<u>Very Much So</u>
1- I get easily irritated	0	1	2	3
2- I feel strained	0	1	2	3
3- I feel distant from my friends	0	1	2	3
4- I am angrier than I am willing to admit	0	1	2	3
5- I feel nervous	0	1	2	3
6- I feel confused and restless	0	1	2	3
7- I feel overwhelmed by "simple difficulties"	0	1	2	3
8- I worry that my condition will get worse	0	1	2	3
9- I am not enjoying the things I usually do for fun	0	1	2	3
10- I am losing hope in the fight against my illness	0	1	2	3
11- I "boil inside", but I try not to show it	0	1	2	3
12- I am losing faith in my medical treatment	0	1	2	3
13- I feel angry	0	1	2	3
14- I feel sad	0	1	2	3
15- I feel like a failure	0	1	2	3

INVENTARIO DE DISTRES EMOCIONAL PERCIBIDO  
Elaborado por Manolete S. Moscoso, Ph.D.

Nombre: \_\_\_\_\_ Edad: \_\_\_\_\_ Sexo: \_\_\_\_\_ Fecha: \_\_\_\_\_

**Estado Civil:** \_\_\_\_\_ **Actividad Laboral:** \_\_\_\_\_

**Instrucciones:** Por favor lea cada frase y haga **un círculo en el número** (0-1-2-3) que describa mejor la manera de como se ha sentido últimamente. No tome mucho tiempo en cada ítem, pero de la respuesta que describa mejor tus **sentimientos ahora**.

**Durante el último mes, hasta hoy día**

	<b>En Ningún Momento</b>	<b>A veces</b>	<b>Frecuente-mente</b>	<b>En Todo Momento</b>
1. Me fastidio fácilmente	0	1	2	3
2. Me siento tenso	0	1	2	3
3. Me siento distante de mis amigos	0	1	2	3
4. Me siento mas enojado de lo que estoy dispuesto a admitir	0	1	2	3
5. Me siento nervioso	0	1	2	3
6. Me siento confuso e inquieto	0	1	2	3
7. Me siento agobiado por las "dificultades sencillas"	0	1	2	3
8. Me preocupa que mi salud empeore	0	1	2	3
9. No estoy gozando de las cosas que usualmente hago para divertirme	0	1	2	3
10. Estoy perdiendo la fe en la lucha contra mi enfermedad	0	1	2	3
11. "Estoy que reviento", pero trato de no mostrarlo	0	1	2	3
12. Estoy perdiendo la fe en mi tratamiento médico	0	1	2	3
13. Me siento molesto	0	1	2	3
14. Me siento triste	0	1	2	3
15. Siento que soy un fracaso	0	1	2	3