

Vol 7, n 3, 2019

Articles

Living with a chronic disease: the role of maternal mediation in the meaning-making process of their children's Type 1 Diabetes

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Abstract

In this article we present a qualitatively-driven study aimed at exploring the meaning-making processes related to the maternal elaboration of their child's diagnosis of chronic illness. In particular, we tried to examine a specific function of this process in mediating between the mothers' own emotional experiences and the management of their children's illness on a daily basis. We analyzed the narratives of 21 mothers of young patients with type one diabetes mellitus (T1D), aged between 6 and 17 years, collected through the "Sense of Grip Interview". The whole narrative corpus was analyzed using the method developed by Auerbach and Silverstein, called Hypothesis-generating research. We identified four macro-processes in which the mediation function of the maternal meaning-making process is articulated: emotional regulation, collaboration in the therapeutic management, presentation of the disease and social sharing of the disease. The mediation function can act on two different levels: an intra-personal level, by fostering maternal elaboration of the disease; and an inter-personal level, by promoting the child's meaning making process and the actions to manage their disease, in accordance with the developmental competencies acquired by their children.

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Keywords:

Chronic disease; Children; Narrative analysis; Type 1 Diabetes; Mothers.

DOI: 10.6092/2282-1619/2019.7.2187

1. Introduction

The qualitatively-driven study introduced in this work concerns the attempts of exploring how mothers try to make sense of their child's diagnosis of chronic illness. In particular, we focused on mothers of children with Type 1 Diabetes (T1D), which is one of the most common pediatric endocrine/metabolic disorders. 20.000 children and adolescents are affected in Italy, with an increase in incidence of approximately 3% per year (Bonora & Sesti, 2016).

Receiving a diagnosis of chronic disease in pediatric age is a traumatic event, which undermines the stability of the entire family system: the frequent hospitalizations as well as treatment limitations may greatly affect individual and family functioning (Cohen & Marcelli, 2012; Cordella et al., 2016; Drotar, 2006; Manna et al., 2018; Parrello et al., 2014).

In particular, the parents' psychological processes and how they react when their child is diagnosed with a chronic disease have been studied from different theoretical perspectives, emphasizing either the grief dimension (Di Cagno, Gandione & Massaglia, 1992; Guerriero et al., 2016; Lecciso & Petrocchi, 2012; Pianta & Marvin, 1996) or the aspects of resilience (Ferguson, 2002; Kearney & Griffin, 2001). After receiving a diagnosis of chronic disease affecting one's child, parents are asked to deal with various kinds of uncomfortable emotions and thoughts and make decisions in the best interest of the child and themselves (Dicé et al., 2016, 2019). It is often difficult to provide care while trying to cope with the diagnosis of a chronic illness affecting one's child. Pianta and Marvin (1996) highlight that, from an intrapsychic perspective it is necessary to modify the parents' internal representation of their child from the ideal child to the real child (Boursier et al., 2018; Main & Solomon, 1986; Main, Kaplan, & Cassidy, 1985). This is how parents can learn to adapt to the new reality and their new caregiving role.

The initial stage of this process can be viewed as semiotic disorientation, what Bury identified as a breakdown of narrative identity (Bury, 1982). As a reaction the parent may initially adhere to the representation offered by medical discourse, by viewing the child as an "ill person". In fact this label helps to fill the gap in the initial absence of suitable cognitive, affective and relational schemas for understanding the new delusional experience of being the parent of a child with a chronic disease. This is coherent with the sense of relief that several parents feel after receiving the diagnosis, as it give sense to their child's symptoms (De Luca Picione, Dicé & Freda, 2015; De Luca Picione, Martino & Freda, 2017, 2018; Esposito et al., 2016; Martino et al., 2019).

From a semiotic perspective, transition through this initial phase of accustoming the child with the disease can be viewed as the need to place the experience of the lived disease within a coherent framework of sense which enables the person to modulate the emotional impact of diagnosis. Moreover, this search for a senses framework also has an agentic function as it enables the person to develop the emotional, cognitive and behavioral strategies required for facing the disease (De Luca Picione et al., 2019; Freda et al., 2016; Leventhal et al., 1982; Martino et al., 2019; Savarese et al., 2017).

Indeed, Lazarus and Folkman (1984) theorized that the implementation of coping strategies aimed at reducing the emotional distress caused by a stressful event, such as the onset of a chronic condition, is strongly associated with the appraisal processes of the event itself. These appraisal processes are consistent with what we refer to as the meaning-making process.

In the pediatric context, parental meaning making of their child's diagnosis can directly influence the biopsychosocial functioning of the child herself/himself, fostering or, conversely, inhibiting her/his capacity to enact adaptive coping strategies (Elliot et al., 1999; Goethals et al., 2017; Pelicand et al., 2018). As several studies on Health Psychology (Knox et al., 2019; Moström et al., 2017; Settineri et al., 2019) emphasize, this influence is crucial since the degree of disability consistent with a chronic disease like T1D, is not only to ascribe to the physiological deficit itself but also to the belief and perception that the subject develops toward the disease (Lyons & Chamberlain, 2006; Lubkin & Larsen, 2006; Marchini et al., 2018; Martino et al., 2019; Quinones et al., 2014; Savarese et al., 2019; Zani & Cicognani, 2000). Tronick, in his Mutual Regulation Model (2011), states that the creation of new meanings relies on the mutual regulation process within interaction and cooperation with another system, identifying it in the caregiver. As regards Stroufe's concept of "dyadic regulation" (Stroufe, 1995), the child begins to construct a number of cognitive and emotional regulative schemas by introjecting the regulatory strategies they experience within the relationship with the primary caregiver.

In light of these considerations, we can state that parental meaning making of their child's disease exerts a specific "mediation" role between the parents' emotions, the management of daily life with the disease and the dialogical exchanges they have with their children about the disease.

1.1 Hypothesis

Given this theoretical framework, the aim of this study is to explore the mediation function that parental meaning making processes of T1D exerts: a) between the parents' own emotional experiences and the actions taken for managing their children's illness on a daily basis; b) in orienting their child's meaning making of the disease and their management strategies.

2. Method

2.1 Participants

This aim of this narrative-based study was to explore the experiences of 21 mothers of young patients with type one diabetes mellitus (T1D) aged between 6 and 17 years. The narratives were collected as part of a broader research project aimed at exploring the psychological aspects of the paediatric experience of chronic physical illness and carried out in the framework of a collaboration between the Department of Humanities of the University of Naples "Federico II" and the "Federico II" University Hospital (Savarese et al., 2018).

2.2 Inclusion criteria

The narratives were administered to parents of children between 6 and 17 years old that had been diagnosed with DM1 for a period of time exceeding 12 months. Children with psychopathological conditions or psychopathologies were excluded.

2.3 Ethics

Participants signed an informed consent to participate to the research and a privacy statement on the most recent legislation on the treatment of personal data (EU GDPR 2016/679).

2.4 Data collection

A team of two trained clinical psychologist and psychotherapists executed face to face individual interviews with the mothers.

Each interview was audio-recorded and transcribed verbatim according to the APA rules for privacy and respect for the participants. The average length of the interviews was 20 minutes.

2.5 Sense of Grip Interview

The narratives of the parents of children and adolescents with DM1 were collected through semi-structured interviews consisting of 11 questions. An ad-hoc interview was developed as part of a specific research study aimed at exploring the parental elaboration process of the illness experience in everyday life, thus not limited to what subjects experience after receiving diagnosis (Freda et al., 2017, 2019; Savarese, 2018).

In particular, this interview attempts to explore the narrative processes related to the interpretation of the disease and the regulatory processes inherent in the relationship with the disease, which concern both the dialogical dimension of sharing the disease and the coping strategies for managing the specific illness experience. Moreover, the questions asked during the semi-structured interview were constructed to explore different synchronic and diachronic narrative perspectives in order to gain a better understanding of the meaning-making process of the specific illness experience (Savarese, 2018).

2.6 Data Analysis Method

The whole narrative corpus was analyzed using the method developed by Auerbach and Silverstein (2003), called "*Hypothesis-generating research*", which is part of the broader Grounded Theory methodological approach (Charmaz, 2006; Glaser & Strauss, 1968), which is based on two basic principles:

- . "*Questioning rather than measuring*", which focuses on the research participants and in particular their subjective experience of the phenomenon, a source of knowledge.

- . “*Generating hypotheses using theoretical coding*”, consisting in developing hypotheses using a specific data analysis procedure called *theoretical coding*.

This method was chosen for this study as it is particularly suitable for achieving our research objectives since it enables us to analyze the phenomenon of interest more subjectively, starting with a careful review of existing literature.

“The function of reviewing the research literature is to suggest important topics on which the questions should focus. However, when one chooses a research issue about which much is unknown, one cannot assume that current literature can provide an adequate set of questions” (Auerbach & Silverstein, 2003, p. 16).

The coding process has been implemented with the intent to find some markers of the mediation function within the narrative corpus that can be viewed as ways that parents can make and convey their own meaning of the disease. The whole process was focused on two fundamental questions:

- 1) What are the processes in which the mediation function is articulated?
- 2) How and along which trajectories are these processes articulated?

The coding process was divided into three phases:

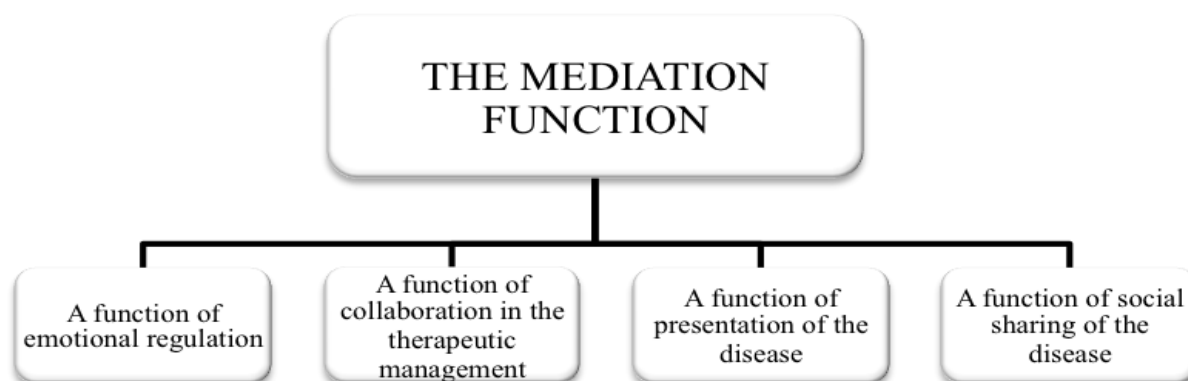
- **FIRST PHASE:** after reading all of the narratives, the most relevant passages of each text were selected and line-by-line coding was carried out with our research goals in mind. A series of "in vivo codes" were identified by carrying out a labelling process aimed at promoting initial categorization and data synthesis.
- **SECOND PHASE:** moving to a more abstract level, by comparing the detached codes, a series of macro-categories were identified that connect and organize the codes in an isolated manner. These macro-categories can be considered macro-processes through which the mediation function of the parental meaning-making process of the illness is articulated.
- **THIRD PHASE:** lastly, using a bottom-up analysis logic, a series of trajectories were identified along which the macro-processes are articulated. These trajectories identify the “nuances” of these macro-processes and therefore they should not be codified as individual parenting styles: they do not aspire to be mutually exclusive, but to achieve a detailed analysis of the multiple forms that these processes assume within the parents' narratives.

3. Results

At the end of this coding process, four macro-processes were identified in which the mediation function of the maternal meaning-making process is articulated. These processes are described by the following functions (Table 1):

- 1) A function of emotional regulation
- 2) A function of collaboration in the therapeutic management
- 3) A function of presentation of the disease
- 4) A function of social sharing of the disease

Table 1. The four macro-processes along which the mediation function of the maternal meaning making process is articulated



3.1 A function of emotional regulation

The first function concerns the need expressed by mothers to modulate the emotional impact that the diagnosis has generated in order to be able to cope with the illness and its different demands. On analysing the narrative corpus, it has emerged that this function is articulated with a series of trajectories (Table 2), which are the expression of the implementation of various more or less adaptive emotion regulation strategies; the main trajectories are:

- To “keep inside” one’s emotions in order to preserve a sense of parental responsibility: in several narratives the mothers reported that the only way of coping with the disease was to suppress their own emotions because experiencing emotions hindered them from achieving their parental roles and aspirations.

“As only I can help her so I have to be strong [...] I can’t lose hope, you don’t decide in life, it is life that decides for you”

(Int. 1, p. 4 lines 210-211; 224-225).

- To consider diabetes as a “condition” rather than a “problem”: to view the disease as a condition to be integrated into everyday life rather than an obstacle to its functioning enables mothers to have a more tolerable representation of the disease, that takes into account both critical and resilient aspects.

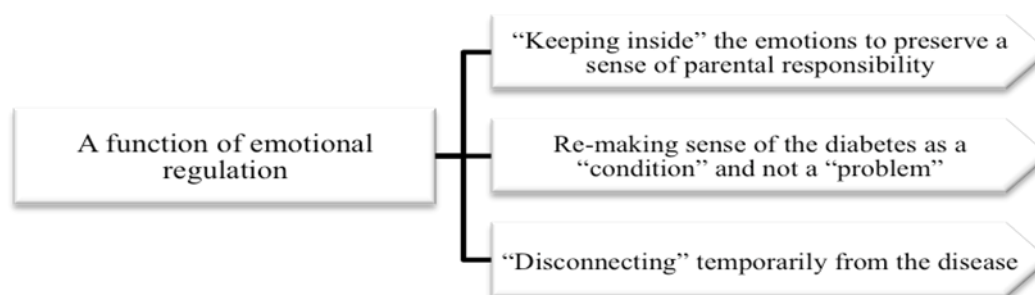
“Everything can become a condition rather than a problem, my children reacted well, they have learnt how to manage their illness and they understand that diabetes is not an enemy, but it is a friend that will accompany them through life”

(Int. 17 p. 2 lines 57-61).

- To temporarily “disconnect” from the disease: being able to find a psychic and temporal space where mothers can momentarily forget about the disease is a strategy that enables them to temporarily escape from this experience and reduce their feelings of anxiety;

“In the evening I spend a quiet hour doing things I enjoy in order to relax, to reset my brain. It is not an easy task but we have to move forward ” (Int. 2 p. 9 lines 373-377).

Table 2. Trajectories of meaning making identified for the function of emotional regulation.



A function of collaboration in the therapeutic management

The second function concerns the degree of collaboration provided by the mothers in therapeutic management. On analysing the narrative corpus, it emerged that this function is articulated along various trajectories (Table 3):

- Promoting self-management: mothers considered it essential that their child acquired a certain degree of autonomy in his/her therapeutic management in order to ensure organic stability in daily management and to become independent adults in the future. This can be achieved by promoting mutual trust and gradually reducing parental involvement in therapeutic management.

"She trusts me and I trust her [...] I am sure she can manage her diabetes treatment alone [...] The nurse asked me "Madam, is she capable of self-injecting?" and so I told my daughter " you can do it alone now".

(Int. 1 p. 10-11 lines 442- 521).

- Dealing with the partiality of their role: it consists in the mothers' ability to preserve their parental role and promote the achievement of a balance between glycaemic control and nutritional intake, without these two conditions being mutually exclusive. A belief emerged from some of the narratives concerning the existence of a close relationship between authority and glycemic decompensation, with the risk of falling into excessive complacency or permissiveness;

"A strong emotion can raise or lower your blood-sugar levels; there are certainly good and bad times for every family and unfortunately my daughter finds herself in a difficult situation, right? It is therefore essential for every parent to avoid emotions or situations that can compromise her blood-sugar levels, but it isn't always possible".

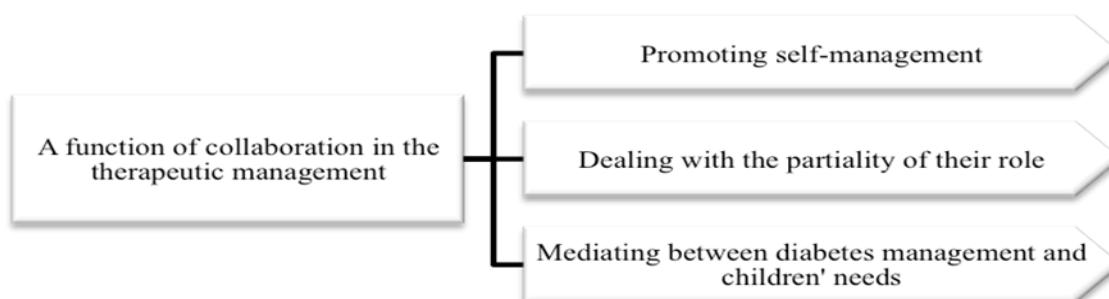
(Int. 1 p. 9 lines 388-397).

- To mediate between diabetes management and the maternal ability to meet their children's evolutionary and emotional needs. In some narratives, mothers revealed the need for "therapeutic flexibility" by making compromises, so that their children's developmental and emotional needs can be satisfied;

"I trust him and I realize that when he goes out with his friends, I can't expect him to just watch them"

(Int. 10 p. 8 lines 294-299).

Table 3. Trajectories of meaning making identified for the function of collaboration in therapeutic management



A function of presentation of the disease

The third process, identified as an indicator of the mediation function of the maternal meaning-making processes, concerns the exploration of the verbal and non-verbal communication methods used by mothers to inform their child of the disease. The mothers who took part in this study reported using various methods (Table 4):

- A gradual presentation of the disease: information is presented in line with the cognitive and emotional abilities developed by the child so he can accept it better;

"I took time to explain to her what was going on because I didn't want to scare her about the chronicity of her illness right away [...] I wanted her to accept her condition gradually".

(Int. 1 p. 6 lines 258-270)

- A presentation of the disease "as it is": the disease is presented by accurately reporting the medical information received at diagnosis; in this way, the child could risk becoming a receptacle of a representation which is not always able to contain;

"She asked me, mum, when can I stop self-injecting, when I get old? I replied, let's not fool ourselves, you will have to take insulin for the rest of your life.

(Int. 4 p. 6 lines 186-188)

- "A presentation of the disease delegated to others": healthcare professionals are responsible for explaining the diagnosis so every communication occurs during appointments with GPs and consultants.

"I didn't tell him anything, they did everything here".

(Int. 2 p. 17 lines 746-747)

- A presentation of the disease limited to the management: the only information reported concerns exclusively the various daily procedures in order to guarantee sufficient therapeutic compliance;

"Of course, we talk about it a lot. In the beginning, we spoke about it gently. You have it, let's see how we can manage it"

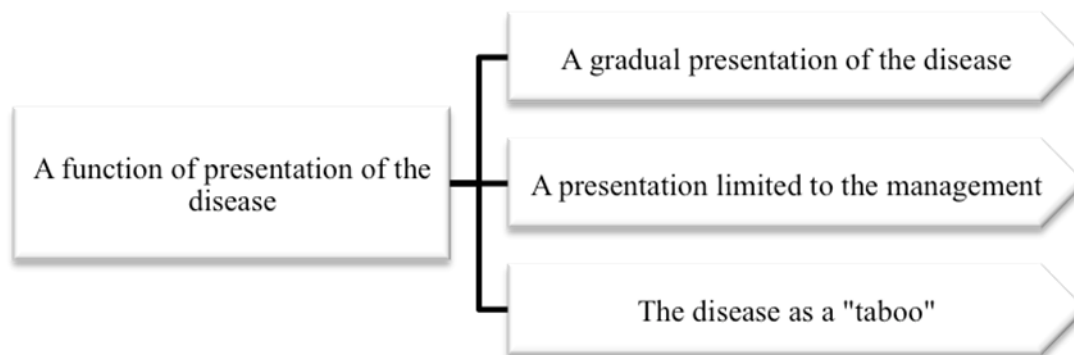
(Int. 10 p. 5 lines 237-238).

- The disease as a "taboo": in some narratives, it emerged that mothers tried to avoid mentioning the illness which was viewed as a taboo.

"I sometimes ask her, are you unhappy about it...? And she says, no mum it will get better. Her father tells her that it will improve. So we don't talk about the disease at home, we try to gloss it over".

(Int. 18 p. 4 lines 229-231)

Table 4. Trajectories of meaning making identified for the function of disease presentation



A function of social sharing of the disease

The last function concerns the mothers' tendency to implement a series of strategies aimed at promoting or hindering the sharing of this pathological experience within the social context. This function is articulated along two trajectories (Table 5):

- By supporting the methods of social sharing of the disease used by the child, in the hope that the child will open up to others more;

"She prefers not to share these things with other people. I have tried to encourage her but I don't want to upset her. For the moment she must manage it...maybe she will understand in the future but for the moment that's fine for me".

(Int. 1 p. 13 lines 601-616)

- By helping the child to find closure regardless of the methods he/she uses due to their own difficulty in sharing the disease and seeking protection from external threats in everyday life;

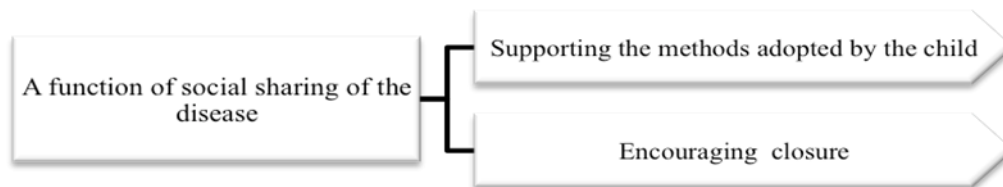
"I see her like that and so I don't want to mix with other people either. So we prefer to stay at home".

(Int. 3 p. 8 lines 222-223)

These modalities reflect the representation that, according to the mothers, the specific condition assumes in their social contexts.

Various representations have emerged from the narratives: in some cases the social context is represented as a source of social support, while in other cases, the social context is considered a source of social exclusion and an obstacle to therapeutic adherence.

Table 5. Trajectories of meaning making identified for the function of social sharing of the disease.



4. Discussion

As our results show, in this study we explored the multifaceted forms of the specific role that maternal meaning making of the disease plays in mediating between the emotions related to their child's diagnosis and the implementation of actions aimed at managing the disease in daily life. The processes that we identified as indicators of the "mediation" function proved to be strongly linked to one another.

The explorative analysis carried out in this study showed that among these processes, the possibility to regulate the emotionality experienced at the moment of receiving the diagnosis seems to represent a prerequisite to the maternal competencies of dealing with the disease itself and of sharing the disease experience with their sons and daughters and with others.

In fact we identified several emotion regulation strategies in the narrative corpus collected: strategies aimed at suppressing the emotional experience, re-focusing strategies and mainly reappraisal strategies which lead to a narrative representation of the disease as it was experienced. As regards the latter, there are a number of narrations in which mothers stated that "making sense" of their child's disease is essential for modulating the ambivalent emotions that emerge when they try to fulfil their roles as mothers, cope with the disease and take care of their child.

However, as children are influenced by their caregivers' cognitive and emotional schemas in the developmental age, the implementation of targeted regulative strategies on the disease experience may help the children to make meaning of their disease and assist them in the management.

These considerations demonstrate how this mediation function can act on two different levels: an intra-personal level, by allowing mothers to foster the elaboration of the emotions related to the disease; and an inter-personal level, by promoting the child's meaning making process and the actions they take to manage their disease.

Our analyses made us consider the specific topic of parental involvement in this double-level process: apart from the mothers' involvement, involvement concerning the gradual developmental competencies acquired by their children should be modulated for the child's construction of representation and for making sense of her/his disease.

From the narrations it emerged that one of the most common objectives pursued by mothers was to encourage and achieve a good level of autonomy for their children, which is in line with the T1D therapeutic guidelines.

This achievement seems to be facilitated by the mothers' ability to provide parental scaffolding (Bruner, Wood & Ross, 1976): for which the parent is able to look by distance her/his child in initial phase of the disease, in order to foster independence in one's child's regarding his/her care management. Nevertheless, this does not mean that in certain circumstances mothers must take over the task of disease management, for instance when the onset of the disease occurs within the first years of life or when the first symptoms are recognized at diagnosis. It is essential to find the most right moment to engage the patient in diabetes self-management.

In this light mothers can be seen as their child's "collaborators" without hindering her/his possibility of achieving a good level of self-management of her/his disease and above all, of becoming an independent and autonomous adult.

These goals can be achieved by gradually reducing mothers' involvement and by sharing the issues that arise during the disease regarding the child's cognitive and emotional development and needs.

Further research is needed in order to examine the children's perception of the mediation function and compare it with the parents' experiences. Comprehending the children's meaning making processes gives us a better understanding of how maternal meaning making affects their children's disease.

Ethics approval and consent to participate

This study was executed under the approval of the Ethical Committee "of the University Hospital Federico II of Naples (protocol number 118/16). All procedures performed in this study were in accordance with the ethical standards of the study coordinating center and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

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DOI: 10.6092/2282-1619/2019.7.2187