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Collaborative Ethics: Professional Perceptions of Patient and Parent Engagement in Pediatric Oncology

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Abstract

The role of patients and parents in Clinical Ethics Support Services (CESS) remains a subject of ongoing debate, particularly within case-based approaches. Although such participation is gradually expanding, practical challenges and ethical considerations continue to limit its implementation. Gaining a nuanced understanding of patient and parent involvement requires examining the viewpoints of those directly engaged in these services and the contexts in which they operate. This study investigates how stakeholders perceive both the practicality and moral justification of including patients and parents in pediatric oncology CESS. Twenty-six healthcare professionals from Nordic countries, working as ethics support staff in pediatric oncology or general pediatrics, participated in six focus group sessions. The discussions were examined through an inductive qualitative content analysis approach. Although involved in Clinical Ethics Support Services (CESS), most ethics support personnel had little to no prior experience with patient and parent participation (PPP) in these services. While they recognized possible advantages of PPP, such as enhancing understanding and trust, these were often outweighed by concerns about inadvertently causing harm. Identified benefits and risks included fostering deeper insight, encouraging open confrontation, and generating ethical dilemmas related to decision-making participation. Participants described strategies to minimize potential negative outcomes and protect against harm, implemented at organizational, relational, and individual levels.

Although ethics support personnel recognized potential benefits of patient and parent participation (PPP) in Clinical Ethics Support Services (CESS), their primary concern was avoiding harm to both children and parents, which may reflect a form of implicit paternalism. The perceived appropriateness of PPP in pediatric oncology CESS appeared to be context-dependent, with no standardized approach applicable in all cases. Tailoring participation on a case-by-case basis, alongside implementing strategies to minimize potential risks, emerged as a key facilitator. This study enhances understanding of PPP in CESS from the perspectives of ethics support personnel in pediatric oncology and provides guidance for fostering participation in ways that are both ethically and practically responsible.

Keywords: Ethics, Patient, Parent, Pediatric Oncology

Introduction

Clinical Ethics Support Services (CESS) are designed to assist healthcare teams in navigating ethically challenging situations [1]. While the structure and procedures of CESS differ across contexts, the core objective is to identify, analyze, and resolve ethical dilemmas [2]. CESS may be provided through clinical ethics committees, individual ethics consultants, or structured group reflections such as moral case deliberations (also referred to as ethics case reflections) [3–6]. Ethics committees often operate at the organizational or policy level, providing guidance, education, and consultation on patient cases [7]. In contrast, clinical ethics consultants typically engage in one-on-one consultations, often adopting a top-down approach led by bioethicists or clinicians with specialized

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ethics training [8]. Facilitated group reflections, however, emphasize collaborative, bottom-up learning, aiming to enhance participants' moral reasoning and competence through structured discussion of specific cases, usually guided by certified facilitators [5, 9]. Because ethical dilemmas frequently involve patients' perspectives on care and decision-making, questions regarding patient inclusion in CESS are increasingly important.

The broader concept of participation in healthcare provides a foundation for understanding patient involvement in ethics support. Participation is generally defined as patients' ability and opportunity to engage in decisions about their care through dialogue that respects their preferences, capacities, and experiences while incorporating professional expertise [10]. Active participation can strengthen autonomy, enhance the patient-provider relationship, and clarify patient experiences and expectations [11]. Pediatric frameworks, such as Hart's "Ladder of Children's Participation" [12] and Shier's five-level model [13], describe pathways from passive listening to shared decision-making, with actual participation influenced by both organizational structures and individual attitudes. For example, research has shown that physicians and parents often determine the extent of children's involvement in care decisions [14]. Participation has also been linked to supporting children's health and well-being [15].

Interest in patient and family participation in CESS has grown over the past decades, both in adult and pediatric care [16–20]. Because ethical analysis requires consideration of all relevant perspectives, which healthcare personnel alone may not fully capture, there are strong practical and moral arguments for including patients and families. Children and families themselves can experience ethical dilemmas, further supporting their involvement [21–23]. Healthcare professionals also recognize families as important participants, ranking them second after the care team [24]. Without structured opportunities for patient and family input, essential perspectives on quality of care may be overlooked. Nevertheless, how, when, and in what form participation should occur remains contested. Key challenges include balancing transparency with confidentiality, avoiding dominance of patient preferences over broader ethical deliberation, and preventing undue burden on patients or families facing difficult decisions [25, 26].

The extent of patient and family participation in CESS varies by setting and procedure [26]. In North America and parts of Europe—including Norway, Germany, and France—practices for involving patients and families in ethics consultations and committee discussions are relatively well developed [20, 26–28]. Despite these formal practices, families rarely request participation [27], indicating potential barriers related to awareness and accessibility. In other contexts, participation remains limited [16, 26]. Evidence on patient involvement in facilitated group reflections, such as moral case deliberations, is scarce; a recent Dutch study reported low participation even where deliberations are widely used [17]. Pediatric contexts show a particular gap in knowledge, making patient and parent participation (PPP) in pediatric CESS an underexplored area.

In Sweden, efforts to develop pediatric CESS have been ongoing, led in part by the authors [9, 21, 23, 29, 30]. Swedish pediatric oncology centers employ various CESS formats, including committees, ethics groups, and teams. In 2017, the Nordic Society of Paediatric Haematology and Oncology introduced moral case deliberations at all six pediatric oncology centers, combining joint training sessions with practice periods at participants' home centers. Facilitators were tasked both with leading deliberations and supporting implementation locally [31]. Despite these initiatives, participation in Swedish pediatric oncology CESS remains largely limited to healthcare professionals, highlighting the need for exploration of patient and parent involvement.

Aim

The study aimed to examine how ethics support personnel (ESP) in pediatric oncology perceive the practicality and ethical justification of involving patients and parents in clinical ethics support services (CESS). The investigation focused on two central questions: (1) How do ESPs view patient and parent participation in CESS, and what factors do they identify as supporting or limiting such involvement? (2)What approaches do ESPs suggest for structuring and implementing PPP in CESS?

Materials and Methods

Study design and setting

This research adopted an empirical, exploratory, qualitative, and descriptive approach, focusing on pediatric oncology in Nordic countries, with the primary emphasis on Swedish contexts.

Study participants

A group of 33 ethics support personnel (ESP) with experience in Nordic pediatric oncology or broader pediatric settings were approached to join focus group interviews. For the purposes of this study, ESP were defined as professionals possessing either formal training or practical experience in CESS. Participants were selected based on their expertise and their potential role in facilitating patient and parent participation (PPP). Ultimately, 26 ESP took part in the study, all of whom provided responses to a sociodemographic questionnaire **(Table 1).**

Table 1. Characteristics of the ESP (*n* = 26)

Characteristic	n	%
Sex (n = 26)		
Woman	20	77
Man	6	23
Profession (n = 25)		
Registered Nurse	11	44
Physician	11	44
Other	3	12
CESS Education (n = 26)		
Yes / Ongoing	23	89
No	3	12
Years of CESS Experience (n = 26)		
< 1	7	27
1–5	16	62
6–10	2	8
> 10	1	4
Hours/Week Performing CESS (n = 26)		
< 1	18	69
1–5	6	23
6–10	2	8
Patient Care in Assignment (n = 26)		
Yes	25	96
No	1	4

Total percentage may be > 100% due to rounding errors

The study engaged a diverse group of ethics support personnel (ESP) from Nordic pediatric oncology. Participants included facilitators of moral case deliberations from the six Swedish pediatric oncology centers, all of whom had completed a facilitator training program, and who were organized into three focus groups. Additionally, a subset of members from two Swedish pediatric ethics committees participated in two separate focus groups during their regular meetings. The study also involved all members of the Nordic Working Group on Ethics in pediatric oncology. The ESP held varied positions within CESS, ranging from leading deliberations and serving as ethics representatives to participating in committees at local, national, and international levels. Notably, approximately half of the participants were engaged in multiple roles, reflecting the overlapping responsibilities common in ethics support practice.

Data collection and analysis

The Swedish Ethical Review Authority approved this study (No. 2022-06171-01). Data collection occurred from January to November 2023 using six focus group interviews, with group sizes ranging from two to eight participants. Four sessions were held in person, while two were conducted virtually. Although groups were planned to include at least three participants, one group proceeded with only two due to a last-minute withdrawal. To encourage context-specific discussion, focus groups were organized according to clinical center or working group. In the facilitator workshop, participants from multiple centers were grouped to ensure optimal group size. All participants received written and verbal information about the study, including voluntary participation and confidentiality, and provided written consent for participation and audio recording. Each interview lasted between 64 and 122 minutes and began with a brief overview of the research project. Discussions were guided by two moderators, with one leading the conversation and the other recording observational notes [32]. An interview guide helped structure the sessions, covering both general questions about patient and parent participation (PPP) in CESS and hypothetical patient cases illustrating ethical dilemmas among healthcare personnel, children, and parents.

Analysis followed a three-step process: preparation, organization, and reporting. In the first phase, all interviews were transcribed verbatim by the first author and de-identified before being imported with field notes into NVivo 13 for analysis. Given the limited research on PPP in pediatric oncology CESS, an inductive content analysis approach was chosen. Initial open coding generated a set of codes, which were then grouped into sub-categories, further combined into generic categories, and finally synthesized into a main category, reflecting increasing levels of conceptual abstraction [33, 34]. Throughout the process, memos were maintained to document reflections and analytic decisions, forming the basis of the preliminary results. The coding and categorization were validated by all authors at each stage, and the final results were further reviewed in collaboration with colleagues experienced in the research area and method.

Results and Discussion

Most ESP had little or no direct experience with PPP in CESS. Consequently, their perspectives were primarily shaped by their broader clinical experience with patients and parents, as well as their roles as ESP within pediatric oncology or pediatrics more generally. A summary of the identified categories is provided in **Table 2.**

Table 2. Overview of categories

Main Category	Generic Categories	Sub-Categories
Potential benefits were outweighed by concern for harm	Benefits and Risks	- Enhancing understanding and building trust- Stimulating open confrontation- Generating ethical dilemmas in decision-making participation
	Strategies to Minimize Harm	**Organizational Measures**- Address ambiguity in ethics and CESS- Preparation and post-discussion debriefing- Establish a safe environment
		Relational Measures- Balance the care relationship- Safeguard the child-parent relationship
		Protecting Individual Integrity- Evaluate child's participation- Evaluate parent's participation- Consider exposure of healthcare personnel

Potential benefits were overshadowed by fear of causing harm

Overall, the ethics support personnel (ESP) perceived that the potential advantages of patient and parent participation (PPP) in CESS were often outweighed by concerns about causing harm to participants. Many ESP considered PPP in pediatric oncology to be a contentious issue, which prompted extensive discussion during the interviews. Their reflections highlighted both potential benefits and risks, with the anticipated harms frequently dominating the conversation. To address these concerns, ESP proposed strategies at multiple levels—organizational, relational, and individual—aimed at minimizing the risk of adverse consequences for participants.

Potential benefits and harms

This generic category comprises three sub-categories that describe the perceived benefits and risks of patient and parent participation (PPP) in clinical ethics support services (CESS). Overall, ESP recognized that PPP could enhance understanding and trust, provoke confrontation, and generate dilemmas related to decision-making participation. While PPP was viewed positively in principle, ESP emphasized that its practical implementation is complex.

Enhancing understanding and trust

ESP suggested that PPP in CESS could help families articulate their values and perspectives, positioning them as the most accurate representatives of their unique situations. Involving families directly could clarify which values are at stake and improve the decision-maker's understanding of the case, potentially reducing misinterpretation or over-interpretation of family perspectives—a challenge sometimes observed in CESS without PPP. As one participant noted: "…because we [the healthcare personnel] also… overinterpret 'this is what the parents think, this is what the child probably thinks' and we have no idea" (FGI 2). Improved understanding could foster trust and a sense of safety, enhancing families' experience of healthcare. However, ESP also noted that deeper insight into the limitations of care or the uncertainties of healthcare personnel could produce unintended negative effects.

Catalyzing confrontation

Another potential effect of PPP identified by ESP was the facilitation of confrontation. While such confrontation could help address disagreements and foster acceptance of differing perspectives, it could also intensify conflicts, particularly when cultural differences or differing principles—such as cost-effectiveness—were involved. One participant reflected: "…it can be very frustrating, especially if there also are cultural differences, because then it can be so difficult to achieve any kind of consensus or common ground" (FGI 1). Thus, confrontation in PPP could both mitigate and exacerbate tensions among participants.

Generating dilemmas in decision-making participation

ESP frequently highlighted that PPP could create dilemmas regarding families' involvement in decision-making, given that CESS is designed to support such processes. On one hand, participation was seen as ethically valuable, granting children and parents the right to understand and discuss the basis of decisions, potentially contributing to a more comprehensive decision-making process. On the other hand, ESP expressed concern that exposure to certain information or involvement in decisions could harm families emotionally. As one participant stated: "…we [the healthcare personnel] have to take some responsibility of shielding patients and parents from the information that we sincerely, with all moral and emotional being, we really sincerely think that is not good for you to know" (FGI 3). ESP emphasized that it would be unacceptable to place families in a position where they might feel responsible for decisions that could inadvertently harm the child. For certain ethical challenges, such as those involving cost-effectiveness, ESP felt that PPP should not be implemented, believing that such decisions should remain the sole responsibility of healthcare personnel.

Strategies to avoid causing harm

This generic category is built from three sub-categories and outlines strategies for conducting PPP in CESS in ways that minimize the risk of harming participants. These strategies operate across organizational, relational, and individual levels **(Figure 1)**. The framework draws conceptually from Bronfenbrenner's ecological model, which illustrates how individuals are shaped by, and situated within, broader relational and organizational contexts [35].

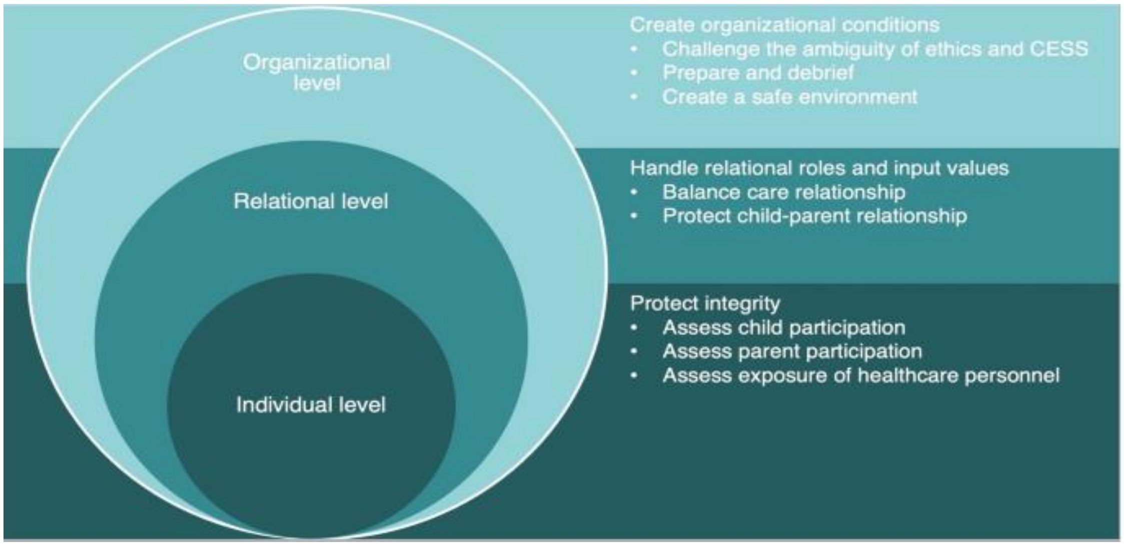

Figure 1. Model of the ESPs' perceived strategies to minimize the risk of harm across different levels

The first sub-category, establishing organizational prerequisites, reflects both the conditions the ESPs felt were already in place and those they believed needed to be developed to make PPP possible within CESS.

One suggested strategy was to address the unclear and sometimes intimidating nature of ethics and CESS. According to the ESPs, the term "ethics" carried emotional weight for both staff and families and often felt overly formalized. As one participant noted, the word can appear "complicated" and even "pretentious" (FGI 2). They pointed out that many struggled to recognize ethical dilemmas or articulate the values involved, which reduced the overall demand for CESS—and by extension PPP within CESS. Moreover, some ESPs said they found it difficult at times to regard families' concerns as authentic ethical issues, interpreting them instead as emotional or relational challenges better suited to counselling or therapy. Staff themselves sometimes considered CESS confusing or challenging to carry out, which further hindered both CESS and PPP. Therefore, ESPs believed it would be helpful to begin with ethics discussions rooted in everyday clinical practice and increase general awareness of what CESS involves. Many also expressed reluctance to bring families into

CESS before gaining more confidence through sessions held only with healthcare professionals.

The ESPs also emphasized the value of thorough preparation and structured follow-up, both seen as ways to reduce potential harm. They highlighted the importance of selecting methods and formats suited to the specific clinical setting and case. A trusting, well-established care relationship was viewed as an essential foundation for safe participation. Participants should be clearly informed in advance about what the CESS will entail. As one explained, staff might tell a child or parent that the session will use a particular method with the aim of seeking solutions rather than escalating disagreements (FGI 4). Providing families with an opportunity to debrief afterwards was also considered crucial.

Creating a psychologically safe atmosphere for PPP in CESS was another priority. Safety depended on who participated and how communication was conducted. The ESPs believed that the group should remain small and composed only of individuals directly relevant to the case, guided by a facilitator who is both neutral and experienced. A participant noted that in the Dilemma method, people sit not as "teams" (e.g., staff vs. parents) but as individuals offering different viewpoints (FGI 6). Adjusting the language and complexity of the discussion to match the child's or parent's abilities was seen as necessary, though some cautioned that too much simplification might limit the ethical depth of the reflection.

This study examined how Nordic ESPs view the involvement of patients and parents (PPP) in clinical ethics support services (CESS) within pediatric oncology. Overall, the ESPs believed that PPP in CESS has the potential to strengthen mutual understanding and trust, stimulate constructive confrontation between participants, and occasionally generate challenges relating to who should take part in decision-making. Although they recognized several possible advantages, these were largely overshadowed by concerns about negative consequences, which strongly shaped the strategies they proposed to prevent harm. The findings suggest that it is difficult to define a single model or shared ethical stance for PPP in CESS in this context. Instead, ESPs emphasized the need to tailor PPP to each individual case and assess its suitability carefully.

Discussions about PPP in CESS often began with the perceived vulnerability of participants, especially when stakeholders met together. This emphasis on vulnerability is noteworthy because it implies that CESS-based dialogue may differ meaningfully from other interactions in healthcare. CESS conversations focus on values, follow a structured format, may include multiple stakeholders, and are led by an ESP who is often not previously known to the family [5]. Beyond this, however, such conversations should share similarities with ordinary ethics discussions that occur routinely between clinicians, children, and their families [36]. ESPs described concerns about exposing families to complex dilemmas—such as uncertainties around treatment decisions—and questioned whether it was ethically acceptable to bring such issues directly to them. While this cautiousness is understandable, excluding patients and parents due to assumptions about their vulnerability risks sliding into a paternalistic attitude [37]. The idea that families cannot cope with certain information may constitute a form of covert paternalism [38], where staff members' own views about PPP shape how patients are treated. Although strong paternalism (directly overriding a competent patient) appears to be decreasing in Nordic countries [38], a softer form—relevant when children are not fully competent—is often considered legitimate, since many medical decisions ultimately rest with physicians and the decision-making space for families is inherently limited. As Lynøe and colleagues argue [39], professionals' personal values may influence what information is shared, thereby restricting both shared decision-making and patient-centered care. Given that participation is frequently tied to decision-making [14, 40, 41], it is important to consider whether this softened paternalism should also inform the ethical deliberation that CESS encourages. Moreover, since the Convention on the Rights of the Child has been implemented in Swedish law [42], including children in CESS aligns with Article 12, which grants children the right to express their views in matters affecting them, in accordance with their maturity. At the same time, CESS does not always aim at making decisions; often, its purpose is to jointly reflect on an ethical challenge [5].

While the ESPs' fear of causing harm is understandable, it is worth questioning whether this fear is justified. A Norwegian study showed that next of kin found CESS participation psychologically demanding, yet none of them regretted attending and most valued the opportunity to express and hear diverse viewpoints [20]. Research has also indicated that PPP in CESS may ease tensions between healthcare personnel and families and help clarify the ethical issue at hand [2]. Moreover, the potential risks of participation must be weighed against the risks of exclusion. A study in neonatal care illustrates this: when asked what they would choose if the extremely premature infant were their own child, pediatricians' responses differed markedly from their professional recommendations [43], demonstrating the importance of understanding parents' perspectives directly.

In the present study, attention was heavily directed toward managing potential negative consequences, as these were seen as central to enabling or improving PPP in CESS. These empirical insights raise the normative question of whether PPP should be a goal in CESS at all. Since PPP in CESS itself appeared to be an ethical dilemma—containing competing values and potential moral trade-offs—it becomes important to clarify the ethical basis for pursuing it. If pediatric healthcare in the Nordic region considers PPP in CESS justifiable from a moral standpoint, efforts should be made to support and develop it despite its challenges, much like the ethically complex yet essential process of obtaining informed consent [44, 45]. While discussing risks with patients can be distressing, this does not remove the ethical or legal duty to do so.

This study contributes to a broader understanding of how complex PPP in CESS can be in pediatric oncology, and what strategies ESPs consider necessary to navigate these challenges. Comparable conditions for enabling children's participation have been identified in social welfare settings as well [46]. CESS itself has previously been described as a "complex intervention" [47], and the present findings suggest that PPP in this context may similarly qualify. Research into barriers and facilitators to CESS in pediatric oncology [6] also points to organizational factors such as timing as highly influential. Given that PPP in CESS within pediatric oncology is still at an early stage—both in practice and empirical investigation—it is essential to explore, refine, and evaluate these approaches before drawing firm conclusions about their overall value. The findings presented here warrant further study and confirmation.

Clinical implications

The strategies identified to minimize the risk of causing harm operate across several levels, and our findings suggest that organizational conditions should form the starting point. These conditions primarily relate to the cultural environment of the workplace—for instance, addressing the uncertainty surrounding the meaning of ethics and CESS, and ensuring that ESPs receive sufficient training, practice, and support to feel confident as CESS facilitators before involving families. Moreover, the insights gained in this study can guide those who educate or prepare ESPs in pediatric oncology by clarifying what they require to develop and strengthen PPP in CESS. The results may also offer valuable direction for other pediatric healthcare areas looking to initiate or expand PPP within their own ethics support practices.

Strengths and limitations

Because most ESP had never previously engaged in PPP within CESS, their reflections were largely speculative and grounded in their broader professional experience—either from their clinical roles or from their work with ethics support in pediatric oncology or general pediatrics. This context may also influence how well the suggested strategies for minimizing harm would function in practice. It is also important to recognize that nearly all participants were trained specifically in facilitating moral case deliberation, which means their views on PPP are likely shaped by that particular CESS format rather than by other ethics support approaches.

Given that the majority of ESP devoted less than an hour per week to CESS, it is reasonable to assume that the organizational barriers previously described in the implementation of moral case deliberation remain unresolved [31] and may impede efforts to enhance PPP. Consequently, conversations about introducing PPP in CESS might have felt burdensome, especially because the ESP themselves would likely be responsible for carrying out such an initiative.

Additionally, most ESP were acquainted with the authors through professional or educational interactions, which may have influenced their responses. At the same time, the authors' active involvement in pediatric oncology and/or CESS training can be viewed as an asset, as it positions them well to apply the study's insights to the ongoing development and strengthening of CESS practices.

Conclusion

The findings show that ESP in pediatric oncology recognize possible reasons to involve patients and parents directly in CESS. Yet, their strong concern about unintentionally causing harm tends to outweigh these potential advantages, which likely helps explain why PPP has not been introduced in practice. Whether PPP is suitable appears to hinge on the specific context, and when it is deemed appropriate, there is no single model to follow. Rather, the approach needs to be tailored to each situation, with particular attention to minimizing risks for those involved.

Because inviting families into CESS can raise complex moral questions—and because practical experience and research in this area remain limited—there is a need for clearer ethical reasoning and more hands-on examples to guide implementation in a responsible and workable manner. More explicit articulation of the moral considerations for and against PPP in pediatric oncology CESS will also be important.

Moreover, the practical and ethical concerns expressed by ESP offer valuable guidance for designing carefully planned pilot initiatives that include participatory evaluation. By proceeding in this way, the field can begin to cultivate the potential benefits of PPP in CESS, while remaining attentive to the challenges and possible harms identified in this study.

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