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A social approach to the effects of childhood cancer: a review of relevant social contexts

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ABSTRACT: *Advances in the treatment of childhood cancer in recent years have increased the survival rate for this disease. This success leads survivors to face another challenge: coping with the physical, psychological, and social sequelae that result from this experience and that can limit their social integration and development. When this disease manifests itself in childhood, the subjects present a double vulnerability: being children and being ill, which is exacerbated by the persistence of a social representation that links cancer to death and favors its constitution as a taboo. The general aim of the paper is to review the relationship between social studies and health studies and the need to integrate both perspectives to favor the social development of pediatric cancer survivors after treatment. In this sense, a proposal of social contexts of interest for analysis will be offered: family, school, peer group, and associations. In these contexts, the relationships of the subjects are altered because of having overcome the oncological disease, generating consequences in their subjective wellbeing and their social trajectory.*

KEYWORDS: *cancer, childhood, health, Sociology, social contexts, family, education, associations, peer-group.*

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I. INTRODUCTION

As a starting point, the study of cancer and its treatment in medicine has evolved over the last few decades, which is reflected in an increase in the survival rate, which currently reaches 70% in children under 14 years of age. This success places survivors before the challenge of developing a full life from the alterations (sequelae) that the healing process has caused in their relationships with the social context. The possible difficulties of integration are determined by the permanence of a social perception that links the concept of cancer to death, endorsed by the results of the latest Oncobarometer, which tends to stigmatize those who have suffered from the disease with important consequences for subjective wellbeing and their social trajectory. Despite the constant allusion to the relevance that areas of interest for Sociology such as the family, school, or peer group acquire when cancer manifests itself in childhood, we find few analyses carried out by this science.

The physical changes experienced by the subjects influence the self-concept, which increases the difference and distance concerning peers. However, cancer is a shared experience with other young people affected, which gives rise to new peer relationships.

The persistence of the cancer-death social construct has consequences for interaction with social contexts, leading to rejection, fear, and social isolation. The spontaneous mention of young people who do not manage to overcome the disease and die during treatment only appears in one of the very brief interviews.

The physical consequences of the disease have an impact on social relations. There is a decrease in personal autonomy (especially linked to mobility in the case of bone tumors of the lower limbs). Likewise, the image of the disease corresponds to progressive physical wear and tear (e.g. hair loss or extreme thinness), which affects self-concept and relationships with others, as they involve distinctive physical features. Another element to be highlighted is the chronic traumatic sequelae that accompany the entire life trajectory after hospital admission of the subjects and often involve an interruption of the daily life of the subject and their environment and the difficulty to develop projects in the medium or long term, as well as a return to the hospital environment.

These physical and cognitive limitations have an impact on the interaction of subjects with different social groups, as will be explained in the following pages. This highlights the need to establish synergies between the study of health and Sociology as complementary fields of study to address the comprehensive needs arising from cancer survivorship.

II. RELATIONS BETWEEN SOCIOLOGY, HEALTH, AND CANCER

Throughout history, numerous authors have considered the social contexts of subjects as key elements in the study of health. The first contributions to the construction of a social dimension of health, and with it, of illness, come from the field of medicine itself and are found even before the birth of Sociology (Moragas, 1976).

The theoretical link between Sociology and Health is one of the first questions we must clarify to understand the phenomenon we intend to address. While it is true that there is a traditional disciplinary division between Natural Sciences, where medicine and, thus, the study of illnesses would be found, and Social Sciences, there are numerous authors who have considered throughout history the social contexts of the subjects as key elements for the study of health. However, it should be noted that these first contributions to the construction of a social dimension of health and, with it, of illness, come from the field of medicine itself and are found even before the birth of Sociology, a trend that will continue until the end of the 19th century (Echeverri, 2010).

Historical background

From antiquity, we find the contributions of thinkers such as Hippocrates, Galen, and Paracelsus on the relevance that social conditioning factors can have on health. Later, in the 17th century, Ramazzini (1700) devoted part of his work to analyzing the influence of the industrial production system on workers' illnesses, while Petty (1623-1687) pointed to issues such as demography and even culture and the role that both elements played in the development of the health of society.

It was not until the 19th century that the first studies on the relationship between social determinants and health began to emerge within the field of social sciences (Echeverri, 2010). At this point, the work of Virchow (1848) stands out for the formation of policies related to the health field based on the knowledge of the social consequences of diseases. In 1894, Dr. McIntire introduced the concept of "medical Sociology", pointing out that "there is an intimate relationship between the medical profession and the problems of general Sociology" (McIntire, 1894: 430 cited in Duarte 1994: 317), although he continued to defend like the previous authors cited, a certain scientific superiority of medicine over Sociology. This question will be widely criticized and refuted by the theoretical precursors of the line of research known as Sociology of Health (Donati, 1994).

Shortly afterward, the first writings of one of the fathers of classical Sociology emerged: Émile Durkheim and his seminal work "Suicide" (1897). For the first time, this work provides the foundations that emanate from social science to explain phenomena that had hitherto been considered purely individual and psychological, as social facts (Balarezo, 2018). Subsequently, Talcott Parsons in his treatise "The Social System" (1951), considers the preservation of the health of individuals as the main element for the proper functioning of society (Cockerham & Scambler, 2009). Thus, a more fertile path began in North America than in Europe for the study of health from a sociological perspective, which was supported by its incorporation as a section in the American Sociological Association and its recognition by the World Health Organization in the 1960s (Balarezo, 2018). Over the following decades, Sociology's interest in health studies continued to grow as demand from medical professionals increasingly required the application of sociological research techniques to understand diseases from a holistic perspective (Briceño, 2003).

At this point, it is worth mentioning a novel approach that crystallizes the relationship between Sociology and the study of health: clinical Sociology. This perspective originated at the beginning of the 20th century thanks to the contributions of members of the Chicago School such as Wirth (1931), who proposed the need to incorporate the figure of the sociologist as a member of the "therapeutic teams". This approach proposes the need for research on the social dimensions and implications of the disease on the subject and their context, applying the methods and techniques of Sociology such as participant observation and in-depth interviews, which allows the researcher to get closer to the field and the actors (De Yzaguirre & Castillo, 2013). From the late 1980s to the present day, clinical Sociology has evolved significantly in Europe, through its incorporation into the work of the working groups of the International Sociological Association (1992) and the Laboratory of Social Change of the University of Paris VII (1990), as well as through the creation of the International Institute of Clinical Sociology (2001).

A political and social perspective on health and cancer

Health is a complex, multidimensional phenomenon necessary for social development. These attributions have given rise to the Bourdieu-inspired concept of the "health field", which is identified as "a place of convergence of actors competing for resources, problems, and interests that form a network of relationships, with relative autonomy, fighting for consolidation or appropriation and predominance" (Spinelli, 2010 cited in Garzaniti & Romero, 2018). Numerous actors take center stage: patients and their families, medical staff, civil associations, educational centers, public decision-making bodies...

Article 43 of the Spanish Constitution recognizes the right of Spaniards to health protection, delegating this competence to the public authorities who protect public health "through preventive measures and the necessary benefits and services". Following the definition of the concept of "health" offered by the World

Health Organization in 1948, we find that it is identified with a "complete state of physical, mental and social well-being and not merely the absence of disease or infirmity". Based on this notion, a multiplicity of dimensions to be considered unfolds, including society's commitment and attitudes towards illnesses and the management of public resources, among others (Vélez, 2007).

Interdisciplinarity is essential both for scientific research and for improving the treatment of diseases (Alcántara, 2008), which requires special mention to be made of the political and social dimension of health and, more specifically, of cancer. The comprehensive health care perspective recognized by the national and international normative framework considers that "all health practice produces and reproduces discursive forms that exceed the specifics of care to operate in a social discourse" (Garzaniti & Romero, 2018).

In this sense, in recent years there has been a notable development of models of comprehensive care in cancer patients that take into consideration the family environment with a special interest in primary caregivers (Grau, 2002; Cacante & Arias, 2009; Pozo et al, 2015), interaction with organizations such as medical centers, schools or associations (Arzate, Ochoa & Alvarado, 2013; Páez, 2015), quality of life and quality of care provided to the patient during the healing process (Fernández et al., 2009) or coping strategies in the face of the illness and possible death of the subject (Folch et al., 2016; Carreño, Chaparro & López, 2017), among others.

However, despite the advances from the sociological perspective that have been developed in the study of the field of health in the area of cancer and, more specifically, when this disease manifests itself in childhood, we find few analyses carried out from Sociology. Although it is true that most of the previous studies point out the importance of the interaction of the individual with different social contexts such as the family, school, or associations during the process of treatment and overcoming the illness, these studies are often not even authored by professionals in the social sciences. However, the constant allusion to the relevance of these areas of interest for Sociology highlights the need for a sociological approach, which has begun to be identified in the scientific literature, especially in Anglo-Saxon literature, in recent years (Kerr, et al., 2018).

III. CANCER IN CHILDHOOD

The World Health Organization (2019) defines "cancer" as a "process of uncontrolled growth and spread of cells that can appear in any part of the body (...) that represents an enormous burden for patients, families, and society". The adjective "childhood" refers to the manifestation of this pathology in the pediatric age group (under 14 years according to the National Registry of Childhood Tumors, RETI).

Considered a very serious disease, in the latest available data from the National Institute of Statistics on deaths, cancer is the leading cause of natural death in the Spanish population between one and fourteen years of age. However, according to the latest available data from RETI, the survival rate of children with cancer treated in this country is 75%, considering for the estimation those patients who have managed to survive five years after diagnosis. The survival rate has increased by around 23% since 1980, when the first records were kept (Pardo et al., 2014). Thus, we can consider this disease, both because of its incidence in infant mortality and a growing survival rate, as an issue of relevance for society. The experience of coping and overcoming, given the young age of the population under study, implies alterations and profound changes in the interaction with different social contexts "as a consequence of the experience of having been diagnosed with cancer in childhood and having survived treatment" (Medín, 2009).

Although all oncological illnesses indeed provoke negative biological, psychological, and social consequences in the patient, when they burst into the life of the person at an early age the adverse effects are exacerbated. The social challenges faced by people who suffer from this illness, both during and after the healing process, constitute an object of study for Sociology insofar as various social agents are involved, starting with the individual, the family, the peer group, public and private institutions such as schools, associations, hospitals...

III. SOCIAL REPRESENTATIONS OF CANCER

In recent years there has been a notable presence in the scientific literature of the application of the Theory of Social Representations in studies on the Sociology of Health and, more specifically in the field of cancer (Quintero et al., 2016; Reina, Hamaty & Molina, 2017). This current focuses on the relationship between the individual and society through the study of the construction of meanings that subjects make about the disease, resulting in social thinking that guides behaviors, attitudes, opinions, beliefs, assessments... in everyday life (Moscovici 1984 cited in Valencia, 2007). Social representations give rise to a "group culture" that generates a shared identity among its members, which influences their interpretation of reality, as well as the coping strategies to be followed for common problems (Moñivas, 1994). Considering the social representations constructed about cancer allows us to understand the attitudes, behaviors, and strategies that those affected and the members of their environment have developed in the face of the difficulties posed by the diagnosis, treatment, and subsequent social reintegration (Llinares, Benedito & Piqueras, 2010).

Social representations and metaphors of the concept of "cancer" can already be found in ancient and medieval writings, and later in numerous dictionaries published between the 17th and 18th centuries. This disease is presented as a very painful ailment, difficult to heal, "that gnaws, devours and consumes (...) associated with death and putrefaction" (Furetière, 1690 cited in Salcedo, 2008). The construction of the concept of "cancer" is historically conditioned by Western culture inspired by religious values and beliefs that have favored for centuries the consideration of this disease as something intimate and secret, favoring its constitution as a taboo (Le Brun, 1984 cited in Salcedo, 2008). There are numerous everyday metaphors that associate cancer with war, such as: "cancer is fought, cancer cells invade the body, chemotherapy forces withdrawal" (Sontag, 2003 cited in Mora & Rivera, 2019). This notion, coupled with pain, fear, and death, has accompanied the construction of cancer as a social phenomenon to the present day.

Despite the growing increase in the survival rate of this disease, the idea that links the diagnosis of cancer with death persists. According to the results report of the Oncobarómetro (2010) carried out by Centro de Investigaciones Sociológicas[1], this disease is the one that most worries Spaniards due to its high probability of death and the suffering that accompanies both the diagnosis and the treatment for the subjects and their families (Barrado & Torres, 2015). This starting point constitutes the origin of a "cancer culture" that promotes, develops, and reproduces various attitudes and values that become protagonists to be considered in the course of the experience of the disease and post-disease, both by the patient and by their social environment (Palacios & Zani, 2014).

This social environment, in which we identify actors such as the family, the educational system, or the peer group among others, is altered after diagnosis to adapt to the needs of cancer treatment. In the case of pediatric cancer, there is a natural contradiction in the collective Western ideology between childhood, a stage associated with the beginning of life, and illness, pain and death, the main manifestation of the end of life, which gives a condition of special social vulnerability to patients affected at an early age (San Sebastián & Sánchez, 2005; González, Fonseca & Jiménez, 2006). For all these reasons, it is necessary to delve deeper into some of the social agents that play a significant role in the trajectory of overcoming the disease and its sequelae by young people affected by pediatric cancer.

IV. RELEVANT SOCIAL CONTEXTS

The meanings that the subject constructs about cancer are determined by the social context in which they find themselves, so it is necessary to observe the changes that occur in the subject's relationship with some actors and contexts after experiencing pediatric cancer.

It should also be noted that there are other social contexts of interest for Sociology that are altered by cancer and which, for reasons of length, have not been considered in depth in this research, such as the work environment (Barragán & Jovell, 2012), the sentimental concerning the partner and the expression of sexuality (Bragado, 2009), religious beliefs and/or spiritual practices (Huerta & López, 2012), migrations due to the detection of the disease (Hernández, Lorenzo & Nacif, 2009) or alternative treatments to traditional medicine (Isaac et al., 2016), among others.

Family context

Cancer, when it manifests itself in childhood, is a problem that has an impact on the family structure given the conditions of special vulnerability, being a child and being ill, of the affected subjects. The irruption of the disease is a destabilizing element within the family due to its unexpected and chronic nature (Grau, 2002). Adaptation to cancer treatment requires coping with this new "crisis" through the development of family coping strategies. A redistribution of roles takes place in which at least one of the parents, normally the mother by cultural assignment, temporarily abandons her daily activities such as paid work, caring for other family members, leisure time... to care for the sick child, both during the hospitalization periods and in the follow-up and readaptation phases (Espada & Grau, 2012a).

Given the young age of those affected, parents act as mediators of the information that the patient receives from the medical system and the rest of the family about their state of health, which orients the meanings, attitudes, and behaviors that the subjects construct in the face of the illness; strengthening or limiting their coping strategies (Espada & Grau, 2012b). Thus, the family group constructs a framework of tactics for coping with cancer-based on the economic, emotional, educational, and relational resources available to them.

The diagnosis of cancer disease in childhood initiates a process of relationships with the medical field that will accompany the subject for the rest of his or her life, as regular medical check-ups are necessary, as well as the intake of drugs or psychological care, among others. When cancer treatment occurs in childhood, doctor-patient relationships are mediated by the family, following a three dimensions model in which the behavior of each of the actors will influence the response of the others (Arzate, Ochoa & Alvarado, 2013). Collaborative

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[1] Social Research Center

relationships or, on the contrary, power conflicts between parents and medical staff may occur if the treatment does not provide the expected results, which will have consequences on the subjects' own coping with the illness (Davies, Young & Salmon, 2016), sometimes even leading to the breakdown of the family structure.

In cases in which the patient overcomes the treatment, families must face a phase of adaptation to everyday life again, marked by the possible social and other related sequelae generated by the illness itself or its treatment (González, 2019). It is worth highlighting the role of the family's social support networks, such as religious groups, groups of friends, or associations, as an element of resistance to the effects of the disease as serious as social isolation (Grau & Fernández, 2010).

School context and peer group

The disease has two main effects on the school environment: temporary abandonment of academic training and isolation of the child from his or her peer group. The diagnosis of cancer entails hospitalization, which can last from months to years, depending on the type of oncological disease detected and the stage of the disease, which implies an interruption in academic education for long periods (Gurney et al., 2009). Once the disease has been overcome, children's return to school may be hindered by fears about the acceptance of peers and teachers or the reaction of their peer group to the physical changes experienced, which leads to limitations in personal and social development (Páez, 2015).

In Spain, as in other autonomous communities, there is currently no standardized protocol for addressing the specific educational needs of these children, which generates indeterminacy in the actions taken by professionals in the educational field (Alfaro & Negre, 2019). The early reintegration of children into school, adapted to the different needs they may manifest, is a fundamental pillar both for the recovery of the relationship with their peer group and for their academic and, later, professional development (Alonso, Márquez & Cid, 2019). Interaction with this group constitutes a fundamental element of analysis, since survivors who have lived long periods of hospitalization may show greater difficulty in establishing social relationships of friendship or partnership; as well as in feeling satisfied as members of the groups they were part of before the diagnosis (Fernández et al., 2009).

Adolescence is characterized as a stage in which peers acquire special importance in the social development of the subject. These individuals share the same level of knowledge and emotions about reality, which is often determined by belonging to the same age range. Horizontal relationships are established between the members of this group, based on bonds of loyalty and trust that give rise to friendship (Sánchez, 2017). In the case of adolescents with oncological diseases, the social support of friends constitutes one of the main resources, together with parents, for coping with the changes caused by the treatment of the oncological disease (Bellver & Verdet, 2015).

Associative context

In recent decades, there has been an increase in the activity of third sector organizations, in response to public demand for social welfare and, more specifically, in health (Grau & Fernández, 2014). The limited nature of the actions of public administrations favors the proliferation of organizations whose aim is to provide advice and support to individuals who share a common problem. In the case of childhood cancer, associative support is generally oriented towards families and the social needs they may develop because of the diagnosis of the disease (Castro & García, 2014).

The associations working on the aftermath of cancer mentioned by the interviewees are made up of family members, people undergoing treatment, survivors, and volunteers, and are articulated as a form of strategic social participation in the search for solutions to common problems (Arrighi, 2014). This social context is transversal to all of the above, as it is generated through the creation of networks of affected people that favor mutual support and the learning of strategies that have been previously developed by other survivors and their environment to overcome difficulties. These organizations also play a role in covering economic and emotional needs through the search for rented housing, means of transport, or accompaniment of families in hospitals by volunteers.

In Spain, there is an extensive network of associations made up of patients, relatives, medical, psychological, and social professionals, volunteers, and interested civilians in general. Among the social actions carried out by these organizations are initiatives to raise awareness in civil society, educational support, and socio-cultural animation, coordination, and training of volunteers, family dynamization, processing of bureaucratic procedures, economic support for families, management of housing for those affected in rural areas and the creation of family networks of mutual support (Rivero & Gallardo, 2005). Associations also play an oversight and political demand role, insofar as they act as pressure groups that demand accountability from public decision-makers, whose role is considered at the regional, national, and European levels. These entities promote the implementation of action plans on the needs of the affected population (Astigarraga, 2014).

The relationship with the associations is maintained after inpatient treatment throughout the survivors' trajectory. The stories identify a link with these entities through involvement in awareness-raising activities, volunteering, or accompanying families with children who are overcoming an oncological disease. Although during and after treatment the subjects experience a certain distancing from their peer group, the associations contact new peers possible. This group shares the fact that their social, cognitive, and emotional development has been conditioned by the cancer experience, which leads to the construction of a common identity. This element motivates survivors to maintain the relationship with the association, even after overcoming cancer.

V. CONCLUSION

The detection of cancer in childhood is a destabilizing element in the life trajectory of subjects and affects their relationships with the different social contexts considered: family, school, peer group, and associations, all of which are interrelated. At present, a social representation of cancer associated with death remains in force and is perpetuated through language and everyday metaphors. This notion generates consequences in social behavior linked to the rejection of pain and suffering and the construction of the concept as a taboo, which favors the social stigmatization of those affected. The early age at which the diagnosis occurs places these young people in a condition of double vulnerability: being children and having cancer.

In terms of the social contexts of interest, the family must first adapt to the needs of the treatment. This process is often conditioned by socio-demographic factors such as rural-urban origin, occupations, and income level. There is an alteration in the distribution of gender roles: culturally assigned mothers usually take on the role of primary caregivers by giving up their jobs, while fathers keep their jobs and are left to care for the rest of the children in the family unit.

The survivors' school career is interrupted by the diagnosis, the period of hospitalization, and the successive interventions that may occur due to physical sequelae. This places them in an unequal position concerning their peers. Besides, school absenteeism and the limitations of insertion in the educational system experienced by the subjects during hospital treatment can lead to alienation from the peer group, an actor that is particularly important for young people in adolescence.

Faced with these difficulties, associations emerge as a response to the needs of survivors and their environment and favor the creation of mutual support networks based on the shared identity conferred by the experience of overcoming the illness. The construction of the associative relationship on a sense of belonging to a collective with its own identity can explain the permanence of the strategic relationship between survivors, families, and associations in the long term, even after the disease has been cured. Through training and awareness-raising activities, these organizations act as a link between those affected and society and try to contribute through their actions to overcome the social representation of the cancer-death binomial.

This bibliographical approach has highlighted the need to integrate sociology and the study of health as necessarily complementary areas to address the specific needs of childhood cancer survivors. The chronic nature of the sequelae and the rupture experienced by their social trajectories after diagnosis require further progress in the knowledge of the needs of both survivors and their families from the field of Sociology.

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