Understanding the Impact of YouTube Videos on Parents of Children with Developmental Delay and Disabilities

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Children go through several developmental milestones at an early age. When a child becomes slow or cannot even reach one or more of these milestones compared to other typically developing children, that condition is called Developmental Delays and Disabilities (DDDs). Children's DDDs create much parental stress, resulting in social isolation and loneliness. YouTubers make videos on DDDs to assist parents and other caregivers. We need to gain more knowledge of how these videos are created and how much they impact the parents of children with DDDs. We followed a mixed-method approach to annotate and analyze 1,532 YouTube videos on children's DDDs. Our analysis found that YouTube videos on DDDs support the community with critical informational content and provide mental and emotional strength through content related to personal experiences. Our analysis of the comments in these videos explored how YouTubers and viewers created a strong community connection through these video content. Most importantly, the interviews with the parents of children with DDDs revealed how parents find these videos relatable and critical for taking necessary actions for their children's DDDs diagnosis and follow-up treatments. We concluded by discussing platform-centric design implications for supporting parents and other caregivers of children with DDDs.

CCS Concepts: • **Human-centered computing** → **Empirical studies in HCI**; **Empirical studies in collaborative and social computing**.

Additional Key Words and Phrases: Developmental Delays and Disabilities, YouTube, Viewers' Involvement, Community Learning, Online Community, Emotional Assistance, Video Styles

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1 Introduction

Children at an early age go through several types of developmental growth, such as physical, cognitive, language/communication, social, emotional, and behavioral skills. In each area, children need to reach specific milestones at certain ages to be considered typically developing. However, when a child is slow to achieve one or more of these milestones or cannot reach them compared to other typically developing children, this condition is called developmental delay or disability.

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Children with Developmental Delays and Disabilities (DDDs) must start early interventions and treatments to make progress or even catch up with their peers [6, 116, 85, 18].

It is important to note that the term "Developmental Delays and Disabilities (DDDs)" is not a medical term; we coined this term to better explain our objectives and findings. We understand that the long-term impacts of developmental delays and developmental disabilities can differ significantly. Untreated DDDs can contribute to early school failures and social and emotional problems [18]. For instance, children with proper and timely interventions can sometimes overcome developmental delays completely, which is especially crucial since developmental disabilities are typically difficult to overcome. In this paper, we consider these two terms together as an umbrella term because, in young children, the early signs and symptoms of delays and disabilities often overlap. Thus, they receive similar interventions and therapies at an early stage.

Identifying the condition of children with DDDs is crucial to start early intervention programs for their recovery. However, identifying DDDs, especially among young children, can be challenging for parents [89, 99]. It becomes more complicated when parents, with a busy schedule and multiple stressors, have little to no knowledge of developmental delay and disabilities [1, 71, 124]. Pediatricians and primary care providers should take the lead role in making parents aware of the complications of DDDs. However, early identification and intervention are not widely adopted among pediatricians, even in the USA, despite ongoing education and promotion efforts over many years. Children often do not receive a periodic developmental assessment [43, 101]. Fewer than half of pediatric practitioners use formal screening tools [93], and only one-fifth of children received parent-centered developmental screening in a 12-month period [8].

Previous work has shown that parents of children with DDDs often experience more strain and prolonged levels of stress than parents of children without these conditions [45, 3, 110, 69]. Many parents withdraw from friends and family members because they feel embarrassed, anxious, exhausted, and stressed. Parental stress has been found to be associated with lower marital satisfaction [96], lower self-esteem [21], lower self-efficacy [48], lower parental well-being [91], and lower satisfaction [31, 58] in the parental role. To help parents understand the concept of DDDs and guide them through necessary actions, experts and domain specialists often use social media platforms such as YouTube to create video content on children's DDDs to meet informational needs. Parents with experience raising children with DDDs also share emotionally supportive videos on YouTube with other parents, where they discuss their journey, challenges, status, and actions.

In HCI, researchers have explored the affordances of Twitter [28], Facebook [35], and Reddit communities[62] in supporting patients and their caregivers. Researchers observed how social media helped caregivers overcome loneliness and assisted them in being a part of the community that cares for them [77, 52]. However, there needs to be more understanding of how YouTube, a social media platform and a relatively passive online community focusing on video content, impacts caregivers. YouTube, the second most popular social media platform [81, 87], encourages people, even those with limited experience in video creation, to spread their ideas and knowledge through videos and allows them to share it with a broad audience. Furthermore, the audience often prefers to consume YouTube videos because this platform does not require a personal profile or direct connections [16]. Moreover, videos convey a comprehensive set of non-verbal cues such as subtlety, nuance, emotion, sincerity, and gratitude to their audience, which help people passively bond with the content and audience of the content. To understand the relevance and importance of YouTube videos from the perspective of parents and caregivers of developmentally delayed and disabled children, we asked the following two research questions:

- **RQ1: How do YouTube videos discuss children's DDDs?**

(a) What presentation styles do creators typically use when making content related to children's DDDs?
(b) What are the major topics discussed in these YouTube videos?

- **RQ2: How do YouTube videos on children's DDDs impact parents and caregivers?**

(a) What do parents and caregivers of children with DDDs intend to learn from these videos?
(b) How do these videos influence the actions of parents and caregivers toward their children with DDDs?
(c) How do these videos provide emotional support (if at all) to parents of children with DDDs?

To answer these research questions, we conducted a mixed-method study. To answer RQ1, we annotated and analyzed 1,532 YouTube videos on children's DDDs. We identified seven types of video content: videos defining concepts, explaining signs of DDDs, presenting treatments, showing resources and facilities, presenting actionable items, sharing personal experiences, and reporting the recovery journey. In addition, we observed four primary video styles having 11 subcategories. This analysis showed us how developmental experts utilize YouTube as a widely accessible medium to teach parents and caregivers about the symptoms, treatments, and at-home care critical for various forms of DDDs in a way that is easily consumable by non-expert audiences. The findings are more detailed in Section 4.

The second research question aimed to observe how these videos impact the target audience. To this end, we decided to take a two-way approach: 1) analyzing the comments section of the YouTube videos and 2) interviewing the parents and caregivers of children with DDDs who consume these videos regularly. An extensive qualitative analysis helped us identify primarily six types of comments such as 1) asking for suggestions, 2) sharing experiences and concerns, 3) thanking content creators, 4) responses from video creators, 5) sharing comments among fellow video creators, and 6) miscellaneous. Overall, the comments showed how parents and caregivers of children with DDDs receive perceptual, emotional, and informational benefits not only by watching these YouTube videos but also by maintaining an empathizing online community.

We extended our investigation by interviewing 16 parents who consumed videos related to children's DDDs from YouTube. These interviews revealed that parents consider YouTube videos prepared by DDDs experts as one of the primary sources of information at various stages of diagnosis, treatment, and follow-up care for their children. We also learned about the emotional support these video creators provide, which is especially crucial since parents often find it hard to share their challenges with immediate friends and family members. Additionally, YouTube videos about DDDs allowed parents to remain connected to a significant source of information. At the same time, parents also felt a sense of seclusion, which is not usually experienced on other social media platforms. In summary, our primary contribution lies in exploring the intersection of community, social platforms, and often marginalized groups [63, 111, 119], specifically focusing on parents of children with developmental delays and disabilities (DDDs). By analyzing YouTube videos and their comments and conducting interviews with these parents, we demonstrated how this social platform functions as a community space, providing emotional support, information exchange, and a sense of belonging. The findings of the comment analysis and interview conclusions are discussed in detail in Section 4, 5, and 6.

2 Related Work

The related work section explains the challenges and interventions related to children's DDDs. We followed our discussion on how online resources and, more importantly, social media platforms impact people's social and emotional state during critical health conditions.

2.1 Developmental Delays and Disabilities and Early Intervention Programs

Developmental delays and disabilities among young children are not uncommon. An "Early Childhood Longitudinal Study" in the USA demonstrated that 13% of newborn children eligible to receive counseling from early intervention programs developed DDDs at the age of 9 to 24 months. More alarmingly, a comparative study showed that between 1997 and 2008, DDDs among young children increased by 17.1% [103]. Yet, only 10% of those children received services, and this percentage is even lower for Black children [98].

The severity of this problem is more intense in low- and middle-income countries (LMICs) as they often lack facilities critical for early identification and intervention of DDDs. Health staff often have limited sensitization, interest, or training in child development or recognition of early delays [65]. Apart from health professionals, parents in LIMCs are often unaware of the significance of serious DDDs [122, 30, 121]. Usually, medical attention is sought because of acute illness rather than developmental or behavioral concerns. Multiple factors influence the acceptance and practice of early detection and intervention. These include physicians' attitudes, awareness, and interest [32], insufficient training [117], non-acceptance of early treatment [76], uncertainty regarding how and where to refer [25], time limitations of the clinic visit [29], and cost factor [27]. In some cases, practitioners might be legitimately concerned regarding unnecessarily alerting a family and would prefer to wait until the problem is too obvious to ignore [109].

Despite these challenges, initiatives and trials demonstrated that there are feasible solutions to detect and intervene in DDDs. For instance, WHO's Care for Development and counseling materials use counseling sessions to promote the healthy development of children. Another strategy is to use a surveillance approach in primary pediatric healthcare for routine observation of early childhood milestones [46, 15]. To incorporate parents and children from remote locations in the detection and intervention programs, telehealth is an effective and highly satisfactory method for its stakeholders [59, 104]. Such initiatives work more effectively when parents and caregivers gain familiarity with this topic. One way to promote this familiarity is through YouTube videos on DDDs. In the scope of this paper, we want to explore how YouTube videos on DDDs of various types impact the informational and emotional provisions of the target audience. Here, we discussed, in general, the effect of online resources and social media platforms in the healthcare domain, which will set up the background of this paper.

2.2 Seeking Health information from Online Resources

Seeking health information from online resources has gained popularity exponentially. One critical aspect of seeking online health information is verifying the credibility of the data. Studies demonstrated that older adults were often found to be less sensitive to the credibility cues indicated by website features and performed less deliberation to assess the credibility of online health information compared to young users (e.g., checking the source of information) [66, 7]. Studies found that older adults consider all online health information credible as they believe people are not allowed to post medical information on the internet unless it is checked by someone knowledgeable [95].

Apart from age, the experience of searching for online health information may differ by sociodemographic groups [92, 72, 82]. For example, in studies published during the last decade, persons who reported more incredible difficulty seeking online health information were more likely to be from socially disadvantaged groups. These groups are more likely to report negative perceptions regarding health care than those from relatively advantaged groups [2, 82, 75, 34]. Moreover, because of low literacy, people often got frustrated when they needed help finding their desired health information online, impacting the overall quality of the information they gathered [72]. However, familiarity with technologies does not necessarily imply a less challenging experience gathering

online health information. Young, tech-savvy users usually prefer to get information from social media platforms. Health information on social media platforms needs not to be more complex, biased, or a combination of both; instead, it should be more detailed, accurate, and well-rounded. Young users are also prone to take shortcuts when seeking information. Such practice can lead to lower quality information, contributing to increased health anxiety [20]. Despite these challenges, the easy and convenient access to healthcare information from online resources made it a dominant source of information for many healthcare conditions, and this trend became more popular through social media platforms (discussed in the following part).

2.3 The use of Social Media in Healthcare Domain

The practice of searching for health information on social media depends not only on the age range of users (young users) but also on the type of information. It was shown that users prefer social media to seek health information on conditions where they expect benign explanations. Although people choose search engines for severe medical conditions over social media [23], the remarkable upsurge of healthcare information on social media changed many existing trends and practices. Prior studies suggest that people should not limit their use of social media just to seeking and sharing health information but also to critically evaluating and actively interacting with diverse and credible health content, as this can support effective self-management of health conditions [33, 107]. Previous works also showed that people use the medium to communicate with their clinicians and other fellow patients [79, 105]. Moreover, public health surveillance [22, 50, 97], disease trend prediction[102, 73], and diseases interventions [114, 120] are other dominant areas in healthcare domain where people accessed social media platforms for their benefit.

Despite the widespread use of social media for healthcare information, scholars have noted the spread of unverified and occasionally misleading content on these platforms. For instance, an analysis of tweets during the Zika virus outbreak found that discrepancies between public concerns, often fueled by unverified sources, and the limited communication from health authorities contributed to public confusion and uncertainty [40, 41]. In another underserved community, false information created anxiety and panic, exacerbating the problem further [94]. Although these findings are concerning, they do not entirely diminish the impact of social media in the healthcare domain.

During COVID-19, people turned to social media to share their distress, often prioritizing emotional connections over privacy [126]. The lockdown further intensified challenges for individuals with functional disabilities, as YouTube comments revealed struggles with care access, isolation, mental health issues, and inadequate legal protections [44]. Studies found that social media became a primary source of healthcare information during the pandemic, and those who consumed such information were more likely to get vaccinated [80]. While the majority of the existing studies on the healthcare domain have focused on text-based social media platforms like Facebook, Twitter, and Weibo, more exploration is needed on the impact of video-based social platforms in this context. One of the most common video-based social media platforms, YouTube, has also become an essential resource in supporting vulnerable communities during crises and in managing health conditions. Vulnerable communities creatively used social media to mitigate COVID-19 impacts, while individuals with severe mental illness found peer support through shared experiences on YouTube [90, 78]. However, the accuracy and engagement with health information on YouTube vary, with misleading content often garnering more attention than informative videos during public health emergencies like the Zika virus outbreak [11]. Additionally, engagement with YouTube videos for chronic condition management is influenced by the level of medical information provided, affecting the overall efficacy of these platforms in delivering healthcare content [67].

The existing research on supporting families with children experiencing DDDs highlights several key themes. Social media's role in aiding social interactions among autistic youth and their parents underscores both advantages and risks, particularly in areas of socialization, communication, dealing with abusive interactions, and managing online threats [37]. Early intervention through structured stimulation programs has been shown to be effective but requires consistent family involvement, which has prompted the exploration of electronic platforms and mobile technologies to provide personalized guidance [70, 19]. The prevalence of developmental conditions has further motivated research into digital phenotyping and machine learning approaches to expedite diagnoses, though current methods remain limited [49, 123]. Additionally, prior work has examined how parents navigate sharing video content of their children online, balancing community building, advocacy, and ethical concerns around privacy and monetization [13]. Our paper takes this line of work one step forward by specifically examining YouTube videos on children's DDDs with the aim of observing how well the structural components of these videos reflect social provisions and facilitate a sense of bonding within the community.

3 Methodology

This research aims to understand the characteristics of video content shared on YouTube on children's DDDs and how that content impacts the viewer community. In RQ1, we aimed to analyze these videos' content and presentation styles. To this end, we collected YouTube videos on children's DDDs, and after initial scrutiny, we meticulously annotated them to examine their content and presentation styles. We extended our analysis further by performing qualitative analysis on comments to understand how these videos created a virtual viewers' community and how viewers consume the content of these videos (RQ2). To answer RQ2, we further interviewed parents of children with DDDs. The qualitative analysis of these interview transcripts revealed why parents consume these videos and how the content of these videos impact them in various context. We summarized our findings and the practical implications of our work in the paper's discussion section, reiterating the thoroughness of our analysis and the validity of our research.

3.1 Data Collection (RQ1 and RQ2)

We used YouTube Data API [125] to crawl the data. We followed an ethical web scraping protocol to avoid automatic bans. Before collecting data, we made developer accounts and were approved for the platform to use the account for collecting data related to academic research. We avoided multiple, fast-paced requests for YouTube API to prevent overloading the platform server. Instead, we set a crawl delay proportional to the time of a regular human speed browsing the platform for videos. We did not set a particular timeframe for the crawler, as we wanted all the videos that we could get for certain keywords. We used a list of keywords such as "developmental disabilities in children," "toddler developmental delays/disabilities," "children developmental delays/disabilities," "cognitive delay/disabilities," "motor delays/disabilities," "sensory delays/disabilities," "social delays/disabilities," "emotional delays/disabilities," "speech delays/disabilities," and "behavioral delays/disabilities" along with different combinations of these keywords to crawl the initial list of videos. Video metadata includes the title, description, duration, publishing date, view count, like count, comment count, subscriber count, and comments. Through our initial crawling, we retrieved 6,735 videos.

After the crawling process was done, we thoroughly scrutinized all videos in two rounds. In the first round, we reviewed the videos and ensured their relevance to children's DDDs by analyzing their metadata. During this process, we eliminated all videos that were shorter than 30 seconds, lacked channel information, were not publicly available, or had unrelated titles or descriptions. In the second round, we reviewed the actual content of the remaining videos, excluding those not directly related to children's DDDs, such as videos on mental health challenges among high school

students or general developmental milestones in non-delayed children. Additionally, we removed any videos that used multiple languages or were presented in a language other than English. Two of us started with 100 randomly picked videos to individually determine our list of videos that should be eliminated from the list. Once those individual lists were made, both of us discussed our reasoning for all the videos we decided to delete. When we both agreed with our initial list of rejected videos, we reviewed the remaining videos individually (the first author examined 3,319 videos, and the second author reviewed 3,316 videos from the remaining list).

After both rounds of cleaning and elimination, 1,532 remained in the dataset that we used for analysis. The videos were from 527 unique YouTube channels, viewed 1,97,68,81,082 times, and received 1,11,020 comments and 1,12,71,278 likes. The median duration of the videos was 5.65 minutes (mean = 13.94, SD = 17.24).

3.2 Analyzing Video Content and Styles (RQ1)

We performed qualitative annotation of a subset of our dataset to identify the content and production styles of the videos. We used Grounded Theory, iteratively open-coding each video, and then created and refined our annotations. More specifically, we annotated a random sample of approximately 500 videos (the first author annotated 532 videos) from our dataset. We had prior experience in analyzing healthcare-related YouTube videos. None of us were doctors. As HCI researchers, we studied children's DDDs-related resources published by CDC, Mayo Clinic, Kennedy Krieger, and Johns Hopkins Pediatric Developmental Medicine for at least three months before this annotation task. Without labeled ground-truth data, we independently adhered to an open inductive coding approach [38]. We organized multiple brainstorming sessions during this coding process, where all three of us discussed our preliminary thoughts, confusions, and opinions. The annotation process began with establishing an initial set of codes. Each video was then independently analyzed, with coders identifying and marking key themes that corresponded to the categories and styles represented by our labels. All of us as coders reached substantial agreement, as reflected by a Fleiss' kappa test ($K = 0.89$, $p < 0.05$).

Once all of us independently finished coding all 1,532 videos, we met as a team to discuss the themes observed and then decide on a refined set of codes. We identified 14 video styles and 12 types of content. Next, we invited five undergraduate students to avoid any bias imposed by us (the authors of the paper). All of them were in their senior year (three Computer Science majors and two Information Science majors) and had prior experience in annotating social media video content. They examined a random sample of 200 videos (only one video was chosen from each channel to maintain diversity and uniform representation). To provide background on the annotation process, we conducted a two-hour-long information session discussing styles and content identified earlier, along with examples. All coders independently coded this set of 200 videos. They could apply any categories from the existing pool (if applicable) or create a new style or content category for each video based on their judgment. Finally, we discussed their coding experiences and received feedback regarding potentially ambiguous, misrepresented, and possible new themes. All of us met together after the annotation session with undergrad coders and finalized four primary video styles (11 subcategories) and seven types of content through this process.

3.3 Exploring Viewer Involvement on YouTube (RQ2)

To understand how viewers interact with these videos, we analyzed the view count, like count, and comments of all videos in our dataset. We could not include the dislike count of the videos as YouTube hid that information from public view starting in November 2021. We calculated the reach and engagement factors for each video using these parameters. YouTube does not disclose the number of unique users who viewed a video. Thus, these platform statistics mentioned above

are usually used to examine viewers' engagement and reach [5, 10, 12, 83, 17, 84]. The total view count of videos measures the reach factor of a video. Furthermore, the engagement factor considers both like count and comment count [42, 68]. These parameters are used to calculate the like rate (number of likes received per 100 views) and comment rate (number of comments per 100 views), which estimate viewer engagement.

In addition to numerical measures of viewers' reach and engagement, we qualitatively analyzed comments collected from our dataset's videos. Creators turned off the comment property for 121 videos in our dataset. We eliminated those videos from the comment analysis. In the remaining dataset, we only considered comments from videos with at least five comments in their comment section (89 videos). Finally, we processed comments collected from 1,322 videos. We performed iterative open-ended coding [112, 113], followed by thematic analysis [24, 74, 88]. To this end, we followed a similar approach in section 3.2 to find the main themes from the comments. We applied the open coding method to identify the first set of themes for 200 randomly chosen comments from our dataset. At most, ten comments were chosen from a single video to maintain variation. Once we identified the first set of themes individually, we discussed the themes and each of us identified and finalized a list of six themes after two iterations. As before, each one of us took a new set of 3,000 comments and coded them separately to verify the efficacy of those six codes. Once those codes were completed, we measured inter-rater agreement using Fleiss' kappa measure and found almost perfect agreement among us ($K = 0.86$, $p < 0.05$). This list covered around 7.74% of the full list of 1,111,028 comments. The analysis helped us perceive how viewers engage with the videos on DDDs and how these videos impact their sense of community bonding and social presence. We briefly discussed all six themes below and provided an example from each theme (presented in Table 4).

3.4 Interviewing Parents of Children with DDDs (RQ2)

A critical aspect of observing the significance of YouTube videos on parents and caregivers of children with DDDs is to learn from the parents directly why and how they consume these videos and how those videos have impacted them. To this end, we conducted interviews with sixteen parents whose children have some form of DDDs. Here, it is critical to mention that interviewing parents of children with DDDs is a complex process. The sensitive nature of DDDs requires an overwhelming amount of physical and emotional involvement from the parents' side. Parents often do not feel comfortable discussing this topic with external researchers because of their personal reservations. Understanding the sensitive nature of this issue, we refrained from contacting parents directly. Instead, we reached out to them through private Facebook groups (dedicated to parents of children with various forms of DDDs) by posting announcements with the help of group admins. Additionally, we distributed paper flyers on bulletin boards in community spaces such as coffee shops, libraries, and grocery stores. Eligible participants were required to be either parents or caregivers of a child with a form of DDDs. They also needed to have experience exploring videos regarding children's DDDs on YouTube or similar social media platforms. Twenty-two parents initially contacted us for the interview, but later, 6 of them had to cancel the meeting due to personal issues. All interviews were conducted through video calls. The demographics of the interviewees are presented in Table 1.

All of our interview participants were women, and they all had children with DDDs. The youngest child in this group was two years old, whereas the oldest child was 17 years old. Each interview lasted for about an hour, and all participants received $25 as remuneration for their contribution except one who wanted to volunteer in the interview study. The interviews were semi-structured. The underlying theme of our interviews was to understand the social support provided by YouTube videos on children's DDDs. We followed the online social support theory

Participant	Education	Race	Age (Child)	DDDs
P01	Master's	White	7	Attention Deficit Hyperactivity Disorder (ADHD)
P02	Bachelor's	Asian	4	Speech Delay
P03	Bachelor's	Black	17	Motor Delay
P04	Master's	White	8	Autism Spectrum Disorder (ASD)
P05	Bachelor's	Hispanic	13	Speech Delay
P06	Master's	Black	5	Tuberculoidosis-cerebrospinal dyskinesia (TBCD)
P07	High School	White	9	Autism Spectrum Disorder (ASD)
P08	Master's	Asian	12	Cerebral Palsy (CP)
P09	Bachelor's	Black	6	Autism Spectrum Disorder (ASD)
P10	Bachelor's	White	7	Attention Deficit Hyperactivity Disorder (ADHD)
P11	High School	Black	8	Global Developmental Delay (GDD)
P12	Bachelor's	White	5	Neurodevelopmental Syndrome
P13	High School	White	16	Motor Delay
P14	Master's	Asian	13	Global Developmental Delay (GDD)
P15	Master's	White	9	Attention Deficit Hyperactivity Disorder (ADHD)
P16	Bachelor's	Asian	11	Autism Spectrum Disorder (ASD)

Table 1. Demographic Information of the Interview Participants

proposed by Sheryl LaCoursiere [60] to formulate our interview questions. LaCoursiere defined online social support as the 1) cognitive, 2) perceptual, and 3) transactional process of initiating, participating in, and developing electronic interactions to seek beneficial outcomes in health care status, perceived health, or psycho-social processing ability. We formed our interview questions based on these three parameters and later pursued exciting topics raised by the participants. We asked them to describe when and why they started looking for YouTube videos on children's DDDs, how those videos impacted them to take necessary actions, how they verified the legibility of the information presented on YouTube, whether they encountered some misleading content, whether they interacted with other viewers of those videos through the comment section, whether they maintain those communications (if any) outside the YouTube platform, and whether they received emotional support as well as informational support.

The interviews were analyzed using elements from grounded theory in particularly open qualitative coding [57] using thematic analysis. After transcription, three researchers read through the interviews and developed themes individually based on the coded data material, which were later categorized. The themes emerged from the data rather than being prescribed from the interview guide. The researchers regularly met to iterate and converge on the broader categorization of themes. This analysis was performed to uncover parents' experience in consuming YouTube videos on children's DDDs and how this content impacted them. The findings of the interviews are discussed in section 6.

4 Results: Styles and Content of YouTube Videos on Children's DDDs (RQ1)

Our qualitative analysis identified four primary video styles (11 subcategories) in our dataset. Moreover, we found seven types of content in these videos. Female presenters presented 73.91% videos, and 64.16% presenters identified themselves as domain experts (such as doctors, researchers, therapists, EdTechs, counselors, and child psychologists). Regarding the channel topics, we identified eight unique channel topics for the videos in our dataset. However, little more than 75% videos were created by "education" and "people & blog" channels (45.37% videos by education channels and 29.92% videos by people & blog channels). Table 2 lists all unique channels and the total number of videos generated by each channel type. Next, we briefly discuss the video styles and types of content identified through qualitative annotation.

Channel Topic	# of Videos (%)	Channel Topics	# of Videos (%)
Education	696 (45.37%)	Entertainment	57 (3.77%)
People & Blog	459 (29.92%)	News and Politics	39 (2.61%)
Nonprofits and Activism	138 (8.98%)	Science and Technology	34 (2.25%)
Howto & Style	78 (5.03%)	Film and Animation	31 (2.07%)

Table 2. Topics of YouTube Videos in our dataset

4.1 Video Styles (RQ1a)

In Table 3, we listed the four primary video styles we identified from qualitative coding. The table shows the subcategories in each video style and the number of videos in each category. Example videos in each video style can be found in Figure 1.

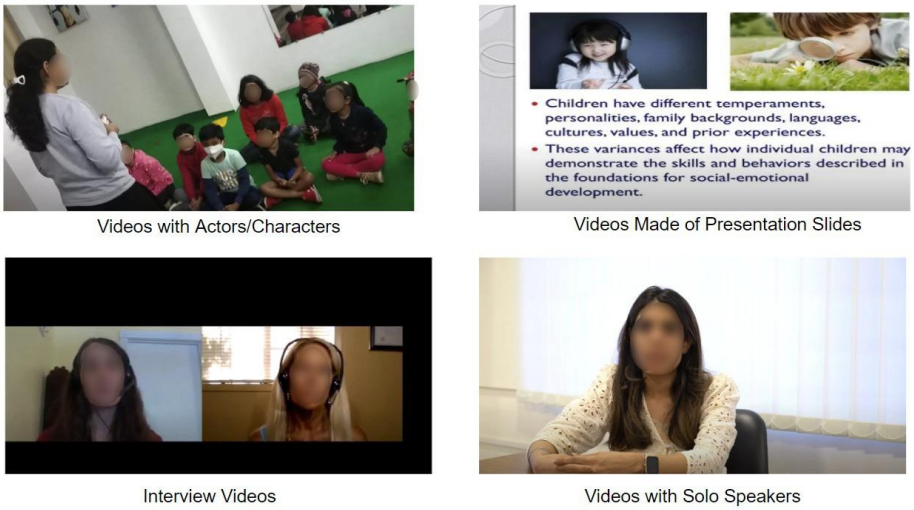

Fig. 1. Snapshots from the four types of video styles

The most frequently used video style was presentation slides. Videos in this category used slides to explain their topics. Some of the latest videos in this category included a small window to show the presenter. In contrast, the older videos in this category used only voice-over narration or subtitles imposed on the video.

The following frequent video style was presenting the topic using actors or characters. Videos in this category put effort into creating their videos in a natural setup. They often included experts in their videos who discussed critical topics and expressed their opinions on different example scenarios. News channels and morning shows created several videos in this category.

The third frequently found style was interview-based videos. Most of the videos in this category presented both the interviewer and interviewee in their videos, where interviewees were primarily experts in the domain. Some recent videos in this category showed Zoom setup for conducting interviews. They mostly talked about actions parents could take to care for their children with developmental delays when conventional therapy sessions were unavailable. A few videos in this

category used podcast setup where the viewer could only hear the voice of the interviewer and interviewee.

The final category presented solo speakers. Parents often created these videos at home, sharing their experiences raising children with developmental delays. A few videos in this category were created by experts as well. Most videos in this category did not use any additional materials. However, experts often used graphs and flowcharts to clarify their points of view in this category.

4.2 Types of Video Content (RQ1b)

We identified seven types of content (defining concepts, explaining signs, presenting treatments, showing resources, presenting actionable items, presenting personal experience, and reporting recovery journey) in our dataset. Two types of videos were primarily created by parents of children with developmental delays (specified as "primarily created by parents")—more than 72% of videos covered more than one type of content. Thus, we counted those videos more than once to calculate percentages.

Video Styles			
Primary Categories	**Sub-categories**	**Count (%)**	**Description**
Videos with actors/characters	Background Narration	7.54	Narrator explained the actions of the characters/actors in the background of the video
	Expert opinions	12.39	With narrator's explanation, experts were introduced in these videos for short bites
	Subtitles	4.07	No narration or expert bites were used, all explanations presented through subtitles
Videos made of presentation slides	With presenter's video and voice	9.81	Presenter's face appeared on the side of the slides along with their narration
	without presenter's video, only voice	22.25	No face appeared, only narration was included
	Only subtitles	6.87	No presenter's view or narration were included, only subtitles included with background music
Interview videos	Face-to-Face Interviews	13.15	Both interviewer and interviewee appeared in the same location for the interview
	Zoom interviews	5.72	Zoom setup was used for interviews
	Podcast interviews	3.69	Static screen was used along with the voice of the interviewer and interviewee taking turns
Videos with solo speakers	With video clips, images, slides	5.45	Solo speaker intermittently used clips, images, graphs in support of their opinion
	Without any supporting materials	9.06	No supporting materials used in the solo presentation

Table 3. Primary Video Styles & Sub-categories

4.2.1 Defining Concepts. The first category of videos in our dataset defined various concepts related to children's developmental delays. Professional experts such as researchers, pediatricians,

and therapists primarily created these videos to explain different topics, such as delays in cognitive development, motor development, social and behavioral development, and physical development. Videos in this category often used text, flowcharts, graphs, and animation to explain these concepts.

4.2.2 Explaining Signs of Developmental Delays. Videos in this category play a crucial role in explaining the early symptoms parents can monitor to examine if their child has any developmental delays. Most videos in this category used short clips of children's interaction to present their topic. One major concern regarding DDDs is to identify the underlying medical condition based on various symptoms. Young children often show similar symptoms for a wide range of DDDs. Experts in their videos highlight the subtle differences in those symptoms to help parents distinguish between developmental delays and disabilities and their subcategories. Moreover, they use YouTube as a widely accessible medium to warn parents that some diagnoses cannot be done at home and should only be done by experts at clinical facilities. Thus, parents should consult their pediatricians or other developmental experts for those evaluations instead of deliberating, underlining the importance of early detection and professional consultation.

4.2.3 Presenting treatments to Developmental Delays. In their videos, physicians and therapists discussed various facilities where children with developmental delays can receive consultations, necessary treatments, and training. We observed that at least 35% of videos in this category were created by television channels such as BBC, ABC News, and CBS. These videos presented a short documentary regarding a facility that provided training, counseling, and necessary guidance to children with developmental delays, emphasizing the wide range of resources and support available for these children and their families.

4.2.4 Showing Available Resources and Facilities. Videos in this category presented a range of services and facilities available for children with developmental delays instead of focusing on one specific facility. Presenters often focused on local facilities in these videos and explained how parents could enroll or nominate their children for these facilities. Presenters also explored alternative resources if parents needed help enrolling their children in state-sponsored programs.

4.2.5 Presenting Actionable Items for Parents and Caregivers. Videos in this category talked about steps and routines parents can follow at home if their children are diagnosed with a specific developmental delay. For treating children with developmental delays, most of the time, parents must invest a significant amount of time and energy and adhere to the practices and routines that their counselors suggest. These videos discuss how parents can incorporate these routines into their daily schedules. In addition, they present apps (GEMINI), books (105 Activities for Your Child With Autism and Special Needs: Enable them to Thrive, Interact, Develop and Play), toys (What Goes Together? Activity Box), and gadgets that parents can consult if they need guidance in this regard. Experts in these videos also explained the mental and emotional challenges that children go through, which they can hardly express to their parents and caregivers. Experts in their videos provided suggestions to parents and caregivers on how to handle those conditions (such as children with cerebral palsy in a crowded airport) in a way so that their children with DDDs feel secure, confident, and comfortable in difficult situations.

4.2.6 Presenting Personal Experiences (primarily created by parents). Parents of children with developmental delays primarily created videos in this category. In these videos, parents explained their journey and the challenges of diagnosing developmental delays among their children. They discussed how it impacted their married life, parenting practices with other kids, professional commitments, and social life. Parents also discussed how other parents could consider taking action proactively to avoid uncertainty and mental stress.

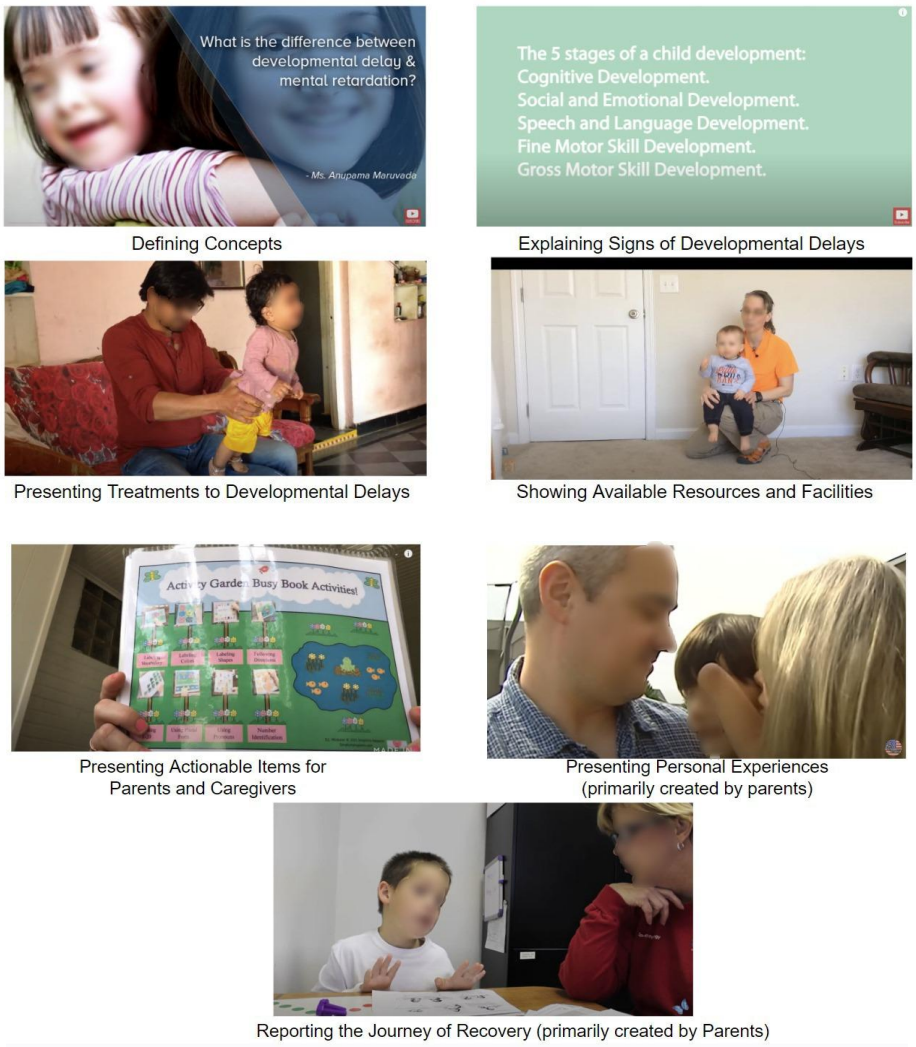

Fig. 2. Snapshots from the seven types of video content identified in our dataset

4.2.7 Reporting the Journey of Recovery (primarily created by parents). This is another category of videos that were primarily created by parents. Parents often made follow-up videos several months after their initial video to discuss the progress of their children diagnosed with developmental delays. They explained the services and treatments they received for their children. They also explained the merits and demerits of those services that they received. In these videos, they often introduce their children and show short moments of interaction with them. As parents mentioned, the primary objective of making these videos was to assure other parents that developmental delays among young children are not uncommon and that, with proper care, children can overcome their delays entirely and perform like other children with early delays. Furthermore, parents of children with incurable conditions such as ADHD and Cerebral Palsy appeared on YouTube to

educate others that no therapies or interventions can fully cure such conditions. However, those interventions helped their children manage their symptoms and improved their lifestyle.

4.3 Summary: Analysis of Styles & Content of YouTube Videos on Children's DDDs

In our analysis, we primarily identified four video styles. Additionally, we categorized the content in our dataset into seven types: 1) defining concepts, 2) explaining signs, 3) presenting treatments, 4) showing resources, 5) presenting actionable items, 6) presenting personal experience, and 7) reporting recovery journey. We have also added snapshots from each type of content in Figure 2. This analysis helped us understand both experts and parents of children with DDDs create video content on YouTube. The expert videos focus on the informational aspect of DDDs. In contrast, the parent videos highlight the personal challenges in a wide range of scenarios that other parents face while raising their child with DDDs and in some cases, how they overcome them. The findings in this section will help us understand the regular interactions and topics of discussion of the audience in the comment section. In addition, these findings will help us understand the broader impact of these DDDs videos on parents of children with DDDs.

5 Results: User Involvement examined from YouTube Comments (RQ2)

In RQ2, we aimed to explore how these impact the parents and caregivers of children with DDDs. To this end, we took two approaches: 1) analyzing the comments of the videos in our dataset and 2) interviewing parents of children with DDDs who watched videos on YouTube on children's DDDs. In this section, we presented the main topics that parents and caregivers discussed in the comment section. In the next section (section 6), we will show the observations made by qualitatively analyzing the interview transcripts.

From our dataset of 1,532 videos, we excluded 121 videos as the video creators blocked their comment property. The remaining 1,411 videos were used in our comment analysis. We performed qualitative coding and identified six primary themes for comments. These themes are discussed here.

5.1 Asking for suggestions

This was the most common category of comments. Parents explained the condition of their children related to the topic of the video and asked for suggestions from experts and other fellow parents. Often, they directly asked video creators whether they could help their children. In many comments, parents mentioned that the video helped them understand the milestones of a specific type of development. The information presented in the video helped them realize that their children might have some form of DDDs, for which they asked for expert suggestions. As a community, parents asked detailed queries about services supported by health insurance, which developmental specialists often recommend. Other parents helped each other by giving suggestions that might help parents negotiate better with insurance companies or use treatment codes that are more likely to be reimbursed.

5.2 Sharing Experiences and Concerns

This was the second most frequent type of comment in our dataset. Parents used the comment section to report the status of their children's DDDs. They discussed the treatments their children received for their delays and how well they responded to those treatments. They also described different aspects of treatment programs, such as the lack of facilities in suburban areas, the high cost of specialized therapies, and the challenges of continuing the treatment program for a long duration. Parents also described how they followed all suggestions in similar videos, but their children did not respond. We observed that parents sought a sense of support from the community

in their comments when they just became aware of their children's DDDs but did not yet know how to go through the treatment, therapy, and counseling programs.

Category of Comments	Example of Comments
Asking for suggestions (38.51%)	My child just turned 3 and he hardly likes to play with other kids, he easily gels up with adults but with kids he seems little nervous or scared can u suggest some more things which i can do to improve his this skills.
Sharing Experiences and Concerns (23.16%)	My baby is 1 year and 2 months...he haven't been able to stand by his own and neither to walk...he walks only with support....iam worried now...
Thanking Video creators and Asking for New Content (11.63%)	Hello dear. I really like your videos and took help from them, so thanks for that, Can you please make a video on problem solving component as u discussed there...
Response of Video Creators (14.69%)	Thank you for taking the first step and expressing your struggle. We want you to know you are not alone in how you feel. We hope you will check out the links to the resources in the description box for where to learn more and where to get treatment and support.
Comments from Fellow Video Creators (4.14%)	Hi, This is a very useful video. I'm working on a project related to women and children health among immigrants in Portugal. Specially with early detection and intervention. Would like to discuss with you about making an awareness video for the beneficiaries.
Miscellaneous (7.87%)	Doc Oyalo can reverse autism with herbs and it's completely perfect. I used it for my son and so far his speech is verbal and social skill is normal and he can now also respond to everything positively on his own

Table 4. Examples of Six Comment Themes

5.3 Thanking Video Creators and Asking for New Content

This category includes a list of comments in which the audience thanked video creators for sharing content on YouTube. Parents thanked video creators for information they needed help finding through traditional web searches. In these comments, parents frequently requested video creators for more content on similar topics. They also asked for further explanations of the topic presented in the video in this category of comments. In thank you notes, parents often referred to other videos of the same creator or other similar creators that helped them take necessary actions for their children's DDDs.

5.4 Responses and Reflections of Video Creators

Video creators used the comment section to communicate actively with their audience. They acknowledged their viewers' thank you notes and reassured their audience about preparing new content in their comments. They also responded to their audiences' queries and sometimes included information for additional resources in their comments. For instance, in one comment, the video creator explained that as they are not certified to diagnose DDDs among children, they could not

tell whether a child has a developmental delay. Instead, they request parents consult a certified physician for that task.

Video creators sometimes focus on reacting to the audience's comments. Instead, sometimes, they proactively asked their audience regarding the progress of their children's treatment and therapy sessions. Video creators use the comments section of their videos to create personal connections and a strong bond with their audience. Many of these creators used the comment section to talk about their connection with children of DDDs and how those experiences changed their point of view on this issue.

5.5 Comments from Fellow Video Creators

Video creators received comments from parents of children with DDDs and fellow experts and activists in their domain. Fellow experts appreciated video creators for creating content on DDDs. They highlighted critical elements of the videos and explained how those content would help parents to make early decisions for their children. Fellow experts often suggested video creators for adding additional content to their videos to make them easier to understand for layman users with little to no knowledge about DDDs. Fellow experts also tried to communicate with video creators for future collaboration opportunities. They often invited video creators to collaborate and create new videos on YouTube. Apart from those invitations, they also offered the video creators the opportunity to join offline collaborations such as voluntary services in community clinics. It is essential to mention that fellow experts only sometimes praise video creators in their comments. Sometimes, they claimed that the video's content needed to be corrected and suggested that video creators change their content to avoid confusion.

5.6 Miscellaneous

Around 8% comments did not fit into any of the five categories discussed above. We included them in this "miscellaneous" category. One group of comments in this category addressed the effectiveness of alternative treatments for DDDs. For instance, several comments discussed the impact of herbal therapy offered by Dr. Oyalo that completely cured speech delay and autism for young children. Other viewers also ridiculed such claims in their comments as they identified Dr. Oyalo as a "modern-day snake oil salesman". Another group of comments in this category discussed unrealistic expectations of family's close relatives regarding children's developmental milestones. For instance, one mother complained about her in-laws, who expected their three-month-old granddaughter to be able to sit independently. When the child could not meet their unrealistic expectations, her in-laws started complaining that the child had some growth delay. Finally, a few comments in this category discussed the rapid progress of their over-achiever kids. For example, in one such comment, parents asked whether they should worry about their child who reached all developmental milestones recommended for 5-year-old kids at the age of 2.5 years.

5.7 Summary: Analysis of Comments of YouTube Videos on Children's DDDs

Overall, the analysis of the comments showed us how the community (video creators, parents of children with developmental delays, physicians, therapists, counselors, and researchers) used the comment section of YouTube to build a strong bond among each other. Parents used this platform to search for and learn critical information on developmental milestones, disabilities, and delays. They also interacted with community members to clarify doubts and find necessary resources. The comment section allowed parents to participate actively in community-wide conversations, inspiring video creators to stay engaged with the community and produce more content demanded by the audience. Experts used this platform to interact directly with their audience and fellow video creators, creating a sense of social bond with the broader community.

6 Findings of the Interview of Parents and Caregivers (RQ2)

In this section, we will explore how parents of children with DDDs perceive YouTube as a social platform for health-related purposes, focusing on four key aspects: accessing information, experiencing a sense of virtual support, encountering feelings of seclusion and reclusiveness, and verifying the credibility of information. The following part of this section provides a comprehensive insight that we have gathered through the interview study of these parents.

6.1 Accessible Source of Information

All participants emphasized the importance of YouTube videos as the first point of information on DDDs. All but three participants mentioned that their children were not diagnosed with any form of DDDs at the time of birth. Instead, they gradually started noticing growth and behavioral patterns that were not usual over several months. However, these observations were insufficient for them to raise concerns with their pediatricians. They all experienced a sense of guilt, denial, and a lack of confidence in admitting their observations. In some scenarios, their spouse was not ready to accept any form of DDDs for their children(N = 2). Such denials delayed the diagnosis for one child more than two years. YouTube videos on DDDs worked for them as a first point of information for which they did not have to reach out to external resources. The videos were free, easily accessible, and, to a large extent, easy for novice users to understand. The availability of these videos allowed them to explore in their comfort instead of asking for suggestions from friends and family members, who often become judgmental in similar cases. As one mother mentioned:

> *"We were with my husband in his European duty station. Our pediatrician never asked us to fill out any developmental surveys. But there was something that bothered me all the time. Luckily, one day, I found a channel on YouTube where a developmental specialist was talking about early signs of developmental disabilities. The information shared on those videos finally convinced my husband that our daughter needed to see some specialists. It turned out that our daughter had GDD (Global Development Delay) because of some abnormalities in the corpus callosum and a mutation on ARF1."* [P7]

The YouTube videos not only assisted parents during the initial stage of clearing doubts but also worked as a consistent source of information after the diagnosis. As P11 mentioned:

> *"The diagnosis was only the beginning of our journey. Taking care of a child with a developmental disability requires continuous searching for the best therapy centers, the best schooling, and the best places to socialize with other children. Only expect to receive some of that information from our pediatricians. We only meet her once every three months unless there is an emergency. Parents like us received much useful information regarding occupational therapy, feeding therapy, or Medek therapy by following YouTube channels on DDDs."* [P11]

Some other parents (P4, P9, P12, P14) explained YouTube as a complementary social media platform to Facebook. On many occasions, mothers of children with DDDs form private Facebook groups to discuss their queries and concerns. P4 remembered multiple incidents when someone in the Facebook group suggested others watch informational videos on YouTube in response to some queries. Moreover, some parents consider YouTube an excellent resource for verifying information they receive from Facebook groups.

> *"[...] I learned from my Facebook group about a center close to my home that provides social skills therapy. I immediately searched for that center on YouTube and found their promotional video. The video gave me a rough idea about the look and feel of the center, and I decided to visit the place in person. As a parent of an autistic child, I cannot afford*

to visit all potential centers in person. Such promotional videos or virtual tours give me critical information about whether someplace is worth visiting." [P9]

Participants found that videos featuring clinical specialists and therapists were rich with information. Those videos helped them understand their children's condition better. However, they found that videos made by other parents or caregivers were equally important as those videos often provided helpful tips on supporting their children emotionally. As P2 mentioned:

"The physical and occupational therapies are necessary for my child to grow and learn essential life skills. But therapists do not stay with my child 24/7. Therapy sessions did not tell me how to deal with my son's emotional meltdowns. Videos made by other parents helped me realize how to handle those difficult moments and support my son through those phases of overwhelming experiences of emotions." [P2]

Some parents (N=4) said consuming information is relatively easier on YouTube than other web search engines. As P6 mentioned:

"[...] My daughter has a rare condition which is not even known to most of the pediatricians. Ideally, I would like to read all research papers published on that condition so that I can provide the best care to my daughter. However, realistically, I feel exhausted at the end of the day and generally have no energy to read a medical journal. Yet, I can watch YouTube even when I am tired, and if I find an interesting video the next morning, I find the original publication and read it thoroughly. So, in a way, YouTube's video format makes the research on TBCD disorder more manageable and accessible for me."

6.2 Experiencing a Sense of Virtual Support

All participants expressed the importance of forming a passive online community not only through the comments section of YouTube videos but also from watching videos that other parents of children with DDDs made. Some participants (N = 9) discussed their inability to be part of regular parent meetings or family get-togethers because of the lack of social acceptance for children with DDDs. This condition made them feel isolated and lonely, which made them more vulnerable to depression. YouTube videos helped them feel a sense of social presence. These videos enabled them to find in-person and virtual communities where they were accepted without judgment. More importantly, these videos gave them the courage and strength to deal with their daily challenges, starting from training their children to go to the toilet on their own at the age of 10 (regularly developed children typically get potty trained at three years of age) to teach them how to talk or behave in a socially acceptable way with other children.

Some parents (N = 3) shared their experiences of creating personal connections with other parents whom they initially started communicating with through YouTube's comment section. Unlike some other entertaining YouTube channels where viewers frequently attack each other at a personal level, viewers of DDDs-related YouTube channels always showed a sense of empathy and a caring attitude to others. As P12 described:

"Initially, when my son was diagnosed with neurodevelopmental syndrome, I constantly fought with my husband. I am not saying that it was his fault or mine. I guess we both felt frustrated and defeated. It was just like the book "Welcome to Holland" where you got on the flight to go to Italy but somehow ended up in Holland and the sense of getting stuck there for the rest of your life. Other parents' experiences (shared on YouTube) gave us the sense of belief that with resilience and patience, we can do this too." [P12]

Other participants (N = 2) also talked about their relationship with their regularly developed children. Many videos created by parents on YouTube not only include their child with DDDs but

also talk about their struggle to allocate sufficient time to their other regularly developed child. As P11 has described, family dynamics are different. So, she expected to avoid mimicking the strategies that worked for other parents. Instead, she found strength and motivation from others' videos and started experiencing a renewed sense of belief in her own family's strength.

6.3 Experiencing a sense of seclusion and recluse

Social media platforms are widely regarded as convenient places for creating virtual support communities and collaborative groups for people with specific needs. However, unlike other social media platforms, some participants (N = 6) considered YouTube a perfect blend of seclusion and connection. As P1 mentioned:

> *"No matter how much support you get from hundreds of resources, this journey is painful. You cannot ignore it. My son goes through good phases as well as bad phases. During his bad phases, I want to stay alone. I wouldn't say I like to meet other parents in the playgroup, but I do not want to talk to people on Facebook. YouTube gives me that sense of seclusion without cutting me off from this virtual world."* [P1]

In other cases, parents also discussed the anonymity features of their YouTube account compared to their public account on Facebook. On YouTube, parents can choose to use pseudonyms instead of using their real names. This feature allows them to maintain a level of privacy when they are discussing their child's developmental challenges. As P11 mentioned:

> *"I sometimes hesitate to share sensitive details about my daughter on Facebook. You know, some of the Facebook groups for GDD (Global Developmental Delay) and ADHD are not private. When I post some of my concerns on Facebook, they could be exposed to all my friends, family members, and even my colleagues at work. That is different from what I want, at least not always. YouTube gives me that subtle sense of separation, but at the same time gives me access to a community to reach out to at the time of need."*

Some participants (N = 5) also discussed their emotional involvement in social media groups with other parents. When browsing groups on various social media platforms, they often find many personal stories. Many of them are emotionally draining, and they could relate to many of those shared experiences with their own experiences. Participants usually avoided those emotional burdens and consumed only informational content. As P7 mentioned:

> *"[...] It is not easy to accept that your child cannot do simple tasks alone. It may sound not good, but I need a break as well. Facebook groups are full of such stories. Sometimes, I do not open them for days to recollect myself. Sometimes, I watch YouTube videos to learn about new research findings during this time, but I do not read the comment section."* [P7]

6.4 Verifying the Credibility of Information

All participants discussed their points of view on the credibility of information presented on YouTube regarding DDDs. The spread of misinformation and disinformation during the COVID-19 pandemic made parents more vigilant when consuming health-related information. All participants highlighted the importance of checking the credentials of the video creators on YouTube. As P2 mentioned:

> *"YouTube is a warehouse of knowledge. Anything you name, you will find it on YouTube. But too much information also comes with too much noise. Sometimes, it is hard to differentiate between a credible one and a non-credible one. That is why I always rely on videos that clinical specialists create. I verify their credentials using other channels, such as Google's search engine. It is hard to fake in two different places."*

Other parents (N = 8) discussed following only channels created by reputed organizations such as the World Health Organization (WHO). This strategy is comparatively safe; however, participants agreed that they could only sometimes follow this rule as one organization, even the large ones, cannot produce sufficient content. In those cases, participants often relied on repeated occurrences of information. When parents found information in multiple videos produced by different channels, they started trusting that information more.

Some participants considered YouTube and other social media platforms as only the initial source of information on DDDs. If they find something useful, they always consult it with their pediatricians before adopting them in any capacity. As P4 mentioned:

> *"No matter what precautions you take, you can never be sure of the authenticity of information found on YouTube. One may feel the temptation to try them right away. [...] I cannot take chances on my kid's healthcare. I always double-check such information with my pediatricians and behavioral therapists before trying them on my child."*

6.5 Summary: Analysis of Interview Study Transcripts

These interviews showed us the breadth and depth of interactions that parents of children with DDDs experience while consuming videos on YouTube. YouTube provides opportunities for parents not only to consume content but also to build a solid virtual community. Our analysis revealed the critical need for seclusion in the age of social media, especially for those populations with highly demanding responsibilities. The findings also helped us reflect on how parents consume YouTube videos on DDDs of different video styles and types of content and how those content types impact parents' trust.

7 Discussion and Design Implications

7.1 YouTube as a Source of Informational Support

Previous research has shown that YouTube is widely used for peer support among individuals with severe mental illness, where personal testimonials and direct exchanges in the comments are common and effective forms of engagement [78]. Similarly, YouTube has been identified as a key platform for Black Americans managing depression, where sharing personal experiences helps in advocating for destigmatization and encouraging treatment [53]. However, the impact of social media on healthcare provider communication varies across different groups. For example, adults with chronic conditions such as heart disease, diabetes, and hypertension do not show a significant connection between social media use and their interactions with healthcare providers [61]. In contrast, our findings indicate that parents of children with DDDs actively use social media to learn new techniques and methods, which they then discuss with healthcare professionals, leading to more informed and collaborative care. This suggests that parents of children with DDDs leverage social platforms as tools for enhancing their engagement with professional healthcare, unlike other communities.

Developmental delays and disabilities among young children may bring a wide range of challenges for parents, especially when parents have no specific reasons to predict such conditions. Observing the early signs of DDDs among young children is not an easy task. It often takes a trained pair of eyes. Yet, many parents do not have the provisions to consult experts at the right time because of their socio-economic conditions. For others, there are high chances of missing the subtle signs and symptoms that only experts can distinguish without confusion. YouTube videos on DDDs are a great source of information for parents. analysis demonstrated that parents view YouTube as a crucial resource for accessing the information on developmental delays and disabilities (DDDs), appreciating its unrestricted video access and privacy features, such as not displaying subscriber

lists. Parents particularly value YouTube for its practical, actionable content that aids in their children's developmental growth from early stages, often using this information to advocate for their children with healthcare providers. In our interviews, we have also observed how passive learning about DDDs from YouTube helped some parents overcome their initial state of denial. Our study aligns with previous research that highlights YouTube's role in peer support and peer feedback for individuals with severe mental illness, where personal testimonials, hopeful comments, and direct communications facilitated meaningful engagement [78, 53, 64]. Informational videos on DDDs gave parents the confidence to ask questions regarding their children's overall well-being and developmental growth, which were sometimes overlooked during regular wellness visits.

Parents and caregivers favored segmented and detailed videos over shorter reels for information on children's DDDs, with personal stories from other parents providing reassurance and a sense of connection. These preferences align with broader research showing that video length is less important than content segmentation and the depth of the presentation, which audiences seeking in-depth information prefer [14, 36]. Furthermore, learning videos where the presenter narrates their personal experiences, particularly in an interactive manner, are more engaging, as seen with vulnerable groups during the COVID-19 pandemic [51, 9]. YouTube was particularly valued for its how-to videos and personal testimonies, offering more relatable and comprehensive insights into their child's developmental growth. Unlike other groups where social media use does not significantly impact healthcare interactions [61], parents of children with DDDs actively utilize these platforms to enhance their communication with healthcare professionals, resulting in more informed and collaborative care. Here, it is critical to understand that the information provided on YouTube, even by experts, cannot be processed as medical advice. Previous work reported that the quality of medical information on YouTube could be better in general [87]. Researchers also observed that YouTube may promote misinformation, especially regarding highly controversial topics (such as vaccination). Misinformation on sensitive issues such as children's DDDs can have long-term and deadly consequences. Channels promoting videos on DDDs need to ensure that the quality of the information is not compromised. As a platform, YouTube can play an influential role in this context by rewarding reliable, expert-driven channels and professional organizations with unique tags for generating certified content on medically critical domains, which is aligned with the recommendations provided by Onder et al. [86] in their analysis on informational YouTube videos on psoriatic arthritis (PsA). This will give parents and caregivers more agency in what they learn about children's DDDs on YouTube.

In our work (RQ1), we investigated the video styles and the content of videos on DDDs. The qualitative analysis revealed how experts use YouTube to explain complex, hard-to-discern ideas more understandably so that parents and caregivers from all backgrounds can consume them and take necessary actions as appropriate. Our findings demonstrated that YouTube has provided expert physicians with an accessible medium to connect and reach a large group of parents and caregivers that was previously not available through the traditional healthcare system. The presentation style has a significant impact on the effectiveness of YouTube videos for parents and caregivers. Although we encountered more videos that used presentation slides and voice-over as their medium of communication, our interviews revealed that parents found interview-style videos and videos with actors and/or solo speakers more engaging. One possible explanation may be the workload of parents managing their children and family while maintaining their professional commitments. In that context, presentation slides may not be the best option for having an engaging medium for communication. This finding supports the opinion of Professor Sherry Turkle from MIT, where she pointed out that presentation slides teach users to make points rather than arguments, encourage presentation rather than conversations, and that the foregoing serve to cultivate users' expectations of not being challenged [56]. Professor Edward Tufte supported the idea that thought and analysis

are sacrificed by presentation slides for the convenience of the speaker, hurting both the content and the audience. He also mentioned that presentation slides allow presenters to pretend that they are giving a presentation but instead corrupt serious communications [118]. Future content creators may find these observations useful when creating YouTube videos on children's DDDs to reach parents in an impactful way. Here, it is critical to mention that the observations of this paper do not prove that one video style is better than another. Instead, our observations highlight the importance of context when creators intend to appeal to a target audience group through YouTube videos.

This paper considered all DDDs-related videos in a single group for analysis. In the future, they can also be sub-categorized into smaller granularity. For example, developmental delay-related videos can be further classified for various delays, such as cognitive, motor skills, speech, and social and behavioral. Developmental delays and disabilities can be divided into separate lists for further classifications. Here, it is worth mentioning that although developmental delays vs. disabilities have significantly different trajectories for adults and children during their initial years, the differences are not always clearly observable. Moreover, children in many scenarios experience multiple types of developmental conditions. Future work may investigate how parents find such classifications valuable and convenient for quick and efficient access to these videos.

7.2 A Mutually Supportive Online Community for Emotional Assistance

We observed YouTube video content and the discussion community as a constant source of emotional support system for parents and caregivers of children with DDDs. The personal experiences shared by other parents provided a sense of hope and motivation and helped them feel part of a community rather than isolated. Our analysis resonated with previous work that discussed emotional support from social media platforms [108, 47], while some of our observations added new knowledge in this domain. For example, we found the need for seclusion without completely withdrawing from social media platforms.

On sensitive issues, emotional support can be overwhelming as well, depending on the mental state of the user. One such example can be the family experiences shared by other parents. While in the majority of the scenarios, personal experience-sharing videos are created in an empathizing way, parents may find them emotionally straining in certain conditions. As P7 discussed regarding her son being at the higher end of the autism spectrum, experiences shared by other parents with the lower end of the autism spectrum did not always match with her own experiences. Stories of gradual progress and improvement may come at different paces for different parents, irrespective of their personal efforts, treatments, and interventions. Emotionally relevant stories may become hard to process during those difficult times. We have seen in prior work similar concerns where Long-COVID patients felt a sense of guilt while sharing their recovery stories [55]. Platforms like YouTube should consider having provisions where users can control their YouTube suggestions. This control will allow them to receive no suggestions for personal experience sharing videos for a specific period, allowing them to recover from their state of mental stress. This design can also be extended to the comments section of the videos, where users may have the control not to see any comments for the videos they watch. Gaining more control over the content of the videos that parents and caregivers prefer to watch and how they want to watch them will be beneficial for the broader community, especially inclined to consume health-related information from YouTube.

7.3 Authenticity of Health Information on YouTube: A Comparative Analysis of Design Implications on Similar Social Platforms

Sharing healthcare information on social media often receives much-concerned attention from physicians and policymakers. The lack of information control on social media platforms like

YouTube bears the risk of spreading misinformation and rumors, which can seriously affect public healthcare [115, 26]. This situation became more alarming during the pandemic when institutional and social privacy concerns reduced engagement with social media apps, highlighting the need for stronger privacy protections, which are also crucial for parents of children with DDDs seeking sensitive information online [54]. Twitter's Birdwatch program reveals that while crowd-sourced fact-checking is scalable, it lacks consistency, emphasizing the importance of reliable content, especially for niche communities like parents of children with DDDs who rely on accurate, trustworthy information [100]. Text analysis of Hypothyroidism forums underscores the value of personalized and detailed support systems, similar to the preferences of parents of children with DDDs for in-depth, segmented video content [39]. TikTok's focus on authenticity and emotional expression through anonymity suggests that creating a supportive environment is essential, much like the community support that parents of children with DDDs find on platforms like YouTube [4].

Despite these concerns, previous research has established niche areas in healthcare where YouTube can have a significant positive impact [106]. Our work contributes to that line of research. Although the primary objective of our work was not to validate the authenticity of the content presented in the YouTube videos on children's DDDs, we acknowledge the importance of verifying the validity of critical healthcare information on social media. Our interview participants also emphasized the importance of validating the information received from YouTube when discussing their cautionary strategies before acting on any suggestions received from YouTube. One way to address this concern is through a mutually collaborative partnership between YouTube and professional experts and organizations that can potentially transform YouTube into a trustworthy online platform for conveying critical healthcare messages and essential education to a wide range of audiences, especially marginalized populations with limited access to quality healthcare. Sources such as the CDC, Mayo Clinic, and Johns Hopkins Pediatric Care, which are attached to informational videos on YouTube regarding children's DDDs, may provide critical validation to YouTube content. Experts creating informational videos on YouTube may promote this practice by providing authentic sources of information enclosed as attachments to their videos. As a platform, YouTube may encourage this initiative by algorithmically upvoting these videos to appear at the top of the search query. The platform can also create curated playlists focused on such verified videos and arrange them sequentially from early intervention to advanced treatment management strategies for various developmental delays and disabilities. These playlists can guide viewers through a comprehensive learning journey, providing reliable, relevant, and actionable information at every stage of their child's developmental growth.

8 Conclusion and Future Work

DDDs is a condition that is frequently observed among young children. Early interventions, in most cases, can help children recover completely from their childhood delays or improve partially overcoming their disabilities. Unfortunately, most children cannot access early intervention programs. Studies found that even when facilities were available to care for children with DDDs, children were not recommended for those services due to a lack of awareness. Thus, parents of children with DDDs went through parental stress, which caused social isolation. YouTubers have created thousands of videos on children's DDDs, both from the perspective of experts and parents raising delayed children. We conducted a mixed-method analysis of YouTube videos on DDDs to identify the primary content and style of videos regarding DDDs. We found informational videos created by experts and emotionally connecting content created by parents of children with DDDs. Our analysis of the comments in these videos demonstrated how YouTubers and viewers created a strong connection through these videos. Most importantly, the interview study shows how these videos may help parents not only gain information regarding DDDs but also overcome various

emotional challenges. This work is the first step in building a community on children's DDDs. The findings of our work can help develop reliable and relatable content storage for children's DDDs and can be expanded for other healthcare communities as well.

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