Desenvolvimento e Validação da Entrevista Clínica para Diagnóstico de Luto Prolongado (CID-PG) e Validação da Escala Internacional da Perturbação de Luto Prolongado (IPGDS)

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Dissertação de Mestrado em Psicologia da Saúde e Neuropsicologia

Orientação: Professor Doutor José Carlos Rocha

Gandra, fevereiro de 2020

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sob orientação do

Professor Doutor José Carlos Rocha

Gandra, fevereiro de 2020

Declaração de Integridade

Eu, Ângela Alexandra Monteiro da Silva de Sousa Nogueira, estudante do Mestrado em Psicologia da Saúde e Neuropsicologia do Instituto Universitário de Ciências da Saúde, declaro ter atuado com absoluta integridade na elaboração desta Dissertação de Mestrado.

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Mais declaro que todas as frases que retirei de trabalhos anteriores pertencentes a outros autores foram referenciadas ou redigidas com novas palavras, tendo neste caso colocado a citação da fonte bibliográfica.

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Resumo

Inicialmente existiam expectativas de desenvolver uma investigação sobre a temática do Luto Perinatal, foram recolhidos dados, no entanto, verificamos uma dificuldade na recolha que nos impediu de dar continuidade a essa investigação, por falta de tempo e dificuldade de encontrar quem aceitasse participar nesta investigação. Posteriormente, existiu a possibilidade de um trabalho conjunto com a Universidade de *Zurich*, no sentido da adaptação e validação de um instrumento de avaliação do luto prolongado, para a população portuguesa.

Dado o impacto na nossa sociedade, e a dificuldade existente de diferenciar o Luto do Luto Prolongado, esta dissertação explora o mesmo tema em concomitância com a validação e construção de instrumentos capazes de diagnosticar o Luto Prolongado, através de dois manuscritos.

O primeiro intitulado "*Desenvolvimento e Validação da Entrevista Clínica para Diagnóstico de Luto Prolongado (CID-PG)*", tem como objetivo a construção e validação tendo como finalidade a realização de diagnósticos claros e robustos de Luto Prolongado de acordo com os novos critérios do *International Classification of Disease* (ICD-11) e para o qual foi utilizada uma amostra de 32 participantes, portugueses, em contexto clínico, que passarem por uma perda perinatal (grupo 1) ou parental (grupo 2).

Já a segunda parte intitula-se "*Validação da International Prolonged Grief Disorder Scale (IPGDS)",* trabalho este realizado em conjunto com a colega Isabel Guedes, tem como objetivo principal a adaptação e validação de uma escala para a população portuguesa, que avalie o luto prolongado, segundo os novos critérios do ICD-11 e para o qual foi utilizada uma amostra de 284 participantes.

Concomitantemente, estes estudos clarificam a nova existência de instrumentos capazes de diagnosticar com robustez o Luto Prolongado. Os resultados demonstram que ambos os instrumentos, revelam boas características psicométricas para o diagnóstico do luto prolongado.

No que diz respeito à validade convergente, através do teste t, foram encontrados resultados estatisticamente significativos.

Palavras – chaves: Luto Prolongado; ICD-11; CID-PG; IPGDS; Luto Parental; Luto Perinatal; Diagnóstico.

Abstract

Initially, there were expectations of developing research on the theme of Perinatal Grief; data were collected, however, we found a difficulty in collecting data that prevented us from continuing this research, due to lack of time and difficulty in finding those who agreed to participate in this research. Subsequently, there was the possibility of working together with the University of Zurich in order to adapt and validate an instrument to assess long-term grief for the Portuguese population.

Given the impact on our society and the existing difficulty in differentiating Prolonged Mourning from Prolonged Mourning, this dissertation explores the same theme in conjunction with the validation and construction of instruments capable of diagnosing Prolonged Grief, through two manuscripts.

The first one, entitled "Development and Validation of the Clinical Interview for the Diagnosis of Prolonged Mourning (ICD-PG)", aimed at the construction and validation of clear and robust diagnoses of Prolonged Mourning according to the new criteria of the International Classification of Disease (ICD-11) and for which a sample of 32 Portuguese participants, in clinical settings, who experienced perinatal (group 1) or parental (group 2) loss was used.

The second part is entitled "Validation of the International Prolonged Grief Disorder Scale (IPGDS)", a study carried out jointly with Isabel Guedes, with the main objective of adapting and validating a scale for the Portuguese population to assess prolonged mourning, according to the new criteria of the ICD-11, for which a sample of 284 participants was used.

At the same time, these studies clarify the new existence of instruments capable of robustly diagnosing Prolonged Mourning. The results show that both instruments show good psychometric characteristics for the diagnosis of prolonged bereavement.

With regard to convergent validity, statistically significant results were found using the t-test.

Keywords: Prolonged Grief; DHF-11; CID-PG; IPGDS; Parental mourning; Perinatal Grief; Diagnosis.

Development and Validation of the Clinical Interview for Diagnosis of Prolonged Grief (CID-PG)

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Abstract

Objective: The Clinical Interview for Diagnosis of Prolonged Grief (CID-PG) is an interview developed to facilitate the structured and standardized diagnosis of Prolonged Grief Disorder accordingly to ICD-11 criteria. Thus, we intend to validate this interview by verifying the operationalization of the defined criteria and obtaining evidence of their usefulness.

Method: After the application to a small group of professionals, a protocol for the assessment of Prolonged Grief was applied to 32 participants in hospital settings with a history of difficulties in dealing with grief, consisting of the CID-PG, International Prolonged Grief Disorder Scale (IPGDS), informed consent and sociodemographic questionnaire.

Conclusion: Here we present the final version, in Portuguese and in English, of the first diagnostic interview with the purpose of obtaining a reliable diagnosis of Prolonged Grief.

With regard to convergent validity, there are statistically significant differences in participants with and without the diagnosis, concerning concurrent symptoms instruments. Convergence with the IPGDS increased considerably changing Time Criterion having better discrimination of Prolonged Grief diagnosis.

The clinical sample, particularly the Parental bereavement group, has a very high level of Prolonged Grief disorder prevalence. There are limitations that suggest future research with test-retest or interrater calculation. Nevertheless, there is an instrument available as gold standard for PGD diagnosis with inherent potential for future research

Keywords: Prolonged Grief; Diagnosis; Parental Grief; Perinatal Grief; ICD-11; CID-PG;

Introduction

Grief is a slow and painful process that is characterized by deep sadness, abandonment of any activity linked to thoughts about the lost object, loss of interest in the outside world, and inability to replace the adoption of a new object of love (Freud, 1915).

The bereavement process is a natural, healthy process, inherent to the loss of a significant person and consists of the ability to cope with the various manifestations of the bereavement process, without this having a negative influence on the life path and without requiring specialized professional help (Golden & Dalgleish, 2010; Stroebe, Schult & Finkenauer, 2001). On the contrary, Complicated Grief implies the allocation of the individual's functional capacities, preventing him from returning to his state of functioning before the loss. This phenomenon is present when the bereavement process differs from what is culturally normative in terms of duration, symptoms and intensity of grief (Prigerson et al., 1995).

The concept of "grief" is naturally associated with the process after the death of a loved one. However, when we are facing a breakup or losing a member of our body after an accident or after surgery, or when we have lost a pet, we are also talking about grief. All of these are examples of loss situations that an individual can experience throughout his or her life, but despite the various situations of grief, we tend to be limited only to grief associated with death (Ramos, 2016).

“Prolonged grief disorder is a disturbance in which, following the death of a partner, parent, child, or other person close to the bereaved, there is persistent and pervasive grief response characterized by longing for the deceased or persistent preoccupation with the deceased accompanied by intense emotional pain (e.g. sadness, guilt, anger, denial, blame, difficulty accepting the death, feeling one has lost a part of one’s self, an inability to experience positive mood, emotional numbness, difficulty in engaging with social or other activities). The grief

response has persisted for an atypically long period of time following the loss (more than 6 months at a minimum) and clearly exceeds expected social, cultural or religious norms for the individual's culture and context. Grief reactions that have persisted for longer periods that are within a normative period of grieving given the person's cultural and religious context are viewed as normal bereavement responses and are not assigned a diagnosis. The disturbance causes significant impairment in personal, family, social, educational, occupational or other important areas of functioning" (World Health Organization, 2018).

Prolonged Grief Disorder (PGD) has emerged as a well-defined mental disorder, distinguishable from major depression and post-traumatic stress disorder (PTSD) or other stress-related disorders (Jordan & Litz, 2014).

Core symptoms are intense yearning and preoccupation with the deceased; reactive distress symptoms, such as feeling stunned or shocked by the loss; avoidance of reminders of the reality of the loss and emotional numbing, and social/identity disruption, for instance feeling detached or finding it difficult to trust other people (Keeley et al., 2016; Prigerson et al, 2009).

Therefore, grief is a very important subject and there is a need to separate normative grief from pathological / Prolonged Grief. In fact, it is not possible to define a number of days, months or years to interpret that grief becomes prolonged.

Thus, the existing need for an instrument that can diagnose Prolonged Grief, to understand from which moment it ceases to be normal or healthy, is the main reason that led to the creation of the Clinical Interview of Prolonged Grief developed by Virgiana Sousa and José Rocha in 2016, when the first diagnostic proposal for introduction to the ICD-11 was made in 2009, this interview was built to facilitate the diagnosis in a structured and standardized way. This instrument has

become in recent years a golden standard for the diagnosis and calculation of cutoffs for Prolonged Grief.

However, the final version of the diagnostic criteria had significant changes aimed at simplifying the process and better adapting it to the clinical context. There was a need to adapt the Interview to the new criteria.

For the construction of this instrument, we used the experiments with its previous version as well as other interviews for diagnosis of Post-traumatic Stress and Complex Post-traumatic Stress. The interview has 36 sequential items related to the criteria defined by ICD-11: Persistent and pervasive longing; intense emotional pain; time and impairment.

The main objectives are the construction of a gold standard instrument to facilitate a clear diagnosis of Prolonged Grief and the validation of the same instrument, to provide evidence of the diagnostic efficacy. It is also intended to apply the interview to a clinical sample to understand the opinion of health professionals in the area, aiming to collecting feedback on the clarity and acceptability of the interview as well as ease of application.

Method

Participants

The sample was collected in hospital context, being constituted by 32 individuals who suffered perinatal or parental loss, mostly female (71,9%), with ages between 26 and 78 (M=50,53, SD=13.65) (Table 1).

Participants were divided into 2 groups. Those who suffered a Perinatal loss were allocated in Group 1 and those who suffered a Parental loss were allocated in Group 2.

Instruments

Three instruments were used as well as an informed consent and a sociodemographic questionnaire. These instruments measured Prolonged Grief.

A Clinical Interview for the Diagnosis of Prolonged Grief was developed in Portuguese by Virgiana Sousa and José Rocha (2016). A new interview adapted to the ICD-11 criteria was developed by Ângela Nogueira, Joana Soares, Isabel Guedes and José Rocha (2018). The interview has 36 sequential items related to the criteria defined by ICD-11 include: persistent and pervasive longing; intense emotional pain; time and disability. These criteria are required in order to obtain a reliable diagnosis of Prolonged Grief. These 36 items are scored on a Likert Scale from 0 to 4, of which 19 have a Yes or No answer, and all others are answered from 0 to 4, where 0 corresponds to "None daily interference", "None Significance" or "Never" and 4 corresponds to "All the time", "Total change in activity" or "Total daily interference". There is also a question that assesses how long ago the loss has occurred.

International Prolonged Grief Disorder Scale (IPGDS) was developed in a collaborative project led by a team of the University of Zurich, which includes collaborations in Portugal and China. The English version was developed in Zurich in 2018, in integration of PG-13 (Prigerson, Vanderwerker, & Maciejewski, 2008) and SCI-CG (Bui et al., 2015). The Portuguese version was developed by our team. The scale consists of 15 items, the response to items is organized according to a rating scale, Likert scale, which ranges from 1 to 5, where 1 point means "never" and 5 points means "always".

Criterion A is composed by 6 questions, based on the ICD-11 criteria, these being the persistent and pervasive longing for the deceased and how often you feel them (Table 2). Criterion B - Examples of intense emotional pain, consists of 18 questions, focusing on sadness, guilt, anger,

denial, difficulties accepting the loss, feeling one has lost a part of one's self, difficulties at social levels, emotional numbness. Frequencies of these thoughts and feelings were assessed (Table 3). Criterion C is divided into 2, c1 and c2, where c1 focuses on the time after the loss and whether or not the subject feels that his feelings of grief extend beyond what is considered "normal" (Table 4). Sub-criterion c2 focuses on the significant changes that death may have caused in the person, such as the occurrence of significant changes in professional, social and intimate life, the feeling of isolation or lack of interest, and in all questions the meaning of the change, or the intensity of the damage caused in the subject's daily life (Killikelly & Maercker, 2017).

To make a clear diagnosis of Prolonged Grief requires the coexistence of Criterion A, plus Criterion B, with the presence of Criterion C. Criterion A is present if the patient answers positively to question 1 and 3, and in answer 2 the frequency is > 1, or if he / she responds positively to questions 4 and 6, and in answer 5 a frequency > 1 must be answered. The presence of criterion B is limited to the number of pairs of questions that the subject answers frequently > 1. Criterion C becomes more complex because it is divided into 2, where in c1 the first response must be > 6 months and respond positively in the second. As for criterion c2, it must answer positively and with intensity > 1 in at least one of the questions. To be present criterion C requires the presence of c1 and c2. In conclusion, to diagnose Prolonged Grief, criterion A, B and C must be present.

Other Instruments

The Clinical Assessment Usability Questionnaire was developed in Portuguese by Ângela Nogueira, André Moreira and José Rocha (2018) and applied to mental health professionals, aiming to clarify the ease of application, clarity and satisfaction with the instrument demonstrated

(Supplemental material). It consists of 8 items scored on a Likert scale from 0 to 5, where 0 corresponds Unclear and 5 corresponds Very Clear.

Procedure

In 2016 a Clinical Interview for Diagnosis of Prolonged Grief (CID-PG) was developed, however, over time the ICD-11 criteria for diagnosis of Prolonged Grief changed, which led to the need to reformulate and adapt this interview according to the new criteria.

Based on the previous interview and considering recent ICD - 11 diagnostic criteria, this team developed the Clinical Interview for Diagnosis of Prolonged Grief (CID - PG). To have a robust interview to facilitate the diagnosis in a structured and standardized way of Prolonged Grief.

In practice, the questions were constructed by adapting the previous interview to the new criteria.

The reduction in the number of questions was obvious, since the number of criteria was also reduced based on the modified criteria. Questions capable of defining these same criteria were constructed, such as criterion A, which is constituted by persistent and pervasive longing for the deceased or a persistent and pervasive preoccupation with the deceased, and the person is asked about the longing and concern he feels about the deceased, some questions associated with this criterion: "*Do you miss the person who died? If yes, how often does the patient feel it? Do you feel (persistent) concern or restlessness about the person who has passed away? If yes, how often does the patient feel this persistent restlessness*".

Regarding the rating of the interview, it is necessary to have the presence of positive criteria A, B and C, which means that to have a diagnostic of Prolonged Grief the three criteria must be cumulative.

In criterion A, for it to be present, it is necessary to have a positive answer in the first question, with a frequency higher than 1, it is still necessary to have a positive answer in the second and third questions, or a positive answer in the fourth, fifth and sixth questions, and the frequency of the fourth question must be higher than 1.

In criterion B, its presence is considered by the number of pairs of questions in which the answer is positive and with a frequency greater than 1 must be equal to or greater than 2 pairs.

Criterion C is slightly more complex, since it is divided into C1 and C2, and to be present, both must be present, i.e., C1 plus C2 make criterion C. In C1, the criterion is present when the answer regarding the time that occurred after the death is greater than 6 months and the respondent answers positively to question 26. In criterion C2 there must be at least one positive response more frequently than 1.

Therefore, the interview defines a diagnosis of prolonged bereavement when criteria A, B and C are simultaneously positive.

After the construction of the new interview according to the recent criteria, the Clinical Assessment Usability Questionnaire, focused on the proposed interview, was applied to five mental health professionals, with experience in the area of grief, aiming to obtain elements about limitations, items and instructions, linguistic details, clinical adaptability, clarity, ease of application, as well as suitability. Based on the answers given by these mental health professionals, changes were made to improve clarity and to facilitate the application of the interview.

After review by the Ethics Committee and based on the review of cases in the Department of Psychiatry and Mental Health of *Centro do Hospitalar Tâmega e Sousa*, Portugal, outpatients who suffered perinatal and parental losses in hospital context were invited to participate in this

research. The protocols were applied to 32 participants after informed consent procedures and data was prepared to analysis.

Inclusion criteria was: to have suffered a perinatal or parental loss. Data collection was performed by applying paper questionnaires. The objective of the study was explained, as well as confidentiality and anonymity to participants through an informed consent, to ensure the ethical norms.

After data collection, the analysis was performed in the statistic program and also, through the JASP Team (2019).

The research protocol was reviewed by *Instituto Universitário de Ciências da Saúde* Ethical Committee, with the reference 31/CE-IUCS/2019.

Results

The results obtained in the construction of the clinical interview for the diagnosis of Prolonged Grief is the interview itself which is composed by 36 items, divided into three criteria (English and Portuguese versions included as Supplemental material).

Throughout the interview, the highest symptom present was time after loss, with 96.3% of the respondents reported that the loss occurred 6 or more months ago. 93.3% of the sample collected reported having missed the deceased, when asked about the frequency 59.3% answered that they feel all the time, and 89.7% reported it occurs in various situations of daily life (Table 2).

The percentage of diagnosis of Prolonged Grief in the sample is 51.7%, which is a high percentage, and in 32 individuals, more than half have Prolonged Grief (Table 5).

We can see that the interview is of convergent validity after performing the T-test, the results obtained are statistically significant, which demonstrates the validity of them. After comparing the presence and absence of the C1B criterion, it can be seen that the absence of this criterion allows a better discrimination of symptoms. It will therefore be possible to make a small change in this criterion, as there is such a significant difference related to one issue. Therefore, the results obtained, being these higher when the question C1B is absent, allows us to realize that the fact that there is no such question, makes it possible to describe and understand more deeply the diagnosis of Prolonged Grief. When there is no such question, the percentage of Prolonged Grief in the sample increases significantly. Since the diagnosis of Prolonged Grief is statistically more significant ($p = .001$) when the C1B question is absent, in the presence of C1B the significance is lower ($p = .05$) (Table 6).

Reinforcing the validity of the instrument, we found a higher prevalence of Prolonged Grief in the parental grief group (68.4%) than in the perinatal grief group (20.0%) with significant chi square test for both distributions (Pearson's Chi Square = 6.15 with Fisher's Exact test p =.021).

It is expected that there will be a higher prevalence of prolonged bereavement in cases of parental bereavement, which happens in this study.

Figure 1 shows the comorbidities of both criteria. The highest prevalence focuses on the comorbidity of Criterion A + B = AB, in which 75.9% was found. Criterion C has the lowest percentage, with the union of A, B and C having the lowest comorbidity (51.7%). We can see that intense emotional pain (B), nostalgia, pervasive and persistent concern (A) are more interconnected (75.9%). The time that occurred after the loss and the intense emotional pain is the comorbidity with the lowest percentage (48.3%).

Discussion

The main objective of this study is to build, to adapt and to validate a structured interview for diagnosis of Prolonged Grief Disorder, making it available both in English and Portuguese.

The CID-PG is a valuable instrument for the characterization and diagnosis of Prolonged Grief, which allows for a professional-patient relationship, since it is not a self-completion instrument. This interview is a key instrument since it helps professionals to distinguish between Prolonged Grief and bereavement. The diagnosis can help and facilitate possible interventions and the calculation of cut-off scores for continuous psychometric scales. Now, is available a robust scale capable of diagnosing Prolonged Grief.

The feedback obtained by health professionals about the interview was positive; some changes suggested by them were made, such as simplification of questions, changes in terms and

increased instructions for health professionals. Therefore, according to these professionals, the interview was considered to be easy to apply, clear and capable of diagnosing Prolonged Grief, and we also obtained positive comments due to the fact that there was a need for an instrument with the ability to perform this diagnosis in a clear and simplified manner.

Also, this research enabled a reflection on the operationalization of ICD-11 criteria, particularly, related the new inclusion of time criteria and cultural, religious or community normative time after loss with a clinical sample with high level of symptoms.

There is a paradox because the respondents who considered that they did not have bereavement symptoms for a longer period than expected were the same ones who reported having an adverse effect on their daily, professional and intimate life.

Due to the possibility of misinterpretation of question number 2 of criterion C1, related to normative time after loss, there was a need to change and / or adapt that question. Patients with very high level of symptoms often accept and consider natural to have such high burden. These may represent a much more serious condition, with chronic, resigned and normalized suffering, considering the very high level of impairment and other symptoms. In order to check which operationalization of the criteria is able to differentiate time criteria (C1a and C1b) we found that C1a alone has higher effect size, time > six months versus time > normative expectations. In future versions, the specific approach the evaluate if time exceed the social, religious or community expectations should be different, particularly in severe cases. This could also provide evidence for discussion on the concomitant need for objective time (> six months) and exceed time for cultural norms.

It is not consistent for participants to show symptoms of high grief and to classify these symptoms as normal after a death several years ago. It is normal for the feelings of grief to remain,

because whoever loses a child will not forget it, which is not normal, after several years, these feelings of grief still cause significant burden and impairment in the daily life of individuals, and they find it normal.

Following these results, it is apparent that this issue needs reformulation or modification as it causes a significant change in the calculated values. After division of questions for criterion C1, cases with Prolonged Grief increased significantly accordingly what would be expected to such specific clinical sample.

As a limitation, no retest or interrater test was performed; however, it may be important to include these aspects in future investigations.

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Tables and Figures

Tables

Table 1

Sociodemographic and clinical characteristics of Perinatal Grief (n=11) e Parental Grief (n=22)

			n(%)	*M(SD)*
Whole Sample	Gender	Female	23 (71,9%)	
		Male	9 (28.1%)	
	Education Levels	Between four and six year	12 (37.5%)	
		More than six years	9 (28.1%)	
		More than nine years	4 (12.5%)	
		More than twelve years	7 (21.9%)	
	Marital Status	Not married	1 (3.1%)	
		Widow	1(3.1%)	
		Married	26 (81.3%)	
		Divorced	4 (12.5%)	
	Death Cause	Natural cause	8 (25.0%)	
		Accident	4 (12.5%)	
		Suicide	4 (12.5%)	
		Homicide	1 (3.1%)	
		Natural Disasters	3 (9.4%)	
		Perinatal Loss	12 (37.5%)	
	Death	Unexpected	29 (90.6%)	
		Expected	3 (9.4%)	
	Age			50,53 (16,65)

Table 2

Description of the presence and persistence of symptoms of criterion A

Criterion A	Presence (%)	Persistence				Pervasive (%)
		"Once or Twice"(%)	"Several Times a Week" (%)	"Daily or Almost Everyday" (%)	"At all Time" (%)	
Symptom 1: Longing	93.3	18.5	3.7	18.5	59.0	89.7
Symptom 2: Preoccupation	73.3	4.5	27.3	13.6	54.5	69.2

Table 3

Description of the presence and persistence of symptoms of criterion B

Criterion B	Symptom Frequency				
	Present (%)	"Once or Twice"(%)	"Several Times a Week" (%)	"Daily or Almost Everyday" (%)	"At all Time" (%)
Symptom 3: Sadness	78.6		18.2	22.7	59.1
Symptom 4: Guilt	22.2	50.0	33.3	16.7	
Symptom 5: Anger	57.1	26.7	20.0	26.7	26.7
Symptom 6: Difficulty of acceptance	63.0	23.5	41.2	17.6	17.6

	Symptom Frequency				
Criterion B	Present (%)	"Once or Twice"(%)	"Several Times a Week" (%)	"Daily or Almost Everyday" (%)	"At all Time" (%)
Symptom 7: Denial	74.1	20.0	25.0	40.0	15.0
Symptom 8: Denial	89.3	8.3	20.8	16.7	54.2
Symptom 9: Feeling lost	85.2	18.2	18.2	13.6	50.0
Symptom 10: Social	42.9	25.0	33.3		41.7
Symptom 11: Emotional numbness	57.1	31.3	50.0	18.8	

Table 4

Description of the presence and persistence of symptoms of criterion C

Criterion C	Present (%)	“Slight” (%)	“Moderate” (%)	“Severe” (%)	“Total” (%)
Symptom 12: Time	96.3				
Symptom 13: Exceeding expected norms	28.0				
Symptom 14: Impairment in professional	39.3	63.6	18.2	18.2	
Symptom 15: Impairment in social	46.4	38.5	53.8		7.7
Symptom 16: Impairment in occupational	44.4		45.5	36.4	
Symptom 17: Impairment in social	51.9	23.1	30.8	15.4	23.1
Symptom 18: Impairment personal	59.3		57.1	14.3	28.6

Table 5

Description of the presence of criterions and diagnosis of Prolonged Grief

	Present (%)
Criterion A	79.3
Criterion B	86.2
Criterion C	58.6
Criterion C1	96.3
Criterion C2	62.1
Diagnosis of Prolonged Grief	51.7

Table 6

Description of IPGDS results for participants positive/negative for PGD with and without C1B criterion

	Positive PGD			Negative PGD			t	p	d
	n	M	SD	n	M	SD			
Presence Criterion C1B	6	56.17	6.80	20	42.35	15.96	2.04	.05	0.95
Absence Criterion C1B	14	53.92	7.91	12	35.75	16.52	3.67	.001	1.44

Figures

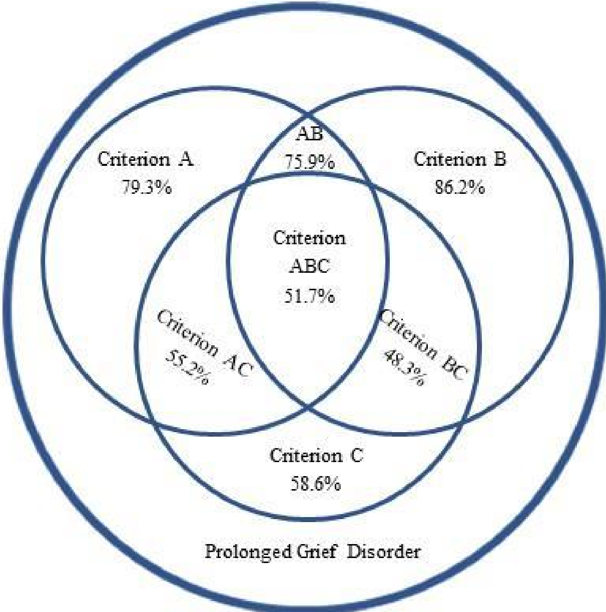

Figure 1. Criteria Comorbidities.

Scientific Presentations

1. Poster presentation, ESTSS 2019 – Rotterdam, Holland

Clinical Diagnostic Interview for Prolonged Grief according to the International Classification of Diseases (ICD- 11)

José Rocha, Ângela Nogueira, Joana Soares, Isabel Guedes, André Moreira

Background: When the 2009 proposal for Prolonged Grief disorder ICD-11 diagnostic criteria were presented, it was developed an interview to facilitate diagnosis in a structured and standardized way. This instrument has become in recent years a gold standard for the diagnosis and calculation of cut-off values for Prolonged Grief in Portugal. However, the final version of the diagnostic criteria had significant changes that aimed at a simplification of the process and better adaptation to the clinical context. *Objective:* We present here the final version of the first diagnostic interview with the objective of obtaining reliable diagnosis of Prolonged Grief.

Method: For the construction of this instrument we use the experiences with its previous version as well with other interviews for the diagnosis of Post-Traumatic Stress and Complex Post-Traumatic Stress. The new interview has 36 sequential items related to the criteria defined by ICD-11: Persistent and pervasive longing; Intense emotional pain; Time and disability. *Results:* Aiming a deeper search for limitations and to increase adaptability to clinical contexts, this interview is applied to five patients and six Psychologists with experience in the area of Grief to obtain reports on the linguistic details, clinical adaptability, as well as to obtain preliminary data on their diagnostic validity. *Conclusions:* Given the results, after fine tuning some details considering the instructions for the interviewer, we finalized a version of an instrument capable of robustly diagnose Prolonged Grief, which may be useful for the construction and validity studies of future assessment scales in this area.

2. Poster presentation, CPTL 2018, Porto, Portugal

Entrevista De Diagnóstico Clínico Para Luto Prolongado De Acordo Com a Classificação Internacional De Doenças (ICD-11)

Ângela Nogueira, Joana Soares, Isabel Guedes & José Rocha CESPU

Quando foi realizada a primeira proposta de critérios de diagnóstico para introdução no ICD-11, em 2009, foi construída uma entrevista com vista a facilitar o diagnóstico de modo estruturado e standardizado. Este instrumento tornou-se nos últimos anos um golden standard para o diagnóstico e cálculo de pontos de corte para o Luto Prolongado. Contudo, a versão final dos critérios de diagnóstico teve alterações significativas que visaram uma simplificação do processo e melhor adequação ao contexto clínico.

Apresentamos aqui a versão final da primeira entrevista de diagnóstico com o objetivo de obter diagnóstico fiável de Luto Prologado. Para a construção deste instrumento foram utilizadas as experiências com a sua versão anterior assim como de outras entrevistas para diagnóstico de Stress Pós-traumático e Stress Pós-traumático Complexo.

A entrevista tem 36 itens sequenciais relativos aos critérios definidos pelo ICD-11: Saudade persistente e pervasiva; intensa dor emocional; tempo e incapacidade.

Com o objetivo de acertar limitações e adaptabilidade, esta entrevista é aplicada a cinco pacientes e a seis Psicólogos com experiência na área do Luto para obter relatos sobre os detalhes linguísticos, a adaptabilidade clínica, assim como, obter dados preliminares sobre a sua validade diagnóstica.

Face aos resultados, neste momento já existe uma versão de um instrumento capaz de diagnosticar com robustez o Luto Prolongado, podendo sem útil para a construção e alidade de futuras escalas nesta área em esforços conjuntos internacionais.

Validation of the *International Prolonged Grief Disorder Scale* (IPGDS)

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Abstract

Objective: Is to validate the *International Prolonged Grief Disorder Scale* to the Portuguese population, in order to provide evidence of psychometric characteristics of a new scale for the assessment of prolonged grief, upon the alterations of the diagnostic criteria, proposed by ICD-11.

Method: For the research, were used the Socio-Demographic Questionnaire, the International Prolonged Grief Disorder Scale (IPGDS), the Inventory Complicated Grief (ICG) and the International Trauma Questionnaire (ITQ), also including an informed consent form. The sample is constituted by two groups of adult participants with history of at least one relevant loss and different sampling approaches: a. collected through an online inquiry, b. from a mental health clinical setting focused on supporting parental and perinatal losses, with face-to-face interviews.

Results: The internal consistency of the instrument is considered very good (α=.93). The optimal cutoff identified for the IPGDS was $\geq$ 38. Concerning convergent external validity, there are positive correlations, for instance, with Complicated Grief and statistically significant results with the unexpected loss.

Conclusion: The results indicate good psychometric characteristics for the Portuguese version of IPGDS, showing an easily administered assessment for symptoms of prolonged grief.

Keywords: International Prolonged Grief Disorder Scale; ICD-11.

Introduction

Grief is an unavoidable and normal reaction to loss. After the death of a loved one, bereaved people may think constantly about the deceased person and about the events that led up to the person's death. They often have physical reactions to their loss problems sleeping, for example and they may become ill. Socially, they may find it difficult to return to work or to see friends and family. For most people, these painful emotions and thoughts gradually diminish, usually within 6 months or so of the death (Prigerson et al., 2009).

Grief and responses to loss that most people successfully navigate without clinical intervention. During the initial days to months after a loss, acute grief can vary in intensity, nature, and time course based on a combination of individual and loss-related factors, as well as cultural and religious factors. Because loss is forever, so too is the state of being bereaved, yet grief changes over time for the vast majority of individuals who ultimately adapt to the loss with a reduction in grief intensity and return to a revised but meaningful and satisfying life without the deceased (Simon, 2013).

Boelen e Prigerson (2007), say that after the loss of a significant other a sizeable minority of people develops debilitating symptoms of grief and predictive of enduring functional and health impairments. More specifically, people fail to adjust and develop mental disorders, including prolonged grief disorder (Prigerson et al., 2009).

Prolonged grief disorder (PGD) is diagnosed as a pathologic response at the extreme of grief and is distinct from posttraumatic stress disorder or depression (Boelen et al., 2010).

PGD is included as a diagnostic entity in the ICD-11 (Killikelly & Maercker, 2018). This inclusion is a response to the increasing evidence of a distinct and debilitating condition that is not adequately described by ICD-10 diagnoses (Bryant, 2012).

PGD is characterized by core symptoms such as longing for and preoccupation with the deceased, along with emotional distress and significant functional impairment that persist (Killikelly & Maercker, 2018).

The prolonged grief disorder is a disturbance in which, following the death of a partner, parent, child, or other person close to the bereaved, there is persistent and pervasive grief response characterized by longing for the deceased or persistent preoccupation with the deceased accompanied by intense emotional pain (e.g. sadness, guilt, anger, denial, blame, difficulty accepting the death, feeling one has lost a part of one's self, an inability to experience positive mood, emotional numbness, difficulty in engaging with social or other activities). The grief response has persisted for an atypically long period of time following the loss (more than 6 months at a minimum) and clearly exceeds expected social, cultural or religious norms for the individual's culture and context. Grief reactions that have persisted for longer periods that are within a normative period of grieving given the person's cultural and religious context are viewed as normal bereavement responses and are not assigned a diagnosis. The disturbance causes significant impairment in personal, family, social, educational, occupational or other important areas of functioning (World Health Organization, 2018).

Characteristically, people with PGD have intrusive thoughts and images of the deceased person and a painful yearning for his or her presence. They may also deny their loss, feel desperately lonely and adrift, and want to die themselves (Prigerson et al, 2009).

As PGD is a newly refined diagnostic category, ultimately, clinic-based field tests and epidemiological studies are required to confirm its clinical utility (Killikelly & Maercker, 2018), as far as this is concerned, this study is the outcome of a research made from Zurich's University, CESPU and other international institutions, in order to create an prolonged grief

assessment tool, upon the alterations of the diagnostic criteria, proposed by ICD-11. In this sense, it has as aim the adaptation and validation of a new tool, the IPGDS, to the Portuguese population, in order to provide evidence of psychometric characteristics of a new scale for the assessment of prolonged grief, General and Items characteristic, Reliability and Validity testing new approaches of Item Response Theory and Network Psychometrics.

Method

Participants

The sample (Table 1) is constituted by 2 groups of adults participants with history of at least one relevant loss: a. collected through an online inquiry (n=218), b. from a mental health clinical setting focused on supporting parental and perinatal losses, with face-to-face interviews (*n*=28). The participants are, mostly women, with 230 (81%) women and 54 men (19%) with a mean age of (*M*=34.66, *SD*=13.86) and amplitude from 18 to 78 years old. The majority of sample are not married (*n*=147, 51.8%). 129 participants had an unexpected loss (*M*=36.30, *SD*=12.41).

Instruments

For the research, were used, the International Prolonged Grief Disorder Scale (IPGDS), the Inventory Complicated Grief (ICG) and the International Trauma Questionnaire (ITQ), Questionnaire of socio-demographic (QDS) to characterize the sample.

The Socio-Demographic Questionnaire was built with the goal of collect demographic information, such as gender, age, marital status, qualifications, jobs, but also the data relating to the person who lost, such as age, degree of kindship and the cause of loss.

IPGDS

The International Prolonged Grief Disorder Scale (IPGDS) has as objective the evaluation of prolonged grief. This tool is constituted by 14 items, which one on the Likert scale (1= “never”; 2 = “rarely”; 3 = “sometimes”; 4 = “frequently”; 5 = “always”), one supplemental item related to time after loss. For this purpose, 20 cultural items were included based on international cross-cultural research work. This scale was build based on an international research network aiming to evaluate Prolonged Grief considering the ICD-11 criteria.

ICG

The Inventory Complicated Grief (ICG) evaluate the symptoms of grief and has as objective make the distinction between a normal grief process and the complicated grief process (ICG total ≥30) (Sousa, 2011). This tool is constituted by 19 items, which one on the Likert scale (1= “never”; 2 = “rarely”; 3 = “sometimes”; 4 = “frequently”; 5 = “always”). According to Prigerson et al. (1995) the instrument is better qualified by a single factor (eigenvalue=10.01, R^2 =.99) showing a high internal consistency (Cronbach’s Alpha=.94). The sample of the ICG tool measurement, made by Frade (2009) for the Portuguese population, is constituted by 127 university students (*M*=19.9; *SD*=1.90), where the results obtained indicate that the instrument has good characteristics at the lever of faithfulness (Cronbach’s Alpha=.91) and validity (variance explained =68.9% and the external validity with strong correlations with depressive symptoms *r*=.50 and with traumatic symptoms *r*=.53) (Frade, 2009).

International Trauma Questionnaire (ITQ)

The ITQ evaluate the symptoms of post-traumatic stress (PTSD) and the PTSD complex (C-PTSD), and is constituted by 24 items, which are measured through the Likert scale of five points, varying form "Never" (0) to "Always" (4). Following the standard practice in trauma research (18, 19), the scores ≥2 (‘Moderately’) were used to indicate the presence of a symptom. The internal consistency values (Cronbach’s alpha) were 0.88 for the C-PTSD subscale and 0.84 for the PTSD subscale. The items were grouped into five components in the factor analysis: negative self-concept (F1); PTSD symptoms (F2); emotional numbing (F3); affective dysregulation (F4); and impulsivity control (F5) (Rocha, et al., 2019).

Procedure

The adaptation and validation process of IPGDS for the Portuguese population started with the translation of the instrument to Portuguese based and consensus three independent translation checking back translation meaning of items. Hereupon, the Portuguese version has been made available online, to maximize the number of participants, but also printed on paper, which was after, delivered to patients in a hospital center.

Because of the ethical questions, it was used for this purpose in informed consent, with the goal of informing the participants about the objective of the study ensuring the anonymity. The research protocol was reviewed by *Instituto Universitário de Ciências da Saúde* Ethical Committee, with the reference 31/CE-IUCS/2019.

Data Analysis

Participants responses were merged in a single database document, using both Limesurvey IINFACTS infrastructure and paper collected protocols. JASP Team (2019) was used for General Characteristics of items and scale, Reliability, Validity (Exploratory Factor Analysis, Network Analysis and further external validity procedures).

Results

General Characteristics of the scale

The IPGDS is an instrument composed by 14 items, which evaluate the prolonged grief symptoms. As we perform the analysis of the general characteristics of the scale, we found that the average result 2.37 (SD=0.67).

Reliability Study

To test the scale fidelity, we resort to the analysis of its internal consciousness. By performing internal consistency analysis, it was found that the value of *Cronbach's Alpha* is of .93, which, according to Pestana and Gajeiro (2008), allow inferring that it's very good.

Factor Analysis

After taking into concern the correlation existent between the items, proceeded to the *Kaiser-Meyer-Olkin* test, which shows the value of .93 and the *Barlett* test (p<.001), that demonstrate the suitability of the sample for factor analysis.

Regarding the factorial structure obtained, in the results of the varimax rotation show that the instrument is unifactorial (Table 2) explaining 64.14% of scale variance.

Network Analysis

The networks were estimated using the Estimate Network function from the R package bootnet, version 1.0.1 (Epskamp, Borsboom, & Fried, 2018).

The network approach conceptualizes mental disorder as a causal system of functionally interrelated symptoms that have settled into a pathological equilibrium (Borsboom & Cramer, 2013).

The 14 items establish 59 connections out of 91 possible.

Centrality is the measure of node interconnectedness (Ross, Murphyb, & Armoura, 2018). The three items showing the highest centrality were negative emotional state (item 10), difficulties in engaging in activities (item 12) and functional impairments (item 13).

Cutoff calculation

In order to verify, the diagnostic capacity of IGDDS regarding the evaluation of the Prolonged Grief Disorder, it was made the analyses of the ROC curve, to later be possible to obtain the cutoff. The analyses of the ROC curve allow the identification of the sensibility (true positives ratio) and the specificity (false negative ratio) of the diagnostic instrument.

The analyses result of the ROC curve demonstrate that the total area of the curve of .82, indicating a good capacity of discrimination of Prolonged Grief Disorder (Figure 2).

By calculating the cutoff, it was found that the optimal cutoff of PGD is ≥ 38, showing 100% of sensibility, and revealing the maximal value of specificity possible, being able to classify correctly 85% of the cases with or without PGD (Table 4).

Evidence of external validity

The evidence of external validity is observed through positive correlations that exist between the Posttraumatic Stress Disorder (PTSD) r=.51, Complex Posttraumatic Stress Disorder (C-PTSD) r=.62 and Complicated Grief (CG) r=.77 (p <.01).

It was also made the t test to verify differences of IPGDS between special groups with higher chances of having prolonged grief. The loss type, expected or unexpected, divide the sample in 2 groups, one with 107 participants and other with 129, having the first on an average of 29.73 (*SD*=9.93) and the second one an average of 36.30 (*SD*=12.41). This difference is statistically significant (t=-5,676 e p<.001). Also, the clinical sample has significant higher values of IPGDS than the general sample, for clinical sample a mean of 43.75 (*SD*=16.10) and 31.74 (*SD*=10.53) general sample (t=5.30. p<.001).

Discussion and Conclusion

The IPGDS adaptation and validation arises from the need to build a psychometric instrument for prolonged grief evaluation, according to the new diagnostic criteria of ICD-11.

The results indicate that the instrument has very high reliability index, due to good internal consistency. The factor analysis shows that the instrument is unifactorial, which indicate whole items have the same underlying construct (Brown, 2006). Regarding external validity, there are positive correlations with PTSD, C-PTSD and CG symptoms, using different instruments. By analyzing the type of losses, IPGDS differentiate participants which lived one unexpected loss versus expected loss, as previous evidence that losing someone from a violent and unexpected loss, i.e. by homicide, suicide or accident, is associated with

an elevated risk for both PGD and PTSD (Boelen et al, 2015). Also, it differentiate clinical participants versus nonclinical.

The Network analysis, reveal that the most central PGD symptoms were recurrent thoughts, negative emotional state, difficulties in engaging in activities and functional impairments and that there is a networking configuration of all symptoms.

Using a structured interview, it was possible to calculate an optimal cutoff for PGD diagnosis proved to be ≥38.

This study has limitations, particularly as regards the sample, for a future investigation it is necessary more male participants, in order to compare both genders, but it is also necessary a comparative study with other populations, in order to discriminate the influence of cultural factors.

The IPGDS is a reliable scale for the assessment of individuals at risk for developing PGD with high scores on internal consistency and adequate levels of reliability and validity.

Validation of this interview is relevant for research and clinical practice, providing a more robust and efficient way to diagnose Prolonged Grief as well as working as a clinical tool to better assess patient symptoms and to improve interventions in this area.

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Tables and Figures

Table 1

Sociodemographic and Clinical characteristics

	Clinical group				General group			
Characteristics	*n*	*%*	*M*	*SD*	*n*	*%*	*M*	*SD*
Gender								
Female	23	71,9			230	81.0		
Male	9	28.1			54	19.0		
Age			50.53	16.65			34.66	13.86
Marital Status								
Not Married	1	3.1			147	51.8		
Married	1	3.1			111	39.1		
Widow(er)	26	81.3			17	6.0		
Divorced	4	12.5			8	2.8		
Education level (in years)								
Between 4 and 6 years	12	37.5			23	8.2		
More than 6 years	9	28.1			32	11.3		
More than 9 years	4	12.5			90	31.8		
More than 12 years	7	21.9			136	47.9		
Death type								
Expected loss	3	9.4			107		29.73	12.41
Unexpected loss	29	90.6			129		36.30	9.93
Death cause								
Natural cause					211	76.4		
Accident					31	11.2		
Suicide					13	4.7		
Substance Abuse					4	1.4		
Homicide					1	0.4		
Natural Disasters					3	1.1		
Perinatal Loss					13	4.7		

Table 2

Exploratory factor analysis, item, characteristics and reliability statistics

						If item dropped
	Factor 1	**Uniqueness**	**M**	**SD**	**Item-rest correlation**	**Cronbach's α**
IPGDS 1	.62	.61	3.85	1.01	.60	.92
IPGDS 2	.67	.54	2.51	1.18	.65	.92
IPGDS 3	.74	.45	2.91	1.26	.71	.92
IPGDS 4	.45	.80	1.29	0.73	.44	.93
IPGDS 5	.75	.43	2.91	1.44	.74	.92
IPGDS 6	.33	.89	1.82	1.14	.34	.93
IPGDS 7	.57	.67	1.79	1.21	.56	.92
IPGDS 8	.69	.52	2.55	1.31	.67	.92
IPGDS 9	.73	.46	3.18	1.40	.69	.92
IPGDS 10	.91	.18	2.23	1.22	.86	.90
IPGDS 11	.86	.26	2.16	1.19	.82	.92
IPGDS 12	.84	.29	1.97	1.16	.80	.92
IPGDS 13	.80	.35	2.00	1.15	.77	.92
IPGDS 14	.57	.68	1.94	1.13	.56	.92

Table 3

Pearson's Correlations between IPGDS and Concurrent Scales

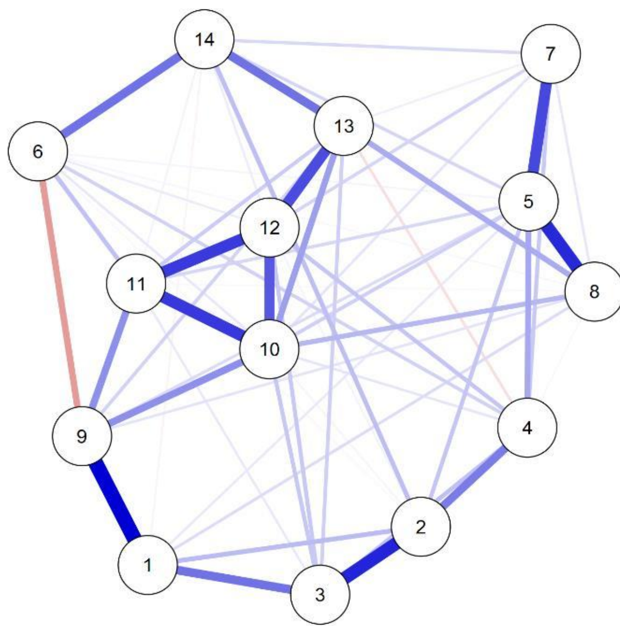
	IPGDS Total	ITQ PTSD Total	ITQ CPTSD Total
ITQ PTSD Total	0.513*		
ITQ CPTSD Total	0.624*	0.633*	
ICG Total	0.768*	0.478*	0.543*

significance level for <.001*

Table 4

Calculation of the Cutoff Point of the IPGDS.

Cutpoint	Sensitivity	Specificity	Classified	LR+	LR-
(>= 35)	100.00%	50.00%	76.92%	2.0000	0.0000
(>= 37)	100.00%	58.33%	80.77%	2.4000	0.0000
(>= 38)	100.00%	66.67%	84.62%	3.0000	0.0000
(>= 44)	85.71%	66.67%	76.92%	2.5714	0.2143
(>= 45)	78.57%	66.67%	73.08%	2.3571	0.3214



Item 1: Missing the Deceased

Item 2: Preoccupation

Item 3: Emotional Pain

Item 4: Fault

Item 5: Anger

Item 6: Avoidance

Item 7: Blame others

Item 8: Acceptance difficulties

Item 9: “I lost part of me”

Item 10: Negative emotional state

Item 11: Emotionally asleep

Item 12: Involvement difficulties

Item 13: Functional impairment

Item 14: More time than expected

Figure 1. Network representation of IPGDS (14 items).

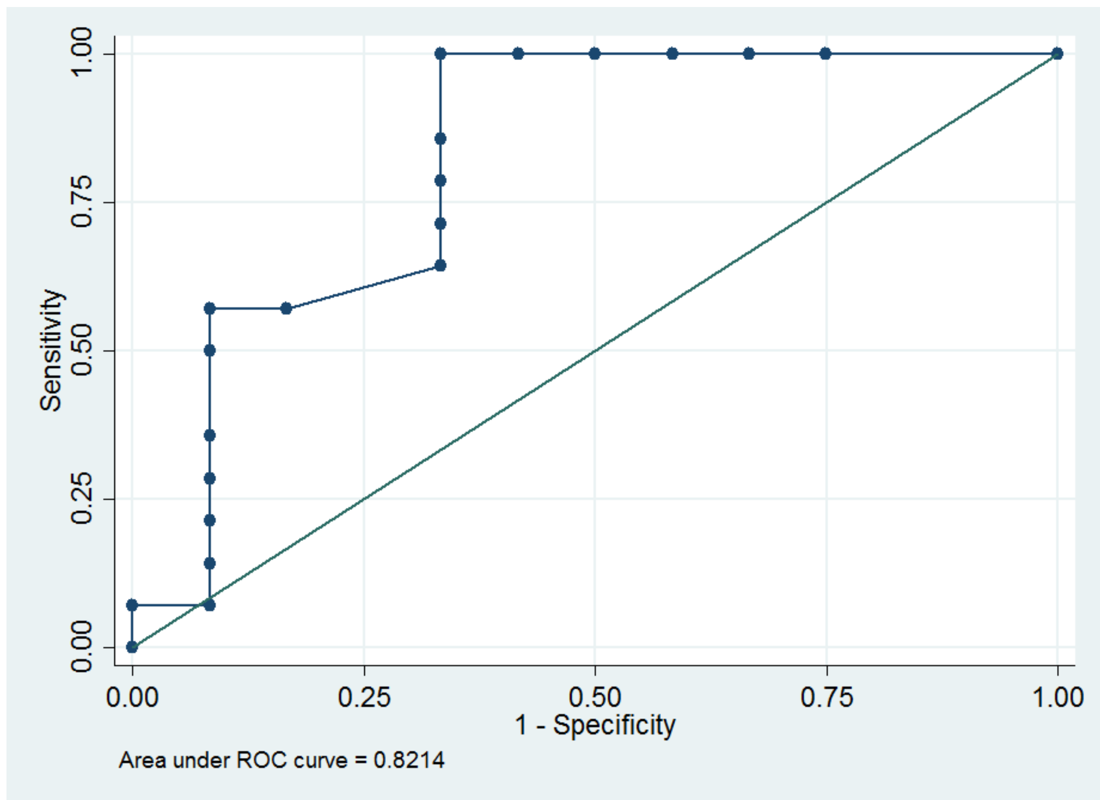


Figure 2. IPGDS ROC Curve and Sensitivity and Specificity Indicators.