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# TO BE A CHILD OF A PARENT WITH ALS: VULNERABILITY AND PSYCHOPATHOLOGICAL RESPONSES. A CASE-CONTROL STUDY

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## Background:

The specific impact of various neurological illnesses of parents on the psychological well-being of their children, until recently, has remained largely underinvestigated, with the exception of multiple sclerosis (Blackford et al., 1992) and Parkinson's disease (Morley et al., 2011). The few studies focused on children's responses to parental neurological illnesses have identified some recurrent non-specific developmental outcomes, such as high levels of depression, anxiety, and low self-esteem. Similar reactive features have been observed in children of a parent at the end-life stage (Yahav et al., 2007; Pakenham et al., 2006; Kalb et al., 2007, Bogosian et al., 2010). In contrast, other authors pointed out the peculiarity of how parental medical conditions may affect the children, in terms of specific



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researchers investigating the psychological impact of a devastating, terminal disease like ALS affecting parents on their children.

The aim of our study is twofold: the first objective was to investigate the psychological impact of parental ALS on children's adaptation, in terms of depressive symptoms, adjustment, and personality structure. The second aim was to investigate the adult attachment, parental sense of competence, and children adjustment as perceived by both parents.

#### Method:

Twenty-three children (17 males, 6 females; age: 5-17 yrs) of a parent affected by ALS (7 males, 5 females; age: 31-52 yrs) and both their parents participated in the study. Twenty-three children (matched for age, gender, and birth-order) and their healthy parents participated as control group. Several psychological measures were collected by two trained psychologists during a domiciliary visit. Depressive, behavioural, and emotional problems in children were assessed with the Children Depression Inventory (Kovacks, 1977; Camuffo et al., 1986) and the Youth Self-Report (YSR, Achenbach, 1991; Molteni & Frigerio, 2001). Rorschach Inkblot test, coded according to Exner's Comprehensive System (CS, Exner, 2003), was used as a clinical assessment method of children and adolescent personality, together with Corman's Family Drawing (Corman, 1967). We administered to both parents the following instruments: (1) the Relationship Questionnaire (Bartholomew & Horowitz, 1991) to assess their adult attachment; (2) the Parenting Sense of Competence Scale (PSOC; Gibaud-Wallston & Wandersman, 1978) as a measure of parental sense of competence, in terms of satisfaction and efficacy; and (3) the Child Behaviour Checklist (Achenbach, 1991) to assess how parents perceive their children psychological youth and adaptation. The study was approved by the Ethics Committee of Padova University. Written informed consent was obtained from all adult individuals who participated in the study.

#### Results:

Main results showed that children of a parent affected by ALS exhibit a peculiar pattern of psychological symptoms and features. Among these aspects, statistical analyses revealed higher anxiety, depressive

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nigher in children of ALS parents than control subjects. When considering parenting sense of competence, results showed significant differences in parents of ALS families and in control families. Parents in healthy families were more satisfied about their parenting sense of competence (parental satisfaction is defined as an affective dimension reflecting parenting frustration, anxiety, and motivation; Johnston & Mash, 1989) whereas parents in ALS families perceived in themselves more efficacy (efficacy is described as an instrumental dimension reflecting competence, problem-solving ability, and capability in the parenting role; Johnston & Mash, 1989).

#### Discussion:

Main results showed that children of a parent affected by ALS are characterized by several psychopathological symptoms when compared to children of healthy parents. Some of these psychological features were already described and reported in studies about children of a parent with a serious, progressive neurological disease, such as multiple sclerosis, and /or in children of a parent affected by terminal, oncological illnesses. Other psychopathological characteristics appeared to be specific of children of patients with ALS, such as the significant presence of indices of thought disorder. Recognizing the relevant emotional and practical needs of children of ALS patients could be a fundamental step to build clinical guidelines for ALS, considering this disease as a family disease and the family as a unit.


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