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EXPERIENCE OF A YOUNG WOMAN'S CANCER AND THE FAMILY CARE CONSTELLATION

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ABSTRACT

We aim to understand the movement of the care provided by the family regarding the cancer illness of a young woman and the way this care occurred according to family, professional and institutional involvement. We opted for the comprehensive approach, situation study and the history of life that was operationalized by in-depth interviews and observation. We performed the analysis by means of readings and reflections/discussions in the context of the research group with elaboration of synthesizing drawings. In this process, the narratives grouped around the theme "Family Care", generating the image of "Care Constellation". The study showed that the family is articulated, in a synergetic movement, to shape the care and, even while immersed in vulnerability, managed to find the strength to use the potential of each family member in care. In this way, the care was offered, usually in ascending order, by friends and religious institutions. However, health professionals and institutions, when cure was no longer possible, distanced themselves progressively from the family. We propose reflections about the value of family care and its modelation, allowing understanding and approach by the nursing for a care practice that meets the ill person's needs, including and reinforcing the family potential.

Keywords: Family. Adolescent. Neoplasms. Nursing. Comprehensive Health Care.

INTRODUCTION

Going into the universe of people who have been seriously ill for a long period of time is to understand broadly their own perspectives, which provides elements to understand that the course of illness is not linear and tight, but is anchored in a steady stream of changes, meanings, adaptations and resignifications[1]. A priori, we consider illness as something unique and personal, which does not detach from the life and the relations 'between and of' people, but it amalgamates into the own living, at the same pace as the needs of daily life[2].

Of the many health problems affecting the Brazilian population, cancer is the second leading cause of death among children, adolescents and young adults (15-29 years old)[3]. The leukemia, tumors of the central nervous system and lymphomas are characterized as the main causes of death, from cancer, until 29 years old[3]. In these phases, cancer leverages stages of the life cycle that are already in constant transformation, resulting in new and complex rearrangements.

The family care regarding the illness from cancer becomes more complex when it involves people who are at the peak of the youth. The peculiarities of a young person require the family a movement that involves reorganization and implementation of strategies for coping with the illness, emerging the need to redefine family roles[4].

In the family relationship, we assume that care is woven in modeling[5], i.e., offered and molded according ofpotentials, possibilities and personality - depending on the circumstances and demands of everyday life. Such circumstances and requirements may, paradoxically generate a healthy movement toward the family well-being.

We consider important the nurse's knowledge on how the family model the care provided to its sick loved one, thus recognizing it as a care agent, enabling a partnership that establishes and strengthens the nursing-family bond, for the construction of a sensitive, human and competent practice[6].

Therefore, we question: how does the family care model from different actors that arise along a situation of serious illness? What actions are perceived as care by both the sick person as his/her family?

Our purpose is to cause reflections about family

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care and the way the family models it, in favor of a health and nursing practice that meets the needs of the sick person and the family that cares and requires care.

In this way, our objective was to understand the movement of the care provided by the family regarding cancer illness of a young woman and the way this care occurred according to the involvement of the family, professionals and institutions.

METHODOLOGY

We followed the comprehensive approach[7], through the situation study[8]. Such an attitude requires understanding the other, taking into account situations, contexts and peculiar micro contexts of family life before the experience of illness and care[8].

We used the following inclusion criteria: a family that took care of a young female member (15-19 years) with serious illness; user of the Unified Health System; residing in Mato Grosso (MT). We consider as potential participants, in addition to the youngster and the main caregiver, different family members, including children, adolescents, young people, adults and elders, provided that indicated by the sick member and/or his/her main caregiver.Our exclusion criteria: difficulty of communication; hospitalized youngster.

Following these criteria, we requested a network composed by nursing professors and students from a higher education public institution of MT, inserted into different contexts. In this way, we located the participating family whose the youngster's mother had a page on the internet about her daughter's history of illness.

The nuclear family resides in a municipality 244 km distant from Cuiabá, capital of MT. Its members are Estrela, a 20-year-old youngster sick from acute lymphocytic leukemia, her mother Missie, her stepfather John and her brother Tommy.The extended family has family nuclei that reside in different cities of MT and in other Brazilian states. The study participants were: Estrela, Missie, John, Lia (maternal aunt), Ana (maternal aunt) and Mila (maternal cousin). Mother and daughter indicated the latter three as women from the extended family who were involved directly in the care. The names are fictitious.

We employed the Life History (LH) in order to establish the uniqueness of what is experienced and the meanings given by people to their experiences[9]. The LH was operationalized by In-Depth Interview (IdI) and by observation. We opted for the IdI to allow people to tell their stories more freely, guided by questions made by the researcher to thicken narrative wires important to understand the experiences of family life[9]. The observation allows apprehending the expressions that go beyond the speech, such as modulations, body movement, among others, which occur in each narrative[9], as well as paying attention to the physical and geographical space where theIdI occurred.

For being LH and IdI, and since we have as participants family members in different perspectives in relation to family care, our first approach, with each participant, took place differently. However, the narratives of the previous interviews guided the subsequent meetings, where we had the opportunity of deepening, clarifying and raising new issues by means of narrative wires found.

In the first interview, we asked Estrela to tell us about her history from the earliest memories of life. This request, open and wide, aimed at guiding the narrative without, however, restricting it. For Missie, the yougster'smother, we asked to tell us about her daughter's illness trajectory and a little about her own history. The maternal history was requested so that we could understand theyougster'slife context, once we understand that every story begins before the person's birth. For the other family members, we asked them to tell about the personal experience of care outside the Estrela's illness.

Data collection occurred from October to December 2016, through six recorded meetings, sometimes in Cuiabá, city where the youngster received outpatient treatment, sometimes in a a city in the countryside of MT, 220 km far from the capital, place of residence of part of the expanded family. The interviews were fully recorded and transcribed in the Research Journal[9], and observations, insights and every movement of understanding of the LH were organized in the same journal.

The review process took place through detailed readings of empirical material, reflections, discussions within the research group and preparation of synthesizing drawings. In this process, different themes began to group. Among these, we highlight the narratives related to family care. When considering these narratives, we realized that the family is arranged into clusters, forming a care constellation. With the intention to express our understanding about the care movement made by family and friends, we elaborated the "Care

Constellation" design, which, in our view, synthesizesthe configuration that modeled the family care to the youngster as an image.

Therefore, to answer the questions and the aim of this study, we focused on the care provided by the family regarding the youngster's illness, keeping the other themes found for future publications. Thus, in this study, issues related to cancer and palliative care, for example, were not covered with the deserved intensity, but set as a background.

This study is bound to the matrix research "Subsidies for care modeling of families in situations of vulnerability", approved by the Research Ethics Committee (671/CEP-HUJM/09. CAAE: 39285114.8.0000.5541). Fictitious names replaced the real onesof all participants, including people, institutions and professionals mentioned by the participants, according to the ethical principles of Resolution 466/2012 of the National Health Council.

RESULTS AND DISCUSSION

Allegory of the Family Care Constellation

Estrela resided in a city in the countryside of MT with her mother, stepfather and brother. As already mentioned, the extended family resided in different cities in the state and in other Brazilian states, but remained in contact with this family nucleus, which allowed, regardless of geographical distance, the involvement of several members in the direct and indirect care to Estrela.

The 18-year-old Estrela was approved in the National High School Exam (Exame Nacional do EnsinoMédio – ENEM), but decided not to start college in order to follow her mother's pregnancy and her only brother's first year of life. When she was 19 years, he received the diagnosis of Non-Hodgkin's Lymphoma, which evolved into Acute Lymphocytic Leukemia, whose treatment had no effect.

We met Estrela when she was 20 years old, already without therapeutic prospects of cure. Just her family took care of the young woman most of the time. The professional care, during this period, occurred at an outpatient clinic and, according to the data, were limited to transfusion of blood products, laboratory tests and medical consultation mainly geared to prescription of symptomatic medicines. The youngster and her family did not have any support or care from the multiprofessional team. The family travelled every week to Cuiabá, running 488km (roundtrip) for outpatient follow-up.

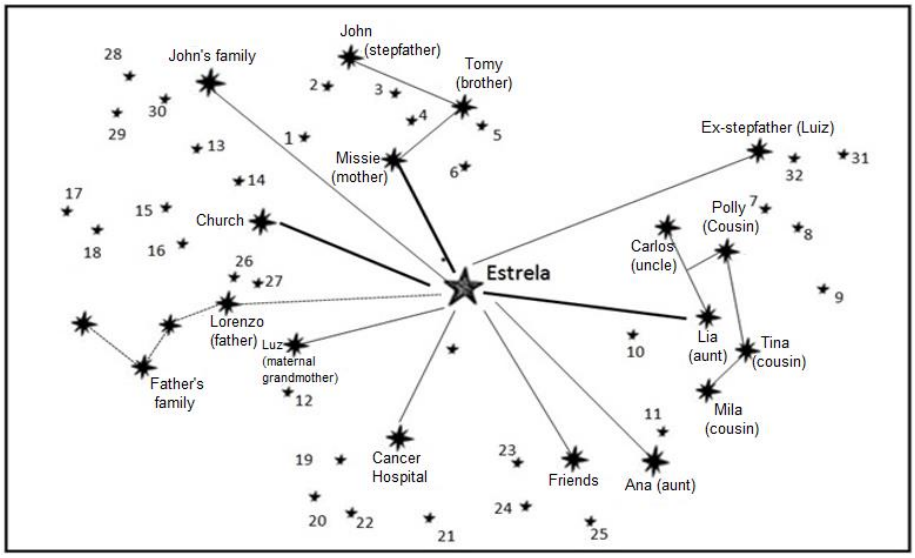

Figure 1. Family Care Constellation, 2017.

The young woman and her family, who walked in a peculiar rhythm of life before the illness, shaped to the new health settings, enhancing affective ties in a continuous movement to be available for the other. Since the healing impossibilityto the desire to live as best as possible became the goal of a lifetime involved by care.

In order to elucidate the minutiae of family care, we systematized, as an illustration, the figure of the "Family Care Constellation" (**Fig. 1**). This allegory consists of "star clusters" denoting situations and arrangements that express the resonances in family care and all surrounding universe for its effectiveness.

The stars,dispersive composition in the sky (Fig. 1), refer, in the family history, to every member present in the care routine, which together offered the youngster moments of zeal, affection, support and search for resolution in health, that is, a care constellation.

In the center of the figure, we placed the young Estrela (Fig. 1) because she was the one that required care regarding the experience of chronic illness situation and the real possibility of death. This dispersion allowed demonstrating that, while **Estrela** required more care, she managed to convey strength, joy and care for everyone.

The picture also shows bigger stars, that is, people who were closest to the youngster in the day-to-day care and that, somehow, included other relatives, professionals or institutions – small stars – in the support actions. There are also links (Fig. 1) expressed by more or less thick lines alluding to caregivers that sustained the strength of the bond for the welfare of the youngster.

The constellation symbolizes the family in a schematic space representation related to a care constellation that emerged in the yougster'sitinerary. The many links, which were consolidated by means of the affections of people responsible for care, generated numerous "small" actions in the form of smaller stars numbered 1 through 32 following a sequential order, since the care took place in own movements.

Family Care Constellation: experience of a life shrouded in care

Estrela's cancer diagnosis occurred about four months after Tomy's birth, her brother. Missie, beyond the intense effort to take care of her daughter during the search for a diagnosis (Fig. 1, star 1) and the chemotherapy treatment (Fig. 1, star 2), also had to dedicate to her little son, who required maternity care.

In the midst of these difficulties, different movements were arising from some members of the maternal family (Fig. 1, star 10). These began to reorganize their routines, postponing the achievement of personal activities, in order to prioritize the youngster's needs. In this way, aunt Lia (Fig. 1), even residing in the countryside of the state, travelled to the capital in order to follow Estrela during the hospitalization (Fig. 1, star5): *My aunt stayed with me, because my little brother was very young, sucking* (Estrela).

The family, in its various configurations, has members full of eccentricities and able to establish a certain degree of relationship and connection, aggregate values, which makes family bond[6] irreplaceable and essential, especially during the illness.

Aunt Ana (Fig. 1) offered stay at her house during the treatment in Cuiaba: *my aunt opened the doors, thank God. Then, we could stay at her place. At least, it reduced the costs a lot* (Estrela). Through this shelter, the maternal family avoided wear that could destabilize its greatest goal: the direct care to Estrela. These solidary actions promoted a dynamic movement of family care (Fig. 1, star 11).

These relationships strengthen that family is the primary caregiver to its member, because it articulates and provides a "care myriad that reveals its effort in the design, creation and implementation of care to each member and throughout life"[10:16]. Such care, as previously stated, expresses the minutiae of daily life, sometimes invisible to health professionals and services, however subtle, diverse and multiple, extrapolating what is rationalized in care practices.

The family feels hit by illness and finds itself in harmony with its manifestations. The disease combines feelings manifested by the family expressed in movements of introspection (sadness, concern) or expansion (happiness) as the situation evolves day after day:

> *[...] this disease not only affects the patient, but also reaches the whole family. When she is fine, everybody's okay, everybody is happy. When she is a little weaker, we all get very sad, concerned*(Mila-maternal cousin).

Regarding affections, the suffering caused by the sickness causes intense emotional conflict in every family, especially in the sick member. Cancer, in particular, causes reactions at social, moral and psychological level, being responsible for revealing diverse and ambiguous expectations, situations and feelings such as sadness and hope[8].

Therefore, the family finds problems, determines priorities and tries to rearrange itself around the needs that arise throughout the illness, so that its members can receive care and that no situation weakens the walk even more.

The aforementioned situations report to a care organization that shows that family organization into a "network". The value of this network weaved by the family, named in this study as "constellation", comes from the fact that it originates inexhaustible

sources of family support. These sources guarantee certain permanence of care in illness, especially when formed, almost entirely, by ties of kinship[11].

The family network represents a "safe haven to which one can always fall back on even if the bonds are not always active in the support provision, they are always there when necessary"[11:158], to offer the best care.

During the severe illness, when a cure is no longer possible, the sick person can develop an aversion to the family power and therapeutic treatment[2]. That did not happen with Estrela, because, for her, pain and suffering caused by the illness allowed her rapprochement with her mother and the rest of her family, which resulted in a more pleasurable and healthy relationship.

It is like a present I won in the chemotherapy. It is a feeling that was born from the love for the family. I was notthat close to my family. *The treatment was not a bad thing. It was a good thing, because it brought us many benefits* (Estrela).

That said,we can see that Estrela permeated intense affective ties (Fig. 1), especially with those who were daily at her side. She ressignifiedthe family unit (Fig. 1, star 6), which she highlights as a gift that emerged in the course of the illness. That way, family care is glimpsed not only as something laborious, but also as an affectionate way of approaching, being present and reaffirming the value of the family meeting.

> *We used to meet only in the year's end, Christmas and New Year. Now, with their presence here, wow! I like it when they come! [...] This is the only way for being closer* (Ana - aunt)

> *Yeah, I have been closer to my family lately* (Estrela).

> *We are closer. Shela {Estrela} even called my dad* (John – stepfather).

The study of Cartwrigth and colleagues[12], carried out with teenagers in chronic condition, highlighted the emergence of positive aspects in the lives of young people from the illness, such as: friendships, greater awareness of love and support coming from the family that tends to strengthen in this situation. In addition to the affective ties, ties of blood are important elements that motivate and reinforce family connections and, in addition to life situations, they solidify the relationships around the care[13].

The proximity brought by illness was evidenced in relation to the care provided by the family for the youngster, particularly the care of aunts and cousins, who,although affected by the suffering caused by the illness, reversed the moment of fragility into support (Fig. 1, star 7), care, solidarity (Fig. 1, star12) and family unit (Fig. 1, star9). Consciousness of derangement/destabilization caused by the disease and the need to walk differently to meet the patient's is clearly perceived. In this way, care becomes a priority and the desire to assist, even facing personal discomforts, reigns within the family cores that surround Estrela: *"we had to reshape our life here, right?"* (Mila - cousin)

A study with family members of children in chronic illness showed that the family reorganizes its professional, personal and academic activities, so that they can take care of the sickmember[4], reinforcing the perception that family, against illness, tends to reorganize and rearrange itself to meet the care needs of the loved one, although not living in the same house. It becomes a custom care, i.e. produced and molded as the walk of illness, just as it exists in concomitance with eah family member's reality[7].

In Estrela's case, many rearrangements were necessary to put the family care into practice. This involved several dimensions, such as: constant displacements from a city to another (Fig. 1, star 8); physical spacing between loved ones who had to stay home for the other to accompany the treatments (Fig. 1, star 3) and hospitalizations (Fig. 1, star 26); the daily concern around the disease evolution (Fig. 1, star 13); the need to learn how to deal with the lack of therapeutic resources for the cure (Fig. 1, star 19) and the financial arrangements (Fig. 1, star 4).

The emergence of new family links also became a source of care, such as John's relatives, Estrela's stepfather, who weaved support care (Fig. 1, star 28) and financial support (Fig. 1, star 29); this care generated relief and gratitude: *Thank God they all* {the stepfather's family} *have a good financial situation [...] and are always helping us, right?*(Missie – Estrela's mother).

Even relationships that became more distant, such as Luís, Estrela's ex-stepfather, were restored amid the struggle over the illness. Although living in another state, Luís acted as a care provider to Estrela through zeal (Fig. 1, star31) and parental care (Fig. 1, star 32): *Until today he* {Luís} *says "my daughter", right? [...] he keeps in touch, much more than her own father* (Missie-mother).

A simple phone call amid the trajectory of illness is perceived as important care that softens the hard days and moves away the loneliness. The support of the maternal family, the stepfather and the ex-

stepfather, is perceived as a breath on the absence of paternal family. The distance from the biological father, Lorenzo (Fig. 1), affected Estrela, who resented his distance: [...] *not only him, but his family as well* (Mila- cousin).

In case of illness, parents usually stand as the main responsible for protecting the sick child, transmitting safety and unconditional love[14]. In the history of this young girl, her mom positioned herself in this perspective, differently from her father. However, this detachment was partially supplied by her stepfathers and their families.

Estrela had the support of friends who provided pleasurable (Fig. 1, star 27) and happy (Fig. 1, star 25) moments. For her, these moments were regarded as a form of care that promoted support (Fig. 1, star 24), strength (Fig. 1, star 23) and comfort (Fig. 1, star 30): I was lucky for having friends. Many people always supported me, comforted me. So, in this time, I had other people's support (Estrela). Relations have the potential to mitigate the impact caused by the disease, friends are like a significant presence in difficult times[15].

Another source of support for the family was the religious community. Support expressed in the form of prayers (Fig. 1, star 15), exaltation of faith (Fig. 1, star16) and hope (Fig. 1, star 18), actions that provided comfort (Fig. 1, star 14) and shelter (Fig. 1, star 17).

> *[...] the church was praying a lot for me. [...] during all this time, I feel God protecting me. And this strengthens me [...] Young people{from the Church}came to my house. They sang the hymn [...] it was a very gratifying morning, you know?*(Estrela).

The religious community consists of people who share experiences and mobilize efforts for family care[16]. For some young people, having a relationship with God ensures His zeal in difficult moments, as well as provide the certainty that He will act in His best interest[17]. Health professionals need to consider the issue of religious beliefs because they interfere in the families face theillness[18].

In this Constellation, the paths walked by the family in the search for solvingits needs find support of the institutions (Fig. 1, star 21)-sporadic and isolated, but important for care. The hospital in which Estrela received the treatment provided clinical care (Fig. 1, star 22), but also the establishment of new relationships (Fig. 1, star20) with the multiprofessional team.

They take care of us very well. *We have loving nurses*[...]*sometimes, when I was feeling sick, they always came to me. The nurses were always more attentive, taking more care of us. So, we begin to become closer with time* (Estrela).

During the hospitalization of young people, the distancing from friends is common, mainly at hospitals institutions that hinder visitation. When this hospitalization is prolonged or frequent, young people begin to identify with some nursing professionals, considering them a kind of "substitute friend", with whom they keep periods of conversations and confidences[19].

In the care of people who experience a serious illness, health professionals, especially nursing professionals, need tocombine the objective and generalizable knowledge, provided by the biomedical model, with the subjective knowledge related to human experience[20], so that they can understand, comprehensively, the complexity of family care in the health disease process.

FINAL CONSIDERATIONS

This study showed that the family is articulated, in a synergistic movement, to model the family care of the sick member, finding power in every person who engages in this process, to the detriment of that vulnerability to which it is exposed. The image of the Care Constellation allows realizing that different actions are considered in the care context, such as: prayers, phone calls, meeting, among others.

The study showed that the involvement of family members, friends and religious institution occurred increasingly, as illness worsened and the possibility of death became real. However, the inverse movement occurred in relation to health institutions and health professionals, who worked occasionally and only when accessed by the family. We reinforce, as previously mentioned, that the family had no access to multiprofessional care.

In this way, we think the need for the nursing to take on the protagonism of its actions and competence with the sick person and his/her family. In situations when there is no more therapeutic possibility of healing, the possibilities and needs to offer a care with the feeling of love and compassion broaden, permeating a compassionate care and managing a way of being integrative in the relation "I-the other ".

Therefore, nursing professionals must seek to develop care that may meet the needs of the

sickadoecida and his/her family, appreciating the care daily provided by the family.

A limitation of this study was covering the history of a single family, making necessary the development of other studies from the perspective of family care modeling, mainly considering families of different configurations, especially those with few members..

Assim, torna-se importante que os profissionais da enfermagem busquem desenvolver cuidados que venham ao encontro das necessidades da pessoa adoecida e de sua família, valorizando o cuidado que por ela é tecido diariamente.

Esse estudo tem como limite o fato de ter abrangido a história singular de apenas uma família, fazendo-se necessária a realização de outros estudos na perspectiva da modelagem do cuidado familiar, considerando principalmente famílias de configurações diferentes, especialmente aquelas com poucos membros.

EXPERIÊNCIA DO ADOECIMENTO POR CÂNCER DE UMA JOVEM E A CONSTELAÇÃO DO CUIDADO FAMILIAR

RESUMO

Objetivamos compreender o movimento do cuidado tecido pela família frente ao adoecimento por câncer de uma jovem e como esse cuidado ocorreu segundo o envolvimento familiar, profissional e institucional. Optamos pela abordagem compreensiva, pelo estudo de situação e pela história de vida que foi operacionalizada pela entrevista em profundidade e observação. Realizamos a análise por meio de leituras e reflexões/discussões no âmbito do grupo de pesquisa com elaboração de desenhos sintetizadores. Nesse processo, as narrativas se aglutinaram em torno do tema "cuidado familiar" originando a imagem da "Constelação do Cuidado". O estudo mostrou que a família se articulou, em movimento sinergético, para modelar o cuidado e, mesmo estando imersa em vulnerabilidade, consegui encontrar forças ao utilizar o potencial de cada ente familiar no cuidado. Nesse percurso, o cuidado foi ofertado, geralmente de forma crescente, pelos amigos e pelas instituições religiosas. Todavia, os profissionais e as instituições de saúde, quando a cura deixou de ser possível, se distanciaram progressivamente da família. Propomos reflexões acerca do valor do cuidado familiar e de como ele é modelado, permitindo compreensão e aproximação por parte da enfermagem parauma prática de cuidado que atenda às necessidades da pessoa adoecida, incluindo e reforçando os potenciais da família.

Palavras-chave: Família. Adolescente. Neoplasias. Enfermagem. Cuidados Integrais de Saúde.

EXPERIENCIA DE LA ENFERMEDAD POR CÁNCER DE UNA JOVEN Y LA CONSTELACIÓN DEL CUIDADO FAMILIAR

RESUMEN

Tuvimos el objetivo de comprender el movimiento del cuidado tejido por la familia frente a la enfermedad por cáncer de una joven y cómo este cuidado ocurrió según el envolvimiento familiar, profesional e institucional. Optamos por el abordaje comprensivo, el estudio de situación y la historia de vida que fue llevada a cabo por entrevista en profundidad y observación. Realizamos el análisis por medio de lecturas y reflexiones/discusiones en el ámbito del grupo de investigación con elaboración de dibujos sintetizadores. En este proceso, los relatos se reunieron alrededor del tema "cuidado familiar" originando la imagen de la "Constelación del Cuidado". El estudio señaló que la familia se articuló, en movimiento sinérgico, para modelar el cuidado y, aunque estando inmersa en vulnerabilidad, consiguió encontrar fuerzas al utilizar el potencial de cada ente familiar en el cuidado. En este recorrido, el cuidado fue ofrecido, generalmente de forma creciente, por los amigos y por las instituciones religiosas. Pero, los profesionales y las instituciones de salud, cuando la cura dejó de ser posible, se alejaron progresivamente de la familia. Propusimos reflexiones acerca del valor del cuidado familiar y de cómo él es modelado, permitiendo comprensión y aproximación por parte de la enfermería para una práctica de cuidado que pone atención a las necesidades de la persona enferma, incluyendo y reforzando los potenciales de la familia.

Palabras clave: Familia. Adolescente. Neoplasias. Enfermería. Atención Integral de Salud.

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