

Audience Reception Toward the Digital Privacy of Children with Medical Conditions in the TikTok Content of @donnamrtunslehah_

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ABSTRACT

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The rise of TikTok has encouraged the sharing of personal content, including that involving children with medical conditions, raising concerns about digital privacy. This study aims to examine audience reception of the digital privacy of children with medical conditions in TikTok content from the account @donnamrtunslehah_ using a reception analysis approach. This research employs a qualitative method with Stuart Hall's reception analysis, which classifies audience reception into dominant, negotiated, and oppositional positions. Informants consist of parents of children with medical conditions, NGO representatives, and caregivers/physiotherapists. Data were collected through in-depth interviews and analyzed based on informants' interpretations of the content. The results show varied audience reception. Some informants occupy a dominant position, perceiving the content as educational and supportive. Others fall into a negotiated position by acknowledging its benefits while considering privacy concerns. Meanwhile, oppositional positions emerge from informants who view the content as potentially violating children's privacy. These differences are influenced by the informants' backgrounds and their understanding of digital privacy.

INTRODUCTION

The development of social media in recent years has changed the way individuals share their private lives in digital public spaces. TikTok, as one of the platforms with high growth and engagement rates, has become a space that encourages users to produce and distribute content on a massive scale. Since the Covid-19 pandemic, TikTok has emerged as one of the fastest-growing social media platforms globally. Launched in 2017, the platform enables users to create and share short-form videos, and it has attracted a massive user base with around 800 million monthly active users and more than 2 billion downloads worldwide. This rapid growth has made TikTok a significant space for digital interaction and content consumption. (Priyono & Sari, 2023). Various forms of content such as mini vlogs, daily life documentation, and personal narratives have become

common trends among users (Sinta et al., 2022). In practice, not only individuals become the main subject of content, but also family members, including children.

Sharenting on social media refers to a new parenting practice in the digital era, where parents share photos, videos, and daily activities of their children online. Although it is often intended to preserve memories and share parenting experiences, this practice also raises concerns about children's digital privacy because personal information may be exposed without the child's consent (Palupi & Irawan, 2020).

One phenomenon that continues to grow is the emergence of content featuring children with certain medical conditions. Such content is generally framed as a form of education, documentation of treatment journeys, or an effort to build empathy and social

support from audiences. In some cases, this type of content is also used as a means to seek assistance or raise public awareness of certain health issues (Koswara, 2025). On the other hand, TikTok's high exposure algorithm allows emotionally charged content, such as sadness or struggle, to gain attention and audience engagement more easily.

This phenomenon is closely related to the practice of sharenting, namely parents' activity of sharing their children's lives on social media (Firdaus et al., 2023). Although it is often driven by positive intentions, such as sharing happiness or gaining social support, this practice raises ethical issues related to children's digital privacy (Hasanah, 2021). Digital privacy refers to an individual's right to control personal information shared in digital spaces. In the context of children, this issue becomes more complex because children do not yet have full awareness or capacity to understand the long-term consequences of the dissemination of their personal data.

Information shared in content, such as identity, face, daily activities, and medical conditions, falls into the category of sensitive data that may pose risks in both the short and long term (Handayani, 2024). The resulting digital footprint is permanent and can be accessed, disseminated, and used by others without the full control of the data owner. In addition, the open nature of digital spaces allows various audience responses to emerge, ranging from support and sympathy to criticism and negative comments.

In this context, the audience is no longer positioned as a passive party, but as an active subject capable of interpreting and constructing meaning from the content consumed (Supianti & Hidayat, 2023). Audience responses to content featuring children with medical conditions show diverse interpretations influenced by social background, values, experience, and individual understanding of digital privacy issues. This indicates that media meaning is not singular, but is negotiated through the audience's interpretive process.

The TikTok account @donnamrtunslehah_ is one relevant case in this phenomenon because it consistently features a child with anencephaly in various posts. The uploaded content includes daily activities, treatment processes, and the child's development. Over time, this account has not only functioned as personal documentation, but has also become public consumption with a wide audience

reach. This gives rise to various responses, both in the form of support and empathy for the struggles of the child and the parents, as well as criticism questioning the ethical and privacy aspects of the child.

This account was chosen as the case study because it consistently features a child diagnosed with anencephaly, a severe congenital condition that is generally associated with a very limited life expectancy of less than 24 hours. However, in this case, the child has survived for more than three years, making the account highly distinctive and emotionally compelling for audiences. In addition, the account has more than 500,000 followers, indicating a high level of public exposure and engagement, which makes it relevant for examining audience reception toward children's digital privacy in TikTok content.

The differences in responses that emerge show the dynamics of audience interpretation toward content containing sensitive issues. Some audiences see the content as a form of education and inspiration, while others consider that displaying a child's medical condition in public space may violate privacy rights and child protection. This situation underscores the importance of examining how audiences interpret such content, especially in the context of the relationship between content creators, media platforms, and audiences.

To understand this phenomenon, this study uses Stuart Hall's reception analysis approach through the encoding-decoding model, which views the audience as an active party in interpreting media messages (Salsabila & Febrianita, 2024). This approach enables researchers to identify audience reception positions, namely dominant, negotiated, and oppositional, in understanding the content presented (Aligwe et al., 2018).

Based on this background, this study aims to analyze audience reception toward the digital privacy of children with medical conditions in the TikTok content of @donnamrtunslehah_, as well as to understand how differences in audience background influence the process of interpreting sensitive content in digital spaces.

LITERATURE REVIEW

Potential for Child Exploitation in Social Media Content

Child exploitation in social media content refers to the use of children for personal gain, both

economically and socially. Children are a vulnerable group (Fayola Zen, 2024) because they are still in a developmental stage and do not fully understand the consequences of being exposed in digital spaces. In this context, content featuring children can potentially become a form of exploitation if it is used for personal interests, monetized, or places children in a disadvantaged position, especially when parents have low digital literacy (Simanjutak & Hanifah, 2023).

One of the most common forms is sharenting, namely parents' habit of sharing their children's lives on social media. Although it is often done with good intentions, this practice can violate children's privacy, especially when it displays identities, personal conditions, or sensitive information that should not be made public. The resulting digital footprint is also permanent and can create long-term risks, including data misuse, cyberbullying, and exploitation by others.

In addition, child exploitation in digital spaces can also be seen from audience responses, such as comments that insult, curse, or humiliate children (Garry & Harefa, 2024). Because digital platforms allow anonymous interaction, negative comments are difficult to control and can worsen the impact on children. Therefore, protecting children in digital spaces is not only the responsibility of parents, but also of society at large, by increasing digital literacy and maintaining the boundaries of children's privacy when sharing content.

TikTok Content

TikTok is a short-video platform owned by ByteDance, launched in 2016, that allows users to create, share, and access various types of audiovisual content. Its content ranges from daily vlogs, education, and entertainment to social and health-related content, while virality is often driven by emotional elements, relevance, and visual appeal.

In many cases, social content that shows life struggles or medical conditions can quickly attract audience sympathy because it uses an emotional combination of audio and visual elements. Creators often share personal experiences for education, awareness-raising, or to show their struggles, but the message conveyed is not always interpreted in the same way by all viewers.

On TikTok, the audience is no longer a passive receiver, but also actively gives meaning through comments, duets, stitches, and reposts (Mannell & Smith, 2022). Because of this, audiences also influence the spread and reception of content, especially when the content touches on sensitive issues such as children with medical conditions.

Ethics of Sharenting on Social Media

The development of digital media, especially TikTok, has encouraged the emergence of sharenting,

namely the habit of parents sharing their children's lives on social media as a form of documentation, sharing parenting experiences, and gaining appreciation from audiences (Saputri, 2023). However, sharenting also carries risks because children's content is often uploaded without their consent and can affect their privacy and digital identity in the future (Palupi & Irawan, 2020). Although the motivations are often positive, such as sharing happiness, providing education, or building social support (Hidayanto, 2024), parents still need to understand the limits of sharing children's content so that it does not create risks of misuse, social pressure, or exploitation. Many parents who have negative parenting patterns often project them through content. For example, some make content out of parenting practices that cause trauma to their children. Such parenting styles have a negative effect on children's growth and development (Berliana et al., 2022). Therefore, protecting children's digital privacy is important in every sharenting practice.

On the other hand, audiences on TikTok are not passive recipients, but actively create meaning through comments, duets, stitches, and reposts. This makes children's content, especially content related to medical conditions, open to various interpretations by audiences, ranging from education and inspiration to being seen as excessive or as inappropriately exposing the child. Thus, sharenting should be carried out wisely, by considering the child's best interests, privacy boundaries, and the long-term impact of the digital footprint left behind.

Indonesia Law Number 23 of 2002 on Child Protection

There are several provisions in the Child Protection Law that will be used as references in this study, including:

1. Article 1 Point 1
2. Article 1 Point 2
3. Article 1 Point 7
4. Article 1 Point 12
5. Article 1 Point 15
6. Article 13 Paragraph 1

This law is used as a normative basis to show how children should be protected, including in digital spaces. TikTok is one of the social media platforms with a very wide reach, making it highly possible for content to be accessed by many people without limits. This can potentially violate the child protection principles regulated by Indonesian law.

The articles discussing exploitation, discrimination, and special protection are highly relevant for examining the limits of displaying children in social media content, especially when a child has special conditions. The child's right to protection becomes the basis for questioning and considering whether the practice of displaying children in social media content is in line with the child's best interests. However, in reality, the fulfillment of children's protection rights in digital spaces is not yet widely understood by the public. This can be seen from the different audience responses to child-related content on social media. This is what makes this law a comparative framework between child protection norms and the reality that occurs in digital spaces.

Stuart Hall's Reception Theory

Stuart Hall's reception theory explains that audiences do not only receive media messages passively, but actively interpret messages through the encoding-decoding process (Salsabila & Febrianita, 2024). The meaning of a message can differ depending on each individual's experience, social background, culture, education, and digital literacy (Supianti & Hidayat, 2023). Therefore, a single media text can produce many meanings or polysemy, rather than one single meaning.

In this model, Stuart Hall (Aligwe et al., 2018). divides audience reception positions into three, namely dominant-hegemonic, negotiated, and oppositional. Dominant-hegemonic occurs when the audience receives the message according to the intended meaning of the sender; negotiated occurs when the audience accepts part of the message but adjusts it to their own conditions or personal experiences; while oppositional occurs when the audience understands the message but rejects it and forms an opposing meaning.

This concept is relevant for analyzing how audiences interpret social media content that features children, especially when it concerns digital privacy issues. In this context, audiences can assess, justify, weigh, or reject the display of children on social media based on their own experiences and views, so reception analysis helps understand the diversity of audience responses to such content.

Conceptual Framework

This study begins with TikTok content featuring a child with a medical condition on the account @donnamrtunslehah_. The content is then examined from the perspective of children's digital privacy, as it contains information and representations of the child that may be freely accessible to the public. After that, this study uses Stuart Hall's reception analysis to examine how audiences interpret the content on @donnamrtunslehah_ through three reception positions. Through this process, the researcher can identify the form of audience reception toward the digital privacy of children with medical conditions in the TikTok content of @donnamrtunslehah_.

METHOD

This study uses a qualitative approach guided by Stuart Hall's reception analysis through the encoding-decoding model to examine how audiences interpret TikTok content about a child with medical conditions on the account @donnamrtunslehah_. The focus is on audience reception toward children's digital privacy in this context.

The research object is audience reception toward child content with medical conditions on @donnamrtunslehah_. The subjects are parents of children with medical conditions, NGO representatives, caregivers, and physiotherapists who have seen or engaged with similar TikTok content. Informants were selected through purposive sampling based on active TikTok use, prior exposure to related content, and willingness to participate. A total of seven informants were considered sufficient, as data saturation was reached.

Data were collected through in-depth semi-structured interviews conducted online via video or voice call, each lasting 45–75 minutes. All interviews were audio-recorded (with consent) and transcribed verbatim. Additional data were obtained through documentation of TikTok posts, captions, and comments in the form of screenshots.

Data analysis followed the Miles and Huberman model (data reduction, data display, and conclusion drawing). The analysis was linked to Hall's three reception positions: dominant, negotiated, and oppositional, using open, axial, and selective coding. Trustworthiness was ensured through triangulation, member checking, and an audit trail.

RESULT

This study used interviews to collect the required data and information, so the researcher obtained seven informants. The informants had different backgrounds and experiences related to children, so they would provide varied perspectives for this study. Several criteria had been established for selecting the informants, including parents of children with medical conditions, caregivers, a foundation that assists child patients with medical conditions, and people who have experience teaching children and have watched content about children with medical conditions. The names of the informants were listed according to the previously agreed arrangement. The following are the informants who participated in this study.

Table 1. Research Informant Data

Name	Age	Occupation	Identification	Detail
Hartati	45	Employee	Parent	Informant 1
Carissa	29	Employee	Caregiver	Informant 2
Fera	45	Teacher	Parent	Informant 3
Mariska	27	Employee	Caregiver	Informant 4
Keysha	21	Student	General	Informant 5
Ezer	27	Educator	General	Informant 6
Tiya	27	Foundation Chairperson	Foundation	Informant 7

DISCUSSION

Child Protection Rights in Digital Spaces

Every individual, including children, has the right to be protected from wrongful acts that may harm or hurt them, and this right is legally recognized in Indonesia through the Child Protection Law (Law No. 23 of 2002). Article 13 explicitly states that children must be protected from discrimination, violence, exploitation, and other forms of mistreatment, and this protection extends to digital spaces where children are increasingly exposed through practices such as sharenting.

In the context of sharenting, parents often share content about their children to document family life or to share parenting experiences. However, this practice can easily cross ethical and legal boundaries when children's identities, medical conditions, and

vulnerable moments are exposed without their consent. The way audiences receive such content appears to be shaped by their understanding of children's rights and digital privacy, not only by their emotional response to the child's story.

Among the informants, parents and caregivers who strongly identify with the content creator's perspective tend to adopt a dominant or negotiated reception. Informant 1, for example, viewed sharing children's daily moments as acceptable as long as there was no violence or explicit exploitation, reflecting a perception that documenting family life is a normal parental practice. This view aligns with the idea that parents often feel they have primary authority over their children's image and may underestimate the risks of long-term digital exposure.

Informant 1

"...but as a mother who has children with medical conditions, I strongly support making this publicly available."

Informant 2 reinforced this by adding that such content can also be educational for other parents, implying trust in the creator's good intentions rather than questioning structural risks to the child's privacy.

In contrast, informants who are more critical of sharenting (Informants 4, 6, and 7) tend to emphasize children's vulnerability and the need for stronger boundaries. They argue that it is better not to share children's content at all, or at least to cover the child's face or eyes.

Informant 7

"...maybe there are also some decisions that should not be shown so explicitly. For example, the child's face could be blurred or something like that..."

Informant 5

"...the boundaries that are set really must exist because not everyone can immediately understand them..."

This oppositional stance is linked to a higher awareness of digital privacy risks and the potential for content to be misused beyond the original context. These informants recognize that even non-violent content can still become a form of unintended exposure that may harm the child in the future.

Thus, the variation in audience reception reflects not only personal preferences but also

differences in social experience, digital literacy, and understanding of children's rights. Those who see the content mainly as personal documentation tend to normalize it; those who are more aware of privacy and legal principles are more likely to adopt a critical, oppositional stance toward sharenting practices on TikTok.

Ethics of Sharenting on Social Media

The current sharenting practice raises important concerns about children's rights and digital privacy, which parents as primary caregivers have a responsibility to protect. Parents hold significant power in deciding what to share about their children, yet many seem to underestimate the long-term consequences of over-exposure in digital spaces. A deeper understanding of ethical boundaries—what may be shared and what should be withheld—is essential to minimize potential harm.

Several informants emphasized that parents should respect children's autonomy and avoid forcing them into the spotlight if they are unwilling to be shared online.

Some suggested practical measures, such as blurring the child's face or at least covering the eyes, to protect identity without eliminating the educational or emotional value of the content.

Informant 5

"...the privacy of a child with a specific medical condition must be protected, meaning that the details of the child's health condition should be kept private..."

Informant 6, for example, stressed that a child's eyes are a core marker of identity and should be covered if the child appears in the video. Informant 7 added that parents should also reduce the frequency and intensity of child-centric content to limit continuous exposure.

When content has already gone viral, informants highlighted the need to reframe the communication strategy.

Informant 6

"...because it has already gone viral and the video is already well-known, I think the account owner needs to change the way they communicate... including not showing the child's eyes and shortening the duration..."

Informant 6 argued that shifting the narrative or tone of the content could reduce the risk of exploitation or misinterpretation. Informant 5 suggested diversifying the content so that the parent, not the child, becomes the main focus, which helps prevent the child from being constantly objectified by the audience. Informant 3 further noted that educational content about parenting and caregiving can be created without necessarily featuring the child, using the parent's experience instead as the core message.

In digital spaces, audiences have the right to comment and interpret content, but this also opens the possibility of harmful or discriminatory reactions. Parents cannot fully control how others respond, so they must carefully curate what they share to minimize hateful or degrading comments. Ultimately, the key ethical principle is prioritizing the child's consent. Every child has the right not to be shared on social media, and parents need to be equipped with digital literacy and legal awareness to recognize the boundaries between sharing a story and violating a child's privacy.

Audience Interpretation of Content Featuring Children with Medical Conditions

Under Law No. 23 of 2002, children with medical conditions are classified as recipients of special protection, and this obligation extends to all members of Indonesian society, including audiences in digital spaces. The practice of sharenting by parents of such children often involves sharing information about the child's diagnosis and daily life during treatment. Many children with medical conditions also have visible physical differences, and their content frequently displays treatment processes, surgical wounds, or moments of pain—sensitive details that arguably should not be made public on social media.

Audiences interpret such content in different ways, depending on their background and experience. Informants 1 and 3, who are parents of children with medical conditions, tend to view the content as educational and informative, helping viewers understand certain medical conditions and fostering empathy. This dominant or negotiated stance reflects their identification with the creator's struggle and their desire for wider awareness.

Informant 3

“...it’s like preserving a moment, of course, preserving that moment with her child, because this is a kind of thing—what I mean is, it’s not common, it’s rare, as you mentioned earlier...”

Informant 2

“...with a condition like this, people become more aware; they realize that cases like this actually exist. So, personally, I feel that I only learned about it because of this TikTok account...”

In contrast, Informant 6, who is more critical, argues that making the child’s physical appearance the main focus of long-duration videos is inappropriate and shows a lack of awareness about children’s privacy. Informant 3, a caregiver, reinforces this view by emphasizing that children with medical conditions should not be the central focus of content, because it may increase their vulnerability to potential harm or exploitation.

Informant 7, as the head of a foundation supporting child patients with medical conditions, interprets such content more positively, seeing it as a sign of perseverance for both parents and children and a source of motivation for other families. Similar to Informant 1, Informant 7 views the content as informative and encouraging, especially for parents facing similar situations.

Informant 7

“...they think, well, they won’t always be able to accompany this child; they might be afraid of the child’s condition getting worse or not living long, so they want to keep good memories ...”

However, Informant 7 and Informant 2 also stress that the child’s screen time and exposure to sensitive details should be limited, pointing to a negotiated position that balances emotional support with concern for privacy.

Reception of the Digital Privacy of Children with Medical Conditions in the TikTok Content of @donnamrtunslehah_

The seven informants in this study, with varying backgrounds and experiences, show different interpretations of children’s digital privacy in TikTok content featuring a child with a medical condition on @donnamrtunslehah_. Those who are parents of children with medical conditions (informant 1 and 3)

tend to adopt a dominant-hegemonic or negotiated stance, as they strongly identify with the account owner’s role as a mother facing rare diagnosis. They empathize with her desire to document the child’s life and raise awareness, but at the same time recognize that the child is highly visible and exposed.

Caregivers and health-related informants (Informants 2, 4, 5, and 6) show more diversity in their reception.

Informant 5

“...more like sharing documentation about her child’s life journey as a child with a specific medical condition...”

Informant 4

“...personally, from a content perspective, I find it less appealing or less agreeable because it seems to expose the child too much, displaying the child’s condition in an excessive way...”

Informant 2, despite recognizing the emotional value of the content, criticizes the long screen time and frequent exposure of sensitive medical details, indicating a negotiated position. Informant 4, in contrast, takes an oppositional stance, arguing that the account owner’s actions violate the child’s rights and digital privacy. Informant 6 expresses even stronger disagreement, viewing the content as evidence of parental ignorance about children’s privacy, and considers the child over-exposed.

Informant 6

“...showing the child with trending songs like that seems to be seeking sensationalism...”

Informants 5 and 6 also agree that the content may encourage excessive sympathy toward the child and suggest that the child should appear less and that the focus should shift more to the parent or caregiving experience. If linked to this theory, the informants in this study are divided into three different types, namely:

Table 2. Informant Reception Data

Detail	Reception Type
Informant 1	Dominant-Hegemonic Position
Informant 2	Negotiated Position
Informant 3	Negotiated Position
Informant 4	Opposition Position

Informant 5	Negotiated Position
Informant 6	Opposition Position
Informant 7	Negotiated Position

These patterns align with Stuart Hall's reception theory, which outlines three main positions: dominant-hegemonic, negotiated, and oppositional. In this study, one informant fully accepts and supports the messages in the TikTok content (dominant-hegemonic), four accept the messages in part but oppose certain aspects such as over-exposure or unnecessary detail (negotiated), and two reject the content and construct alternative meanings by emphasizing child protection and the need to reduce the child's visibility (oppositional). This distribution shows that audience reception is not only shaped by emotional connection, but also by professional experience, digital literacy, and understanding of children's rights

CONCLUSION

The interviews reveal that audiences interpret TikTok content about a child with a medical condition on @donnamrtunslehah_ in diverse ways, reflecting differences in education background and life environment. Their reception fits Stuart Hall's three positions: dominant-hegemonic, negotiated, and oppositional. Even when viewing the same account, audiences construct different meanings based on their personal experiences.

In the dominant-hegemonic position, the content is seen as normal, personal documentation and a source of motivation. In the negotiated position, audiences accept the display of the child as long as there is no violence or abuse, but they call for clearer boundaries for parents. In the oppositional position, audiences reject the content, arguing that it over-exposes the child and risks violating digital privacy.

The findings also show that audience reception is not determined by whether someone is a parent of a child with a medical condition. Instead, the key factor is their understanding of children's digital privacy. Those who understand children's privacy rights better tend to be more critical and oppose the publication of such content.

From a legal perspective, displaying a child in the digital space must align with the Child Protection Law (Law No. 23 of 2002, Article 13 paragraph 1), which protects children from harmful actions such as

exploitation and abuse. The publication of a child with a medical condition on @donnamrtunslehah_, even if accepted by some audiences, raises concerns about potential violations of privacy and child protection.

This study extends Stuart Hall's reception theory to the context of sharenting children with medical conditions on TikTok, showing how the same content can be received in dominant, negotiated, or oppositional ways. It highlights the need for digital literacy among parents to avoid over-exposing children's identities, medical conditions, and vulnerable moments in public content.

The study is limited by a small number of informants, a focus on only one TikTok account and the absence with the child protection experts. Future research can address these gaps with larger samples, different accounts, and multidisciplinary perspectives.

Author Contribution

Shinta Dewi Cahya Wulandari carried out all stages of the research, including conceptualization, design, data collection, analysis, and writing. The author applied relevant theories, conducted representational analysis, and developed the final discussion. Dra. Dyva Claretta, M.Si supervised the study and provided guidance and feedback to improve its theoretical and structural quality. All authors approved the final manuscript.

Declaration of interest

The authors confirm that there are no financial or personal conflicts of interest that could have affected the objectivity or outcomes of this study.

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