

León y Olvido (2004): Family and Disability

José Martín Ruano¹, María Gloria García Domínguez², José Antonio Mirón Canelo³

¹Centro de Salud "Santa Marta de Tormes". Santa Marta de Tormes. Salamanca; ²Psicóloga Servicios Sociales Exma. Diputación Salamanca;

³Departamento de Medicina Preventiva, Salud Pública y Microbiología Médica. Facultad de Medicina. Universidad de Salamanca (Spain).

Correspondence: José Martín Ruano. Centro de Salud "Santa Marta de Tormes". Calle Ignacio Ellacuría s/n. 37900 Santa Marta de Tormes. Salamanca (Spain).

e-mail: josemaruano@gmail.com

Received 21 January 2009; modified 20 September 2009; accepted 5 October 2009

Summary

León y Olvido recounts the cohabitation problems and the complicated relationship between León, a young man with Down's syndrome, and his twin sister Olvido who, since the death of their parents, has to take care of her brother after he has been expelled from several centres. León finally manages to go to live with his sister, but he finds difficulties in looking after himself and in assuming a minimum of responsibility. As far as Olvido is concerned, she does not want to lose her independence by fully devoting her life to taking care of her brother. Amidst this hard bargaining, León, under pressure from his sister's brusque attitude, will begin to accept and take up new tasks and roles at home and to assume different degrees of responsibility. The lack of social assistance, economic precariousness, and Olvido's personal and job-related changes spark a number of difficult situations and moments and are the leitmotiv of the lives of these young siblings.

Keywords: Down's Syndrome, Family, Disability.

Technical details

Title: *León y Olvido* (Figure 1)

Original title: *León y Olvido*

Country: Spain

Year: 2004

Director: Xavier Bermúdez

Music: Coché Villanueva

Photography: Alfonso Sanz

Film editor: Javier Alberto Correa Harley

Screenwriter: Xavier Bermúdez

Cast: Marta Larralde, Guillem Jiménez, Gary Piquer, Mighello Blanco, Jaime Vázquez, Rebeca Montero, Nerea Barros, Laura Ponte, Pilar Pereira and Miguello Blanco.

Color: color

Runtime: 112 minutes

Genre: drama

Production Companies: El Paso Producciones Cinematográficas S.L. and Xamalú Filmes

Synopsis: Olvido and León (a young man affected by Down's syndrome) are twins whose father died at sea and whose mother

died from a dramatic illness. After becoming orphaned León is shuffled from one centre to another without remaining for long in any of them, his only goal being to go back to his sister and live with her in the family home, the rented house left to them by their parents. León finally manages to go to return to his sister, for whom the responsibility for his care is a real problem since on top of working away from home she has to do the housework. León is a very dependent boy who always expects his sister to take charge, demanding that she attend almost all his needs. Overwhelmed by the situation, she insists that León take responsibility for his personal care and acquire abilities that might allow him to gain limited amounts of personal autonomy. León, however, is reluctant and begs for time to get used to the new situation. Their relationship suffers continuous ups and downs due to Olvido's personal and job-related problems and the extra burden involved in having a 21-year-old disabled brother. The film finally addresses the topic of the importance of sexuality for the group to which León belongs.

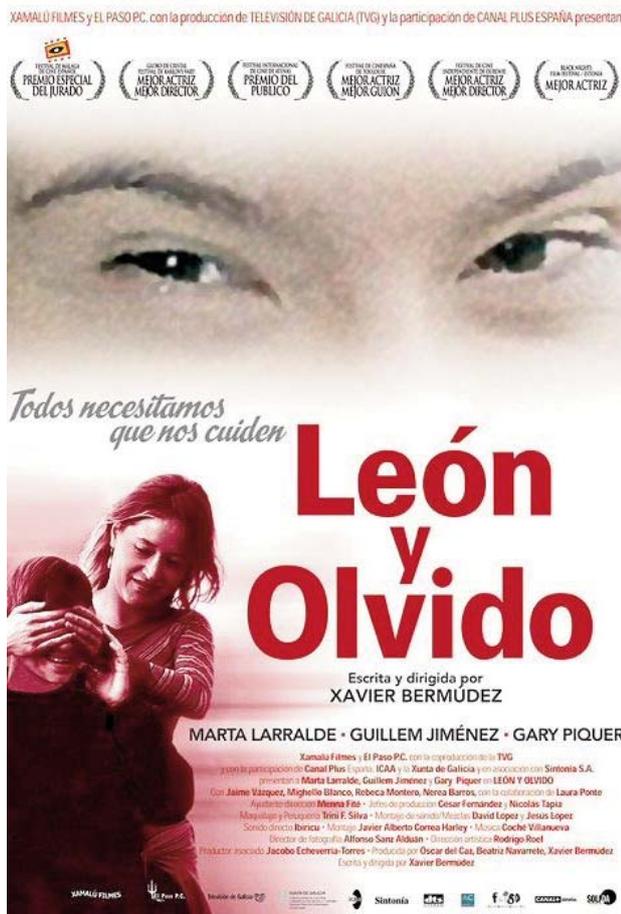


Figure 1: León (Guillem Jiménez) and Olvido (Marta Larralde) are two orphaned siblings

Awards: Special Jury Award at the Málaga Spanish Film Festival (2004). Best Director (Xavier Bermúdez) and Best Actress (Marta Larralde) Crystal Globe at the Karlovy Vary International Film Festival (Czech Republic, 2004). Audience Award at the Athens International Film Festival (Greece, 2004). Best Screenplay Award and Best Actress Award (Marta Larralde) at the Cinespaña Festival (Toulouse/France, 2004). Best Director Award (Xavier Bermúdez) and Best Actress Award (Marta Larralde) at the Ourense Independent Film Festival (Spain, 2004). Best Actress award (Marta Larralde) and Jury Award to the Best Film at Black Black Nights Film Festival (Tallinn/Estonia, 2004). <http://www.imdb.com/title/tt0414225>

Cinema and disability

The images provided by cinema of the disabled and of disability itself have become more numerous with the passage of time. Like other professionals, film directors have begun to become aware that this population group, different and specific, is

truly part of society. Within the cinematographic treatment given to the topic there are films that use the problem of disability in their scripts, either as the central theme or in an anecdotic way. However, the image transmitted by the plots has frequently been inadequate and the approach is rarely achieved in an accessible, natural and everyday manner. People with disabilities have been assigned very heterogeneous roles, sometimes being portrayed wicked, marginalized and allied with evil, and on other occasions as naïve or submissive victims¹.

The representation of disability in the cinema has probably developed along the same lines as what has happened in society, more and more films attempting to present a positive and more realistic view of the disabled. This new approach is useful for the understanding, awareness and change in attitude of society concerning this group of people and for preventing stigmas and biases in the perception, information and training of people with disabilities.

There are films with characters who suffer different types of physical disabilities [*The Sea Inside/Mar adentro* (2004) by Alejandro Amenábar, *Million Dollar Baby* (2004) by Clint Eastwood, *Born on the Fourth of July* (1989) by Oliver Stone, *Children of a Lesser God* (1986) by Randa Haines, ...] mental disabilities [*The Flight of the Phoenix* (1965) by Robert Aldrich, *Radio* (2003) by Michael Tollin,...], cerebral palsy [*Le chiavi di casa* (2004) by Gianni Amelio, *My Left Foot: The Story of Christy Brown* (1989) by Jim Sheridan, *Piedras* (2002) by Ramón Salazar.], ... and also genetic disabilities such as Down's syndrome [*Vida y color* (2005) by Santiago Taberner, *Le Huitieme jour* (1996) by Jaco Van Dormael, *Las palabras de Vero* (2004) by Octavi Masià, *Jewel* (2001) by Paul Shapiro and *León y Olvido* (2004) by Xavier Bermúdez]². It is this last film that is addressed in the present contribution.

The viewer is confronted by an additional problem: the ability to believe in actors who are not affected by any type of deficiency or disability but are playing the role of disabled characters. This is not the case of the film discussed here since it is the first Spanish film starring a disabled person with Down's Syndrome.

The film:

To gain an approximate idea of the film's plot, it suffices to analyse the names of its main characters: León (Guillem Jiménez), which expresses the

strength and impetuosity of the disabled person, and Olvido (Marta Larralde), which reflects the need to flee from harsh reality,

The film is a continuous sequence of bitter-sweet moments: some of them funny, raising more than one smile, and others harsh, involving extreme situations in the lives of its protagonists. The film portrays constant ups and downs in the relationship between two siblings, León and Olvido, who are orphaned by the premature death of their parents (Figure 2).



Figure 2: Olvido has to take charge of her brother on her own owing to their parents' premature death

León has been in several specialist centres, being expelled from all of them for *his damaging attitude towards the rest of the inmates* and his refusal to adapt. Olvido has to take charge of him and foretells *“you have no idea of what I am going to have to take on”*, since she knows this will affect her independence.

The film alternates between very moving scenes and extreme situations in the siblings' relationship that lead to highly emotional moments. Olvido tries to rid herself of her brother four times (challenging him on a cliff, with an overdose of pills, abandoning him by the roadside, shooting at him). All these situations are triggered by external factors: the expulsion of her brother from the centre and his arrest by the Civil Guard or her losing her job and her disappointment in love. But all these attempts to get rid of him fail. Alongside these tragic moments there are others of tenderness and affection and even of high spirits.

With León Olvido is surly and frequently violent as a strategy to get him to take on responsibilities (to help with the housework, to take care of his

personal hygiene and appearance, to become self-sufficient in basic everyday situations such as going to school, doing the shopping...). *... I'm not doing what you don't do yourself... , ...I am your sister but not your mother or your servant... Faced with this challenge León begs for time to learn but the ultimatum is clear: ...you either learn to fend for yourself or you go with the nuns... It is a continuous give and take in the relationship³.*

Society's image of disability is reflected in the attitude displayed by Doña Dorita (Pilar Pereira) who now and then offers affection and even some money; but there is no long-term commitment. Words like *...if it happened to you... there must be a reason, ...what is going to become of you.....* frequently reflect the self-condemning and patronizing attitude of a large part of society concerning disability. Olvido's frame of mind is not that different, she tells her brother that he must realize that *...he will never be able to fend for himself., ...he will never learn anything..., ...you need someone to constantly keep an eye on you....* These ideas are evidence of the negative opinion prevailing about people with disabilities, a negative opinion that can be perceived in society and even in the family setting. This simplistic and ominous image limits the possibilities and opportunities of people who suffer from disabilities and banishes from us a realistic view that might favour actions and attitudes aimed at developing their potential. At the same time, this view generates a great deal of anguish and stress in carers, who become afraid of being unable or not knowing how to take proper care of these people's needs. In addition, it causes feelings of loss and personal renunciation: lack of time for oneself, deterioration of social and interpersonal relationships, loss of freedom, etc., all of them clearly reflected in the film. León sidesteps his need to assume his responsibilities by using his condition as an excuse; he does not feel required to accept his responsibilities because he is different, or has been treated as such. It is striking that the only environment that tends to accept him as normal and not stigmatize him, respecting his differences, is the school, where he also responds normally. The film reflects that this is the only environment where integration has reached certain levels of effectiveness⁴.

At the school we learn about the rest of León's friends (Figure 3), Jonathan (Xavier Bermúdez), Raquel (Rebeca Montero),.... They express desires and dreams that are no different from those of present-day youth, since their life projects

include *getting a job, having a boyfriend, getting married and going on holiday*. However, León provides an additional obligation: *I have to look after my sister, I promised it to my mother*.

León is intelligent—capable of understanding syllogisms—but he is lazy. He waits for things to be done for him, either by his sister or by the social services, without making any effort. This underscores the negative effects of over-protection by the family, which he probably experienced when he was a child. At the same time, he displays a selfish attitude in his refusal to share the money given to him by the neighbours and in spending it on things for himself. Is it that he is unable to understand her sister's difficulties with their economic needs or does he just reject all responsibility because he has not been taught to take part in the economic running of the home? All he does is satisfy his own needs.



Figure 3: León goes to a special-education centre with other disabled people

On the other hand, León's classmates teach us a lesson when they question the teaching methods related to the integration in the school of people with special educational needs. They specifically talk of syllogisms: *I must regret that these sentences have no logic nor even any democracy or progress, and neither do they solve current problems*. That is to say, they show up the lack of real curricular adaptations in teaching as far as student diversity is concerned.

Olvido's relationships are not going well either. Iván (Mighello Blanco), her boyfriend (Figure 4), is not very different from León, he is a doctor but he does not work and is kept by his parents. He is neither willing to assume responsibilities nor to

become formally engaged to Olvido and he dreams about going to Africa.

León does try to change, and one day, when returning home, as a prize for his willingness to change and his assumption of responsibilities he sees a girl through a shop window who seems to like him. But nothing further happens; when he arrives home his sister continues to put pressure on him to take on more tasks. León worries, asks for reasons, but when none are forthcoming he decides to watch his sister when she goes out with her friends at night. At this, Olvido believes her independence is threatened and she abandons him by the road, where he is found by the Civil Guard who put her in contact with the Social Services. The following scene, through a tense and bleak dialogue, reveals the inflexibility of the Social and Benefits Services. At this point the film reflects the loneliness of the families and the lack of support and institutional response to the difficulties they very often come up against.

León tries to become independent and gain his own autonomy by attempting to rent a room in Jonathan's flat. This attempt is fruitless. Is it because Jonathan dies? Is it for lack of support, encouragement and motivation to continue? Is it that he does not take his attempt at emancipation seriously? This shows that he is not comfortable in his situation of independence either. A new crisis threatens Olvido when she is dismissed from her job at a clothing factory and the situation worsens when she receives the news of the departure of her boyfriend, Iván, and his refusal to live with her. She blames her brother for it, which triggers a new attempt to get rid of him. A victim of the pressure she is under, she prepares an over-



Figure 4: Iván (Mighello Blanco), Olvido's boyfriend, is almost as dependent as León

dose of pills mixed with juice to poison her brother. When he refuses to take the concoction, she uses emotional blackmail to get him to drink it (she uses León's unconditional love and his sexual needs (Figure 5) offering him the possibility of incestuous sex). Despite these attempts to get rid of him there are no reproaches from León to his sister, only flattery and affection.

León dreams that things are going to improve, since he is going to find a girlfriend and Olvido will find the job she is looking for, and his dreams seem to come true when his sister does get a job in a wedding dress shop. Jonathan is run over by a car and dies, saddening the group: *so much preparation for this*. León displays great sensitivity in detecting moods; it is easy for him to emotionally connect, although his interpretation of others' moods leads to one of the craziest and most charming scenes in the film when he says to Jonathan: *"you are going to die, ...if not your mother would not be so sad*.



Figure 5: León's sexual impulses are made apparent in many scenes

Damián (Gary Piquer), the owner of a wedding dress shop, goes shopping with León and offers him his particular view of women, putting a price to every one of them that comes their way. He uses León to approach Olvido and begins a relationship with her (Figure 6). Olvido's situation of vulnerability due to her family and economic situation turns her into easy prey for an unscrupulous boss, who proposes that she become involved in something illegal for lucrative ends.

In spite of León's lack of control of his sexual impulses, he does not commit any sexual assaults; it is simply not in his nature to hurt anyone.

His lack of sexual inhibition leads him to become involved in a scene of exhibitionism in which he shows his genitals to a shop assistant (Nerea Barros) -the woman he had previously seen through a shop window and whom he has fallen in love with- and he is duly arrested. Challenged by this new blow from her brother (which adds to her recent dismissal and the proposal that she become a prostitute), overwhelmed by the situation, and unable to face so many difficulties without help, Olvido again tries to get rid of León by preparing a picnic and trying to shoot him. She fails yet again and they return home together, where in her own particular way Olvido expresses the love she professes towards her brother.



Figure 6: Damián (Gary Piquer), the owner of the wedding dress shop where Olvido works

Olvido's personal situation does not seem compatible with looking after her dependent brother. Thus, she is torn between ambivalent feelings of love and hatred, and sometimes addresses him with violence and aggression.

Olvido's ambivalent feelings of love and hatred for her brother are a constant theme in the film but are only half mutually reciprocated, since León returns tenderness and affection whatever the circumstances, a characteristic shared by people with Down's Syndrome. Olvido's love for her brother only turns into rejection when situations overwhelm her and overstep her capacity to deal with them. In addition, it is when she sees no possibility of escaping from them successfully (lack of money, unrequited in love, a critical phase in her life cycle) that the aggressive behaviour towards her brother steps into the limelight. It is also the product of her inter-

nal rebellion against her loss of freedom and personal autonomy.

León only rebels verbally: he shouts at his sister's demands; he is impulsive, with a high degree of emotional instability, and he clearly lacks self-control. Nevertheless, as is frequently the case with people with this type of disability, he displays spontaneous expressions of affection and is unable to remain angry or bear resentment, despite being aware that the other person has tried to hurt him (Olvido tries to kill him on several occasions and he is aware of it).

Down's Syndrome

Down's Syndrome is the main known genetic cause of intellectual disability. The cause lies in the presence of an extra 21st chromosome, this being responsible for the morphological, biochemical and functional alterations that are produced in several organs (nervous system, osteomuscular system, endocrine system...) and that affect the behavioural and learning abilities of such individuals. It is the most common genetic alteration in humans, its presence is estimated at 1/700 conceptions, and its frequency increases with the mother's age, especially when over 35⁵.

It includes a combination of congenital defects: several degrees of intellectual disability, characteristic facial and physical features and frequent heart, intestinal and other endocrine, neurosensory, etc. problems. The seriousness of these alterations varies greatly among those affected and most of them can be adequately treated⁶.

León presents the typical phenotype: upslanting eyes (mongoloid obliquity), epicanthus, small ears that are slightly folded on the upper part, macroglossia, a small nose and a flat nasal bridge, a short neck and small hands with short fingers. He suffers from developmental disabilities and his joints seem particularly flexible. Many of his classmates present an increase in adipose tissue and a tendency to obesity; it is possible that endocrine alterations (thyroids and diabetes) could be behind this, together with a sedentary lifestyle and disorderly eating habits. León also has a slight speech disorder.

The degree of mental disability is variable and it is not related to the physical characteristics. In

most cases it ranges from minor to moderate and, with adequate intervention, few will suffer from serious mental disability⁷.

Sexuality in the disabled

All young people, regardless of their intellectual ability, have a right to a wholesome education in all aspects of their personality, affective and sexual included. However, as far as the integration of people with intellectual disabilities is concerned, as a general rule their sexual dimension is not taken into account, leading to lack of sympathy and prejudices from a large part of those who surround them regarding their sexual behaviour. People with intellectual disabilities do not live in a kind of everlasting childhood, but they develop at a certain pace and in some very particular ways that do not prevent them from fully enjoying their sexuality. From the beginning of the film this aspect is made very clear, since apart from being one of the reasons why León is expelled from the centres, the carer herself stresses his special sexual needs, offering to satisfy them herself if it were possible⁸. The desire for a partner and children is one of the longings expressed by the whole class *they want to have a girlfriend, children, to get married, and have a job and go on holiday*. Olvido not only has to satisfy León's material needs, but also his sexual needs since in several scenes there is an insinuation of incestuous relations under the pretext of *playing pirates, kissing on the mouth, to cure the syndrome*. León is finally arrested for exhibitionism.

The importance of the family

There is a widespread belief that the family is the basic unit for socialization and that its role is outstanding in the evolution, development and ability of its members to function. The family unit introduces its members into and immunizes them from the world of people, things and relations with their biopsychosocial environment. Families with a disabled or chronically ill member suffer serious deterioration and alterations to their dynamic, which is especially the case when dealing with a disabled child⁹. In face of the need of permanent care, a member of the family (main carer) takes charge of him/her. The people who take up this role are under great pressure; they often show contradictory feelings and emotions, and they are helpless and left at the mercy of a social context that may be a source of support or may become a cause of stress and even illness. In the specific case of the film, Olvido has to

take charge of her brother without help due to the premature death of their parents, and this during an especially vulnerable evolutionary stage in her life cycle. This special situation causes the appearance of several emotions towards her brother (love, hatred, loneliness, fear, resentment, affection, aggressiveness, excessive responsibility...). In addition, she does not feel ready: *you have no idea of what I am going to have to take on*. Despite admitting a lack of suitable care to the social worker, she has not received any guidance or professional support (medical, psychological,...), and nor has she received any institutional help (sufficient economic aid, appropriate institutions for her brother,...).

The social and health services should not overlook the consequences disability might have for patients and their families, nor how it might affect the different subsystems (patient, family, social network, public health services, institutions, etc.). Several stressful factors often appear in families where a member needs special care and attention, one of the most serious of these factors being the need to make the different life projects of the family members compatible with attending to the dependent person. In the adaptation process, families undergo structural alterations (redefinition of roles), functional alterations (in family dynamics) and psychological alterations (stress, anxiety, displays of emotions, cognitive disturbances) that must be taken into account. If there is appropriate care and attention from the health and social point of view, and if information is provided and there is guidance concerning specific resources available, adaptation becomes easier and situations of risk for the disabled and their families are prevented, thus improving the personal resources of all family members. It is also positive to receive advice concerning the request and use of social, educational and health services, etc. in order to provide a better response to the families' needs and problems. It is thus possible to establish a healthy support system to maintain the best quality of life and welfare for everyone.

“A family should be a place where its different members might find all the necessary factors to fully develop. If in a family all or most of the resources are devoted to the development of only one of its members, the whole building rocks and could collapse” (10). The loss of social relationships and the lack of support devices and help resources have a great impact that conditions and/or determines family dynamics and frequently affects its members'

health. Accordingly, physicians, from their consultancies, should not neglect the need for comprehensive monitoring, referring if necessary to the most suitable resources available.

The supporting social network is a basic pillar to maintain stability and to adequately respond to the particular difficulties of each case. The lack of effective institutional support is the greatest concern of families, especially parents. Their development and establishment should be one of the goals of a progressive, modern and sympathetic society. The development and effective enforcement of the “Law of Promotion of Personal Autonomy and Attention to people in dependency situations” is expected to improve the conditions of people and families who suffer from dependency due to disability.

Finally, it should be added that the cinema, through its films, can do a lot to sensitize society towards the disabled, helping to eradicate mental barriers and reduce stigmas and social prejudices.

Translation by the team of the Languages Service of the University of Salamanca

References

- 1.- Martínez-Salanova Sánchez E. Cine y discapacidad. Cine sobre mujeres y hombres con diversidad funcional. [Internet]. [cited 2008 Dec 20]. Available from: <http://www.uhu.es/cine.educacion/cineyeducacion/temas/discapacidad.htm>
- 2.- Confederación Andaluza de personas con discapacidad física y orgánica. (CANF). Cine y discapacidad. Guía de largometrajes. [Internet]. [cited 2008 Dec 20]. Available from: http://www.canfandalucia.org/public/media/Exchange/Documentos/guia_cine.pdf
- 3.- Tú y yo aprendemos a relacionarnos. Programa para la enseñanza de habilidades sociales en el hogar. Dolores Izuzquiza Gasset. Fundación Prodis. Down España . Available from: http://www.sindromedown.net/adjuntos/cPublicaciones/32L_hsocialesfamilias1.pdf
- 4.- FEISD (Federación Española del Síndrome de Down. Plan de Acción para las personas con Síndrome de Down en España 2002-2006. AS-2869/2002. Madrid 2002. Available from: http://www.sindromedown.net/adjuntos/cPublicaciones/31L_plandeaccion1.pdf .
- 5.- Martínez Gómez AP. Las personas con Síndrome de Down en España. Perfil estadístico. Documentación Social 2003; 130: 207-227. Available from: http://www.caritas.es/Componentes/ficheros/file_view.php?OTExMg%D%3D
- 6.- Soriano Faura FJ, Grupo PrevInfad / PAPPs Infancia y Adolescencia. Actividades preventivas en el síndrome de Down. Rev Pediatr Aten Primaria 2006;8(32):641-57. Available from: <http://www.pap.es/documentos/Articulos/PDF/634.pdf>
- 7.- Down Syndrome: eMedicine Pediatrics: Genetics and Metabolic Disease. Chen H. [Internet.] 2009 Jun [cited 2009 Aug 1]: [around 5 screens]. Available from: <http://emedicine.medscape.com/article/943216-overview>

8.- Educar la sexualidad de las personas con Síndrome de Down. Propuestas de orientación [Internet]. Amor Pan JR. Fundación Iberoamericana Down21; [cited 2008 Dec 20]. Available from: http://www.down21.org/educ_psc/sexualidad/sexualidad.htm.

9.- Navarro Góngora J, Fuertes Martín A, Ugidos Domínguez, TM. Prevención e intervención en salud men-

tal. Salamanca: Ediciones Amarú; 1999.

10.- e-México. Los Hermanos de las Personas con Síndrome Down [Internet]. México: Sistema Nacional e-México [updated 2004 Feb 24];[around 2 screens]. [cited 2008 Dec 20]. Available from: http://207.249.10.121/wb2/eMex/eMex_5ff5_los_hermanos_de_las