

## Biographical ruptures and flows in the family experience and trajectory of children with cystic fibrosis

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**Abstract** *Biographical disruption (BD) became a core concept of sociological studies on the chronic illness experience by showing how this event can be strongly affected by ruptures in the ways of living and organizing the biographical trajectory through narratives. Critical reviews have pointed out that the widespread use of this concept was not sufficiently attentive to its analytical limits, e.g. addressing experiences of children with genetic diseases, when biographic flows (BF) rather than BD would be probably found. In this paper, we employed the concepts of BD and BF to analyze the relationships between the illness trajectories of children with cystic fibrosis (CF) and the experiences of their parents, taking into account the narratives about their histories and family contexts, drawn from semi-structured interviews with 10 children with CF and 14 family members. The results pointed to potentialities and limits of the concepts of BD and BF for the analysis undertaken in this study. We conclude that both concepts can be applied to the analysis of family experience involving child genetic diseases, provided that this occurs in a critical and sensitive way to subjects and contexts investigated, keeping in mind the more broader theoretical concerns.*

**Key words** *Illness behavior, Medical sociology, Personal narratives, Genetic diseases, Child*

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## Introduction

Chronic illness sociology has been interested especially in the perspective and experience of the subjects affected by these conditions, seeking to understand how chronic illness requires interpretations and stances *vis-à-vis* oneself (feelings, expectations, identities), about daily life and about own life stories, in different interactive contexts<sup>1-3</sup>.

In the last decades, the investigation of the chronic illness condition emphasized the exploration of the narrative and biographical perspective, boosted by growing narrative studies<sup>3,4</sup>. A seminal concept was biographical disruption (BD) formulated by Bury<sup>5</sup>, which gained centrality by showing that chronicity can cause discontinuous forms of living and biographical trajectories expressed narratively. The concept fostered an intense theoretical dialogue, in which it was sought to identify the place occupied by narrative reconstructions<sup>6</sup> triggered by “critical situations” that affect the experiences and can even cause the loss of the self of the affected subjects<sup>7-9</sup>.

Critical reviews, such as that of Williams<sup>10</sup> have pointed out that the widespread use of BD was negligible *vis-à-vis* its analytical limits, when used, for example, to understand experiences related to genetic diseases among children. In the latter case, it is argued that biographical continuities (BC), rather than BD would mark such experiences. In this debate, several authors advocate the importance of sensitive analyses to the mediating factors of the broad and specific social contexts in which such experiences are elaborated<sup>11</sup>.

In this paper, we used the concepts of BD and BC with the general objective of analyzing the relationships between the illness trajectories of children with cystic fibrosis (CF) and the experiences of their parents/caregivers, taking into account the narratives about their family courses. More specifically, we aim to reflect on the adequacy and relevance of the use of these two concepts to analyze the experiences elaborated in the context of serious genetic diseases among children, thus contributing to the broader theoretical debate. This was an idea put forward in other works<sup>12,13</sup>, but which will be considered in better terms.

## Methodology

CF causes disturbances in the regulation of chlorine, sodium and water flow in the cell mem-

brane, resulting in dehydrated cell surface and ensuing the formation of a thick mucus that can lead to obstructed ducts and chronic inflammation, followed by the fibrosis process in the affected tissues. This is a very serious, chronic, hereditary, systemic and progressive disease that mainly affects respiratory and digestive systems, predisposing to sinusitis, bronchitis, pneumonia, bronchiectasis (enlargement or irreversible distortion of the bronchi), gastroesophageal reflux, pancreatic failure, fibrosis and respiratory failure. At present, when under treatment, a 40-year “survival” is estimated<sup>14,15</sup>.

A study was carried out with ten children selected at a specialized outpatient clinic in the Campinas region, which provided a list of names of children under treatment for at least one year, with different severities not reported to the interviewer. Families were invited by telephone to participate in the study. Semi-structured interviews were carried out with eight family cores, including ten children with CF (between 5 and 12 years of age), eight mothers, four fathers and two siblings without cystic fibrosis, totaling 24 interviews. Six families were interviewed at home and two in a room near the specialty outpatient clinic (for the convenience of the respondents). All interviews were individual, except those performed with two family nuclei; and they addressed the children’s illness trajectory, their help-seeking pathway and the personal and family biographical courses of respondents. Interviews with adults lasted, on average, an hour and a half; sessions with children lasted ten minutes. All interviews were carried out and transcribed by the first author and analyzed from a biographical perspective<sup>16</sup>. The children interviewed belong to working class families and live in neighborhoods inhabited by low-income population in Campinas or surrounding region (Chart 1). In general, they were diagnosed with CF at 2-3 years of age. All adults signed a free and informed consent form at the time of the interview, as well as one of the children’s legal guardians. The Research Ethics Committee of FCM/UNICAMP approved the research.

## Results

### The illness experiences of children with cystic fibrosis

Children interviewed do not feel sick. The disease appears much more because of the fa-

**Chart 1.** Cases of cystic fibrosis.

Child*	Age interview	Age diagnosis	Mother*	Father*
Cibele	10 years	9 years	Paula	Arnaldo
Cíntia	05 years	5-6 months	Renata	Jorge
Rebeca	10 years	3 years	Fernanda	Rodrigo
Josiane	09 years	5 months	Maria	Paulo
Jeferson	13 years	5 years		
Fabiana	07 years	birth	Carla	Ricardo
Isadora	08 years	birth	Júlia	Carlos
Tatiana	09 years	7-19 months	Vanessa	Fábio
Pricila	09 years	2-3 years	Camila	Pedro
Felipe	06 years	birth		

\* Fictitious names.

tigue generated in games or by the endless visits to health services (causing an annoying school absenteeism) than by life-threatening signs of severity (even in the most serious cases). CF seems not to be part of the time of their life experience until they demonstrate a clear notion of its severity, a situation in which the notion of finitude would be more intense.

Although the disease is an important mediating element in their school and family social interactions, there is a strengthened idea that children believe that CF did not establish a BR. They reported having positive expectations about their future, imagining that they will become doctors, hairdressers, etc.

Next, two cases will be shown in which one of the concepts discussed herein (BD and BC) was more pertinent and sensitive than the other to the analysis of the trajectories and experiences in question. Hence, cases are not specimen of the trajectories and experiences of subsets of the family contexts investigated, but rather provide rich empirical material for contrasting analyses relevant to the conceptual discussion herein intended.

Seven years old at the time of interview, Fabiana was diagnosed with CF at birth and provides an excellent case of biographical continuity. On the other hand, Cibele, ten years old at the time of the interview, was diagnosed with CF only a year earlier, points out important discontinuities. As will be seen later, beyond the moment of diagnosis, the family context and pathway, as well as narrative strategies assumed by their mothers will be relevant to denote lines of continuity or ruptures in the analyzed experiences.

### **Cibele and the context of biographical disruptions**

Cibele had a life marked by ruptures. When she was four years old, she saw her father die at home in her mother's arms. That same day, he had returned from a prolonged hospital stay caused by a deteriorated ulcer condition, which eventually "burst" after discharge. Paula, mother of Cibele, says that the girl was very close to the father. Cibele does not talk about her father's death and refuses to go to the cemetery. She recently started asking her mother if she is not going to get a father for her.

Paula reports that, even after the death of Cibele's father, with whom she lived for twelve years, she continued to rely on a strong social support network. Her husband had been working for a long time as a baker and was well regarded by his employer. The family had long lived in a small town and was well integrated into the community.

Another rupture was triggered by the recent and unexpected arrest of Cibele's brother, son of Paula's first marriage. He was involved in a robbery in the neighborhood, prompting Paula to move to another city, losing the social support network and assistance received from the municipal health department. The interview took place on the edge of the sidewalk, since Paula's current home had almost no furniture. Cibele played in the street and got closer from time to time. She did not seem to care too much about the interview.

Those losses took a toll on Paula and added to the problems of hostility and stigmatization suffered by Cibele in the new school. According to Paula, *she has suffered a lot of discrimination;*

*fibrocystic people have that cough that looks like tuberculosis, a bronchitis [...]; many people have moved away from her, sometimes children ... the mothers themselves ... she suffers from it (Paula).* On the other hand, Cibele puts the situation as a result of envy, in the face of some “secondary gains” obtained by her in the classroom, because she reported other children saying at school *that I’m cocky, because the teacher has to stay by my side; [...] I do not [play] with them ... and [they say] that I am sick ... and that I want to be the best of the class (Cibele).*

The perspective of death is inscribed and very much felt in Cibele’s life experience: *I think about whether I’m going to live a lot still ... I believe I will ... They told me that it’s a genetic disease that cannot be cured ... it’s like an eternal scar (Cibele).* The scar metaphor is emblematic of the symbolic mark of cystic fibrosis in her body, an invisible mark renewed in different ways in her life: in the genetic, chronic, incurable and severe character of the disease, in stigma and differences with other children, with deaths and losses endured.

Paula says that the death of another girl, in treatment in the same outpatient clinic, shook Cibele and that, therefore, she always tries to emphasize differences between the two cases to reduce the negative impression caused in Cibele, emphasizing the passive stance that mother and daughter (deceased) assumed vis-à-vis the disease. Paula says that the severe situation should not generate paralyzing fear or sadness. Thus, as her daughter, she minimizes the severe situation to seek positive meanings for the experience of illness and care: *“She took a little shock ... I also did ... I just ... I try not to pass on my fear [...] to her [...] So I don’t see it as a disease. I see it as an experience, I see it as a way I can help other people in the future” (Paula).* However, this minimization does not erase the severity of the disease, evidenced in Cibele’s help-seeking pathway.

*She was born, and when she was three months old, she ended up in an ICU, where she stayed eighteen days. A meningitis was found [...] I believe today it is a reaction of fibrosis [...] She was discharged ... and for two years she was fine ... Then, she was always hospitalized, always with pneumonia, nobody knew what it was one exam after another. She was submitted to asthma treatment for two years... bronchitis, took vaccine ... which never solved anything ... When she was four ... she was already in a very advanced pneumonia crisis. [...] A sweat test was requested [...] [They said]: - ‘There is no vacancy today or tomorrow’. I had an appointment to take this exam the day her father*

*died ... I missed it! In addition, I kept on renewing, one day, there was no van available so that I could go there; the other day, I woke up late. It was a hassle [...] We left the city for a while [...] she took a long time off. [Then] Cibele seemed to be well, but she could not put on some weight [...] and began to atrophy. She was already struggling ... I took her ... and the resident ... fought with me ... because she was admitted with fifteen kilos [9 years old], 43% of blood oxygenation and she did not breathe anymore. (Paula)*

This long passage brings several elements of the late diagnosis of the disease - related to the encounters and mismatches between Paula and health professionals - received with fear and relief: *I felt good because our suffering had stabilized. We have another kind of suffering. However, it is a milder suffering ... I said: - ‘Oh, that’s good, at least it’s not something worse.’ Because if it was a cancer or AIDS... (Paula).* The comparison with other serious diseases occurs as another element of minimization of the situation. However, Paula is fully aware of the severity of CF, stating that: *I know that this bacterium in the liver now is serious. I know she is at risk of... losing a liver ... but why am I going to martyrize myself before in advance (Paula).* Finally, she points out a deeper biographical sense of the daughter’s experience of illness when she says *Cibele was not born to live, she lives to be born. Because every passing day a new Cibele lives. She gives that scare [...] she stayed in the ICU; she had two cardiac arrests. She was gone, and then came back. (Paula)*

This case shows us how the context of destabilization of family dynamics marked by several biographical disruptions experienced by Cibele and her mother potentiated the disruptive character of CF in their lives, updated in critical (physical and psychological) situations marked in the course of illness and help-seeking pathway. The experience of care to minimize the severity (and uncertainty!) of the disease resulted in a particular way of looking at the now, without anticipating the future, in the face of the experiential closeness of death.

### **Fabiana and the context of biographical continuity**

Fabiana was born in a context of family stability. Her parents are from the same city, they have a large family, with intense affective and solidarity relationships. They have studied together since they were little. They had been dating for seven years and had been married for three years

when Carla had been treated to get pregnant and had immediate success. The family has been living in a good working-class neighborhood of Campinas for ten years. Ricardo, Fabiana's father, has worked in the same automotive industry for eighteen years. The birth of Fabiana was expected and celebrated by the whole family and, according to Carla: *she was born calm, was a scheduled cesarean delivery and the doctor was waiting for me [...]* [However], *on the second day, she did not come to breastfeed. Then I asked the doctor the reason why she did not come. She said that she had not defecated and had just vomited and was sent to the ICU at the maternity hospital.* Carla says that she felt adrift in a whirlwind of events and *on the third day, she [Fabiana] was submitted to surgery ... But nobody could explain why this meconium ileus, why it was stuck [...]* *She had excesses of phlegm stuck on stools and no one could explain why [...]* *Until the surgeon ... called [to the specialty outpatient clinic and explained that] meconium ileus is the first symptom of fibrosis* (Carla).

In the first month of life, four of the seven surgeries to which Fabiana was submitted until she was seven occurred. This is because the intestine struggled and could not function properly due the colostomy closure, implying successive surgical attempts. With only seven months (and weighing only three kilos!), it was possible to definitively seal her colostomy. During this period, she was hospitalized in the ICU several times, due to dehydration, malnutrition and surgical infection, until *she improved, grew, gained weight and became fat, developed a lot, started walking and talking* (Carla).

Carla had extensive family and husband support at that early stage. Then, roles were distributed among the couple, so that care was concentrated almost exclusively on Carla, although her husband chose to work on an hourly basis in order to be able to go home whenever it was more necessary.

The interview took place with mother and daughter in their apartment. Fabiana is a very cheerful, caring, smart and active girl. She complemented and corrected her mother throughout the interview when it came to the family's course (subject of her highest interest), making comments and asking questions about her own trajectory of illness. A significant and interesting fact was the use of photos to report the trajectory of life and illness of Fabiana. Carla and Fabiana took this initiative and were very excited about the photos, making sure to show them to the interviewer. Pictures not only illustrated, but also

directed the story. They showed several episodes of Fabiana's life, illness trajectory and help-seeking pathway: the first days of life in the ICU, the first surgeries, the first hair, the first time she ate at the table or went to the bathroom and her first birthday.

Fabiana was well acquainted with the pictures and their details, leading the story with her mother: *Look! My first hair* (Fabiana). - *It was after the surgery, hair started to grow, because she had shaved all her head. Look how thin she was. Look at the colostomy* (Carla). *What is this, Mom? Was this that big? Was it red?* (Fabiana) - *This was a piece of your intestine that was out, where you pooped* (Carla).

Carla was fully aware of the production of meanings for Fabiana's illness experience and life trajectory, in progress in that narrative, so she recorded her whole trajectory of her. *I said, 'One day she'll know' [...]* *I started to write a diary telling her the day she was born, how she was expected, what happened and telling her story. I leave these pictures because one day, when she is older, she will see how she was as a little baby, she will know how her life was* (Carla). The way Fabiana handles and actively comments the pictures, knowing in detail most of the events portrayed shows how this feature was incorporated in her biographical experience. Although her illness trajectory includes very critical situations, since birth, the narrative construction of this trajectory seeks to reaffirm continuities, much more than ruptures. Fabiana's social and family context, marked by strong affective bonds, emotional and economic stability certainly supported the sustenance of these lines of continuity, even in the face of critical events in her help-seeking pathway.

When asked about death, she resorts to one more narrative resource to situate her response: *When one day I watched TV soap opera 'Escrava Isaura' with my mother here, I went like this: - Am I going to die? Am I going to die, mother? 'It must be bad to die* (Fabiana). At another point in the interview, however, it is clear that death does not hold the same place in her biographical experience as that of Cibele. Fabiana who thinks *more in the future than in the past [...]* *In the future, I think I'm going to get married, I'll have a house, a car in the garage, a barbecue, near the beach, my son running around and I want to be a dog doctor...* (Fabiana).

Although Carla also seeks to develop a stance inspired by the *carpe diem* motto - *I try to live a normal life. Without much, much expectation* (Carla), she does not do it by minimizing sever-

ity. On the contrary, she sought to record and incorporate disease severity into the family narrative, situating it in a broader context of stabilization. Fabiana produces an image of herself in which the disease seems inexistent, although it is very seriously manifest from the beginning of her life. Despite the advanced disease normalization and care process, the life-threatening disease features are inscribed in the family's experience; but delimited in a context of stability and control, responsible for reinforcing biographical continuities.

### The experience of fathers and mothers

The experience of having a child with CF has generally caused a biographical disruption in the life course of mothers and fathers, both at the pragmatic and symbolic levels. Initial expectations were frustrated, unexpected challenges emerged, new survival and physical, economic and emotional support strategies had to be adopted, individual and family life projects and courses have been changed. This occurred even in cases where the diagnosis was made at the child's birth. However, late diagnosis led to critical situations with serious physical and symbolic effects.

Only four children received an early diagnosis of cystic fibrosis: Fabiana, Isadora, Felipe and Joseane. If we consider that the latter two have older siblings with the disease, which forced the investigation of the diagnosis at the time of the birth of these children, professionals face a clear difficulty to achieve this diagnosis, in the broader set of cases.

Thus, the pre-diagnostic phase was a prolonged, dramatic period with an intense repercussion on the experiences of children and, especially, their parents. The persistence and development of symptoms led to various health services, diagnoses (reflux, bronchitis, meningitis, etc.) and poorly resolved treatments. Worsening health conditions (pneumonia, acute malnutrition, etc.) led to critical situations in which the physical, operational and symbolic resources of the parents of these children were no longer enough to provide positive answers to overcome hurdles in their pathway. In this context, there was strong moral condemnation of maternal care<sup>12</sup> by health professionals and family members. Some professionals became suspicious of the effectiveness and orientation of this care, accusing mothers either of negligence (for example, by introducing supplementary food to breast

milk in the face of their children's incessant vomiting and diarrhea) or of excessive concern before the various symptoms identified. Accusations were also followed by demands, suggestions and suspicions of family members (usually children's grandparents) about the type of maternal care. This creates a real ordeal in which each step seems to be decisive for the ultimate result. This broader situation had a distinct repercussion in each family context, but always with important inflections in the biographical experiences and family trajectory in question.

The role of a caregiver of a child with a serious disease has gained a central place in the biographical experience of its parents (especially mothers). With the exception of one case, all parents had their first (or only) child with CF. Therefore, it should be remembered that the inauguration of the maternal/paternal experience would already represent a watershed in their lives. However, the experience of being a mother or father of a child with a serious disease, facing prolonged critical events that evidenced a near possibility of death (and mother and father "failure") led to true BD in the strong sense of this concept.

Even the most stable family contexts (in economic and bond terms) have been transformed since the onset of the first symptoms of cystic fibrosis, especially with regard to the plans and images drawn for family life after the birth of children. Thus, Rodrigo, the father of Rebeca, who was ten at the time of the interview, is very clear about receiving the diagnosis given to his daughter when she was three years old: *A bomb! [...] We knew that something was wrong, but we did not expect this* (Rodrigo). Rodrigo and his wife, Vanessa, live in the same city where they were born, close to their families, dated for seven years and married for fifteen years at the time of the interview. Rebeca's birth, as well as the organization of the couple's family life were the subject of prior planning, which reinforces the above-mentioned experience.

Receiving the diagnosis also brought relief by providing a more appropriate interpretation and line of conduct for the situations faced. However, this did not diminish the disruptive nature of the diagnosis: *In the maternity hospital, she already had an allergic reaction, but people there found ... she went on and on and she had the first pneumonia at four months... In addition, we found out with... seven months... This is where our life began* (Vanessa). Tatiana, daughter of Vanessa, was diagnosed with about one year of life, and was aged nine at the time of the interview. Her par-

ents were married only a year ago, at the time of her birth. However, with a stable life, a job and a large family support network, the diagnosis had a great impact on this context of stability and was signified as a timeline marker in their lives (*this is where our life began*).

In families experiencing less “stable” social and relationship contexts, birth was not often planned by their parents and emerged as an unexpected event in their lives. For some, an unplanned event, however not totally unexpected and therefore welcome. For others, this birth alone led to quite unwanted changes.

*“I was so young; I was not even nineteen years old... I was getting stressed and angry... not wanting that kind of life for me. However, there was no way I can change that anymore. My elder son was cared for by my mother, my sister, he did not stay with me... I lost almost all the stages of his growth... It came to a point that I was exhausted, I couldn't bear it anymore, I already wanted her [Priscilla] to receive [a diagnosis]... She would be hospitalized for fifteen days, and come home. She would stay two, three days at home, she would get worse again ... That was death to me [...] Then you have another child, you have a husband, you have a home. I had to manage all this yet, but she was very important (Camila).*

Camila has always had a hard life. She lost her father when she was one year of age and began working at the age of twelve; she belonged to a poor rural family from Paraná who moved to a city in the Campinas region, not counting on strong social network support. She had her first child (no CF) when she finished eighth grade and dropped out of school, which is a source of great resentment. Priscilla was diagnosed at about three years of age (therefore, after a long pre-diagnostic phase, with a strong symptomatic manifestation of CF) and her younger brother at birth. Many adversities mark the life of Camila, but, among all, she emphasizes the fact that she abandoned life projects (especially school), obliged to provide intense care of two children with CF. Thus she organizes care by focusing on promoting the autonomy of her children through the exercise of self-care, eagerly awaiting a new phase of her life, when she will no longer be bound by this obligation, understood as a spiritual “karma”.

The context of strong emotional and economic pressure experienced by these families was aggravated by CF in the “pre” and “post” phases, favoring the observed BR, so that symbolic and material resources to address the illness and care of the children were gradually depleted, as Paulo,

the father of two children with CF, tells us: *“On top of the refrigerator, a microwave pizza package was always full of medicines before finding the problem. Jefferson almost died [...] it is a hard situation. Then one loses his job and the other cannot be working [...] Everyone is shaken. If you had a structure to say, ‘No, I have a plan, I’m going to buy a house ten years from now.’ You’ve already unstructured everything ... It was a blow for us, I almost committed suicide (Paulo).*

Paulo painstakingly describes the scene of his suicide attempt, showing that it was not a mere conjecture, as two friends prevented him from such action at the very time of execution.

Despite the BRs identified in the experiences of these subjects, continuity lines were also established. For example, Renata was born to a poor family in inland Bahia and faced serious health problems in her childhood, highlighting child paralysis that caused severe sequelae: *How did I face this [child paralysis]? I faced it with a very wise mother who, in front of her twenty children, did not see me differently ... my mother always spoke beautiful things about me ... I have to gain strength, I have to have the strength so that she has the strength to live ... This is what she has ... that's why she did not kick the bucket... She is very dedicated, it's the girl God prepared [for me] (Renata).*

Thus, amidst a context of disruption in her biographical trajectory, she finds a line of continuity between her own experience of illness and care, lived in childhood, and the current situation lived by her daughter. She establishes a clear correspondence between the maternal care received from her mother and the maternal care she seeks to undertake with her daughter. The meaning of this care is to promote a “life force” and “determination” that gains the connotation of “family legacy”, a line of generational continuity.

## Discussion

### Family biographical disruptions and continuities

The BD concept was proposed by Bury<sup>5</sup> to understand the experience of illness in middle-aged women diagnosed with rheumatoid arthritis at a totally unexpected age, producing ruptures in the assumptions and knowledge that structured their daily lives and consequently affecting their way of interpreting, being and acting in the face of the hardships. Inspired by Antony Giddens' reflections on war experiences, Bury interprets

the emergence of that diagnosis as an unexpected event and “critical situation” responsible for transforming the lives of those women, leading to a “biographical narrative reconstruction<sup>6</sup>”. Thus, the contextual nature of the concept is emphasized from its formulation. In doing so, some authors have shown how chronic diseases can be “diluted” in broader contexts of adversity<sup>17</sup>; or even considered “expected events” by working-class elderly people<sup>18</sup>, without producing BR; or confirming elements of their life course, expressing “biographical reinforcement”<sup>19</sup>.

Our study shows results that traverse the “middle pathway”, pointing out the presence of both BD and BC, when considering the contexts in which these are located. The families investigated are located in the working class, albeit in diverse socioeconomic extracts. We try to be sensitive to the stability and instability of the children’s family contexts in a way that is attentive to how respondents put into perspective the effects produced by socioeconomic aspects, affective bonds and support networks in their lives, on the trajectories and experiences under review.

Even the most stable family contexts (in economic terms and in terms of affective and supportive ties) have been transformed since the onset of the first symptoms of CF, especially with regard to the plans and images outlined to family life after the birth of the children. In families experiencing less stable economic and relational contexts, the various lines of concern and instability often add up to family life. Thus, unlike Faircloth *et al.*<sup>17</sup>, in our study, more unstable contexts, marked by different types of adversities did not dilute the disruptive effect of CF. On the contrary, they strengthened such ruptures. Still, even in the middle of a BD context, some parents have laid out BC lines in their family trajectory and in the life pathway of their children, from the experience of illness. Children’s own experience has reinforced the sense of continuity.

Early or late diagnosis was an important element in the definition of the identified BR. This element should not be seen in isolation, since it does not establish a mechanical cause-effect relationship; but is rather considered in the contexts of life events, illness and family pathways of children. Interactions with health professionals and problems of accessibility to health services were particularly relevant to the significance of the diagnosis.

Late diagnosis intensified drama and challenges in the pre-diagnosis phase, reinforcing its role as a watershed in family life, by establishing

a shift in the perspectives and actions underpinning the experience of care and the pathway of illness.

Although it is a genetic disease, the diagnosis of CF appeared as something completely unexpected in the family context, since there was no news about previous cases. This situation sometimes caused the children’s grandparents concerns about the diagnosis. The general lack of knowledge about CF contributed to this situation, to the late diagnosis and to confusions in the understanding and meanings produced at the time of diagnosis.

Resuming the idea that late modernity leads to “reflexivity”, marked by “uncertainty”, thus inducing a symbolic work on the self, Williams<sup>10</sup> argues that BRs can reflect such a context, much more than specificities of illness experience. Moving forward, we could say that in contemporary times, it would be difficult to assume the pre-existence of a biographical “stability” context transfigured by ruptures caused by the onset of a serious disease. However, the biographical narratives analyzed point to the assumption of a biographical stability, projected from the expectations of the parents around the family life after the birth of their children. This assumption gains more support in more stable family contexts, but is not entirely absent from unstable contexts, as José and Camilla show us.

The severity of CF was also an important element for the analyses performed, inasmuch as it imposed not only fluctuations, but also extreme critical events on the illness courses analyzed, and played an important role in the definition of BR.

Williams<sup>10</sup> also argues that BD would be concept centered on the experience of adult individuals, since it would imply the existence of a “before” and an “after” in the subjects’ life history, assuming a period not affected by the disease. Thus, it assumes an unmediated relationship between the genetic determination of the disease and its significance. It should be remembered that the late symptomatic manifestation of some genetic diseases might delay their significance in people’s lives. In addition, late and/or misdiagnosis of the disease (when it manifests symptomatically at an early stage) leads to interpretations guided by reference conditions different from those sustained by its definitive diagnosis. This last situation had important physical and symbolic implications for children and their caregivers in our study.

We understand that, by linking the temporality of disruptive experience to adulthood, Williams<sup>10</sup> loses sight of the specific weight



of different stages of the illness pathway in the construction of the biographical experience, as well as mediations between the children's and their parents' experiences. Children do not live in isolation, but in different contexts of social interaction (family, school, neighborhood, etc.). Travis<sup>20</sup> puts the situation well: *Children, families and sickness are intertwined in a dynamic and constantly changing constellation* (Travis, 1976: 43). Therefore, if chronic conditions are not *a priori* experienced by children as a rupture in their lives, they may be so signified in their family dynamics and pathways. Moreover, they must be seen as active agents of the construction of their social life<sup>21,22</sup>. Fabiana expresses this situation well, by actively participating in the narrative construction of her life and illness course; as does Cibele (albeit in a less evident way), when intercalating the negation of her chronic condition with the minimization strategy assumed by her mother.

### Final considerations

When we locate biographical ruptures and continuities in the context of the family trajectories of children included in this study, we sought to point out the existence of interconnections and mediations between the experiences of these children and their parents. Thus, the BD concept was relevant to the analysis of the trajectories of children with a genetic disease that manifested symptomatically very early in their lives and was significant for their parents, albeit not under the context given by the definitive diagnosis.

The critical and reflexive posture *vis-à-vis* the use of the BD concept allowed us to observe how the combination of this concept with BC could benefit the in-depth understanding of the experiences and pathways in question. As Williams<sup>10</sup> pointed out, our study contributes to the broader theoretical debate, insofar as it not only points to the existence, but locates the identified BD and BC in their social and significance contexts, comparing the relationships between them.

We argue that a serious chronic health condition, such as CF can cause "family biographies", even when these conditions affect children (and especially when they do). The narrative reworkings identified outlined new relationships between future, past and present in the family and life history of the subjects investigated. These reworkings involved explanations about the disease (or lack thereof) and their relationships of proximity or distance from biographical contexts; the construc-

tion of the caregiver role; the redirection of family trajectories, from the child's chronic illness; effects of social and socio-affective contexts of stability and family instability. In addition, it would be important to consider that children are apprehended in their becoming; therefore, the idea of a threatened future, updated by the CF produces effects especially found in their family context<sup>12</sup>.

We agree that late modernity induces (self) reflective stances of subjects, facilitating a fluid "invention of the self" (biographical creation). In addition, when we measure the experience of chronic illness in the family pathway, we see biographical new elaborations take place in meanings, time and contexts not isolated from the broader social structures (access to health services, material resources, support networks, etc.). However, this study showed that these experiences of illness and care gain specificities in their life trajectories (personal and family) and interaction contexts. Therefore, the biographic measurement of the analysis was sensitive to the narrative reconstructions of those experiences, without losing sight of the inter-contextual relations in which they are located. For reasons of space, several elements and discussions that would allow a deeper analysis of these relationships were only superficially mentioned or even suppressed from the text. We highlight, for example, gender issues related to the organization of care in the family context and the discourses related to maternal care; the significance of the genetic character of CF and the genetic research and counseling practices mentioned by the respondents; specific situations of interaction with the services and health professionals of great interest to identify conflicts of perspective and power relations; the place of therapeutic advances and expectations generated among families and health professionals; the relationships between phases of children's growth and development and the education of their bodies; the relationships of family narratives with the broader repertoire of narratives and narrative genres available, among others.

The inclusion of the perspectives of fathers and of children themselves, along with the ones supported by their mothers is an important differential in relation to the studies traditionally carried out on the subject – a differential that allowed a broader look at the experiences and trajectories analyzed. The short time of interviews with children reveals the need to adapt research tools to their specific dynamics.

We conclude that the concepts of BD and BC can be used critically and sensitively to the un-

derstanding of familiar experiences of chronicity and their narrative reconstructions caused by genetic diseases among children.

### **Collaborations**

MEP Castellanos participated in the design, outline, data analysis and interpretation, writing of the paper and its critical review. NF Barros participated in the design, outline, writing of the paper and its critical review. SS Coelho participated in the critical review of the paper. All participated in the approval of the version to be published.

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