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Adaption strategies used by siblings to childhood cancer patients

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Abstract

Objective: Siblings of childhood cancer patients experience social challenges. The results presented in this article are part of a larger qualitative study aiming to generate empirical knowledge about social consequences of childhood cancer from the family's perspective.

Methods: Data were collected through interviews, observational studies, and questionnaires. The study included 68 childhood cancer patients, 39 siblings, and 39 parents from a total of 78 families. Grounded theory informed the data analysis.

Results: Major life changes caused by childhood cancer entail an emotional hierarchy regarding the accommodation of each family member's need for help. This study identified a dynamic three-variable, four-adaption model for adaption strategies among siblings towards their parents, based on the sibling's perspective: (1) receives help without asking; (2) receives help after asking; (3) receives no help despite asking; and (4) receives no help and does not ask. Three variables are elaborative to understand the dynamic in adaption strategies: the patient's prognosis, the course of the disease, and the current situation of the diagnosed child. Even though the adaptions are reported by siblings, both patients and parents are aware of and concerned about the siblings' challenges.

Conclusions: These results have implications for practice and have the potential to improve social and health care professionals' awareness and ability to offer support and information needed by the families and the siblings. The knowledge presented in this article should be considered basic health care information in line with other information such as treatment protocols.

KEYWORDS

cancer, childhood cancer, family, interactions, oncology, psychosocial, qualitative research, siblings

1 | BACKGROUND

Approximately 300 000 children 0 to 19 years old are diagnosed with cancer worldwide each year.[1] This affects the entire family in varying degrees, characterized by changes in individual and family life stories and routines both during treatment and in the years following.[1-3] Parental attention is focused on the child with cancer, and the parental absence and loss of family routines causes the healthy sibling to experience a disintegration of life.[3-9] Siblings report numerous unmet needs, such as lack of parental attention, related to the diagnosis and the new life situation.[2] Several studies have investigated the impact of childhood cancer on the healthy sibling and found both positive and negative outcomes. The sibling might experience positive psychological and social growth, including increased responsibility, stronger family bonds, personal maturation, and an increased ability to exhibit empathy, especially as older siblings undertake a caregiving role.[4,9-17]

Sibling's social activities are often reduced as cancer-related issues cause logistical challenges in the family.[4,9,10] Siblings might experience feelings of isolation or exclusion, leading them to cope with negative perceptions alone instead of seeking parental support.[18,19]

Furthermore, even though siblings only show a minor increase in the incidence of psychiatric disorders (eg, posttraumatic stress disorder [PTSD] and depression[20,21]), they experience negative emotions such as fear, anxiety, loneliness, helplessness, and guilt related to the cancer and the future.[4,7-10,16,18,20-26] They are also affected at school, their academic performance declining as a result of learning difficulties.[4,12,15,19,27,28]

Although the impact on siblings has been examined and acknowledged in recent decades, few studies have included the perspective of both the siblings themselves and other family members' perception of the siblings' perspective.[2,4,5,7,8,17,20,26,29-31] This article aims to examine the consequences of being a childhood cancer patient's sibling primarily from the sibling perspective. However, since both the parents and patients themselves have substantial concerns for the siblings, we consider it valuable in a minor degree to present their perspective to understand the background of the siblings' challenges and the overall consequences for the entire family.

2 | METHODS

2.1 | Setting

The data are a part of a larger study, "Social Consequences of Childhood Cancer." Inductive qualitative approach was used to fulfil the aim of this study. The preliminary stage demonstrated that survivors of childhood cancer are concerned about their siblings presently and retrospectively and that they feel guilt for their siblings' negative feelings and challenges.[32] This result initiated this specific part of the study that focused on social consequences siblings experience during the treatment period and the two following years from the perspective of all family members and the siblings themselves.

2.2 | Participants and recruitment procedures

This study included 68 childhood cancer patients (33 boys, 35 girls), aged 3 to 17 years—all affiliated with a paediatric oncology unit in Denmark—39 siblings (13 boys, 26 girls), aged 5 to 17 years, and 39 parents (17 fathers, 22 mothers) from at total number of 78 families. As illustrated in Figure 1, the participants were classified according to the International Classification of Childhood Cancer, Third Edition (ICCC3). Sibling characteristics are described in Table 1. The participants were recruited through Facebook page announcements aimed at families affected by childhood cancer, notices at the Danish Cancer Society counselling centres, through suggestions from participants, and groups or camps related to childhood cancer. This recruitment approach was chosen for ethical considerations; by exclusively including families who applied themselves, we wanted to ensure that the participating families had a mental surplus.

When a family showed interest in participating, a detailed project description was sent. It included a shorter description for the participating children, individualized based on the child's age, maturity, physical and mental health, and understanding. Telephone conversations were used to arrange meeting times and answer any questions. A minor part of the data collection took place at camps or in group settings. In these cases, corresponding written material was handed out to both the parents and the children forehand, and the researcher presented the study and received written consent on site. The children's comfort levels were carefully evaluated at all points of the data collection. Children were met either in their homes or in a group setting with parents or a familiar professional present. Follow-up support was offered.

2.3 | Data collection and analysis

Classic grounded theory (GT) informed the analysis to generate empirical knowledge.[33-35] Choosing GT as the method of analysis affected both the type of data needed and the collection order. The data were generated over a period of 3 years in Denmark, including several meetings with the majority of the participants. All the participants (or their parents) were asked to provide their personal details in a questionnaire, including disease history, age, and composition of the family. All interviews were audio-recorded and transcribed, including emotional expressions, pauses, and interruptions, etc. Fieldnotes and,

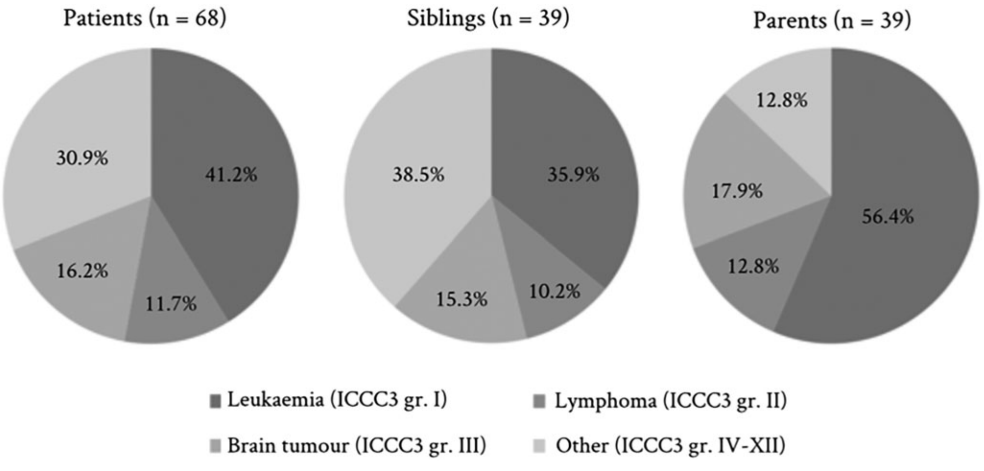

FIGURE 1 Classification of informants according to the International Classification of Childhood Cancer, Third Edition (ICCC3)

TABLE 1 Characteristics of siblings

	Leukaemia (ICCC3 gr. I) (n = 14)	Lymphoma (ICCC3 gr. II) (n = 4)	Brain Tumour (ICCC3 gr. III) (n = 6)	Other (ICCC3 gr. IV-XII) (n = 15)
Age (y)	10.9 (±4.5)	10.0 (±4.7)	12.2 (±2.0)	11.9 (±2.4)
Gender (boys)	7 (50.0)	1 (25.0)	2 (33.3)	3 (20.0)
Order of siblings (oldest)	8 (57.1)	2 (50.0)	4 (66.7)	8 (53.3)
Participation from all family members (yes)[a]	9 (64.3)	4 (100.0)	3 (50.0)	4 (26.7)

Data are reported as number (%) or number (±SD).

[a] Interview with both the childhood cancer patients, siblings and at least one parent.

in some situations, short recordings were obtained during the observational studies.

The data collection and analysis were divided into parallel open and selective phases followed by a final theoretical analysis phase (Figure 2).

2.3.1 | The open phase

The first phase consisted of open, individual interviews and observation studies in a camp setting in order to explore the siblings' perspective. The introductory question to the open preliminary individual interviews was individualized to the informant group and was as follows: How does it affect you that a child in the family is diagnosed with cancer? Afterwards, both semistructured individual and focus-group interviews were utilized to elaborate on concerns at an explorative level. Data from all groups of participants were carefully analysed and coded for perspective on siblings.[33]

2.3.2 | The selective phase

The selective phase was initiated as the interview turned semistructured, asking for participants' personal experiences with the sibling's adaption as revealed in the initial open phase. Subsequently, selective observational studies were initiated in order to gain insight in topics mentioned and experiences shared in group settings.

A "questionnaire" was presented to both patients and siblings, formulated as a letter to a child in a similar situation, and was based on four themes revealed in the analysis. The completed questionnaire letters were discussed in focus-group sessions where the children could choose to present their answers with subsequent comments and affirmations from the other children. Following, the children had the opportunity to deepen their answers with the researcher in open individual or group interviews. The researcher lastly organized follow-up interviews on specific indicators identified such as sense of guilt, changes in family relations, or challenges in school.

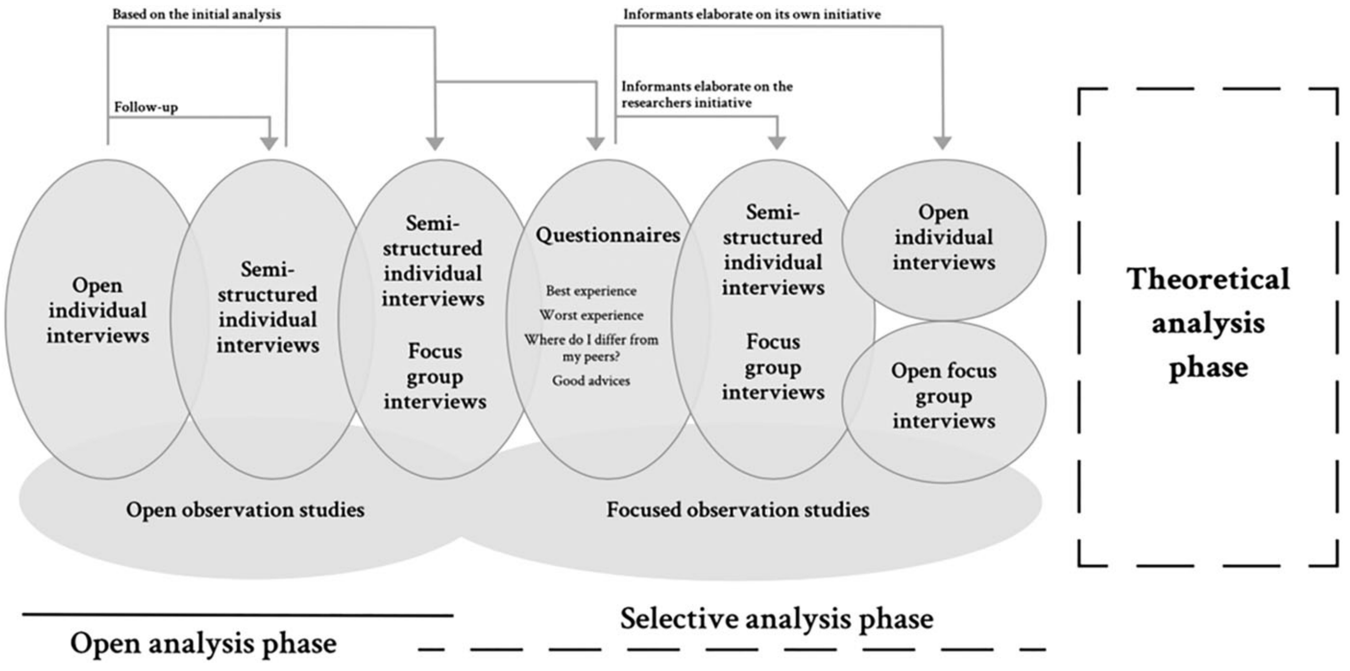

FIGURE 2 Data collection and analysis with two parallel phases and a theoretical analysis phase

2.3.3 | The theoretical phase

In the theoretical phase, the codes, indications, and subcategories were interconnected in terms and concepts, and the theory was formulated[33-35] The theory revealed an emotional hierarchy encompassing a four-adaption, three-variable model for the siblings of childhood cancer patients.

3 | RESULTS

This study identified an overall concern from all family members for an emotional hierarchy in the family in terms of who is most affected and who has the right to “demand” their needs be fulfilled. Siblings seemed to be and positioned themselves at the bottom of the emotional hierarchy. The siblings' challenges affect and concern the whole family mentally. Three variables (Figure 3) were identified as useful to understanding this dynamic: prognosis, course of a disease, and the current status of the diagnosed child, including symptoms and side effects, hospitalizations, intensive care treatment, and risk of death.

We identified four adaptions strategies from the sibling's perspective. The severity of the variables affects both how the hierarchy appears in the family and the type of adaption, which the siblings consciously or unconsciously use.

These adaption strategies are dynamic (Figure 3), and each sibling can experience and exhibit all adaption strategies at different times during and after the treatment:

1) Receives help without asking
2) Receives help after asking
3) Receives no help despite asking
4) Receives no help and does not ask

The siblings report a lack of help, highlighted in adaption three and four, concerning basic care such as mental and physical presence, and reasonable family routines such as common meals, help with homework, and everyday life activities. The siblings also describe a need to involve their parents in serious thoughts such as feeling alienated from their classmates, having difficulty concentrating in school, and anxiety about the present and possible future situation.

The sibling's age is not directly related to a change in the parental-sibling relationship or the sibling's attempts to adapt to the overall life situation. However, it is important to consider maturity and verbal skills when expressing needs. Oldest female siblings tend to become more practical at home and take responsibility for siblings and housekeeping, whereas oldest boys reach out to friends, sports, and boarding school.

The next section elaborates on the emotional hierarchy from the perspective of patients and parents to give an understanding of both the awareness and the contributory cause of the siblings' interactional adaptions presented in the following section.

Afterwards, the four adaptions' characteristics are exemplified with pertinent quotations from the perspective of healthy siblings. All quotes are anonymous, the names are changed, and representative of situations described by the majority of participants.

3.1 | An emotional hierarchy

All informant groups reported situations regarding an emotional hierarchy. Patients were concerned and felt guilty about the consequences for their siblings (eg, absent parents and hospitalizations) and about their sibling's struggle to articulate their feelings. As elaborated by Tim, a 14-year-old patient: “I feel so guilty about my younger brother; he does not get the attention he deserves and needs, because my parents spend all their time and energy on me.” Vera, a 12-year-old patient with substantial emergency hospitalizations, says, “my younger brother just does not get the devotion and attention from my mother that he deserves, but when he asks for it, he risks appearing like a brat.”

Parents made comparable statements, expressing despair and reflection with concerns centred on the patient's physical and emotional status and practical challenges. As expressed by two mothers, “it will never be ordinary for us; organizing and basically surviving as a family” and “listening to the doctors: ‘your daughter has a tumour, and we don't know if she will survive.’ You just fight for the child.” They expressed a sense of powerlessness. A father explains, “I was afraid all the time. One day my 8-year old healthy son made me laugh. He asked me ‘dad, do you stop crying now?’ It knocked me out. One day, I heard him go singing ‘I hope he will not die.’ I should have gone out there, but I could not.” Another father continues, “I told my oldest

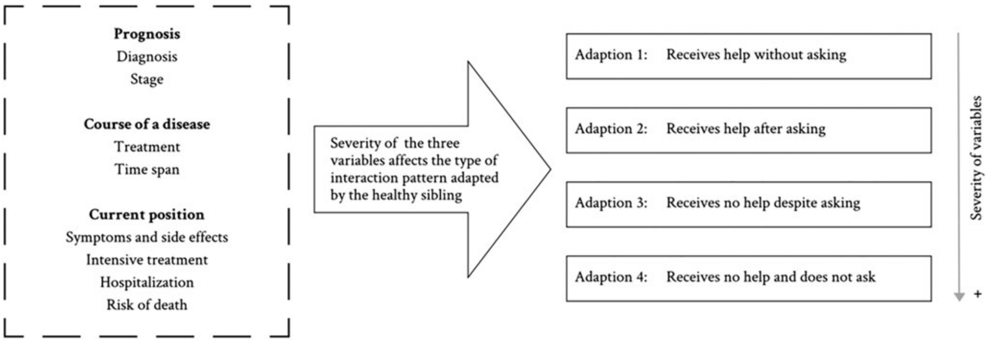

FIGURE 3 The four-adaption, three-variable model for interaction patterns in siblings

that his brother had cancer. He was not capable of listening, but I told him it was not about him or his needs, but his brother's needs. Afterward, I regret this conversation." These quotes substantiate the claim all informant groups, independent of family roles, report a priority of the patient over the sibling.

3.2 | Categories of adaption

3.2.1 | Receives help without asking

The siblings experience understanding and sympathy regarding their needs and challenges from their parents. They are in charge and take responsibility for the siblings' well-being. Isabell, a 12-year-old sister, described how her parents took her to dinner while the grandparents cared for her younger brother: "They paid me full attention and were sincerely interested in the stories I told."

Another situation was described by Charlotte, a 9-year-old sister: "My parents told my grandparents that I, as well as my sister, had a really difficult time, and that we both deserved presents and extra attention." The parents took responsibility and asked for the sibling to be treated with care and sympathy, expressing a significant, highly valuable affirmation of how challenging aspects of the new life situation were for the siblings.

3.2.2 | Receives help after asking

The siblings experience their parents support after expressing their needs. The siblings sometimes struggled to articulate their needs. They often felt selfish when requesting for help, as they understood the severity of the situation and knew that their parents would have done the same for them in a reverse situation. This sentiment was expressed by Amanda, a 15-year-old sister: "Sometimes, when I asked for it, my mom and I went out. I missed her so badly, but it was so difficult to say it out loud even though she would listen." The quote also presents a simultaneous experience of pleasure from parental attention and guilt for taking attention from the patient. Another dimension is added by Robert, a 10-year-old brother: "I know that my older brother needs my mom all the time. He is often scared, vomits, and all that kind of stuff. But I still need my mom. Some time I sneak up after bedtime and just hugs her." He, as well as other siblings, describes feelings of shame when seeking attention, yet they asked for it because they missed the parents' emotional presence.

3.2.3 | Receives no help despite asking

These siblings' needs are not accommodated following the diagnosis as their parents' lack of logistical or mental surplus leading to unconscious neglect. Recalling the urgent hospitalization of 11-year-old Charlie's older sister, he says, "My parents had called for an ambulance. They could not wake her up. They took her with them, and I am just standing outside: 'Mom, what is happening?' I wanted to go, but my parents pushed me away. I could not come along with her." Mike, a 13-year-old, expressed his needs through verbal and physical aggression: "Sometimes I yelled at my parents that I wanted my life back. I ran to my room and slammed the door. They got really angry at me." According to Mike, his parents' reaction resulted in a change in his behaviour: "Now I just stop involving them." Both situations are illustrative, as the siblings became introverted and loses faith in themselves and their closest relatives. They frequently coped by internalizing their feelings.

Overall, siblings who experience nonaccommodated needs several times within a limited period may stop asking their parents for help and progress to category number four.

3.2.4 | Receives no help and does not ask

This category describes periodic situations of limited or no verbal, emotional, or physical interaction between the parents and siblings. As two older brothers described, "You just keep it in, so you do not stress them," and "I stay at my friend's house when it is difficult. It can easily explode at home when my parents are stressed out." Maria, a 10-year-old younger sister, explained that she struggles: "Sometimes I touch my arm to be sure that I am still here. It is like no one sees me. I understand that they must focus on my brother. He is fighting; they would have done the same for me. But still, it makes me feel hopeless. Will they ever look at me in the same way as they used to? Will I ever stop being invisible to them?"

The siblings had several motives for not involving their parents: protecting their parents and the diagnosed child from additional pressure and protecting themselves from disappointment or rejection.

4 | DISCUSSION

Like previous research, this study reports that siblings are affected by changes in their daily life and interactions with their parents.[2,9,10,12,20] The siblings involuntarily face situations of unfulfilled needs, and they must respond to a life situation beyond the limits of their previous experience. The cancer diagnosis introduces an emotional hierarchy in the families, and our study finds that all family members are aware and concerned and feel guilty for the dramatic changes that the siblings endure.

We find that the siblings exhibit four dynamic adaption strategies in relation to their parents resulting in introverting of their reaction patterns. Three variables influence these adaption strategies: prognosis, course of disease and treatment, and current situation of the diagnosed child. Corresponding to previous research, when the severity of these variables is nonsubstantial, siblings often experience good times during the treatment as parents have a mental surplus. Most of the siblings express that they can adjust to the situation relatively easily, as seen in adaption types one and two. However, if any of the three variables intensifies, our study demonstrates that siblings will adjust to this change by suppressing their requests and shift to adaption type three or four. Siblings are thereby positioned at the bottom of the hierarchy and ignore or defer their needs. Parents have previously reported that they attempt to protect siblings from distress and that their parent-sibling relationship has changed, leading to decreased discipline and increased spoiling.[2,20,36] Yet, siblings position themselves actively as optimistic and positive to support their parents and continuously try to guard the rest of the family from additional psychological pain.[2,5,8,10] The siblings explained that if they articulate their needs, they appear dissatisfied, ungrateful, or even ill mannered. In line with previous research, they changed their behaviour and mode of interacting with their parents, trying to be cooperative and nonconflicting.[2,5,8,20,36-38]

This study demonstrates that the need for intervention is greater when severity of the three variables increases. In relation to this result, the review by Lang et al[20] concluded that siblings request more psychosocial support from services when they experience strong cancer-related emotions.

We recommend that social and health care professionals increase their focus on siblings in both the initial phase, during treatment and follow up. This recommendation is in alignment with prior research, which argues for the relevancy of nursing interventions and a focus on the parent-sibling relationship and support for childhood cancer families.[30,39] Results from relevant interventions show an improvement of siblings' overall health-related life quality.[40]

5 | CONCLUSION

This study identified an emotional hierarchy in terms of who is most affected and who is getting their needs fulfilled. Siblings, patients, and parents all expressed awareness of this hierarchy and the siblings' struggle. The siblings tried their best to protect the patient, their parents, and themselves; while they cognitively understood that their parents were doing their best, they still found the situation emotionally difficult.

To elaborate on the reaction following the hierarchy, the study identified a dynamic three-variable, four-adaption model for siblings' interactional adaptions towards their parents. Siblings of all ages included in the study experienced a change in the parental-siblings relationship, and all siblings attempted to adapt to the overall life situation.

Overall, this study adds knowledge to previous literature and confirms that the consequences experienced by siblings are not only important for them but for the entire family. A special focus from both health care and social professionals on siblings will benefit the family as a whole, and therefore, our results have implications for practice.

5.1 | Study limitations

Further research should incorporate considerations for the following limitations, which induced noncontrolled variables. First, as the perspectives were only from the family themselves, their self-understanding might not reflect their actions in practice. Moreover, the results do not reveal whether the reported changes were due to other social conditions, as we are not aware of how the family life and hierarchy would have been without the diagnosis. This study aimed to be representative of childhood cancer families in a welfare state, and an overrepresentation was seen of cohabiting ethnic Danish families in which both parents had jobs. Additionally, participating families were in a mental surplus, considering the circumstances; therefore, we estimate that the clarified issues are even more widespread in families not included.

5.2 | Clinical implications

We recommend that the emotional hierarchy, as captured by the three-variable, four-adaption model, should be basic information given to parents along with information about treatment protocols. We suggest that the family should be informed by health care professionals that it is inevitable for siblings to be affected and that a neglect of siblings' needs will follow as a normal reaction to the diagnosis. Additionally, the information can be shared in multidisciplinary network sessions in the paediatric oncology department. In this way, adults in all settings of the sibling's life (eg, social and health care professionals in hospital and teachers, as well as additional family) can be aware of their struggles and abate undesirable adaptions, especially when escalation of the three variables occurs.

5.3 | Ethics approval

We followed the basic rules for ethical conduct in qualitative research. The study is notified by the Danish Data Protection Agency, reg. number: J.nr. 2016-41-4895. According to Danish law, qualitative studies are not subject to review by the National Committee on Health Research Ethics.

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CONFLICT OF INTEREST

No conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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