



EQUIVALENCE FROM THE PERINATAL GRIEF SCALE TO THE PARENTAL GRIEF SCALE AFTER THE LOSS OF A CHILD

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ABSTRACT

Introduction: The most common manifestation of complicated grief comes with the death of a child. In this context, there is an urgent need for using scales aimed at parents in order to identify parental grief. **Objective:** To establish an equivalence from the Perinatal Grief Scale to the Parental Grief Scale after the loss of a child. **Method:** This is a methodological study involving data collection and analysis by means of a linguistic, semantic, cultural, conceptual and colloquial equivalence from the perinatal grief scale (Perinatal GS) to the parental grief scale (Parental GS) in Brazilian Portuguese. **Results:** For the equivalence from the Perinatal GS to the Parental GS, one proposal, applied to Brazilian Portuguese, and bearing in mind that the latter is a language with gendered words, was to replace *bebê* (baby) with *filho(a)* (son/daughter), and both feminine and masculine words were used when referring to parents. The committee of expert judges participating in the cross-cultural adaptation and validation of the Perinatal GS agreed on 100% of the changes. **Conclusion:** The proposal of the Parental GS expands the investigation of complicated grief for parents who have lost their children in all age groups.

Keywords: Grief. Mortality. Methods.

INTRODUCTION

Grief is a habitual and universal feeling manifested in the face of a loss; it is characterized as complicated grief when this feeling becomes complex and difficult to elaborate, persistent, debilitating and incapacitating, being previously called pathological grief in the literature⁽¹⁾.

The most painful experience that a human being can go through and the most common manifestation of complicated grief is the death of a child, whether small, grown or still unborn⁽²⁾. The death of children before their parents is considered a paradox, an alternation of the "natural order of life". There is no word to express this loss; if it is the death of a spouse, one is a widow(er), whereas if it is parents who die, one becomes an orphan. Now, what about when a child dies?

Parental grief, specifically, is characterized by emotionally intense reactions that can last for months, years, or even never cease. Among the psychosocial impacts that the loss of a child causes, in addition to complicated grief, psychosomatic diseases stand out, especially

depression, impairment of marital and social relationships, which can affect work, religion and leisure⁽³⁾.

Studies dealing with parental grief reflect contemporary society, which does not give way to the experience of loss, as capitalism encourages parents to move on, causing, in most cases, intense feelings of pain. In addition to the scarce bibliography focused on maternal grief and the beginning of studies addressing paternal grief, which shows improvements in the process of recognizing men's fragility, fathers are still seen only as responsible for providing and cannot stop to process the loss of their children⁽³⁾.

The grief for children who have died in the uterus is still "invisible", as they have not smiled or cried in society. When it comes to small children, there is a need for social resignifications, since there will no longer be a mother and a father. As for the loss of an adult son or daughter, grieving parents are often sidelined in favor of the deceased's widow and children, who seem to be the ones most in need of support and care. The loss of a child is very painful due to the intrinsic desire of motherhood

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and fatherhood of most human beings, even when unplanned, but accepted, it is a life project that has been interrupted.

For fetal and neonatal mortality, as well as mortality of children up to five years of age, the main causes of death are congenital malformations and conditions originating in the perinatal period. In the age group from five to 19 years, the main causes of death are diseases of the digestive system, neoplasms, and endocrine and metabolic diseases. For adults aged 20 to 60 years, the main causes of death are neoplasms and diseases of the digestive and respiratory systems, whereas for people over 60 years of age, the main causes of death are endocrine and metabolic diseases, and diseases of the nervous system⁽⁴⁾.

The Covid-19 pandemic brought about a number of other factors that can make it difficult to elaborate grief, such as sudden death, circumstances of total isolation in a hospital unit, the experience of dying in a situation of intense suffering and physical pain, suppression of the time necessary for one to be able to make sense out of their loss, exposure to stigma and social discrimination, rarefaction of rites and rituals, lack of social support, tension in family relationships, and occurrence of other losses simultaneously with death⁽⁵⁻⁶⁾.

Scientific evidence highlights the need for specific care in identifying complicated grief aimed at parents who have lost their children⁽⁷⁻⁸⁾. A proven instrument in the investigation of complicated grief for parents who have had a miscarriage, fetal or neonatal loss is the Perinatal Grief Scale (PGS)⁽⁹⁾. Organized in English in 1989 and translated into Brazilian Portuguese in 2015⁽¹⁰⁾, it is the most used scale to investigate perinatal grief in Brazil⁽¹¹⁻¹³⁾ and in several countries around the world⁽¹⁴⁻¹⁶⁾. The PGS is composed of statements that aim to assess thoughts, feelings and symptoms of adaptation in parents' loss concerning death⁽⁹⁻¹⁰⁾.

Given the various causes of child deaths that occur daily and the Covid-19 pandemic, the urgency of using instruments aimed at parents to identify parental grief has intensified. In addition to the expectation of research involving the impact and experience of grief in the case of deaths, and given the exposed scenario of dying, the present study aimed to establish an

equivalence from the Perinatal GS to the Parental GS after the loss of a child.

METHODS

This is a methodological study involving semantic, cultural, conceptual and colloquial equivalence⁽¹⁷⁾ from the Perinatal GS⁽¹⁰⁾ to the Parental GS in Brazilian Portuguese. Semantic equivalence represents the same meaning of words in terms of vocabulary and grammar; in cultural equivalence, the situations portrayed in the original version must be consistent with the cultural context for which the instrument will be translated; conceptual equivalence refers to maintaining the concept proposed in the original instrument; and colloquial equivalence refers to the equality of idiomatic and colloquial expressions, which must be congruent in the culture for which the instrument is being translated⁽¹⁷⁾.

The cross-cultural adaptation and validation evidence process concerning the Perinatal GS for Brazilian Portuguese was carried out in 2013, with the authors' permission to translate the original version into Portuguese. All the steps of the methodological framework for translation and adaptation of instruments were taken, which resulted in a satisfactory psychometric value, with a Cronbach's alpha coefficient of 0.93 and the validation of the PGS for Brazilian Portuguese⁽¹⁰⁾.

For the equivalence from the Perinatal GS to the Parental GS in Brazilian Portuguese, one proposal was to change the term "baby" to "son/daughter", with the same method for adaptation of self-applied instruments⁽¹⁷⁾ and by the same team of expert judges participating in the Perinatal GS proposal. Two translators worked on the equivalence process, one being a specialist in the health field and informed about the research topic, and one sworn translator, who was not familiar with the field and did not have information about the research; the scale was reviewed by one of the study's researcher, and a back-translation into English was performed by two translators with no knowledge of the health field and without research information.

Subsequently, the version was prepared by a committee of expert judges composed specifically of the two translators, two back-

translators, two authors of the research, two observers (lay fathers whose children died of Covid-19), four nurses with experience in research in the family health field and construction of questionnaires, and one linguistics professional. That is, the observers changed from women who had a fetal death to two male observers, who were fathers whose children died of Covid-19.

Then, the final version was prepared by the committee of expert judges for future application of the test and psychometric analysis. The recommendations for adapting instruments⁽¹⁷⁾ aim to ensure full understanding of the content of the translation, such as the use of a writing that can be understood by individuals aged between ten and 12 years.

Because in the Portuguese language it is standard to keep the masculine gender in most words, the term *filho*, meaning “son”, was kept and combined with the letter “a” in parentheses (a), to become *filha*, meaning “daughter”; no other gender adjustments were necessary in the Portuguese language, since, in the original scale, the term used was “the baby”, meaning *o bebê*, and the latter can be generically used to refer to both genders. The scale was previously addressed to mothers, so the questions, in Brazilian Portuguese, used the words for feelings directed towards the female gender, with the letter “o” being added in parentheses “(o)” for the application of the scale to fathers; however, since words are not gendered in English the way they are in Portuguese, this difference does not apply to this manuscript.

The study followed the guidelines on research involving human beings, in accordance with resolution 466/12 of the National Health Council, and an expansion of the research to parental grief was requested under opinion 407.840/2013 (CAAE 20291013.3.0000.0104), being approved by the Research Ethics Committee of the State University of Maringá.

RESULTS

The committee of expert judges agreed 100% on adapting the equivalence by changing the term *bebê* (baby) to *filho(a)* (son/daughter), thus expanding the investigation of perinatal grief to parental grief in Brazilian Portuguese. The term *meu bebê* (my baby), which is masculine in Brazilian Portuguese, due to the pronoun *meu*, was replaced by *meu(minha) filho(a)*, meaning “my son/daughter”. Since the version of the Parental GS is not restricted to the loss suffered by the mother, that is, it also includes the loss suffered by the father, another proposal was to add the letter “o” in parenthesis next to the words *depressiva(o)*; *assustada(o)*; *incomodada(o)*; *viva(o)*; *afastada(o)*; *culpada(o)*; *desprotegida(o)*, meaning, respectively, “depressed”, “scared”, “uncomfortable”, “alive”, “withdrawn”, “guilty”, and “unprotected”; however, then again, this difference does not apply to English and will not be reflected in this article; moreover, the term “grieving mother” was used along with “grieving father”. The Perinatal GS was changed to Parental GS, as shown in Table 1 below:

TABLE 1. Final version of the equivalence from the Perinatal GS to the Parental GS in Brazilian Portuguese.

Perinatal grief scale in Brazilian Portuguese			Parental grief scale in Brazilian Portuguese
Subscale I Active Suffering	1	I feel depressed	I feel depressed
	2	I feel an emptiness inside of me	I feel an emptiness inside of me
	3	I feel the need to talk about my baby	I feel the need to talk about my son/daughter
	4	I am grieving for my baby	I am grieving for my son/daughter
	5	I am scared	I am scared
	6	I miss my baby so much	I miss my son/daughter so much
	7	It is painful to have memories of the loss	It is painful to have memories of the loss
	8	I feel uncomfortable when I think about my baby	I feel uncomfortable when I think about my son/daughter
	9	I cry when I think about the baby I lost	I cry when I think about the son/daughter I lost
	10	Time passes very slowly since my baby died	Time passes very slowly since my son/daughter died
	11	I feel very lonely since my baby died	I feel very lonely since my son/daughter died

Subscale II - Difficulty in facing the situation	12	I find it difficult to have a relationship with certain people	I find it difficult to have a relationship with certain people
	13	I cannot handle my usual activities	I cannot handle my usual activities
	14	I have been thinking about suicide since the loss	I have been thinking about suicide since the loss
	15	I feel that I have adapted well to the loss	I feel that I have not adapted well to the loss
	16	I have let other people down since my baby died	I have let other people down since my son/daughter died
	17	I get angry at friends and relatives more than I should	I get angry at friends and relatives more than I should
	18	Sometimes I feel like I need professional advice to help me get back to my normal life	Sometimes I feel like I need professional advice to help me get back to my normal life
	19	It feels like I just exist and have not really been alive since my baby died	It feels like I just exist and have not really been alive since my son/daughter died
	20	I feel somewhat withdrawn and distant, even among friends	I feel somewhat withdrawn and distant, even among friends
	21	It has been hard to make decisions since my baby died	It has been hard to make decisions since my son/daughter died
	22	It is great to be alive	I feel like dying
	23	I take tranquilizers	I take tranquilizers
Subscale III - Despair	24	I feel guilty when I think about my baby	I feel guilty when I think about my son/daughter
	25	I feel physically sick when I think about my baby	I feel physically sick when I think about my son/daughter
	26	I feel unprotected in a dangerous world since my baby died	I feel unprotected in a dangerous world since my son/daughter died
	27	I try to laugh, but I do not find anything funny anymore	I try to laugh, but I do not find anything funny anymore
	28	The best part of me died along with my baby	The best part of me died along with my son/daughter
	29	I blame myself for my baby's death	I blame myself for the death of my son/daughter
	30	I feel worthless since my baby died	I feel worthless since my son/daughter died
	31	It is safer not to love	It is safer not to love
	32	I worry about what my future will be like	I worry about what my future will be like
	33	Being a grieving mother means being a "second-class citizen"	Being a grieving mother (grieving father) means having less value in society

The process of adapting and validating research instruments takes time to make them official. In the proposal, the equivalence from the Perinatal GS to the Parental GS kept the format of the original scale in all items of the instrument, with 33 psychometric statements divided into three subscales defined as active suffering, difficulty in facing the situation, and despair. For the evaluation of the psychometric characteristics, the committee of expert judges maintained the Likert-type Parental GS, with five response options, ranging from 1 to 5 points, corresponding, respectively, to "strongly disagree", "partially disagree", "neither agree nor disagree", "partially agree" and "completely agree".

To calculate the total PGS score, the statements "it is great to be alive" and "I feel that I have adapted well to the loss", which should be reversed

in the order of the Likert scale scoring, were changed to "I feel like dying" and "I feel that I have not adapted well to the loss"; consequently, it was not necessary to change the order of the score that was previously recorded by the researchers when using the scale, thus improving understanding and facilitating its analysis.

Thus, each Parental GS subscale maintains 11 statements, and scores of a minimum of 11 points and a maximum of 55 points each. The sum of the three subscales then ranges from 33 to 165 points. The cutoff point for identifying the state of complicated grief is set at a sum greater than 90 for parents with complicated grief, and a sum lower than or equal to 90 points for parents without grief, in accordance with the Perinatal GS^(7-8,11).

Therefore, it is considered that there is conceptual and operational equivalence and a

promising validation of the construct of the scale, due to the original instrument of the Perinatal GS in English and in several other languages as a reference instrument (gold standard) for the grief of parents who have had a miscarriage, fetal and neonatal loss. Thus, the formatting of the Parental GS questionnaire, based on the opinions of the committee of expert judges participating in the adaptation and validation of the Perinatal GS, is ready for further studies that can assess its psychometric conditions.

DISCUSSION

The normal grief process is gradually extinguished with the disappearance of sadness and crying, installation of consolation, and return of interest in the outside world. In the end, with the definitive rupture of the affective bond, the lost person becomes just a memory; the feeling of sadness disappears, and affective life resumes its course, making it possible again to establish new affective connections. For most scholars, grief can last two to four months, or extend for years, ending only when it is harmoniously integrated into the experience of the present⁽¹⁾.

For some people, “normal” grief leads to complicated grief because, in this situation, people manifest characteristics of obsessiveness, begin to have intrusive, negative thoughts that are difficult to unfocus and that cause immense discomfort and anxiety, with images of the deceased and painful yearning for their presence. In the same way, they may also behave in the sense of denying the loss, feel desperately alone and wish for their own death⁽¹³⁾. Regarding the death of a child, the literature evidences that it can lead to prolonged grief and that its length can vary from person to person; in some cases, it never ends⁽²⁾, with constant suffering remaining.

The diagnosis of complicated grief is manifested when at least five of the nine symptoms appear characterized by an emotional feeling of numbness, haze, or that life is meaningless; dealing with mistrust; bitterness for the loss; difficulty in accepting the loss; identity confusion; attitude of avoiding the reality of the loss; or difficulty in moving on with life. Complicated grief meets the criteria for a distinct mental disorder, which involves reactions to a significant loss, with intense

suffering due to death, at sufficiently high levels and associated with functional deficit⁽¹⁾.

The authors of the 4th Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), focused primarily on the issue of overdiagnosis, omitted complicated grief because of insufficient evidence. However, more than 10% of the population manifest complicated grief and the stress caused by grief, which can increase the likelihood of the appearance or worsening of other physical or mental disorders. Thus, grieving individuals need to be evaluated, diagnosed and treated when necessary⁽¹⁸⁾.

Despite concern about the possible unnecessary medicalization in the uncomplicated grieving process, it is important to pay attention to the severity that these conditions can reach. Grief is a strong stressor and, as such, can trigger serious mental disorders. Therefore, it cannot be assumed that, because it is a common reaction, it cannot be experienced pathologically. In this way, the proposal to include the diagnosis of complicated grief in the fifth and latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) aimed to allow individuals who are experiencing severe psychological distress to receive adequate care, including pharmacotherapy, when necessary⁽¹⁹⁾.

With the few manifestations and possibility of expression of grief in Brazilian culture, by applying the Parental GS, the expectation is to find similar prevalence rates of complicated grief in Brazilian mothers (35%) compared to 12% in mothers residing in countries with grief support services. A more pronounced state of complicated grief is associated with women without a partner, less education, no employment relationship, having no religion and not being visited by religious figures, previously born alive child, non-occurrence of previous loss and unplanned pregnancy, gestational age greater than 28 weeks, high anxiety, and postpartum depression⁽¹³⁾.

The high demand of deaths caused by the coronavirus, from the beginning of the Covid-19 pandemic, in March 2020 to the present, of infected and dead people, respectively, in the world and in Brazil⁽²⁰⁾, with more than 190 million and 19,342,448, and more than 4 million and 541,266, caused health professionals to invest in finding support strategies for coping with illness and finitude⁽²¹⁾. Studies point to spirituality and

religiosity as strategies to support grief in the events of death and dying^(13,22). They also show the importance of health professionals considering the beliefs, values of each person, and the many meanings that are assigned to the spiritual and religious experiences of each patient and their family members in the event of death and dying. Finally, it is about knowing how to be there to the one who is preparing to leave this life and to the family member who stays⁽²²⁾.

CONCLUSION

To identify parental grief, reliable instruments adapted to the cultural context of the investigated population are needed in order to ensure adequate time for identification and support. The Covid-19 pandemic has intensified the need for an instrument that identifies parental grief for parents who have lost their children to the coronavirus and all to other causes of death that continue to exist. Thus, the equivalence of the Perinatal GS, the most used instrument and the one which more accurately measures the complicated grief of parents who have experienced a miscarriage, fetal and neonatal deaths, has been established with the Parental GS, expanding the investigation of complicated grief

also to parents who have lost their sons and daughters regardless of age.

The findings presented are favorable to the application of the Parental GS in the identification of the state of complicated grief in parents who have lost their children. Great is the value of the translation stages, adjustment of cultural and colloquial concepts, the opinion of experts and people who have gone through the situation, in accordance with the research proposal of the instrument's theme, so that, in the psychometric evaluation, the flaws in the process do not harm or hinder external comparisons. Further studies involving reliability, validity of the dimensional structure and of the construct via hypothesis testing should be carried out in order to complete the process of cross-cultural adaptation of the Parental GS.

In Brazil, death is still a taboo, and there is a lack of health professionals trained on managing the death of a child along with parents. The Parental GS can be used as a prevention tool by health professionals in their practice, as it is able to identify mothers and fathers at risk of developing complicated forms of grief and in need of specific referral and support.

EQUIVALÊNCIA DA ESCALA DE LUTO PERINATAL PARA ESCALA DE LUTO PARENTAL APÓS A PERDA DE UM FILHO

RESUMO

Introdução: a manifestação mais comum do luto complicado é diante da morte de um filho. Neste contexto, observa-se a emergência da utilização de escalas direcionadas para pais na identificação do luto parenteral. **Objetivo:** realizar equivalência da Escala de Luto Perinatal para Escala de Luto Parental após a perda de um filho. **Método:** trata-se de um estudo metodológico, que envolve a coleta e análise dos dados através da equivalência linguística, semântica, cultural, conceitual e coloquial da escala de luto perinatal (EL Perinatal) para escala de luto parental (EL Parental) na língua portuguesa do Brasil. **Resultados:** para equivalência da EL Perinatal para EL Parental foi realizada a proposta de alteração da palavra “bebê” para “filho(a)” e as palavras do gênero feminino também foram possibilitadas para o gênero masculino na abordagem aos pais. O comitê de juízes especialistas participantes na adaptação transcultural e validação da EL Perinatal concordou em 100% das modificações. **Conclusão:** a proposta da EL Parental amplia a investigação do luto complicado para os pais que perderam seus filhos em todas as faixas etárias.

Palavras-chave: Luto. Mortalidade. Métodos.

EQUIVALENCIA DE LA ESCALA DE DUELO PERINATAL PARA ESCALA DE DUELO PARENTAL ANTE LA PÉRDIDA DE UN HIJO

RESUMEN

Introducción: la manifestación más común del duelo complicado es ante la muerte de un hijo. En este contexto, se observa la emergencia de la utilización de escalas dirigidas a padres en la identificación del luto parenteral. **Objetivo:** realizar equivalencia de la Escala de Luto Perinatal para Escala de Luto Parental después de la pérdida de un hijo. **Método:** se trata de un estudio metodológico, que involucra la recolección y el análisis de los datos a través de la equivalencia lingüística, semántica, cultural, conceptual y coloquial de la escala de luto perinatal (ELPerinatal) para escala de luto parental (ELParental) en la lengua portuguesa de Brasil. **Resultados:**

para la equivalencia de ELPerinatal para ELParental fue realizada la propuesta de alteración de la palabra "bebé" para "hijo(a)" y las palabras del género femenino también fueron posibilitadas para el género masculino en el abordaje a los padres. El comité de jueces expertos que participaron en la adaptación transcultural y validación de ELPerinatal estuvieron el 100% de acuerdo con las modificaciones. **Conclusión:** la propuesta de ELParental amplía la investigación del luto complicado para los padres que perdieron a sus hijos en todas las edades.

Palabras clave: Duelo. Mortalidad. Métodos.

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