

# Maternal coping strategies in response to a child's chronic and oncological disease: a cross-cultural study in Italy and Portugal

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## Abstract

A child's oncological or chronic disease is a stressful situation for parents. This stress may make it difficult for appropriate management strategies aimed at promoting the child's wellbeing and helping him or her cope with a disease to be adopted. In particular, this study focuses on the possible connections between the variable national cultural influences and the parental strategies used to cope with a child's severe disease by comparing the experiences of Italian and Portuguese mothers. *The study investigates differences and cross-cultural elements among the coping strategies used by Italian and Portuguese mothers of children with oncological or chronic disease. Two groups of mothers took part: 59 Italian mothers (average age 37.7 years; SD=4.5) and 36 Portuguese mothers (average age 39.3 years; SD=4.6). The tool used was the Italian and the Portuguese versions of the COPE inventory that measures five coping strategies: Social Support, Avoidance Coping, Positive Aptitude, Religious Faith and Humor, Active Coping.* There were statistically significant differences between Portuguese and Italian mothers regarding Social Support ( $F_{(3, 94)}=6.32$ ,  $P=0.014$ ,  $\eta^2=0.065$ ), Religious Faith and Humor ( $F_{(3, 94)}=20.06$ ,  $P=0.001$ ,  $\eta^2=0.18$ , higher values for Portuguese mothers) and Avoidance Coping ( $F_{(3, 94)}=3.30$ ,  $P=0.06$ ,  $\eta^2=0.035$ , higher values for Italian mothers). Regarding child's disease, the only statistically significant difference was in Religious Faith and Humor ( $F_{(3, 94)}=7.49$ ,  $P=0.007$ ,  $\eta^2=0.076$ , higher values for mothers of children with chronic disease). The findings of specific cultural transversalities provide the basis for reflection on important factors emerging on the relationship between physi-

cians and parents. In fact, mothers' coping abilities may allow health workers involved in a child's care not only to understand how parents face a distressful event, but also to provide them with professional support.

## Introduction

A child's chronic and/or oncological disease is a cause of emotional distress for all parents all over the world.<sup>1-10</sup> Such an event is not easy to elaborate at an emotional or cognitive level, or to integrate into a person's psychic system.<sup>11</sup> This distress may affect the process of coping with the risk condition experienced. Such a process represents the adaptive management that will help safeguard the child's wellbeing and his or her adjustment to a disease.<sup>10,12</sup> Actually, most of the literature in this field has focused on coping strategies and adjustment outcomes of the parents of the sick child or adolescent.<sup>1,4,8,10,13-16</sup>

As an extension of these studies, this research project focuses on maternal coping strategies in response to a child's severe disease (chronic or oncological) and, at the same time, on the possible relationship between such strategies and cultural differences. It has been designed as a cross-cultural study aimed at investigating coping strategies of Italian and Portuguese mothers of children suffering from chronic neoplasias and other pathologies. This approach arose from the consideration that people's coping and behavior strategies are always guided by personal representations (in this case referred to health/illness) that, in their turn, are guided by the social representations provided by the individual cultural context.<sup>17-20</sup> Cultural variables such as origins, religion, costumes and traditions affect the family's adjustment behavior and their strategies of coping with a chronic pathology as well as with a tumor. It is possible to claim that maternal response to a child's disease has a collective rather than an individual nature. Therefore, parents' inclination to respond more or less actively to the critical issues brought up by the child's disease and its treatment may be ascribed to the social representations of disease and health.

This cross-cultural research project takes these considerations as a starting point, but it also takes into account the typology of disease, either oncological or chronic, because most studies in the field only focus on one parental functioning variable according to a single pathology and its distinct phases. This is a tendency that underlines the connection between particular pediatric pathologies and the relevant impairments of a child's caregivers. For this reason, when the child suffers from an oncological pathology, what has usually been

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considered is the parents' recurring fear of death, as well as the parents' physical and/or mental fatigue that often result from dealing with chronic conditions.

This study also explored maternal coping strategies to understand whether the mother displays not only specific but also transversal tendencies when dealing with a child's different pathologies. Furthermore, certain severe chronic diseases were compared with tumor, which nowadays is mostly considered a curable rather than a chronic pediatric pathology.<sup>21,22</sup>

The comparison between Italian and Portuguese data was made for transversal reasons and, at the same time, due to the differences between them. Portuguese pediatric hospitals admit several multiethnic patients coming from different countries such as Brazil, Rumania, Cape Verde Islands, the Ukraine, the United Kingdom, China and New Guinea, hence *nationality* is a very complex variable. From a transversal point of view, however, Portugal is characterized by the strong influence of the Catholic Church, and the spiritual dimension and religious beliefs associated with Catholicism may affect the representation of health/disease. Finally, the University of Porto and the University of Palermo have been

working together on scientific projects for some years.

The reading model used for this research project interprets coping strategies as behavioral, mental and emotional responses aimed at minimizing negative feelings connected with distressful situations.<sup>23,24</sup> They are strategies of *attentive and vigilant coping*, as defined by the literature,<sup>25-27</sup> and they refer to: i) *problem-focused mechanisms* that, in this case, may help the parents' effort to solve the child's problems;<sup>24,28-30</sup> ii) *emotional-experience focused mechanisms* to reduce emotional stress;<sup>24,28-30</sup> and iii) *potentially maladaptive mechanisms* that do not minimize negative feelings.<sup>23,31</sup>

This study investigated five coping strategies.

- i. *Social Support*: a search for a partner's or other family member's empathy and for information about the critical situation, as well as to the chance to unburden oneself. It may reduce the levels of psychological distress that are caused by the disease and its treatment.<sup>32</sup>
- ii. *Avoidance Coping*: an escape from the stressors using a sense of humor, and the denial of or the detachment from the real situation, even if only for a limited amount of time.<sup>15</sup>
- iii. *Positive Aptitude*: the acceptance of reality. It also refers to the positive reinterpretation of the critical event, as well as to the tendency to adopt positive thoughts and behavior.<sup>4,33,34</sup>
- iv. *Religious Faith and Humor*: a coping strategy characterized by the search for help and relief in religious faith and spirituality, aimed at promoting positive as well as reducing negative thoughts.<sup>5,35</sup>
- v. *Active Coping*: emphasizing activities that enhance the management as well as the control of the distressing event.

## Materials and Methods

### Research objectives

The aim of this between-subjects research project was to detect differences and cross-cultural (transversal) elements among the coping strategies used by Portuguese and Italian mothers to manage the critical events connected with a child's distinct pathologies. Hence, given this objective, the research hypotheses are to be found in verifying the presence of statistically significant differences among the coping strategies such as *Social Support*, *Avoidance Coping*, *Positive Aptitude*, *Active Coping*, *Religious Faith and Humor*, used by both Italian and Portuguese mothers of children suffering from an oncological or a chronic pathology, which may be ascribable to: i) the variable *maternal country of origin*; ii) the variable *typology of a child's disease*; iii) the

combination of the two variables: *country of origin* and *child's disease*.

### Participants

Participants in this study were two groups of mothers of children suffering from a severe pathology (total n=95) divided according to nationality (Portuguese or Italian) and the typology of the child's pathology. More specifically, the two independent groups were made up as follows: i) a group of 36 Portuguese mothers (average age 39.3 years, range 33-52 years, SD=4.6) of whom 44.4% had a child suffering from an oncological pathology and 55.5% had a child suffering from a chronic disease (average age of children 10.3 years, range 6-17 years, SD=4.1); ii) a group of 59 Italian mothers (average age 37.7 years, range 26-44 years, SD=4.5) of whom 42.4% had a child suffering from an oncological pathology (mainly acute lymphoblastic leukemia) and 57.6% with a child suffering from a chronic disease (average age of children 9.8 years, range 6-16 years, SD=3.5).

In relation to the socio-cultural background of both groups, the mothers belong to a social middle class (on average to a one-income family) and have a secondary school education (average 13 years of schooling, SD=8 years)

*The study was conducted in accordance with the ethical research guidelines established by the Declaration of Helsinki in 1964. The informed consent of participants was obtained after they were given a clear explanation of the study protocol.*

Cases of congenital heart disease, diabetes and asthma were included in the category of *chronic pathologies* according to certain common characteristics,<sup>36</sup> such as the high incidence rate in the Italian and Portuguese pediatric population, and the use of pharmacological treatments that significantly affect the management of the family's everyday life.<sup>1,37</sup>

### Measures and procedures

The coping strategies activated by the mothers in order to get through the distressing situations caused by their children's disease were measured by means of the Italian and Portuguese versions<sup>29,30</sup> of the Coping Orientation to the Problems Experienced (COPE) Inventory proposed by Carver *et al.*<sup>31,38</sup> This is structured into 15 scales: active coping, planning, suppression of competing activities, restraint coping, seeking social support for instrumental reasons, seeking social support for emotional reasons, positive reinterpretation and growth, acceptance, turning to religion, focus on and venting emotions, denial, behavioral disengagement, mental disengagement and alcohol-drug disengagement, and one extra strategy, humor.

More specifically, the COPE-New Italian Version<sup>29,30</sup> is a standardized and validated self-report questionnaire made up of 60 items

arranged on a 4-point Likert scale (1=I usually don't react like this; 4=I often react like this). The internal structure of the tool, validated on a sample of 458 Italian subjects (mean age 49.2 years, SD=16.2) was obtained through a factorial analysis that detected the above-mentioned 5 factors/strategies: social support, avoidance, positive aptitude, orientation toward problem, and transcendent orientation. Moreover, the Italian questionnaire has good internal consistency (Cronbach's alpha >0.70; coefficients of correlation among different items -total r>0.30), and good test-retest reliability (test-retest=>0.70).

In relation to the Portuguese adaptation of COPE, following the recommendations by Carver,<sup>38</sup> the 15 scales (using scale totals as raw data) were submitted to data reduction and five main components have been extracted, explaining 61.65% of total variance (Table 1 presents the rotated principal component factor analysis not the 15 scales).

These five coping second-order factors were denominated as follows: (I) Avoidance Coping, (II) Social Support, (III) Active Coping, (IV) Positive Aptitude and (V) Religious Faith and Humor. The alpha coefficients ranged from acceptable to very good (range 0.66-0.82).

In general, the five factors joined the original dimensions that assess similar concepts defined by Carver *et al.*<sup>31</sup> since the structure was similar to the original. Also, the results of the factor analysis obtained in this study are very similar to those found by Sica *et al.*<sup>29,30</sup> In fact, two differences are observed. The first regards the Restraint scale, that is in the same factor of the scale Active Coping (also including Planning and Suppression of competing activities), while in the Sica *et al.*<sup>29,30</sup> study, Restraint comes together with Acceptance and Positive Reinterpretation and is included in the so-called Positive Aptitude factor. The other difference concerns the Religion scale. In the previous Italian study,<sup>29</sup> Religion was loaded on its own in one factor while in the present study, Religious Faith comes along with Humor, in accordance with the most recently published Italian report,<sup>30</sup> for the so-called Transcendent Orientation factor. The other factors have the same composition.

### Statistical analyses

The data were previously tested to verify the possible application of parametrical tests. The Kolmogorov-Smirnov's test was used to verify the normality of the distribution of the coping strategies scores ( $P>0.05$ ), and the Levene's test to verify the homogeneity of the variances between the groups (homoscedasticity,  $P>0.05$ ). The data then underwent a descriptive statistical analysis through the Statistical Programme for the Social Sciences (SPSS 16.0) for Windows.

An analysis of a multivariate variance

(MANOVA) through continuous variables, obtained by the COPE questionnaire, 2 (country of origin)  $\times$  2 (oncological/chronic disease), was conducted to analyze differences in the use of coping strategies between Italian and Portuguese mothers in response to different children's diseases. Scores were analyzed to detect differences among the different scales (dependent variables), considering the country of origin and the typology of disease as independent variables. The main effect of each independent variable (country of origin/child's disease) and the combined effect of the two (interaction effects) were also analyzed.

## Results

A two-way between-groups multivariate analysis of variance was performed to investigate country of origin (Portugal and Italy) and child's disease (oncological and chronic) in mothers' coping strategies. Five dependent variables were assessed: Avoidance Coping, Social Support, Active coping, Positive Aptitude, and Religious Faith and Humor. The effects were significant with regard to the single variables of country of origin (Wilks  $\lambda_{(5, 87)}00.76$ ;  $P=0.001$ ) and child's disease (Wilks  $\lambda_{(5,87)}00.84$ ;  $P=0.009$ ) as well as with regard to the interaction between country of origin  $\times$  child's disease (Wilks  $\lambda_{(5, 87)}00.74$ ;  $P=0.001$ ) (Table 2).

There was a statistically significant difference between Portuguese and Italian mothers regarding *Social Support* [ $F_{(3, 94)}=6.32$ ,  $P=0.014$ ,  $\eta^2=0.065$ ], with Portuguese mothers presenting higher values (Portuguese mothers: mean 33.30,  $SD=6.07$ ; Italian mothers: mean 29.49,  $SD=7.87$ ), on *Religious Faith and Humor* [ $F_{(3, 94)}=20.06$ ,  $P=0.001$ ,  $\eta^2=0.18$ ], also with Portuguese mothers presenting higher (mean 33.36,  $SD=6.07$ ) values than Italian mothers (mean 29.46,  $SD=8.08$ ) (Tables 2 and 3). Differences between these two groups almost reach significant values on *avoidance* ( $F_{(3, 94)}=3.30$ ,  $\eta^2=0.035$ ;  $P=0.06$ ), with Italian mothers presenting higher mean scores (Portuguese mothers: mean 22.36,  $SD=4.40$ ; Italian mothers: mean 25.59,  $SD=7.61$ ) (Tables 2 and 3).

Considering the type of child's disease, the only statistically significant difference was in *Religious Faith and Humor* ( $F_{(3, 94)}=7.49$ ,  $\eta^2=0.076$ ;  $P=0.007$ ), with Italian and Portuguese mothers of children with chronic disease presenting higher values (Tables 2 and 3).

These results are confirmed by the interaction effects between the two independent variables (country of origin and child's disease). Indeed, there is a significant statistical interaction effect between mother's Portuguese nationality and child's chronic disease, in relation to *Social Support* and *Religious Faith and*

*Humor*, as well as between mother's Italian nationality and child's chronic disease in relation to *Avoidance Coping* (Table 2).

## Discussion and Conclusions

Results of the data analysis revealed some interesting topics that form the basis for reflection about certain elements of specificity and transversality of the coping strategies used by

parents and, in particular by the mother, to manage the distress related to a child's disease.

Among the differences due to *nationality*, it stands out that Portuguese mothers have had a higher tendency to use active and adaptive coping strategies that are mainly focused on controlling their negative emotions. In fact, they have resorted to social support in order to receive understanding, information, suggestions, assistance and advice as to how to manage the situation, as well as to unburden themselves of their feelings and fears.

**Table 1. Principal component analysis: scale loadings, explained variance and internal consistency.**

	Coping strategies				
	I	II	III	IV	V
Behavioral disengagement	0.78				
Denial	0.78				
Mental disengagement	0.64				
Substance use	0.55				
Use of emotional social support		0.87			
Use of instrumental social support		0.78			
Focus on and venting of emotions		0.61			
Active coping			0.76		
Restraint			0.64		
Suppression of competing activities			0.59		
Planning			0.55		
Positive reinterpretation and growth				0.77	
Acceptance				0.63	
Religious coping					0.80
Humor					0.66
% variance explained	14.58	14.00	13.26	10.60	9.21
Alpha coefficient					
Avoidance coping					
Social support	0.77	0.82	0.75	0.66	0.82
Active coping					
Positive aptitude					
Religious faith and humor					

**Table 2. Mother's coping strategies: between-subjects test (n=95).**

Coping strategies	Effect		
	Country of origin (Portugal/Italy)	Child's disease (oncological/chronic)	Country of origin Child's disease
Social support	$F_{(df3, 94)} 6.32$ Sign 0.01	$F_{(df3, 94)} 0.69$ Sign 0.40	$F_{(df3, 94)} 3.98$ Sign 0.04
Avoidance	$F_{(df3, 94)} 3.3$ Sign 0.06	$F_{(df3, 94)} 0.25$ Sign 0.61	$F_{(df3, 94)} 6.46$ Sign 0.01
Positive aptitude	$F_{(df3, 94)} 0.05$ Sign 0.82	$F_{(df3, 94)} 1.96$ Sign 0.16	$F_{(df3, 94)} 0.11$ Sign 0.73
Active coping	$F_{(df3, 94)} 1.72$ Sign 0.19	$F_{(df3, 94)} 0.43$ Sign 0.51	$F_{(df3, 94)} 0.20$ Sign 0.65
Religious faith and humor	$F_{(df3, 94)} 20.06$ Sign 0.001	$F_{(df3, 94)} 7.49$ Sign 0.007	$F_{(df3, 94)} 4.92$ Sign 0.02

This finding is also significant if related to the transversality ascribable to the diversity of the child's pathologies, because it shows that social support may allow the parent to react better to psychological distress independently of the child's disease, in contrast to some studies that considered it particularly helpful in pediatric oncological cases.<sup>4,5,34</sup>

The data regarding the mothers' need of social support show how significant it is for the well-being of parents facing a child's severe pathology to receive help or, at least, not to feel alone while they are managing such critical events. Therefore, according to other studies in the field,<sup>8,39-42</sup> social support may be considered as one of the primary moderator (buffers) and mediator between a stressful condition and psychological well-being. The more supported a mother is by other important figures such as relatives, friends and hospital professionals, the more confidently she will be able to guide a child who has to face and manage his or her own disease. Hence, the social support aimed at mothers is also an external protection factor for the child's adjustment process.<sup>8</sup>

A mother who does not feel alone may be more easily integrated and actively involved in the process of cure-care of her child and, therefore, she may be more willing to develop the therapeutic alliance known as adherence, a synergic relation beyond compliance useful to the child's well-being.<sup>10,43,44</sup> Obviously, this gives some pause for thought about the way the process of cure-care is to be managed. The operators involved, such as physicians, nurses, psychologists, hospital social workers, etc., should never minimize the importance of an effective communication channel with parents that may help them understand the critical events and offer support to meet their needs.<sup>8,10,45</sup> Therefore, improved effective practices of integration and synergy-based support between the cure and care, rather than separation and delegation, should be provided in settings in which pediatric patients with oncological and chronic pathologies are cared for.<sup>46</sup>

Portuguese mothers have also looked to religion (the transcendent) to try and control their distress by praying for their children. This strategy could be explained by consideration of how important the religious and spiritual dimension is in Portugal and how it may affect the maternal representation of a child's health/disease, and the mother's efforts to adjust whatever the disease is. Therefore, as some previous studies of the field stated,<sup>5,36</sup> it is possible to claim that the belief in God, in any form of spirituality, would seem to help Portuguese mothers remove their negative thoughts in favor of positive thinking.

The inclination to resort to spiritual and transcendental resources also seems to be linked to the data concerning social support. It

**Table 3. Descriptive statistics (n=95).**

Strategies	Child's disease	Portuguese mothers (n=36)		Italian mothers (n=59)	
		Mean	SD	Mean	SD
Social support	Oncological disease	32.87	6.62	28.44	7.99
	Chronic disease	33.65	5.76	30.26	7.80
	Total	33.30	6.07	29.49	7.87
Avoidance	Oncological disease	24.18	4.23	23.20	4.18
	Chronic disease	21.40	4.24	27.35	9.04
	Total	22.36	4.40	25.59	7.61
Positive aptitude	Oncological disease	36.12	6.07	34.08	4.09
	Chronic disease	32.20	5.92	34.76	5.63
	Total	33.94	6.22	34.47	5.00
Active coping	Oncological disease	35.81	4.88	33.80	5.43
	Chronic disease	34.45	4.74	33.55	5.81
	Total	35.11	4.77	33.66	5.60
Religious faith and humor	Oncological disease	32.87	6.62	26.75	8.41
	Chronic disease	33.65	5.76	31.51	7.25
	Total	33.36	6.07	29.46	8.08

is the mother's need that leads her to look for outside help rather than looking for solutions within herself, although in this case she does not seek help in people but in abstract elements. Besides showing the importance of support aimed at parents, these data provide the basis for further reflection on the significance of their involvement respecting and recognizing their religious and ethical dimension. Therefore, any effective supportive practice should aspire to satisfy the human needs<sup>46</sup> of all parents of a sick child.

Italian mothers mainly used the *avoiding* and *detachment* strategies that lead them to behave as though the stressful event had never occurred. This reaction could be ascribable to the feeling of helplessness that is often displayed in the mother of a child with pathology. As shown in the literature,<sup>47,48</sup> since a child's disease is a distressing event that is extremely difficult for parents to handle and/or accept, the mother activates a sort of mental detachment involving herself in other situations in order to minimize the efforts to manage and cope with the critical event. It would seem, furthermore, that such a response to a chronic disease is independent of the maternal reference cultural context. Therefore, a pediatric condition caused by an infantile diabetes or a kidney failure is, for the mother, a daily challenge that becomes part of her family routine, and that consequently leads her to re-define her own parental competence.<sup>8,17,49</sup> The mother learns how to live with a child's disease, merging together the child's care with the cure of the pathology, eventually succeeding in lowering her feeling of continuous threat. Obviously, the persistence of such a coping strategy would make it more difficult to create and maintain the therapeutic alliance with

medical staff that is so important to the quality of the process of the cure of the child.<sup>43,50</sup>

With relation to cultural transversalities, few coping strategies focused on the problem, such as strategies of planning as well as of active management of the event, were recorded.

Hence, it seems important that the support aimed at the mothers who experience such a stressful condition should be constructive and should help mothers re-define their representations of their child's disease that are dysfunctional to the management of the critical events in which they are involved.

However, the study was limited by the similarity between the two cultures analyzed (Italian and Portuguese). Therefore, further studies comparing different cultures have already been planned.

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