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Pain and Distress in Inpatient Children According to Child and Mother Perceptions

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Abstract: The present study aimed to examine the associations between pain experiences in children with respect to self-perceptions and mother perceptions and stress indicators. The study sample included 30 hospitalized children of 6-12 years of age and the children’s mothers. The Faces Scale-Revised, Child Stress Scale, and Inventory of Stress Symptoms for Adults instruments were used. A data analysis is performed via descriptive statistics and correlation analyses. The results showed that higher pain intensities in children was associated with higher stress, psychological and psychophysiological reactions in children. Higher pain intensities in children also increase mothers’ perceptions of pain in children. Seventy percent of the mothers studied in the sample presented clinical indicators of stress. Psychological support during child hospitalization should address the management of pain and stress in children and stress in mothers.

Keywords: pain, stress, hospitalization, mother-child relations

Dolor y Estrés en Niños Hospitalizados Según la Percepción de los Niños y sus Madres

Resumen: El estudio examinó las asociaciones entre la experiencia del dolor en los niños, considerando la auto-percepción y la percepción de las madres, y los indicadores de estrés en los niños y sus madres. La muestra abarcó a 30 niños hospitalizados de 6-12 años y sus madres. Los instrumentos utilizados fueron: Escala de Faces Revisada, Escala de Estrés Infantil e Inventario de Síntomas de Estrés para Adultos. Los datos fueron sometidos a análisis estadístico descriptivo e correlacional. Respecto al dolor, cuanto mayor es la intensidad del dolor evaluado por el niño, mayores son el estrés y las reacciones fisiológicas y psicológicas de los niños. Cuanto mayor es el dolor percibido por el niño, mayor es la percepción de la madre acerca del dolor en sus niños. El 70% de las madres muestran indicadores clínicos de estrés. El apoyo psicológico durante la hospitalización de los niños debe tratar del manejo del dolor y el estrés experimentado por el niño, así como el estrés de las madres.

Palabras clave: dolor, estrés, hospitalización, relaciones madre-niño

Illnesses can negatively affect children and their family members. Children who contract illnesses are exposed to stressful circumstances that alter their daily lives. Such changes include interruptions the child’s daily routine, the presence of unfamiliar and threatening equipment, the need to endure painful treatments and diagnostic procedures, contact with unknown persons and helplessness over such circumstances (Barros, 2003). Therefore, when hospitalization is required, associated transitory or permanent losses can magnify the stressful aspects of an illness.

According to the World Health Organization (WHO) (2005), chronic illnesses include one or more of the following characteristics: they are permanent, they generate residual incapacities/deficiencies, they are caused by irreversible pathological changes, and they require the delivery of special rehabilitation training or extended patient supervision, observation and care. Chronic diseases may trigger stronger psychological and physical stress responses than acute diseases (Marin, Chen, Munch, & Miller, 2009). The term stress can be understood as a state of tension that causes internal disruption in an individual. Stress responses occur as a defensive reaction to situations.

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in which an organism’s incapacity to respond to a situation exceeds the adaptive capacity (Lipp, 2001).

According to Lipp (2002), there are four stages of the stress response: (a) alert, constituting a positive phase of stress during which the subject automatically prepares for action; the production and use of adrenaline renders the individual stronger and more vigilant and motivated; (b) resistance, which manifests after the alert stage has been maintained for long periods of time or when new stress triggers manifest, forcing the body into action to prevent the body’s energy from depleting; (c) quite exhaustion, when tension levels exceed a manageable extent; physical and emotional resistance begins to decline, and moments of normal functioning are followed by moments of severe discomfort; the person becomes anxious and feels emotionally unbalanced, rendering the individual vulnerable to disease; and (d) exhaustion, the most severe phase of stress that is considered pathological; periods of intense inner imbalance manifest during which the individual is severely depressed, is unable to work or concentrate and makes hasty decisions; this phase may render the individual susceptible to serious illness.

In the case of mothers of sick children, the presence of maternal stress was detected in half of the caregivers of children with leukemia, with the resistance phase and psychological symptoms of stress being the most prominent traits (Del Bianco Faria & Cardoso, 2010). An assessment of stress levels in mothers accompanying hospitalized children for surgical procedures also revealed that 82% of a sample of 54 mothers presented clinical indicators of stress. In these cases, the resistance phase with psychological symptoms was the most frequently detected state among mothers (Carnier, Rodrigues, & Padovani, 2012).

Parents of hospitalized children with chronic illnesses respond to these circumstances in several ways, and their reactions depend on factors such as past experiences with crisis situations and health problems, socioeconomic levels, knowledge levels, education levels, and the quality of health services and support networks (Grau & Fernández Hawrylak, 2010). Parent stress levels are also related to certain variables such as their child’s age, gender, diagnosis, length of stay and previous experiences of hospitalization (Rocha, 2012).

Stress symptoms in children are similar to those of adults in several respects, and when excessive, they may have serious psychological effects on children (Lipp & Romano, 1987). Repeated exposure to stress and risk can interrupt the development of the prefrontal cortex while causing emotional, memorization and attention problems and inhibitory behavioral control problems (Shonkoff, 2012). According to this author, stress symptoms can take the following forms: normative stress, an essential aspect of healthy development; tolerable stress, during which highly stressful conditions are present but managed via effective coping skills that are facilitated through adult support; and toxic stress, which involves the excessive and/or prolonged activation of stress response systems in the absence of protection, support and proper care from responsible adults.

Toxic stress can program physiological memories of lifelong risk, thus having long-term effects on children (Shonkoff, 2012). This form of prolonged or excessive stress during childhood leads to physiological disturbances that promote the development of diseases later in life. Early childhood adversities are associated with the appearance of several problems in adulthood such as increased inflammation (Miller, Chen, & Parker, 2011), cardiovascular disease (Agrawal et al., 2009), liver cancer (Berasain et al., 2009), asthma (Chen & Miller, 2007), chronic obstructive pulmonary disease (Yao & Rahman, 2009), autoimmune diseases (Li, Zhou, Feng, & Su, 2009), poor dental health (Poulton et al., 2002) and depression (Howren, Lamkin, & Seas, 2009). Hospitalized children are exposed to stressful and painful experiences that result from both illness symptoms and invasive and painful medical procedures conducted as part of treatment routines, which in turn exaggerate stress reactions.

According to the International Association for the Study of Pain (IASP), pain can be defined as a sensation or unpleasant emotional experience associated with actual tissue damage (Merskey, Albe-Fessard, & Bonic, 1979). Pain interferes significantly with an individual’s quality of life and considerably affects child development. There is a positive relationship between acute pain and anxiety, fear and stress, and there is a positive association between chronic pain and feelings of helplessness and depression (Duffon, Dunn, & Compas, 2009). Anxiety, stress and fear trigger activation systems (alarm signal) that can amplify one’s pain and provoke feelings of helplessness during painful experiences. Persistent pain can interfere in the social development of children and adolescents to the extent that it prevents children from engaging in activities with their peers while increasing child dependency on caregivers (von Baeyer & Spagrud, 2003). Chronic diseases and treatments constitute major sources of stress and pain for children and adolescents, and ways that parents mitigate these factors may affect child and adolescent adaptation responses (Compas, Jaser, Dunn, & Rodriguez, 2012). Parents can have either a positive or a negative influence on experiences of pain in children.

The Socio-communication Model of Infant Pain is a comprehensive model of child pain that contextualizes its evaluation and management (Craig, Lilley, & Gilbert, 1996; Craig & Pillai-Riddell, 2003; Prkachin & Craig, 1995). This model suggests that a child’s extended family, community and culture are related to both the child and the caregivers of the nuclear family. According to Chambers (2003), researchers and clinicians who are concerned with child pain should develop studies on complex relationships between parents and children and examine how family relationships influence and are influenced by child pain. Although a number of studies have found maternal variables that may manage infant pain such as stress (Lipani & Walker, 2005), anxiety (Chambers, Craig, & Bennett, 2002) and the presence of psychopathology (Pillai-Riddell, Stevens, Cohen, Flora, & Greenberg, 2007) few studies have examined these
variables in the context of hospitalization for the purposes of reiterating how these variables are associated with pediatric pain. The present study aimed to examine the associations between pain experiences in children with respect to self-perceptions and mother perceptions and stress indicators.

**Method**

**Participants**

The study convenience sample consisted of 30 children of both genders of between six and 12 years of age and their respective mothers. The children had been admitted to a pediatric ward in the Hospital das Clínicas at the Faculdade de Medicina de Ribeirão Preto of the Universidade de São Paulo (HC-FMRP-USP). The following study inclusion criteria were used: school age between six and 12 years, enabling the researchers to obtain a self-report to assess pain and stress levels according to child perceptions; indicators of appropriate cognitive and communicative functioning; a minimum length of stay of three days that could include different pediatric clinical or surgical treatments; and the presence of the child’s mother as a companion throughout the hospitalization period. Additionally, the participants provided consent to participate in the study. Accordingly, the following exclusion criteria were applied: children who had experienced less than three days of hospitalization; children or mothers with poor indicators of cognitive and communicative functioning; and children under the influence of medications that may alter their level of consciousness (as assessed through patient medical records).

Throughout the data collection period (from March 2011 to December 2012), 93 children of the requisite age range were hospitalized. Forty-seven of the children did not meet the inclusion criteria: 26 children had been hospitalized for a shorter period than that of the study parameters, and 21 children were admitted without their mother’s accompaniment. Of the remaining 46 children, 13 were excluded because eight of the children and five of the mothers presented poor cognitive indicators. While the eligible sample included 33 children, three mothers refused to participate in the study, resulting in a final sample of 30 children.

**Instruments**

*Faces Pain Scale - Revised (FPS-R)* (Hicks, von Baeyer, Spafford, van Korlaar, & Goodenough, 2001) Brazilian Portuguese version is validated for the Brazilian population (Charry, Piola, Linhares, & Silva, 2014; Poveda, Silva, Passareli, Santos, & Linhares, 2003). The instrument measures pain intensities on a scale of 0-10 and presents strong psychometric qualities (von Baeyer, 2006).

*Child Stress Scale (CSS)* (Lipp & Lucarelli, 1998) is composed of 35 items related to stress reactions that may present psychological and psychophysiological dimensions.

*Lipp Stress Symptoms Inventory for Adults (LSSI)* (Lipp, 2000), consisting of 53 items, evaluates clinical signs of stress, symptom types (somatic or psychological) and the phases of stress symptoms (alert, resistance, near exhaustion, and exhaustion).

*Brazil Economic Classification Criterion (CCEB)* of the Brazilian Association of Research (Associação Brasileira de Empresas de Pesquisa - ABEP, 2010) classifies family socioeconomic status into the classes A1, A2, B1, B2, C, D and E through an analysis of household characteristics (the presence and availability of comforting household items, and the education level of the head of household).

*Additional Scripts* were used to describe the children based on age, gender, diagnosis or diagnostic hypothesis, length of stay, clinic location and type of treatment. Other scripts describe family characteristics such as parent traits (age, education, occupation, number of children, marital status, and number of persons in the household).

*Medical records* were used to supplement characterization script data with information on hospitalization period length, reasons for hospitalization, and diagnostic and pediatric clinics responsible for hospitalization.

**Procedure**

**Data collection.** All of the participants were contacted by the researcher (psychologist specializing in Pediatric Psychology) and invited to participate in the study. After the signing of the Informed Consent Form, the instruments were applied to each mother and child separately in the psychology office of the respective ward. The mother responded to Child and Family Characterization Scripts, CCEB-ABEP, FPS-R and LSSI. After a rapport was established, the child responded to the FPS-R and CSS. While applying the FPS-R, respondents were asked to remember the worst pain that they had experienced or perceived in the last 24 hours until the moment of the evaluation (recalled pain).

**Data analysis.** First, the data were subjected to descriptive statistical analysis. Relationships between maternal stress, child stress, children’s pain perceptions, and mothers’ pain perceptions were analyzed using different tests: Pearson correlation (two continuous numerical variables), Qui-square (two categorical dichotomous variables) and Mann-Whitney (one categorical dichotomous variable and one continuous variable). The analyses were processed using the Statistical Package for Social Sciences (SPSS, version 19.0, Chicago, IL, USA). The significance level of the study was 5% ($p \leq .05$).

**Ethical Considerations**

The study was approved by the Research Ethics Committee of the Hospital das Clínicas of the Faculdade de Medicina at Ribeirão Preto - Universidade de São Paulo (Case No. 10709/2010).
Results

Sample Characteristics

The sample was composed of 53% girls (n = 16) and 47% boys (n = 14), and the average age was nine years (SD = 2). Children were hospitalized in eight wards, namely: Nephrology (20%), Endocrinology (20%), Pneumology (17%), Gastroenterology (17%), Rheumatology (13%), Cardiology (7%), Hematology (3%) and Immunology (3%). The reasons for hospitalization included clinical worsening of chronic disease (50%), diagnostic investigation (34%), surgery (13%), and routine disease treatment (3%). Most of the families were composed of a couple in a stable relationship (80%). Most of the mothers had completed Elementary School (47%) or High School (37%), and most were homemakers (54%). The rest of the mothers held a regular job (43%) or were unemployed (3%). Most of the fathers worked outside of the home (77%), 20% were unemployed, and 3% were retired. The majority of the fathers had completed Elementary School (33%) or High School (33%), reflecting similar educational levels as the mothers. According to CCEB-ABEP socio-economic criteria, families were classified under level C (37%), B (27%), D/E (23%) and A (13%) categories.

Evaluations of Child Pain

The average FPS-R scale score for perceived pain in children was 5 (SD = 3.39), and an average value of 6 was acquired for the mothers (SD = 3.35). Figure 1 shows that for scores indicating that a child felt no pain (score = 0) and those that detected extreme pain (score = 10), there was greater agreement between responses given by mothers and children. Intermediate values of pain, however, diverged with respect to the following: score = 2 (30% of the mothers reported this pain intensity, while only 20% of the children reported this value); score = 4 (20% of the children reported this pain intensity, whereas approximately 13% of the mothers cited this value); score = 6 (20% of the mothers reported this pain intensity, while only 10% of children referred to this value); score = 8 (20% of the children reported this pain level, whereas only 7% of the mothers reported this pain level). These data show greater agreement between mother and child identifications of minor or extreme levels of pain. Mother and child ratings for moderate pain levels instead diverged and showed less agreement.

Reinforcing the results shown in Figure 1, a significant positive correlation was found between overall pain scale FPS-R scores given by the children and mothers. The higher the pain score provided by a child, the greater the pain score assessed by his or her mother (r = .57; p ≤ .001).

Indicators of Stress in Children and Mothers

The data shown in Table 1 illustrate that 33% of the children studied exhibited positive clinical indicators of stress. With respect to the predominant type of reaction that the children exhibited when presented with stressful situations, psychological and psychophysiological reactions were more common relative to physical and psychological reactions accompanied with depressive components.

Unlike the children, most of the mothers exhibited positive clinical indicators of stress. Most of the mothers were
experiencing resistance or exhaustion stress levels (63%). Half the mothers had developed psychological symptoms in response to stress. Reinforcing the data shown in Table 1, it was found that no statistically significant association exists between the presence of stress in mothers and the existence of stress in children for the examined sample.

**Relationship Between Child Pain and Stress Levels Among Children and Mothers**

A statistically significant correlation was found between pain scale FPS-R scores provided by the children, total stress scores \((r = .42; p \leq .02)\) and physical \((r = .44; p \leq .02)\) and psychological \((r = .46; p \leq .01)\) reaction scores. Higher child-reported pain scores correlated with higher total child-reported stress scores. Additionally, higher child-reported pain scores correlated with higher physiological and psychological stress reaction scores.

On the other hand, no significant correlations were found between psychological reactions items with a depressive component and psychophysiological reactions to stress according to the Child Stress Scale and based on pain scores provided by the children. No statistically significant difference was found between children with stress symptoms and those without such symptoms with respect to pain sensations (children with stress, medium FPS-R score = 7.20; children without stress, medium FPS-R score = 5; \(p \leq .09\)). Likewise, no statistically significant difference was found between mothers who presented stress symptoms and those who did not present such symptoms with respect to maternal perceptions of child pain levels (mothers with stress, \(M = 4.95\); mothers without stress, \(M = 4.67; p \leq .84\)).

**Discussion**

With respect to perceived pain, average pain scores reported by the mothers and children were similar; both values detected the presence of mild to moderate pain 24 hours prior to the evaluation. One must take into account that because these children were hospitalized, several of them may have been medicated for pain relief, which would have lowered their pain levels.

In addition to these similar average values, a relationship between mother and child FPS-R pain scale scores was verified. In this case, higher child-reported pain levels correlated with higher pain scores assessed by their mothers. Mothers were also able to detect whether their children were feeling more or less pain. The relationship between child and caregiver pain perceptions has also been confirmed in other studies based on surveys of children and mothers (Barakat, Patterson, Daniel, & Dampier, 2008; Morrow, Quine, Heaton, & Craig, 2010). The emotional connection between caregivers and children and the primary caregiver’s proximity to his or her child affects perceptions of emotional indicators and of pain experienced by the child (Pillai-Riddell & Craig, 2007). Therefore, primary family caregivers may act as good informants of pain levels experienced by their hospitalized children, as observed previously by Lawrence et al. (2012).

Although parents provide reliable information about the pain of their children, the present study found that there may be small differences between the perception of pain intensity evaluated by the child and by the mother. Comparing the averages of each value in the adopted pain scale (FPS-R), one may notice slight differences in the values of pain assigned by the dyads (child-mother). There was greater similarity between the responses of mother and child when identifying minor (no pain) or extreme (very strong) levels of pain. In the intermediate levels of pain, on the other hand, there was greater discrepancy in the values assigned by mother and child, which indicates the difficulty to identify the nuances in these levels. This aspect was also observed in the study by Chary et al. (2014), which shows that in the Faces Scale, it is harder to evaluate moderate levels of pain than the extremes ones.

The ease of caregivers to evaluate the child’s pain at extreme levels can be better understood through the Social Communication Model of Child Pain (Pillai-Riddell & Chambers, 2007). The model emphasizes variables pertaining to children and caregivers, which are correlated to each other. Additionally, one of the variables related to the children concerns their expression of pain. Children can express pain in many ways, through verbal or non-verbal communication and with a series of motor behaviors, such as crying, moving the body and with facial activities. All of these activities favor the identification of discomfort among children (Pillai-Riddell & Chambers, 2007). Caregivers, in turn, interpret these manifestations of the child. It is possible that the child’s expression of no pain and extremely strong pain present remarkable characteristics, which can be easily interpreted by the caregiver. This model asserts the importance of such interpretation because it determines the behavior and attitudes to be taken in the face of pain. Behaviors such as hugging, giving comfort, talking to the child, requesting medical help or nursing are consistently executed when the mother can evaluate effectively the pain of her child.

Regarding stress levels assessed in the present study, 33% of the 30 children presented clinical indicators of stress that involved psychological and psychophysiological reactions. Our findings echo those obtained by Mendes, Sant’Anna and March (2013). In their study, stress was detected in 38% of 50 children of seven to 12 years of age who had been diagnosed with asthma, and major psychological reactions to stress were detected. The absence of stress in the majority of children examined in the present study may be related to low pain intensities registered for the sample, as a correlation was found between child pain and stress. Nonetheless, the fact that approximately one-third of the children showed signs of stress demonstrates the need to deliver psychological support to facilitate adaptive coping in such situations experienced during hospitalization. Stress
levels in hospitalized children should be seriously considered because, as Shonkoff (2012) shows, excessive or prolonged exposure to stress can severely affect child development.

As expected, the present study found an association between pain and stress; the higher the level of pain reported by a child, the greater the total stress score provided by the children. In turn, higher reported pain levels correlated with a higher prevalence of physiological and psychological responses to stress. It is important to note that while not all stress is caused by pain, pain induces stress in hospitalized children. In addition to its association with stress, other studies have found strong associations between pain and psychological symptoms. These studies suggest that higher pain levels are correlated with considerable increases in anxiety levels (Barakat et al., 2008), depression (Lewandowski, Palermo, & Peterson, 2006), internalizing symptoms (Thompson, Gil, Burbach, Keith, & Kinney, 1993) and fatigue (Gold, Mahrer, Yee, & Palermo, 2009). Data provided in the literature and in the present study reinforce the fact that pain could induce stress and discomfort in children.

Psychological preparations for certain invasive medical procedures can help minimize stress levels in youth patients. Pre-surgical psychological preparations for children have been shown to reduce child stress levels (Broering & Crepaldi, 2011). In addition, other non-pharmacological approaches to pain management such as distraction and relaxation techniques could be applied (Linhares & Doca, 2010). A study by Gil et al. (2003) that examined journal entries that evaluated patient pain and stress levels, moods, activities and health care treatments found that pain induces a significant decrease in mood and high levels of stress. In addition, an association was found between negative moods and stress levels on days when children experienced pain.

Various studies underscore the importance of interventions that help patients cope more effectively with hospitalization (Compas et al., 2012; Jaser & White, 2011; Motta & Enumo, 2010). To mitigate risks to child development, psychological intervention measures should be incorporated among care procedures applied to hospitalized children. This would help youth patients and their families apply adequate coping strategies in response to medical treatment (Motta & Enumo, 2010).

Unlike stress indicators found for the children, most of the mothers surveyed in the present study showed positive clinical indicators of stress. Most of the mothers exhibiting stress symptoms occupied phases of resistance or near exhaustion and presented psychological symptoms in response to stress. According to Lipp (2001), the resistance phase occurs when the body actively attempts to prevent total energy exhaustion. This results from prolonged exposure to stress or increasingly stressful situations. A number of hypotheses can be presented with respect to the high stress and emotional distress levels found among the mothers. First, stress levels among this group may be associated with concerns surrounding the presence of chronic disease in children or on the absence of a diagnosis, as was shown for most of the patients included in the study sample. In addition, mothers may be overwhelmed with the role of accompanying their children over the course of hospitalization. Finally, the maternal stress levels found may be related to external home and family concerns because hospitalization separates the caregiver from her house, from her other children and from her domestic and marital responsibilities.

Our findings complement those of previous studies focusing on the parents of surgical or chronic patients. Stress levels among parents of children undergoing cardiac surgery remained at moderate to high levels throughout the hospitalization period both before and after surgical procedures were performed (Franck, McQuillan, Wray, Grocott, & Goldman, 2010). Stress levels showed no relationship with disease severity. One study showed that clinical indicators of stress, and especially resistance phase and psychological symptoms, were also present in 82% of a sample of 54 mothers of children who were hospitalized for various surgical procedures (Carnier, Rodrigues, & Padovani, 2012). Mothers of children with chronic diseases (leukemia) also present high levels resistance phase stress in combination with psychological symptoms (Del Bianco Faria & Cardoso, 2010).

It must be emphasized that parent anxiety levels reflect typical responses to the presence of chronic disease during childhood, and hence, they do not necessary indicate the presence of psychopathology (Palermo, Eccleston, Lewandowski, Williams, & Morley, 2010). However, it is important to remain cognizant of parent clinical stress to the extent that it can negatively affect family functioning and the emotional and physical functioning of a child in addition to interfering with child treatment decision-making (Palermo et al., 2010). Therefore, parent clinical stress must be considered in Pediatric Psychology to help parents identify and reduce their emotional stress levels at different stages child treatment. Although mothers showed higher levels of stress, only one-third of the children presented clinical levels of stress.

Final Considerations

The present study presents some limitations. The sample was composed of children with various clinical diagnoses, and thus, the specific characteristics of illnesses and treatments may have affected the results. Participants were surveyed after varying periods of hospitalization, which may have affected the pain and stress levels reported. In addition, a convenience sample was used and reports were obtained from only one informant caregiver for each child. Despite these limitations, this study verifies the significant relationship between pain and stress for hospitalized children. The study found that mothers subjected to such experiences may exhibit clinical levels
of stress. However, mothers’ stress levels do not appear to affect perceptions of child pain.

The present study demonstrates that mothers, as primary caregivers, suffer from impacts of child illness and hospitalization and that these individuals need support from health professionals to cope with such stress-inducing situations. Care for mothers is critical because in addition to caring for their children, mothers are the main informants of their children’s physical condition and these individuals mediate the relationship between health professionals and their children. In addition, because pain contributes to stress during child hospitalization, pain levels must be identified, evaluated, and managed appropriately.

Future studies may examine different aspects of pain in addition to pain experiences based on memory. In addition to examining mothers’ perceptions of child pain, future studies may also examine perceptions held by health professionals and other family caregivers. In the realm of intervention, clinical protocols for reducing caregiver and child stress may be investigated in addition to strategies for reducing pain levels in hospitalized children.

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