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RESEARCH NOTE/NOTA DE INVESTIGACIÓN

Surviving Cancer in Adolescence. An Approach to the Social Sequelae based on Life Trajectories[1]

Sobrevivir al cáncer en la adolescencia. Una aproximación a las secuelas sociales a partir de trayectorias vitales

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ABSTRACT

Adolescents cured of cancer can see their path in life altered by the consequences of the disease, since the understudied social sequelae play an important role in their academic and relationship trajectories. The research note aims to contribute to the analysis of educational contexts and the effects they have on the subjective construction of adolescents through the different experiences in the varying dimensions affected by the diagnosis and treatment of childhood cancer, taking into account the educational, family or leisure environment. Of particular interest is the impact of the diagnosis and the treatment interval (one year for bone tumours) on social interaction and resuming a normalised social life.

KEYWORDS: childhood cancer; survivors; trajectories; social sequelae; clinical sociology.

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RESUMEN

Los/as adolescentes curados de cáncer pueden ver alterada su proyección vital por las consecuencias de la enfermedad, pues las secuelas sociales, poco estudiadas, tienen un protagonismo importante en sus trayectorias académicas y relacionales. La nota de investigación trata de contribuir al análisis de contextos educativos y sus efectos en la construcción subjetiva de los adolescentes a través de la experiencia de la diferencia en las distintas dimensiones a las que afecta haber sido diagnosticados y tratados de un cáncer infantil, considerando el ámbito educativo, familiar o de ocio. Especialmente interesa el impacto del diagnóstico y el paréntesis del tratamiento (un año en tumores óseos) en la interacción social y la recuperación de una vida social normalizada.

PALABRAS CLAVE: cáncer infantil; supervivientes; trayectorias; secuelas sociales; sociología clínica.

1. Introduction

Changes in cancer treatment have increased the survival rate among the child population. However, survivors must face another challenge: the social sequelae. In the most recent data[2] from the Spanish National Statistics Institute (INE) on deaths, cancer is the leading cause of natural death among members of the Spanish population aged between one and fourteen years old. On the other hand, according to data from the latest report by the Spanish National Registry of Childhood Tumours (RETI-SEHOP), the survival rate of children who receive treatment is 81% (patients who survive a period[3] of five years following diagnosis).

The experience of facing and surviving cancer at such ages results in disruptions and profound changes in the interaction with different social contexts (Khan, Ahmad and Imran, 2021) and, given the involvement of various social agents such as family, peer group, public and private institutions, amongst others, this is an object of study for the field of sociology. The continued lack of awareness around the specific psychosocial needs of childhood cancer survivors affects their subjective well-being and their return to a full life following the healing process (Hendriks, Harju and Michel, 2020). Interested in the health/disease experience, we approach this topic from a sociological perspective that addresses the clinical sociology, relationship aspects and their transformations following the disease, which affect the patient directly (self) and their relationship with their social context.

2. Objectives and Issues to Resolve

The overall objective of this research note is to explore the changes and repercussions felt by childhood cancer survivors in their social interaction, and specifically:

> OE1. To analyse the impact of the disease from the experience of the survivors in the school environment and peer group.
>
> OE2. To investigate the capacity for, potential and results of individual action (survivor) to cope with the social sequelae after medical discharge following cancer from the different life trajectories of those young people who have been cured.

We depart from two basic premises: firstly, the established social perception of cancer adversely affects the interactive relationships that survivors build with the school context and peer groups. Secondly, childhood cancer survivors are said to have seen their interactive relationships with the school context and peer groups altered owing to the physical, psychological and social sequelae caused by the disease and its treatment, and which are also determined by their initial social status.

3. Methodology

The methodology used for data collection is qualitative and biographic (Pujadas, 2002), by means of in-depth interviews that follow the life-story structure of clinical sociology. These data enable the constrictions perceived by the subjects in their social environment to be determined, as well as their reactions and the strategies that they implement in response (Verd and Lozares, 2008; De Gaulejac and De Yzaguirre, 2018). In line with Hall (2006), the clinical sociology is centred on the learning on the part of the researcher through the accounts of the subjects.

The study population corresponds to adults cured of Ewing sarcoma and conventional osteosarcoma who have been diagnosed with childhood cancer, which has a very high incidence among adolescents. The need for surgical intervention to replace the damaged limb with an internal or external prosthesis may lead to image and mobility issues, affecting the personal and social development of the adolescent for life (Brown et al., 2015). The selection of adults who were diagnosed with cancer during adolescence responds to an interest in reconstructing their life trajectories from the moment of diagnosis until the present day. Of interest are the repercussions perceived over time in the social environment, during hospitalisation and following discharge (Aragón and Martínez, 2021).

As can be seen in table 2, the profiles of the cases in question present initial socio-demographic variations; however, seeing their lives interrupted by the same *event* during adolescence is a factor that they all have in common.

The analysis of results has centred on the dialectical relationship between the social determinants that shape the subjects' life trajectory and the capacity for action and adaptation that they develop based on the analysis of their life experiences, reconstructed through language (Grasseli and Salomone, 2012). In line with the contributions by Dumas et al. (2015) and by means of an exploratory analysis, a scheme of relevant categories and subcategories has been drawn up based on the consulted literature and the experiences of the interviewees (table 1). This framework accounts for the wide variability in the situations faced by the childhood cancer survivors with two main elements: the health trajectory, marked by the period of the disease and its physical sequelae; and the social trajectory, centred on the impact of cancer on daily life and, in particular, on the relationship with different social contexts of interest.

Table 1

Coding categories for the analysis of the interviews carried out

General category	Subcategory
1. Socio-demographic variables	
Social background	1.1 Birth place 1.2 Educational attainment 1.3 Socio-economic status
2. Impact on the self and social relationships. Point of inflection in the life trajectory	
Diagnosis of the disease	2.1 Previous illnesses, unidentified malaise (uncertainty) 2.2 Communication of the diagnosis 2.3 Initial state of depression/disconnection from the world, at the start of treatment 2.4 Lack of knowledge on cancer/bone tumours 2.5 Emotional strategies for coping with the diagnosis 2.6 Strategies of discourse for talking about the disease 2.7 Use of the 'cancer' concept
3. Social isolation	
Hospital life	3.1 Place of treatment/admission and transfer to the place of residence for treatment 3.2 Relationships with other inpatients 3.3 Hospital monitoring and monitoring of care following treatment
4. Personal and social importance of image	
Physical changes (internal/external dimension)	4.1 Autonomy/dependence 4.2 Hair loss 4.3 Weight loss, physical exhaustion 4.4 Fertility/motherhood 4.5 Trauma-related sequelae 4.6 Rehabilitation/caring for the body 4.7 Disability recognition
5. The reconstruction of interactions between peers and personal projects for the future	
Relationships in the educational environment/peer group	5.1 Academic year of the diagnosis 5.2. Not attending classes (interruption of academic life) 5.3 Communication between the educational centre and family 5.4 Marks 5.5 Adaptation of the syllabus by the centre, academic monitoring 5.6 Explanation to the peers of the current/past situation 5.7 Relationship with classmates 5.8 Relationship with teachers 5.9 Academic expectations/projects for the future 5.10 Student orientation by the centre 5.11 Needs detected by the survivor that must be met and that were not met at the time

Source: Own research.

Table 2

Summary of technical information of the interviews carried out

	Age at diagnosis	Current age	Sex	Birth place	Educational attainment	Occupation
I1	13	30	Female	Gines (Seville)	Higher education	Scientific research
I2	17	24	Female	Ubrique (Cádiz)	Higher education	Student
I3	13	31	Male	Barbate (Cádiz)	Further education	Hospitality

Source: Own research.

4. Preliminary Results

4.1. The diagnosis of cancer in childhood as a major disruption in the life trajectory

In the observed cases, the disease is detected through initial discomfort of unknown origin that is attributed to other causes such as tiredness or physical injuries. Treatment requires one-year hospital admission according to protocol, for which reason the day-to-day relationship with the family and peer group changes, and a close relationship with the medical personnel develops.

There is an initial period of social isolation. In two of the cases, the treatment involved travelling from the usual place of residence, an additional difficulty in the experience of being a cancer patient as it forces them to leave their main residence and cease attending educational centres, they are separated from their parents and it is, general speaking, a temporary financial burden. Following the initial social isolation, they give special recognition to the relationships with other "actors" in the oncology unit: other diagnosed children, families, medical personnel, volunteers, and so on. New peer relationships based on the same life experience are established.

> 1_I1: at the start, it was as if I was in a state of depression...[4]
>
> 2_I2: I didn't interact a lot...
>
> 3_I3: at the start, well, what can I say...

While the peer group prior to the diagnosis was made up of a sports team or classmates, treatment sees the introduction of other children as peers who share their physical, psychological and social sequelae. The physical changes as a result of the disease and the treatment affect the self-concept of the individuals who experience the sequelae and how he/she is perceived by others. Thus, the opposition between them (healthy adolescents) and us (adolescents diagnosed with childhood cancer) is established, forging a new self and group identity that creates special links after hospital treatment is completed, strengthening the set-up of support networks between parents that, at times, extend to association activity.

> 4_I1: there was a boy who was the same age as me...
>
> 5_I2: my parents were there...
>
> 6_I3: you have to empathise, talk to people...

4.2. Strategies of discourse for talking about the disease. "Cancer" as a taboo

In their accounts, there is a lack of contrast between the cancer-death and cancer-survival pairings. They highlight the prevalence of the former in those groups without experience of the disease, attributing a lack of knowledge and information that the subjects also recognise they lacked prior to their cancer diagnosis.

Identification as a cancer patient may result in rejection, and one of the main attitudes that the interviewees identify is “pity/sympathy” on the part of those who do not experience cancer, and which stigmatises those who are affected.

7_I1: the people felt like...

8_I2: family members and I...

Nevertheless, the experience of healing gives a different meaning to the term for the subjects, who begin to establish a link between cancer and survival, now as a synonym of a curable disease.

9_I3: I started to realise that that word...

10_I1: there are people who you tell...

4.3. Impact of the physical sequelae resulting from cancer treatment on social relationships

Adolescence is characterised as a period of emancipation, in which the subject becomes more independent from their parents. However, given the localisation of the osteosarcoma in the lower limbs of the body, reduced mobility is one of the main sequelae in their accounts of the experience. The limitations associated with mobility entail the use of a wheelchair, crutches or other support elements that are incorporated into the daily life of the adolescents, as well as discomfort/pain to a greater or lesser degree throughout life.

Hair loss is another of the most significant physical changes encountered and it forms part of the social image with which they are identified. The social construct of femininity includes long hair as one of the attributes of women, for which reason hair loss during adolescence may take on different meanings depending on the sex of the adolescent, as the two women interviewed express.

11_I1: I had long hair...

12_I2: to be a female and a teenager...

Nausea as a result of the pain and chemotherapy cause decreased appetite and very accelerated weight loss in adolescents (their physical appearance changes entirely in a short space of time). I3 indicates that at the age of treatment, he was was around 1.80 m tall and his weight fell to “forty and a bit kilos, so I was all head and no body”.

Following surgery (the application of a prosthesis is generally required), there is a series of trauma-related sequelae that are very significant in the subsequent life trajectory. The challenge of living with an internal prosthesis becomes more complex due to different adverse effects (infections and fractures) that result in additional surgical interventions, additional periods of rehabilitation and new physical sequelae, which, in turn, have social repercussions. In the two accounts with a longer subsequent trajectory since diagnosis (I2 and I3), references are made to surgical interventions due to trauma on numerous occasions.

The constant uncertainty at the possibility of a new sequela favours the appearance of "Damocles' syndrome", the chronic fear of cancer and/or trauma recurrence, in the subjects and their environment (Cupit, Syrjala and Hashmi, 2018). This continual exposure to risk affects the subjects' decisions and the opportunities they encounter in an academic or work environment, among others. Caring for a prosthesis after each intervention requires daily rehabilitation for a period of approximately one year, which is incorporated into the daily life of the survivors throughout the entire subsequent trajectory. This requires time and effort to be invested on a daily basis that, at times, interferes with the conciliation of other activities such as work, family or studies.

4.4. A social response to inequality: disability recognition

Disability recognition is a response to the social inequality that arises from the physical sequelae. The interviewees state that they initially had qualms about being recognised as "people with disabilities". This recognition may lead to the subjects' double stigmatisation: having had cancer and being identified as disabled (Kim and Yi, 2014).

In the case of the interviewed women, both obtained this benefit and they consider that it enabled them to alleviate certain hardships that they encountered during their trajectories. They highlight the educational opportunities, given that their academic life was interrupted for long periods of time, and assert that the degree of disability has enabled them to access and/or complete their studies. They think that this recognition has favoured their personal autonomy, education and finding a job.

> 13_I1: thanks to that, I enrolled, for example...
>
> 14_I2: they recommended we request the degree of disability...

In contrast, the account by I3 expresses rejection of the disability recognition, establishing an ongoing relationship between obtaining the degree of disability and receiving an economic benefit for "not working". A striking element is the use of the concept of being "disabled" as a synonym for "person unfit for work". This subject is the only interviewee to use the term ***"minusválido"*** (handicapped, disabled) in their account, and they give it a meaning based on the contrast between being more or less valid (***"ser más válido/ser menos válido"***). Thus, he considers that this recognition would diminish his personal autonomy, as he would be identified as a subject who is less fit for the job.

> 15_I3: I thought that that would be saying that I couldn't earn...

4.5. Interactive relationships in the educational environment

A cancer diagnosis in childhood is at the expense of performance and psychosocial development in the educational environment (Tsimicalis et al., 2018). The academic context in the accounts refers to the context of "school career" in that it considers the trajectories a "diachronic construct of the social and subjective identity of the pupil through their interaction with the educational institution" (Verhoeven, 2013: 89).

The relationship with the educational system breaks down when the disease is detected. The school career must consider two elements that determine the trajectory of the subjects: the multiplicity of causes that may converge to give rise to inequality, and the individual capacity for developing strategies as their situation becomes more complex in the educational context. The inequality that the interviewees are exposed to is determined by three main sources: "the redistributive dimension (resources), the symbolic dimension (recognition of the inequality) and the power dimension, understood as the subject's capacity for action" (Verhoeven, 2013: 89).

Hospital admission means that the pupil stops attending the educational centre and their development may be impaired (Brinkman et al., 2018). The three interviews mention sporadic school attendance when the evolution of the treatment so permitted, with the aim of avoiding complete disconnection from the academic system. There is an attempt to maintain those habits associated with "student life" (homework, reading, studying, and so on), even from the hospital itself. These activities facilitate the normalisation of life away from the usual context in order to enter a hospital environment, a nexus between life prior to the disease and life after. Treatment, however, may impair school performance, as it reduces "their energy and concentration and negatively affects their cognitive, affective and social development" (Grau, 2005: 49).

> 16_I1: I was completely focused for the first two days...
>
> 17_I2: the anxiety that I felt before each exam...
>
> 18_I3: everything started off really well, but...

According to the accounts, there is no academic monitoring when a standardised protocol is followed in all the centres, but rather it arises from an informal agreement between the families and teachers. This indetermination may give rise to arbitrary decisions that affect the learning trajectory of the pupils (Paré-Blagoev et al., 2019). The academic tasks were received through classmates (taking them to their home, by telematic means); however, none of the interviewees received learning support from extracurricular teachers, either in the hospital or in their homes. The means of each family to offer educational support are unequal and depend on the parents' prior education and the cultural, time and cognitive resources within their reach (Castejón, Montes and Manzano, 2020).

> 19_I1: my parents took the enrolment...

> 20_I2: school didn't see any problem...

In the observed cases, those adolescents who previously obtained higher average grades, whose parents are skilled workers and who have higher social statuses, are able to maintain certain academic activity during the period in which they undergo hospital treatment and can join the class the following academic year with the rest of their classmates. However, in the case of I3, as someone who obtained pass and, at times, fail grades, and whose parents had a basic level of studies and a minimum income level, not attending school in person during the year he was an inpatient resulted in the need to repeat the school year.

> 21_I3: well, I didn't get top marks...

Repeating the school year intensifies the distancing from the peer group, which makes the inclusion of the pupil in the school context more difficult and may have discriminatory effects (Hill, 2014; Choi et al., 2018). Being recognised as a "pupil repeating the year", a "pupil with cancer" or a "pupil with a disability" forms part of the symbolic dimension of inequality that the survivors encounter in the educational environment. The fear of rejection by the peer group may even lead to these adolescents hiding the diagnosis and/or the possible physical and psychological sequelae that may manifest as a result of the disease (Barrenetxea, 2021).

The subjects' capacity for action in situations of inequality gives rise to different strategies that vary depending on the opportunities that they learn throughout their trajectories. An example is seen in the use of disability recognition as an opportunity to gain access to higher education or to obtain grants that enable them to keep learning. On the contrary, the perception of a lack of options or a lack of awareness of the "rules of the educational game", as well as "school orientation processes as imposed [...] may generate feelings of impotence or passivity in the face of their own school destiny" (Verhoeven, 2013: 90).

The trauma-related sequelae experienced by the subjects following cancer treatment exacerbate the difficulty to maintain continuity and development during the learning and, subsequently, work trajectories, despite this element being closely related to the occupation sector.

> 22_I2: they caught me...

> 23_I3: it was one of the things that limited me...

4.6. Interaction with the peer group in adolescence stigmatised by cancer

The experience of cancer has an impact on the cognitive and emotional development of the adolescents interviewed, for which reason, following diagnosis, the reference peer group deviates from what was known up until that moment. The survivors maintain a link with the peer group during the treatment period, but the way in which they interact changes. Prolonged absence from school and the physical impossibility of participating in group activities and plans requires the peers to adapt to the needs of the diagnosed subjects. The three cases analysed perceive distancing on the part of the group both during and after hospital treatment and the loss of some relationships with friends.

Interaction with other young people leads to acceptance, but also to confrontation between personal experience and the collective identity of the group that may limit mutual acceptance. Two of the interviewed subjects textually express how they see themselves as being more mature after overcoming the disease than those young people of the same age who have not had the same experience, perceiving greater post-traumatic growth in comparison to those who were their equals prior to diagnosis (Howard et al., 2017).

> 24_I1: emotionally, I would not know…
>
> 25_I2: I think that maturing…

5. Concluding thoughts

This exploratory approach suggests that the detection of childhood cancer destabilises the life of the subjects and affects their relationships with the different social contexts, resulting in social sequelae. The clinical sociology approach enables the experience and evolution of the sequelae of cancer to be investigated, following a diachronic time perspective to observe the changes in social interactions before and after the diagnosis. In the accounts, there is an allusion to the current validity of the social representation of cancer associated with death that favours the social stigmatisation of those affected. That said, the experience of healing lends a different meaning to the term for the subjects, establishing a link between cancer and survival.

The sequelae of the disease alter the subjects' interactive relationships with their school context and peer group, disrupting the relationship from the moment of diagnosis for hospitalisation and the successive interventions resulting from physical sequelae. This places the interviewed survivors in a situation of inequality on multiple levels, which is determined by the resources (social status and academic performance prior to diagnosis), the symbolic dimension (being recognised as a "pupil with cancer") and capacity (being recognised as a "disabled pupil" or a "pupil repeating the year"), whereby all these dimensions may manifest themselves at once.

Educational inequality is exacerbated by the non-existence of a standardised institutional protocol to attend to the specific educational needs of children with cancer. Absence from school and the limitations of insertion in the educational system during hospital treatment lead to distancing from the peer group. The isolation is compounded by the physical changes (image) that the young people express and by unequal cognitive and emotional development among young people who have had cancer and young people who were their *equals* prior to diagnosis. However, a new collective identity is reinforced with the creation of mutual support networks among those affected and the relationship with *new equals* with the same experience in a trajectory marked by cancer and its sequelae in the medium and long term.

Although the interviews carried out are limited, the exploration presented suggests the need to keep investigating, from a sociological perspective, the social sequelae experienced by the survivors of childhood cancer. The relationships with their family, school and peer group context, among others, have been marked by the diagnosis and by the different sequelae over the course of their trajectories. It would be necessary to gather more life experiences and investigate other contexts of interest that, for reasons of space, have not been developed in this article.

The relevance of social interaction in overcoming the disease must be considered to a greater degree by public powers, favouring the equality of opportunities for young people who overcome childhood cancer. All this will facilitate their access to disability recognition and establish specific educational monitoring programmes adapted to this group and their families, and so on. Adopting these initiatives, among others, requires that the perspective of survivors be integrated in the development of programmes aimed at encouraging full social development and raising people's awareness of the challenges of surviving cancer in adolescence.

Notes

1 The project that provides the framework for this proposal was awarded the 2020 Youth Prize for Scientific Culture ***(Premio Joven a la Cultura Científica 2020)*** in the Social and Human Sciences category by the City Council of Seville and CSIC (Spanish National Research Council).

2 INE death statistics according to cause of death in the period 1980–2020.

3 In this report from 2021, 2014 is the most recent year of incidence that offers a follow-up of 5 years from diagnosis.

4 Due to reasons concerning the length of the article, the complete snippets from the testimonies are available at: https://drive.google.com/file/d/1zZuoLAvHTXpcO1VH8GiURY4G16U1dTQ6/view (in Spanish only).

5 Work, non-profit, healthcare environment, etc.

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