

Disability, Gender and Narratives of Pain: The Caregivers' Perspectives

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This paper analyzes how caregivers' narratives about pain and illness are constructed, and also what narrative identities are formed during the lengthy process of taking care of a woman with cerebral palsy, from the years of 1972 to 2014. Of particular interest is how these voices narrate feelings of struggle in order to cope with their own needs and the needs of a disabled woman. How this situation affected their way of living, their views about life through gender-sex, violent, discriminatory, psycho-social and cultural perspectives (Lamas, 2002)? This study also draws from Hydén's ideas regarding narratives about illness to identify diverse forms to represent reality by means of creating affective bonds, including aspects such as plot, metaphors and the construction or reconstruction of the Self (1995; 1997), which can be related to the transformation of the narrative identity (Ricoeur, 1995; 1996) of each caregiver. This study aims to open other scenarios to establish public policies of support for caregivers and for the disabled, and to question the role that government and medical institutional have played in order to benefit the society as a whole.

Keywords: gender, caregivers, narrative identity, narratives of pain

Introduction

Eva's fate was determined the day she was born in 1972 at the Instituto Mexicano del Seguro Social (IMSS) in Monterrey, Mexico. Doctors expected a regular labor for Eva's mother, as it was her ninth pregnancy; her conditions appeared to be optimal, thus everything regarding the labor was to have a normal procedure. But she had a wrong diagnosis, the child was not in a good position for a natural birth, so doctors decided to perform a C-section surgery at the last minute as it was life threatening for both of them. The consequences of this medical error, of delaying the surgical treatment, for the mother was to stay at the hospital for 20 days in danger of losing her life, and for Eva, a life of disability and dependence on her caregivers. Soon after birth, the doctors gave the bad news to Eduardo, Eva's father. The diagnosis was cerebral damage with only 10% of neurons alive. Cerebral palsy infantile (CPI) is one of the most common, it occurs in 2 to 2.5 cases per 1,000 live births, it is considered that this 10% has severe CPI (Dzienkowski, Smith, Dillow, & Yucha, 1996, pp. 21, 45-59). What this meant was that Eva would always have a vegetative life. The medical term for this condition is known as neonatal hypoxia presented at birth with a diagnosis of severe ischemic encephalopathy-anoxo. Eduardo shared this sad news with her eldest children, but Eduardo's direct knowledge of how this had

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happened was limited, it depended on the doctors' short statements, which did not elaborate on the exact recount of events. In the early 1970's, the general social collective imaginary was that the doctors had all true knowledge, and most importantly they had no errors. Unfortunately, this kind of medical practice, amounts to what is now known as obstetrical violence. In the case of women, medical staff does not recognize that in many cases, the complications that women suffer during pregnancy, childbirth and the postpartum period are a result of interventions, unnecessary medical treatments, incorrect or aggressive diagnoses (Camacaro, 2005). According to Information Group on Reproductive Choice (Grupo de Información en Reproducción Elegida, GIRE, 2014), a powerful Mexican NGO, 72% of pregnant women were in risk of having obstetrical violence in 2015. This stresses the fact that public participation in the financing of health care in Mexico is one of the lowest among the countries of the Organization for Economic Co-operation and Development (OECD).

Around one million women die annually in the world from complications during pregnancy and childbirth. In addition to this, about two million newborns die during the first 24 hour life. According to the World Health Organization, 99% of infant deaths occur in underdeveloped countries (WHO, 2001). Regarding persons with disability the World Health Organization estimated in 2010 that about one billion people or 15% of the world population live on a disabling condition (WHO and BM, 2011:8). As far as this paper is concerned, statistics regarding caregivers are not available; there is a high percentage of disabled people in the world but no information of the persons who take care of them.

Mexican Historical Context

In the 1970's in Mexico, there was a widespread social and governmental belief that severe cases of disability in patients were to be taken of only within a family context, as there were no specific institutional practices to improve their life conditions. Disability was traditionally confined to the limits of individual body. It was not until the late 1990's that this issue started to gain social recognition, but from a perspective that it focused mainly on rehabilitation; and in the late 2000's to obtain human rights for disabled patients. There has been an evolution toward their understanding and social construction (Barnes, 1998, pp. 59-76), and some achievements in 2003, among which, the most important is the Mexican Federal Law to Prevent and Eliminate Discrimination and the creation of the National Council to Prevent Discrimination CONAPRED (INEGI, 2010).

In the international field, in 2006, the United Nations General Assembly (Hesla & Kennedy, 2008) adopted the Convention on the Rights of Persons with Disabilities. One of the main objectives of the Convention was to generate a change in mentalities on a collective basis to be more sensitive to people with disabilities, and to recognize each one as holder and subject of rights. However, one wonders where the rights of the caregivers are and what about their own families? A great majority of them are productive aged women.

This topic has not been thoroughly analyzed in gender studies, with just a few studies in this regard (Camacho, Yokebed-Hinesterosa, & Jiménez, 2010). In particular, the role of caregivers in the collective imaginary is believed to be an exclusive obligation of women as the patriarchal mandatory beliefs assign this responsibility just for being a woman. Also, part of this collective imaginary is to be a mother, implying also the attributes of caring for the family. In cases of a disabled family member, she would assume the primary caregiver role, in cases where she is not alive, or absent for some other reason, the responsibility pass on to the daughters, or any other woman living at home (Estrada, 2012; Lamas, 2002).

From 1969 to 2009, the Mexican National Institute of Statistics and Geography (INEGI) registered the average number of children who have Mexican women; these figures declined from 7 to 2.4 children per woman in that period. National official records of 2010 in Mexico indicate that there were 40.8 million women over 15 years of age, of which 71.6% have had at least one child; that is, seven out of ten. According to INEGI, people with disabilities in Mexico during the year of 2010 were a total of 5 million 739,000, representing 5.1% of the total population (p. 40). Being a disabled person can take several shapes, INEGI classifies them into four main groups: birth, sickness, accident and old age. In Mexico, percentage figures regarding disabilities are diagnosed as follows: 39% because they have suffered a disease; 23% are affected by aging; 16% the acquired by inheritance, during pregnancy or at birth; 15% were a result of an injury from an accident; 8% due to other causes (INEGI, 2010, p. 39). Eva's disability was caused at birth.

Addressing the subject of caregivers of a person with severe disability is a complex socio-cultural problem study, because it involves biological, and socio-cultural and psycho-affective spheres that influence the life story of the person, and especially the people around the disabled person and the people who perform as caregiver. This study aims to open other scenarios to establish public policies of support for caregivers and for the disabled.

Recent studies show that health conditions affect not only the disabled person, but also, caregivers, family members, community, and anyone who supports the development of society (Martínez, Robles, Ramos, Santiesteban, García, Morales, & García, 2008). This is particularly acute in situations after a severe diagnosis of a disabled chronic illness in which the family dynamics is significantly modified, as most of the attention and energy are given to the disabled person. Mexican traditions normally give this responsibility to a family member who is the main support and mentor. The primary caregiver is thus a very close relative who does not receive any payment, neither any form of training to deal with a patient (Armstrong, 2005). The responsibility is met in a very kind, humane way, free of any personal interest, just to assist the other and is called Primary Informal Caregiver. One must differentiate the Primary Informal Caregiver (Wilson, 1989), from other caregivers called Formal Primary Caregivers, who are employees with a specific health training or education that give professional service paid for a limited time (i.e., doctors, nurses, social workers, etc.).

Primary Informal Caregivers' Narratives and Their Perspectives

The relation between narratives and identity construction has been widely examined; in some cases, a critical stance in regards to the interview as a methodological tool has been included. Nevertheless, it is convenient to note that the narratives produced during the interview can have an enhancing and provocative path in research, given the position and opportunity they give to create a character out of the person that is narrating (Hernández, 2014, p. 466). Some analyses emphasize the ability of narratives to constitute reality and not just representing it, the research question is rather "how it operates as an instrument of mind in the construction of reality" (Bruner, 1991, p. 6).

The above is particularly evident in narratives of pain. Previous studies from different theoretical perspectives of narratives about illness (Hyden, 1995; 1997; Guber, 2004; Hamui, 2011) have associated the act of narration with illness as a way to establish a meaning and understanding of the painful process; thus cognitively is a form of constructing reality. In particular, Hydén mentions that the importance of a narrative about chronic illness gives the opportunity to patients to cope with the consequences and changes that it brings, among those, the problems of identity (1997, p. 51). The latter is also valid for caregivers who need to make

sense of a disrupted life, their lives lose their continuity as there is a before and after. Narratives, in this case of pain and illness, offer new scenarios to construct other identity, to close the gap between the life there was and the one there is now, linking the past with the future. To this respect, Guber stresses the relevance of caregivers as subjects of research giving an opportunity of an interactive dialogue with the other, with the outcome for building a relationship between ethnographer and subject (2004). Most importantly, it is how these narratives shape and manifest the caregivers' experience. In Mexico, Hamui has explored the narratives of suffering as mediation between the introspective thoughts, feelings, and the external world of actions and situations. In this case, the act of narration, or the listening to a narrative, are both active and constructive processes in a culture (2011, p. 64).

This paper relies in an ethnographic technique based on the primary familiar caregivers' narratives through a semi-structured interview about the history and background of a disabled woman with CPI, Eva (1972-2014). The theoretical framework draws from Ricoeur's narrative identity notion which has been applied widely in discursive and literary studies (Zarate, 2011). Narrative identity concept as such has two aspects or dimensions according to Ricoeur: Idem-identity as sameness, and ipse-identity as selfhood. Idem-identity in a narrative has continuity in time and it responds to the question What am I? Meanwhile the ipse-identity in a narrative is related to the question Who am I? It is worthwhile to note that a narrative provides the opportunity for the self, the ipse-identity, for continuity in time that links past events with future ones (Ricoeur, 1995, pp. 109-112; Rasmussen, 1996, p. 164). For some theorists, the importance of narrative identity lies in its power to manifest the temporal aspect of selfhood, or ipse-identity (Rasmussen, 1996, p. 168). As mentioned previously, some other studies underline the act of narration as a setting to create a character of the person that is narrating (Hernández, 2014, p. 466).

This analysis takes into consideration the primary informal caregivers' narrative starting from Eduardo, her father, Paz, her sister, and Andrea, her sister-in-law. Through their narratives, it is explored the plurality of narrative identities as a way to examine, violent, discriminatory, psycho-social and cultural perspectives in discourse. It should be observed that in the case of Eva besides women caregivers, there was a male caregiver who was her father, Eduardo, and who broke the traditional role male of being detached from family care, in particular of a disabled family member.

Eduardo, a Father's Narrative

Eduardo, an 83-year-old man, factory worker, with a second grade elementary education, was Eva's primary caregiver from 1972 to 2014. His identity has a plural meaning in the sense that he constructs a narrative identity as sameness, or idem-identity, responding to the question What am I? He's a Mexican man, widower, caregiver of Eva, and also the father of other eight children, with the corresponding responsibilities. But what narrative identity, in its ipse-identity aspect, is constructed during the act of narration? Eduardo states his selfhood, his emotions, his memories, his thoughts about the beginning of the devastating story in his family:

Everything was going fine the day my last child was to be born, my wife had not had any problems during the pregnancy. But unfortunately at the time of delivery, the little girl had problems to get into position for birth, still they [doctors] were expecting to have a normal birth delivery, but when they saw that the girl pulled out a hand, the doctors took my wife to the emergency room for a C-section, but it was too late, the girl died and they resuscitated her, and because she was strong, she lived, but in bad condition, and unfortunately it was because of the doctors incapacity who took care of her. Her disability was very strong and devastated both of us, my wife and me. Life was no longer the same; it was a lot of pain and anguish. (Interview with Eduardo, June 2, 2013)

Eduardo as an elderly man follows a conventional way of narration. He starts setting the ambience in a positive mood "Everything was going fine the day my last child was to be born". He recalls the event when he was a young man and was confronted with an extreme life situation, which is introduced by the discursive markers "But unfortunately". This is the element in a story which announces a disruption in the flow of events. Something was happening that would change his life in a dramatic way. Eduardo continues his narrative stressing the fact that the doctors' decisions were crucial as they waited until the last minute to operate Eva's mother.

As Hyden states emotional responses are expressed in the process of narratives about illness, which have a clear beginning, middle and ending (1997, p. 50). The narratives thus follow a regular structure pattern, indicating the temporality of events. This can be observed in the previous quote and also in the following one:

I was 41 and my wife 34 with nine children to support, but I focused on the youngest child and neglected the others. I felt guilty for not giving the necessary to them, and I had to quit the glass company where I was working in order to set up my own business (grocery store), so that I would be close full time with the family. I got depressed and started smoking several years, but I quit it after, but never drank and did not want to get married again, I promised my wife when she died that I would take care of our little girl and I kept my promise, the word is the word. (Interview with Eduardo June 2, 2013)

Eduardo's narrative tells a story of frustration, impotence and pain, all within a context of daily family responsibilities. He pictures himself, his ipse-identity, as a young man of 41 years old. In Mexican culture to be a young and productive man means to have freedom and open opportunities with a wide spectrum of possibilities. In this case, Eduardo decided to forfeit the latter, offered by the status quo system to all men, and instead took the caregiver responsibilities. The needs of other family members are evident in the recollection of Eduardo's memory. His obligations in terms of affection, of paying tuition for his other children were met with the fact that the cost of having private health care service for Eva was too high:

When I saw the girl lying motionless, I filed for a paid therapy, as the IMSS did not have that service for children with this condition. It was expensive in time and effort to move the little girl. When she was older, it was cancelled because there was no one to take her and bring her and there was not enough money for the other children, as they were all at school studying, and that was important for me too that they had some schooling, prepared to life. (Interview Eduardo, June 2, 2013)

Paz, a Sister's Narrative

The middle of the story is represented by Eva's sibling, Paz, a 53-year-old woman, educated to a graduate level, separated, teacher, who took care of her from 1973 to 1980. Derived from observing her father, Paz conceptualizes the notion of guilt. In this case, one can draw from Wendel who mentions that having a deficiency generates some kind of guilt in those persons that have not been able to prevent that disability. They are stigmatized socially because they are a reminder of this lack of control; they provoke fear in society as even the strongest person can become sick (1998, pp. 435-452). This can be related to a social widespread belief, and fear, of those different; and especially, that even without disability a healthy person can become sick in any moment:

My father always felt guilty because he did not accompany my mother at the time of consulting the doctor as he was working and could not neglect the economic support for men is very important in the collective imaginary be the supplier with his wife to attend with her a routine checkup, maybe this guilt made him the be strength to face her daughter's disability. (Paz, Interview May 3, 2013)

In Paz's narrative the discursive marker "guilty" condenses her observations about Eduardo's feelings, derived of his absence at the "time of consulting the doctor". The narrative includes an important fact in a man's life, that of a provider for the family. Paz stresses the latter by using the notion of "collective imaginary"; it was his first responsibility, but also, he had to be by his wife's side.

A tale of frustration from Paz narrates a painful scene with a teacher, trying to distance herself from the disrupted flow of family life, before and after Eva. Paz uses a third person narrative at the beginning of her narrative, as if she were someone detached, impartial, not herself, not her own needs, changing to a first person narrative of her experience as 13 year old girl:

Eva was taken care by all the women in the house, the first caregiver was me, I was 13 years old and it was very depressing, I was like this for five years until I woke up and made the decision that lives continues and neither my sister nor my mother were given proper medical care on time, oh well. I remember a teacher told me one day that disabled people were like that because in a previous life, they had done bad things and that made me angry against my little sister, but I changed my mind very quickly, the teacher was wrong in his comment and I realized for the first time that in the world there were a lot of ignorant people with no respect to persons with disabilities. (Interview with Paz, May 3, 2013)

In her recollection of her teenage years, the discursive marker "I woke up" symbolizes the waking up of a nightmare. The adult Paz explains herself the feelings and contradictions she had as a girl: She was waking up from a bad dream, something that it was not real. Her narrative identity blurred that what was from what was not. The continuity of time links those feelings of yesteryear to the woman she is, it is the temporality of existence. On the other hand, the confrontation with her former teacher situates her within the limits and fears of society, but mostly "ignorant people".

The narrative becomes a narrative of anger towards the medical institution, IMSS, and the divinity. The narrative identity questions the restrictions imposed by society:

My sister's disability severely affected the family role, but above all the people who took care of her, this caused us anger and impotence because we lacked financial resources, transport and time required to carry her to the health institution where she could get rehabilitation and proper medical care. I was 13 years old when I started to take care of her, because when my mom went to the hospital to have a surgery, she asked me to take care of my little sister, but she never came back and I blamed god and I asked myself why that health institution didn't do its work right, why their negligence to people, especially women. (Interview with Paz, May 3, 2013)

The temporality in her narrative identity was disrupted, expressed by "My sister's disability severely affected the family role, but above all the people who took care of her". And who were these people but themselves, Paz, Eduardo, and Andrea.

Andrea, a Sister-in-law's Narrative

The ending in the caregivers' narratives corresponds to Andrea, sister-in-law to Eva, married, a high-school graduate, a housewife, who provided the primary care attention from 1997 to 2014:

The disability affected my relationship with my husband, as it was not my duty, but I did it with pleasure because I am a religious woman and that's what God wants. However, it was very hard to take on that responsibility and also for my children. There were not enough resources and that made the crisis even worst. Also, it influenced our family days out, sometimes we had to return quickly in case the attendant did not show up, I had to do it even on Sundays. It is wrong the IMSS did not accept the responsibility in Eva's case. And that depresses, but it is job that has to be done, she was an innocent one who could not take care of herself. (Interview with Andrea May 2, 2013)

Although not a direct relative to Eva, Andrea takes on the responsibility of caregiver with the argument of her religiosity by the discursive markers "I am a religious woman and that's what God wants". So, she assumes the tasks willingly albeit there are personal costs involved. Through the adverb "However", Andrea's narrative introduces the high cost of that responsibility in addition to her maternal duties. The flow of narration goes on to express that the family routine adapted to her caregiver demands, as sometimes "the attendant did not show up" referring to the professional paid caregiver, "even on Sundays". In this case, the temporality of the caregiver duties interrupts Andrea's family life and outings with her husband and children. Life patterns changed as a consequence.

Using a third person narrative and passive voice, Andrea continues her recollection of Eva's daily routine, dissociating herself from that burden:

Feeding, hygiene, personal care, clothing, medications, space room were all taken of very carefully for Eva. Her development was very slow, and she could not move at all. Her body's immobility made my back hurt because when I had to carry her, she was already heavier and she shrunk herself a lot and that was a lot of work for me and I remember that she loved to take baths and she enjoyed it a lot and smiled. (Interview with Andrea, May 2, 2013)

In addition to her family activities rescheduling, Andrea's narrative incorporates the cost in terms of her physical well-being by the discursive markers "because when I had to carry her, she was already heavier". In this case, the adjective heavier can be read in two senses, more laborious and more difficult to cope physically with the caregiver's duties, and also, emotionally because it expresses an extra burden to see the immobility of Eva's body. And Andrea, as her caregiver suffered, even without realizing it at the moment. These feelings are intertwined within the narrative as she acknowledges Eva's apparently detachment:

We felt that she did not listen to us, that she did not remember anything, inclusive; we thought it was in vain to hold her, because she did not respond to our affections, there were only certain reflexes when we touched her and she just smiled. (Interview with Andrea, May 2, 2013)

Andrea's words "she did not listen to us", "she did not respond to our affections" manifest frustration as she would have expected some sort of affective response, as a way to thank her for taking care of which a healthy person would do. So a self-reflection in this regard is evident in the discursive markers "we thought it was in vain to hold her", in which Andrea includes herself among the other caregivers, no expecting such demonstrations; it was a collective voice that was both, frustrated and willing, to go to extreme pain to help another human being.

Conclusion

This paper examines how informal primary caregivers of a woman with cerebral palsy (CPI) are affected in their path of life, family, social relationships, health and work. As direct family relatives, they become themselves the only ones to give patient care. This is a form of social oppression, imposed on a sector of society; this fact, however, would not be admitted publicly; sometimes, even the same caregivers would not recognize it. Cultural imaginary caregivers profile has been assigned so far to women, according to the traditional role in the sex-gender system, even in the 21 century. It is argued in this research that this should be a shared obligation of the State, society, medical institutions, NGO's, women, men, everyone in the community; this issue should be in the government agenda. In spite of advances in prevention, in human rights of disabled people, statistics have increased. It is necessary to take action to avoid and reduce the current situation in the

society. In mass media and in support programs, organized by private companies, accepted by government, it has been observed that one of the main objectives is to call upon pity and alleged social inclusion, which the only thing it spreads is to take advantage of a collective willingness and money generosity to reach out.

From a theoretical perspective in narratology, specifically Ricoeur's notion of narrative identity applied to primary informal caregivers, this article analyzes how narratives about illness construct meaning and understanding of the painful process of taking care of another human being. As stated in this paper, narratives provide the opportunity for caregivers who need to make sense of a disrupted life, since their lives lose their continuity, there is a before the irruption of caregivers obligations and there is an after. Narratives of pain, thus, present new scenarios to construct cognitively other identity, to connect the gap between the life there was and the one there is now, linking the past with the future. Through the dialogue between the idem-identity and ipse-identity in narratives, this research has aimed to open a window in the caregivers' narrative identities, and their different responses to the questions related, what am I, and most importantly who am I. In other words, the analysis included the idem-identity as sameness, and ipse-identity as selfhood. Idem-identity in a narrative has continuity in time and it responds to the question what am I? In the case of Eva's caregivers their idem-identity is for Eduardo, father, male, adult; for Paz, middle sister, woman, teacher, but a teenager girl at the time of taking the position of caregiver; for Andrea, sister-in-law, woman, and housewife. Ipse-identity, on the other hand, is related to the question Who am I? In these narratives about illness and pain, the response lies in the words intertwined as Eduardo, Paz and Andrea narrate who they are, what were their needs and feelings during the moments of taking care of Eva. So their narratives offer the path for the self, their ipse-identity, for continuity in time that links past events with future ones, and especially for healing.

Further studies may explore social mechanisms of exclusion as theorized by Michel Foucault, that is to say, the incorporation of narratives to express the personal truth about reality or in opposition to the official's truth or status quo; erase the invisibility of those who do not exist in society as a way of trying to make them visible, and their needs.

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