“Wearing a High Heel and a House Shoe at the Same Time”: Parents’ Information Needs While Navigating Change in their Child’s Behavioral Care

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Change is an inevitable part of a parent’s role, whether due to their child’s development, family life, or external events. To understand the information needs of parents navigating change, we studied the effects of the COVID-19 pandemic as a widely experienced disruption in the lives of parents and children. We interviewed 16 parents about their caregiving experience as the COVID-19 pandemic collapsed boundaries between home, school, and work. In particular, we asked about adjustments to behavioral care, or the social learning, supports, and interventions through which children develop social and emotional skills. We focused on parents of children already receiving accommodations and behavioral support from their school, to understand how disruptions in these services affected the role of the parent in meeting their child’s individual needs. Applying role theory and the Kübler-Ross change curve, we describe the coping mechanisms that parents used to navigate the stages of change, as well as the information needs that remained unmet, despite their efforts. We discuss how practitioner-initiated and parent-centered supports can be designed around the lived experience of change, by accommodating a parent’s capacity to accept and use help at different stages.

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

Additional Key Words and Phrases: role theory; social support; school; special education; information seeking

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1 INTRODUCTION

Children develop differently, in terms of personalities and strengths, and therefore require different kinds of support to meet their individual needs. The role of a parent in meeting these individual needs is substantial and can be stressful, and this important role is linked to the functioning of both the parent and the child [24]. A child’s behavioral development requires a parent to adjust their

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role over time in support of the child's social and emotional functioning, including coordinating with professionals who help them with addressing behaviors of concern. According to role theory, roles help guide people's behavior, delineate the goals and tasks to complete, and impact how they understand and operate within the world [12]. The role of a parent involves a set of expected behaviors and obligations, which are context-specific and relative to other roles, such as a child's teacher, pediatrician, or therapist [12, 39].

Change in the role of a parent is inevitable, as behavioral development is dynamic and evolves in response to a child's interactions with others and their environment [83, 96]. At times, an external event—such as loss of a loved one [66, 74], illness of a family member [60, 84], divorce [74, 98], or natural disaster [76]—may require a parent to adjust their role and respond to their child's arising emotional and behavioral needs. From the child's perspective, continuity of care can be thought of as the degree to which they experience their care as aligned and cohesive over time [95]. In this work, we are concerned with behavioral care that reaches the level of tailored accommodations, interventions, or therapies [38], along with the everyday interactions necessary for children to develop socially and emotionally [34]. Social and emotional skills, accrued through each stage of development, form the foundation for behavior and mental health over the life course [32]. Behavioral care involves (1) continuity across parenting and caregiving within family life; (2) social and emotional learning among peers and authority figures; and (3) support from any psychologists, social workers, or therapists (e.g., behavioral, occupational, and speech) [35, 70, 78, 91]. Children are embedded within their larger ecological and sociotechnical environments—interpersonal, community, and institutional—and develop within these systems, not independent of them [16, 17]. When changes occur within this environment, parents must renew their role in their child's care and their understanding of their child's needs.

Information is an important component of maintaining continuity of care, linking stakeholders in a child's care across time and settings [30, 36]. Communication between parents and practitioners (i.e., clinicians, educators, or other professionals involved in the delivery of care) is necessary for sharing information about the child's needs, and how to meet them effectively and consistently. However, information systems should not only enable stakeholders to communicate and share information with one another, but also be designed around the lived experience of change and how people respond to it [25]. We apply role theory to understand and examine how parents respond to change as it relates to their role in supporting their child's continuity of care, and in doing so, we complement other studies on parents' information needs (e.g., [1, 8, 54, 73, 80]). As parents work to maintain continuity in their child's behavioral care, they can encounter collaborative breakdowns [64], limited team-based care efforts [2], and barriers to developing shared understanding of their child's needs [80]. For example, parents do not always have real-time access to their child's electronic health records [48, 62] or school-based behavioral health records [64, 90]. Since schools implement behavior documentation policies, processes, and tools with a focus on their internal needs, such tools are limited in their usefulness for keeping parents informed about their child's behavior [64, 90]. Instead, systems could be designed to help practitioners build and maintain a relationship with parents, sharing the kind of information that will be helpful to them in the moment they need it, thus preventing burnout and information paucity or overload [73, 80].

To elicit sociotechnical considerations for designing around experiences of change, we studied how parents navigated a change in their role caused by the COVID-19 pandemic and the resulting loss of professional behavior support for their child. The COVID-19 pandemic has had significant adverse impacts on parents and children across the globe. In a U.S. survey, conducted approximately six weeks after the World Health Organization (WHO) declared the Coronavirus a pandemic, 35% of parents reported their children were more sad, depressed, acting out, and lonely since the onset of the pandemic [55]. Yu et al. [100] found that parents experienced additional burden from having to create learning experiences, search for resources, facilitate their child's learning, and communicate with their children's teachers, all while facing other challenges, including teachers' high expectations and the lack of interaction with others. In Finland, Häkkilä et al. [37] describe how parents faced the challenge of taking on multiple roles to lead their child's remote schooling (e.g., teacher, technological support, and daytime chef) while potentially working from home themselves. The COVID-19 pandemic has been especially challenging for children with disabilities and their parents. In Australia, Masi and colleagues found that the majority of caregivers of children (aged 2-17 years) with neurological developmental disabilities (NDD) reported that their child's NDD and/or comorbid mental health status had worsened during COVID-19 [65]. Another survey of Australian parents found that 82% of them experienced a lack of information, which exacerbated their own distress and feelings of uncertainty [26]. In a UK study, 72% parents felt they did not receive adequate support (e.g., guidance and appropriate resources) for their child's educational and psychological needs, resulting in parents' feeling unprepared and children not attending virtual school [33].

With a focus on parents' experiences of change and related information needs, this study contributes to CSCW literature on how parents can monitor and support their child's behavioral development in collaboration with practitioners [50, 51, 64, 71], and how parents can be supported in their role as caregivers [20, 28, 72, 84]. Using the widely experienced shock of the COVID-19 pandemic, we provide a novel perspective on designing for parents' well-being and information needs that can be generalized to any change or disruption to the continuity in their child's care. We also studied parents of children receiving significant behavioral support from practitioners in the educational system before the pandemic to understand how this disruption in support was experienced. We addressed the following research questions:

- RQ1: How do parents experience change to their child's behavioral care?
- RQ2: How do parents adjust their role to cope with change and maintain continuity in their child's behavioral care?
- RQ3: How can technologies be designed to meet parents' information needs while navigating change?

Typically, structures and boundaries will help define and constrain roles, allowing parents to understand and act on their role in supporting the behavioral development of their child. However, the COVID-19 pandemic collapsed the boundaries of home and school, providing a unique opportunity to understand how parents perceive support from members of their child's care team, while they renegotiate their role amid significant change. Using role theory and the Kübler-Ross change curve, we identified how systems can be designed for (1) practitioner-initiated support to meet parents' information needs and (2) parent-centered support during stages of change. These theory-driven and empirically-based findings can apply to many types of change that a parent and child can experience, and they can inform the design of supports that may benefit parents more universally.

2 RELATED WORK

This study adds to CSCW literature on the tensions associated with negotiating one's role as a parent along with other roles, such as caregiver when the child is a patient (e.g., [20, 46, 47, 72, 84]). Chen et al. [20] argue that a caregiver's emotional self is integral to their care activities, that care activities must be negotiated alongside other aspects of their lives, and that such social-emotion work of caregiving must be considered in the design of any health or wellness system. Our work also relates to research that has addressed information and support seeking during the transition into parenthood [8, 79], as we examine ongoing changes for parents as their child develops.

In this section, we describe how we apply role theory and the Kübler-Ross change curve to understand how parents experienced significant changes to daily life caused by the COVID-19 pandemic, in relation to their role in meeting their child's behavioral needs. We then describe behavioral care, and how we focused on parents of children receiving behavioral services prior to the pandemic.

2.1 Role Theory: How Role Conflict Initiates Role Change for Parents

All people enact multiple roles over the course of their daily lives (e.g., mother, father, child, partner, friend, employee, employer). In this study, we applied role theory to understand how parents perform various roles in relation to their child's behavioral care, how these roles conflicted, and how parents navigated change when they lost professional behavioral support during the pandemic.

Briefly, role theory posits that day-to-day social behavior and interactions are defined by people carrying out their roles in response to social expectations, complex social structures, and reciprocal action(s) [11, 12, 39]. It outlines both the macro- [75] and micro-level [31] perspectives of human behavior in relation to other people. At the macro-level, role theory suggests that everyone has a place and a function within the larger social structures, and as such, modify their roles in response to these complex structures [75]. At the micro-level, it proposes that people also adjust to different contextual factors (e.g., time, space, and other people) to 'perform' their role in a way that will be accepted and acknowledged by the audience [75]. Accordingly, applying role theory in our study, at the macro-level, a parent may enact their role differently in their own home than in a teacher's classroom or a clinician's office, for example, as those are the practitioners' domains and the parent is expected to conform to the larger structures of education and healthcare, respectively. On a micro-level, for example, a parent may take pride in their parenting, and therefore, be affected by others' (e.g., clinicians') perceptions of their behaviors as a parent, as well as how their child's behaviors reflect on their parenting.

Role theory also helps us better understand role conflict [11, 44, 45, 81] which can occur when a person does not feel they can meet certain expectations placed upon them, whether due to skill, capacity, and/or resources. In our study, many parents experienced severe role conflict, by having their children home from school, while they simultaneously worked from home. Role conflict creates significant stress and can cause a person shock, which initiates their role change [81]. To this point, within the first few months of the outset of the pandemic, Lee and colleagues found that 40% of parents surveyed met criteria for major or severe depression, which was "negatively associated with parents' perceived preparation to educate at home" [55]. Additionally, Michelson et al. described a juggling of roles by parents experiencing a lack of infrastructural support from school [69]. In this paper, we explore how parents navigated this pandemic-initiated role conflict and role change by applying the Kübler-Ross change curve, which we describe in the following section.

2.2 Kübler-Ross Change Curve

The Kübler-Ross change curve [52] is a tool for understanding how people experience change, and identifying how they can be supported in adapting to change. All change comes with some form of loss and requires a person to positively accept what has happened and adapt to their changed circumstances. The change curve uses five non-linear stages—denial, anger, depression, bargaining, and acceptance—to represent different reactions a person may have to change. The stages help to identify where a person is currently, and where they need to be to live healthy lives. Perhaps most commonly known as a representation of grief in relation to death and dying, the change curve was extended by Kübler-Ross and Kessler to include any type of change, loss, or grief [53]. It has therefore been applied to a variety of contexts to understand how people individually and collectively respond to change. Recently, Kessler has explained that it is important to understand current experiences of the ongoing COVID-19 pandemic, and the widespread loss of many social patterns, through this framework [9]. Of relevance to the present study, within the context of the COVID-19 pandemic, the change curve has been used to manage how students experience stress and frustration when adjusting to a flipped classroom structure to which they are not accustomed [61], and how organizational change results in employees who experience loss of their co-workers, technology, or location [27].

As a nonlinear framework, the change curve does not predict someone's experience, but instead enables us to understand and make meaning of an experience. Kübler-Ross and Kessler [53] explain:

> "The five stages...are tools to help us frame and identify what we may be feeling. But they are not stops on some linear timeline in grief. Not everyone goes through all of them or goes in a prescribed order. Our hope is that with these stages comes the knowledge of grief's terrain, making us better equipped to cope with life and loss" (p.7).

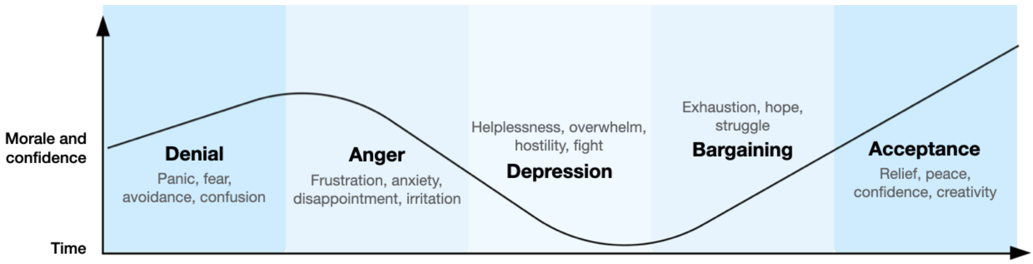

Fig. 1. We apply the Kübler-Ross [52] Change Curve to our study. The role conflict as a result of the COVID-19 pandemic was a shock to parents. The loss of professional behavioral support was the catalyst that caused parents to navigate the role change through the Kübler-Ross Change Curve.

The change curve further visualizes these stages according to the level of morale and confidence experienced. For instance, denial is high on the curve because confidence is high, while depression is the lowest point on the curve. Figure 1 illustrates the five stages along the curve. A person can cross between these stages over periods of months or years, or they can switch between multiple stages within a matter of minutes:

1. **Denial:** People commonly experience denial first, as a temporary defense that carries them through the initial wave of pain. Denial can help people cope with the change, making eventual acceptance possible. In denial, people would rather the change not be true and therefore genuinely struggle with the fact that their daily life might alter dramatically.
2. **Anger:** When people are not in denial, but instead begin to react to the change, they may feel anger. In this stage, it is common for someone to feel resentment, concern, fear, or frustration, and think 'why me.' They resist the change actively or passively, and may also feel the need to express their feelings and concerns, to vent their anger, to blame themselves or someone else for the change. It can be difficult to care for others in the stage due to the outpouring of emotions and anxiety, which can overwhelm the person.
3. **Depression:** When a person has a deeper realization of the inevitable change that has occurred, depression may also set in, and their mood and energy tends to go down. Their morale is at its lowest point in this stage, as is their confidence for coping with the change.

(4) **Bargaining:** In this stage, a person seeks a way out of their situation by asking themselves and others propositions of 'what if' and 'if only.' They may also experiment and seek out supports that help them adjust to and even accept the change, such as obtaining advice, delegating tasks, or adopting technology.

(5) **Acceptance:** If a person has realized that fighting the change will not make it go away, they stop resisting the situation and begin to accept it. Acceptance is the stage in which a person can stop resisting change and move forward with it. They may be less emotional as they move forward. If they expressed intense feelings of depression and/or anger, they may be tired or weak when they are in a stage of acceptance, but their confidence and morale receive a boost.

Rather than predicting the journey of a person's experience, the usefulness of the stages is in identifying what a person may be feeling at any given moment, and what type of support could therefore be appropriate. The stages help us understand why a person is not receptive to support. Knowing this will be a sign to revamp support efforts—try a different approach or alternate timeline—to meet the person where they are (i.e., at the stage they are currently experiencing), instead of just abandoning support efforts. For instance, providing informational support to someone in denial may not be appropriate because they are not likely to feel they need it. Whereas, providing tangible support (e.g., setting up a piece of technology) for someone in the depression is likely to be appreciated, as they may find it difficult to take care of such tasks themselves.

2.3 Continuity of Behavioral Care

Behavioral care encompasses the social learning, supports, and interventions that parents and practitioners use to help children develop social and emotional skills. These skills enable children to regulate their emotions, develop positive interactions and healthy relationships with others, and cope with challenges and stressors that arise in their schoolwork—all of which lead to improved long-term outcomes [38]. Family life [34] and school [82] are important contexts for children's behavioral care. Slovák and colleagues have studied the design and use of technologies in each of these contexts for helping children learn social and emotional skills [87–89]. We complement this work by focusing on the experiences and role of the parent in maintaining continuity of behavioral care across contexts.

When it comes to meeting their child's individual needs, just as a child's medical diagnosis (e.g., diabetes, cancer) changes the role and responsibilities of a parent [29, 84], so too does a behavioral diagnosis. A diagnosis such as attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder (ASD), oppositional defiant disorder (ODD), or post-traumatic stress disorder (PTSD) can help a parent understand their child's behavior and needs. In turn, the child will then be able to understand and advocate for their own needs. A behavioral diagnosis also helps parents and children access appropriate support, accommodations, and services. By law, the education system is responsible for providing these to ensure a child's equal access to education—as per the Individuals with Disabilities Education Act (IDEA) in the United States. Our focus in this work is on behavioral and emotional disabilities, which can affect academic learning as much as they affect social and emotional learning. Once a behavioral disability has been identified in the school setting, practitioners are required to document and implement an individualized behavioral plan, in what is known in the United States as an Individualized Education Program (IEP) or 504 Plan. A range of school-based practitioners, such as special educators, speech-language pathologists, occupational therapists, psychologists, and social workers may be involved in assessing and meeting the individual needs of a child. Therefore, parents may need information from a network of practitioners representing various disciplinary perspectives and approaches to their child's needs.

Behavioral diagnoses and disabilities can be subjective to measure, classify, understand, and accommodate [62]—making effective collaboration between parents and practitioners especially important [80]. However, communicating with practitioners can involve real barriers and breakdowns for parents. Within the educational system, coordination challenges persist despite an increasing number of communication mediums, including email, SMS, mobile applications, and classroom management software systems [19, 64]. As behavioral services cross from education to healthcare, clinical information systems do not always support quality of care and communication [7]. For example, these systems may not give parents real-time access to their child's data, and may not include features that help them get to know their care team or prepare for change such as hospital discharge [48]. At the core of these challenges is the amount of effort that it takes to develop a shared understanding of the child's behavioral needs, and how best to address them, among distributed caregivers (e.g., family, informal, and professional) [80]. Developing shared understanding requires building relationships and sharing actionable information across organizational and disciplinary boundaries [80]. For example, school-based practitioners can provide parents with prescriptive information via behavior management resources and training, and descriptive information via regular meetings and observation. The nature of this collaboration is highly organic, and not always supported by information systems that tend to enforce structure and standardization [63].

3 METHODS

This study is part of a larger mixed-methods study that aimed to better understand what parents need to deliver consistent behavioral care at home following a stoppage of professional support due to the COVID-19 pandemic. Within the first few months of the COVID-19 pandemic, we engaged parents across the United States in a diary study, followed by an interview study with a smaller subsample. We asked about their lived experience of providing care amid disruption. In doing so, we were able to gather rich qualitative data on how they continued to respond to change. This paper reports on the in-depth qualitative analysis of the interviews, which provide an empirical characterization of how parents navigated role conflict and role change due to a disruption in their child's behavioral care.

3.1 Recruitment and Sample

Upon IRB approval, we recruited parents to participate in the larger diary study using three methods: word of mouth snowball sampling, social media ads (i.e., study posts shared on Facebook, Reddit, and Nextdoor), and through our University's Health Research website (i.e., our study ad posted on their free and secure website). Each mode directed participants to an online screening survey hosted by Qualtrics. Potential participants were not compensated for completing the screener and it took, on average, 1 minute and 21 seconds to complete. To qualify for the larger diary study, participants needed to be: (1) a parent or guardian of a child in 8th grade or below with documented behavioral needs (e.g., IEP, 504), (2) at least 18 years old, and (3) fluent in English. We focused on parents of children in middle school or younger because, at this stage of development, children are not fully managing their schoolwork or other activities independently, given the range of their behavioral health diagnoses. Of the 116 parents screened, 78 qualified, and 59 participated.

Within the final survey of the diary study, we asked parents if they would be interested in participating in our follow-up interview study. Of the 59 parents, 50 indicated that they would like to participate. From the 50, we invited 37 parents via email to participate in a one-hour interview. Of these, 18 parents accepted our invitation, 16 completed the full interview. Thus, our final sample size for the current study is 16. Table 1 describes the demographics of these participants. The average number of children in their household was 2.06 (σ=1.19). Table 2 describes their children's demographics.

		n=16	%
Gender	Woman	13	81.3%
	Man	3	18.7%
Race	White	12	75 %
	Black or African American	2	12.5%
	Hispanic or Latino	1	6.25%
	Mixed Race	1	6.25%
Marital Status	Married	10	62.5%
	Single	4	25 %
	Divorced	2	12.5%
Location	Midwest	13	81.3%
	South	2	12.5%
	West	1	6.2%
Highest Level of Education Completed	Bachelors	7	43.8%
	Some College	4	25 %
	Associates	2	12.5%
	Technical	2	12.5%
	Doctoral	1	6.2%
Income	\$10,000-29,999	2	12.5 %
	\$30,000-59,999	5	31.25 %
	\$60,000-89,999	3	18.7 %
	> \$90,000	5	31.25 %
	Prefer not to answer	1	6.3 %

Table 1. Parent Demographics. Most parent participants were white (75%), women (81.3%), from the Midwest (81.3%), and had two children (μ=2.06, σ=1.19). All participants obtained a level of education beyond high school.

3.2 Data Collection

We conducted the 16 interviews between June and July 2020, which was approximately two months after COVID-19 was declared a global pandemic and most schools shut down. Using a semi-structured interview protocol, we asked parents about their experiences coordinating care for their children with behavioral needs, how they interacted with other members of a care team, and the information they wanted to be exchanged among care team members. We also asked parents about communication with their child's school before and during the pandemic; the experience of managing their child's behaviors and educational needs at home; resources, support, or strategies they might have needed and/or used to help with managing their child's behaviors at home; and what they might have learned during the stoppage of school-based behavioral care. Because the pandemic was such a widespread and collective experience, it provided an opportunity to discuss experiences of change with relative openness and less participant burden (i.e., parents did not have provide context to the changes in their lives). The significant disruptions across a range of behavioral services enabled parents to reflect on their dependency on various supports (e.g., teachers, therapists, and technology) as well as what information is most important to them in order to maintain continuity in their child's behavioral care.

Interviews lasted between 29 and 66 minutes (μ=49 min, M=48 min) and were conducted remotely using Zoom. Each participant received a \$25 gift card to a store of their choosing. All interviews were audio-recorded and fully transcribed. We uploaded interview data into NVivo for analysis.

		n=16	%
Gender	Boy	11	68.8%
	Girl	5	31.2%
Type of School	Public	13	81.3%
	Charter	3	18.7%
Age	6 years	6	37.5%
	7-10 years	4	25 %
	12 years	4	25%
	13-14 years	2	12.5%
Diagnosis	Attention Deficit Hyperactivity Disorder	10	62.5%
	Autism Spectrum Disorder	7	43.8%
	Oppositional Defiant Disorder	6	37.5%
	Anxiety Disorder	5	31.3%
	Learning Disability	2	12.5%
	Post-Traumatic Stress Disorder	2	12.5%
	Other Disorders	4	25 %

Table 2. Children's Demographics.

Children were mostly between the ages of 6-8 (μ=9, σ=3.06, Range=[6,14]). Nine of sixteen parents reported more than one diagnosis for their child (μ=2.31, σ=1.7, n=16). 'Other disorders' reported include Obsessive Compulsive Disorder and more specific health conditions.

3.3 Data Analysis

In weekly meetings, the first and third authors reviewed the transcripts and discussed their interpretations. They developed themes over time by comparing findings across interviews. Our initial analysis revealed tension and conflict in parent's role in their child's behavioral care following the loss of professional behavioral care due to COVID-19. The first author developed structural and descriptive codes to explore recurring themes in the transcriptions of the interviews and notes from interviews. The first author coded the data, wrote memos, and took notes. They later discussed the data in weekly team meetings to generate, review, and refine themes over time around the concepts of information needs and role conflict, using reflexive thematic analysis [15]. Finally, using the lens of role theory, we used a deductive approach to analyzing parents' experience with role change [22] according to Kübler-Ross' stages of change [52].

4 FINDINGS

Home and school are typically siloed environments, where a child is nurtured by either parents or teachers, respectively. However, the COVID-19 pandemic collapsed the boundaries between home and school, expanding the role of parents in their child's development. Our study revealed that as parents experienced new aspects of their child's daily life, they felt role conflict specifically, the pressure to fulfill more than one role at once [e.g., parent, teacher, therapist, etc.].

Attempting to provide the same level of behavioral care at home, as special-education teachers and therapists do at school, was a significant change in their role as a parent. This role change led parents in our study to seek information from practitioners (i.e., special education teachers, speech and occupational therapists, counselors, psychologists, social workers, and more)—to help them provide behavioral care at home in conjunction with how it is delivered by school practitioners.

We also found that parents' information needs are tightly coupled with their experience of role change. When parents better understood their role, they were better equipped and more confident in supporting their child's development. Therefore, to provide information resources that meet parents' information needs, we must understand their journey through Kübler-Ross' stages of change. To this end, we found that when parents had support for themselves and their child in the earlier stages, they were better able to navigate their role change and reach the final stage of acceptance more easily.

We first characterize our findings around the stages of role change that parents experienced because of the COVID-19 pandemic. Next, we describe parents' strategies for addressing the new and/or changed needs that transpired for them during each of the stages of role change (e.g., information-seeking). Finally, we conclude by describing the unmet information needs that parents in our study had, despite their best efforts to seek support. Taken together, our parents' shared lived experiences shed light on the opportunities and limitations of technology for delivering behavioral health care at home.

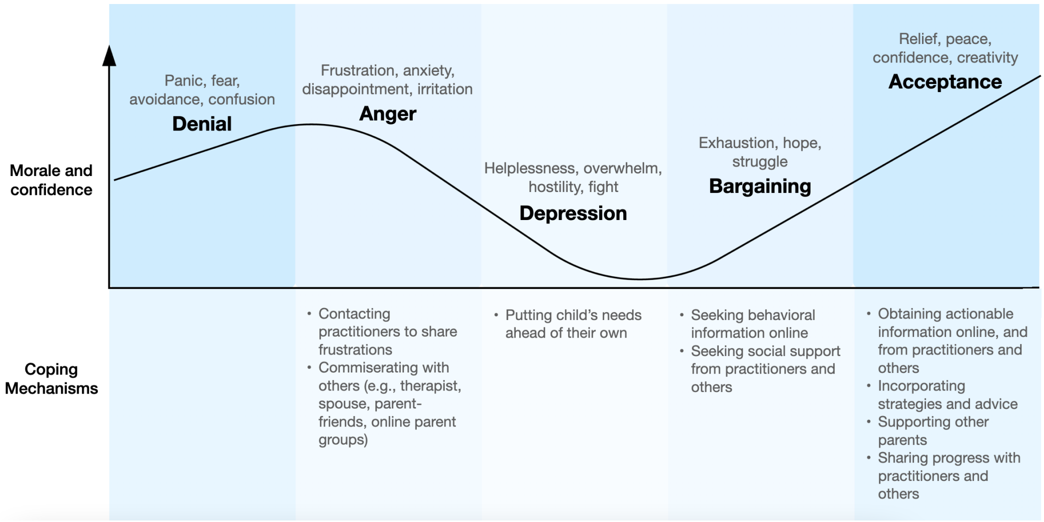

Fig. 2. We apply the Kübler-Ross [52] Change Curve to our findings and describe parents' coping mechanisms in navigating role change. Applying Role Theory, the role conflict from the COVID-19 pandemic was shocking and the loss of professional behavioral support was the catalyst

4.1 Parents Navigating Role Change

Figure 2 summarizes Kübler-Ross' stages of change—denial, anger, bargaining, depression, and acceptance—that parents experienced as they negotiated their role change. Understanding this process can help us identify information needs across the different stages of change, so that we can design appropriate supports for parents. We can, for example, design for collaboration, where the care team is meeting the needs of a parent in a way that accounts for their unique experience(s) in each stage of the change curve, rather than working against it. In doing so, it increases the likelihood that acceptance and support for the child can be more easily achieved.

4.1.1 Loss of professional behavioral support: Catalyst for role change. At school, various practitioners provide behavioral services, according to each child's specific needs and individualized IEP (e.g., physical, occupational, and/or speech therapist, social worker, special educator, etc.)[85, 86, 99].

However, pandemic-related school closures caused a stoppage of federally mandated professional behavioral care in the U.S.

We found that the COVID-19 pandemic collapsed the boundaries between home and school, taking away the support and collaboration parents had to provide behavioral care and support for their child at home. This was problematic for many parents, as they reported relying on the behavioral care their child received at school. For example, as articulated by Andrea[1]: *"I think parents like me and our situation, look forward to them going to school to get that special help that they need."* Further, many parents reported feeling alone and abandoned without this hands-on professional care and expertise. Lauren explains this well: *"I don't know that the schools could've done anything, but that's where we felt most abandoned. Like gosh, now with no notice, we're trying to scramble and figure out [childcare]."*

Many parents in our study also felt the overwhelming feeling of role conflict (i.e., being pulled in multiple directions). They tried their best to fulfill all the roles that were now left unfulfilled in their children's lives (e.g., teacher, therapist, occupational therapist, and behavioral analyst). Adrienne describes the panic associated with her role conflict:

> *"At the beginning it was hard, I think, because...my husband at that time was home... We're both working 40 hours. And then to top it off...my husband is awesome at teaching but I suck at teaching. So I tried to do my best. And I kind of harped in on what I think I do best. And then I left the rest of the stuff for my husband. But then my husband had to go into the office, and I panicked. Because I thought, "I have to do work. I have to be a home school. I have to be a mom." And it takes a toll eventually, right?"* (Adrienne).

Additionally, in this example, Adrienne clearly articulates how she, and likely many other parents, also feared the anticipated emotional and physical toll that trying to serve in multiple care roles would take on them and their capacity to help their children. Together, these feelings—of fear, insecurity, abandonment, and loss—served as the catalyst for parents' role change. In the application of Kübler-Ross' change curve, we describe the stages of parents' role change and provide specific examples of each.

4.1.2 Stage 1: Denial. In denial, parents in our study were in shock and struggled with the fact that their daily life might dramatically change. They rejected the need to change their role. As a result, most had not yet reached out for support or refused to accept it, should it be offered. From some parents' perspective, the pandemic and subsequent change was going to be 'temporary' and 'normalcy will return soon,' thus negating the need for help. Parents who were less sure of the temporality also seemed to reject the idea of needing help. Perhaps, amidst their confusion as to what was happening and their questioning how long 'it' (i.e., the loss of normalcy) would last, this group of parents did not know what, if anything, they needed, so reaching out for help seemed pointless. Indeed, Paul shared that *"What's been most challenging is not having any answers. Not having the answer about, when we first got quarantined, is school going to be re-established? Or is it going to be like this until the end?"*

Denial is a coping mechanism that acknowledges and prevents people from handling too much at once (e.g., role conflict). Not accepting change helps to stagger the full impact of it. Once the denial and shock fade, people can begin to work towards acceptance. At this point, those feelings that were once suppressed now to come to the surface and people start to move along the curve. In our study, parents quickly moved out of denial due to the gravity of their child's needs.

4.1.3 Stage 2: Anger. As reality set in, that the pandemic was not temporary and their roles have or will dramatically change, parents were faced with the pain of a loss of normalcy and role conflict as

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[1] All parent and child names have been changed to pseudonyms.

they became full-time behavioral support for their child. This led to feeling frustrated and helpless, which for some parents, turned into anger.

In expressing their anger, some parents talked about their struggle with and/or questions about their "new" duties and role conflict—was it all up to them now? Are they now responsible for every role in their child's life? For example, Andrea spoke about all the practitioners whose support she was accustomed to and felt she [still] needed:

> *"Anything in-person would have been better than nothing...There needed to be some exception for these kids who needed the extra help...I'm not qualified and all of a sudden I had to be a social worker, a therapist, a teacher, an OT. I shouldn't have been thrown into something like that with Saquon. I would have liked to have been able to take him somewhere at least for an hour, to be with someone qualified to deal with his education"* (Andrea).

Andrea was willing to do almost anything for in-person care and she was frustrated because she felt her child needed such support.

Competing demands, the unknown about the pandemic and their child's schooling, and confusion over what they needed to do to support their children all amplified parents' anger. Because most parents grappled with these things, many also expressed feeling frustrated, irritated, and anxious about the loss of professional behavioral support for their child. Shanice explains some of what was happening in this stage for parents:

> *"The family balance, and the dynamic of working from home, children, being a full-time behavior support for her in a sense, as well as my other children. It's like wearing a high heel and a house shoe at the same time. Doing everything for everyone, 24 hours a day"* (Shanice).

Parents were also angry that their right to professional care for their child, which is required by law, became blurry, forcing them to think about having to meet this new gap in their child's care. Andrea explained how she and other parents were angry, living in "a lot of chaos" without an understanding of the implications of the pandemic on the delivery of legally mandated care:

> *"They were all wondering and waiting. What is going on? What are we supposed to do? Are they supposed to follow the IEP [or] the 504? What are my rights? We were all in the dark. We didn't know what to do... now that [daily behavioral care] was taken away from us and put on all of us. It was very frustrating...every question on the groups turned into something like that. What do we do now that they're not in school? He's going to be so far behind. It was a lot of chaos"* (Andrea).

While angry about the lack of professional support they received, many parents also grappled with having conflicting feelings about this reaction: On one hand, parents tried to be understanding—that teachers and professional care team members were also experiencing the stress of the pandemic—but, on the other hand, they wanted answers to their questions and assistance in supporting their child. Shanice provides an example of this internal conflict:

> *"30 kids, one teacher. I only can imagine...the circumstances that they have. But I say [I need communication] at least once a week...to feel supported...I say, 'Hey, I'll hold on to these questions till Friday,' if there's something that's going... the biggest thing is that I don't feel very supported right now"* (Shanice).

Although several schools provided families with technology for their children's learning (e.g., Chromebooks and iPads), they did not provide behavioral support, leaving many parents upset that the school did not seem to be doing enough for their child—if this was their best, it wasn't enough, and they needed to do more. Several parents were upset because they could not understand how there were no exceptions or additional resources for their children, as they know that one-on-one care is crucial for their child's behavioral development. For example, Lauren expressed her dissatisfaction with the lack of (necessary) physical support for her child:

> *"Parents with special-needs kids can't just rely on anybody. A lot of people were like, 'Oh, my kids are going to go to their grandparents' house, or I'm going to work from home.' None of these were options for us. [We needed] some kind of respite"* (Lauren).

Andrea was equally frustrated and upset that in-person care was unavailable, stating *"It was hard and anything other than someone else doing it, really wouldn't help. Because I tried so many things."*.

As a result of this frustration and as a way of coping, many parents contacted their child's school and behavioral support system for resources and with questions about accommodations for their child, amidst the COVID-19 pandemic. Some parents felt supported by practitioners with frequent communication, frequent check-ins, and openness to questions. These few parents felt better knowing they had help and that they could reach out when and if they needed support. For these parents, this conspicuous support was encouraging and helped them move through this stage. However, this was not the case for all parents. Instead, many parents reported experiencing infrequent communication that was generalized to the entire class (not specific to their child's needs), which only further angered them. For example, Rich shared that he had contacted his daughter's speech therapist to verify an online resource, and was frustrated to not receive a response until *"several weeks in [to quarantine]... And it was sub-optimal at best."*

In an attempt to manage or cope with their feelings and new/changed roles, many parents commiserated with parent-friends, joined support groups, and/or met with a therapist as a *"safe space to go and just kind of rant"* (Mallarie). Some parents, such as Andrea, talked about how they spent time in online groups that are dedicated to children with behavioral needs, as these spaces provided them with a safe place to share their similar experiences and find community.

4.1.4 Stage 3: Depression. In our study, parents entered the depression stage largely because they were struggling with navigating role conflict. They were trying their best to carry out all the roles of the entire care team, as they had not yet negotiated the bounds and requirements of their new role as a parent during a pandemic. Several parents even explicitly said that they "tried to do it all," (e.g., Lauren, Adrienne, and Eve), but nothing was working for their child or by extension, them. As a result, these parents experienced feelings of helplessness and defeat, which are hallmark signs of depression. Parents, like Lauren, also described how role conflict caused them stress and significant burden:

> *"I really wish [the hospital] had furloughed me or laid me off so I could be [at home]. I think just the stress of suddenly I don't have a childcare option. I've always had to put those plans in place very early, and during the pandemic… it was really difficult like, 'How am I going to find somebody to come into my house and keep my child, when everybody's so stressed out about their health and avoiding this?' ...I don't have family here...there was no option...just that stress... was the worst part"* (Lauren).

The loss of professional child support also left many parents feeling overwhelmed and alone, which can lead to feelings of sadness. Shanice, for example, felt alone as she acted as her daughter's behavioral therapist and teacher:

> *"I would have liked for engagement, or not to just feel like I'm alone in the behavior part of her schooling and her changes, her adapting to this...It's been overwhelming at times, especially considering the circumstances...I have two other children in the home. I am trying to understand...what she was going through... So, trying to say you understand, but then at the same time, issue praise when she does good things. But then not make the*

> *other kids feel neglected, and feel like they're getting full attention. It's hard. It is honestly hard"* (Shanice).

Talia and Adrienne similarly felt alone with fear and worries of the future implications of the stoppage of professional behavioral support for their boys. Talia shared how her son's *"ODD is what worries me because it says they're going to have problems at school and work. And I'm like, you know, he's going to be an adult one day and what am I... I'm just so worried."* Similarly, Adrienne cried while reflecting on her fears of her child regressing and constant confusion about the expectations that she and her husband set for their son:

> *"A month into the pandemic, when we had his IEP [meeting], all I could do was cry...I know he's different, but I don't think of him as being different...And so they told us, 'You need to cut back and do half or quarter of what he was doing in real school, and understand that a typical kid will be delayed.' And that was my fear. I didn't want him to regress...I'm very much like, 'You have to do A, B, and C.' And my husband was more like, 'Hey, you need to back off. You need to give him his space. He needs to be a kid and run around'...I said 'I'm going to do a little more than what she said.' And he's like, 'Listen to her. Stop being hard-headed. Just do it." And I did. It made my life a little easier. It made his life easier. And [my son] got back to being his regular kooky self, like, 'Okay, I don't want to do this assignment,' but not meltdowns, like crying or telling me, 'Mom, you need to back off' "* (Adrienne).

Many parents also reported that they did not have support from their child's school to learn how to support their child, which only added to their grief. Parents are typically removed from their child's school and unfamiliar with their child's learning style(s), nor do they have the behavioral expertise, education, or training of the practitioners who support their child. Coming to terms with this loss of professional behavioral support, and seeing their child struggle through daily activities and/or regress in their skills, contributed to many parents' feelings of depression. Several parents talked about how they did not want to watch their child suffer the consequences of the change, including Eve: *"The struggle of watching him struggle was really hard for me."*

Most parents did not discuss how they attempted to cope with depression. Instead, they seemed hyper focused on their child, putting their child's needs ahead of their own mental health and well-being. For example, Talia shared *"I'm more concerned about him. If he's okay, then I'm okay."* However, as time went on, and parents moved into bargaining, they developed a better understanding of their child's needs and began to bargain for help.

4.1.5 Stage 4: Bargaining. Parents sought out ways to get them through their current situation (i.e., role change) in the bargaining stage, often negotiating with others for "things" that might help (e.g., more or different technology, communication, and/or physical help). The parents who previously received offers of professional support (e.g., for anytime email or phone access), now began to accept them. Parents were still trying to do it all in the bargaining stage, but they were now asking for help and resources. At least five participants explicitly shared how their child needed in-person professional behavioral care. Andrea clearly indicates how she would be happy to take her son anywhere that would provide in-person behavioral support *"behind plastic with masks, whatever they required... I feel like anything in person would have been better than nothing."*

Parents were also desperate for behavioral management strategies. In effort to engage her son and manage his behaviors, Andrea shared how she was reading books and frequented several parent groups on Facebook to *"get ideas from other people...to come up with a reward system that he will respond to."* She explained that she would *"try anything"* with her son since *"trying to get him to do daily life tasks and skills is difficult."*

Several parents also shared struggles in managing their child's behaviors due to educational plan(s) and school requirements. More specifically, the virtual school structure and class-wide video calls were not working for their children, including Adrienne and Mallarie, who noticed that her child did not do well in the chaotic online environment, saying: *"it was like a classroom style. She had everybody on, and she would read a book, and they were talking about different things."* However, since parents were in the bargaining stage, they reached out for help and experimented with the strategies they found. For example, Adrienne talked about how she emailed her child's teacher, requesting a one-on-one meeting. Even though she *"wanted him to have that social aspect of it,"* Adrienne disclosed that it was a battle to get him in front of the computer and did more harm than good. In response, Adrienne said, the teacher offered to set up individual video calls with her son and exchange letters via postal mail. This small suggestion gave Adrienne hope that things might get better.

As parents asked questions and bargained for help, they began clarifying their role. Here, in this stage, many parents realized they are not alone, and they did not have to be everything for their child. Narratives like these, around making and asking for adjustments—that it was okay to ask for help because they were never expected to do it all—indicate that parents were entering into and reaching the final stage of acceptance. In communicating with members of her child's professional care team, Mallarie, for example, realized that she is bound by her capacity and doing her best, exemplifying this final transition well: *"I'm home with five kids and trying to work... I know him and I can help him, but I'm not his therapist. So I can't do everything that he needs. And so that was hard...I'm not Wonder Woman...I can't be everything for him... all the time."*

4.1.6 Stage 5: Acceptance. Eventually, almost every parent in our study entered the final stage of acceptance. Parents arrived at acceptance once they fully resigned to the loss of professional support precipitated by the pandemic. These parents stopped resisting their role change and instead, moved ahead with it. In doing so, they recognized that they needed help from other roles (i.e., a practitioner) and that they did not have to do it all. These resilient parents now obtained actionable information from practitioners and integrated the advice they received across the stages.

In acceptance, parents in our study:

1. Acknowledged a great willingness to learn. Catherine, for example, mentioned how the quarantine motivated her to learn how to best help her daughter:
   > *"It's definitely taught me a lot being in quarantine and having to deal with Addie throughout the day. So, right now, I'm just keeping notes, keep watch, keep talking to her therapist, me kind of learning more techniques on my own on what I need to do to kind of help her at home"* (Catherine).

   She relied on her daughter's professional care team for support in managing the challenging behaviors that arise from autism.
2. Realized that they need, and subsequently accepted help, whether it was from people or technology. For example, as a front-line worker, Lauren depended on her other children to manage her son's care. She also shared that because of the pandemic, she got out an unopened Amazon Echo device, which she received as a gift (but never used prior), to creatively ease daytime transitions of care while she was at work:
   > *"I felt responsible for everybody's education, but I'm still at work all day. We have an Alexa and I built their schedules into the Alexa...We relied on that technology so much. That was how the kids knew to change shifts with their brother like, "Hey, you've had him for two hours. Now, you need to pass on the responsibility to somebody else"* (Lauren).
3. Creatively approached their child's behavioral care and education. As parents' confidence grew, so did their willingness to try unconventional methods of learning such as nature

walks or cooking. They were comfortable with trial and error decisions about their child's educational and behavioral needs. This also helped them become more comfortable in their role as a parent. For example, several parents decided that learning does not have to be done on paper, including Lauren, who used dinnertime to *"instruct with him"* since *"he's very motivated by food,"* and Andrea, who *"did other things to sort of incorporate learning. We went on walks and talked about things in nature and did art projects, and stuff like that that he could do, that wasn't school but was still teaching him something."*

(4) Shared that this experience will forever (positively) impact how they collaborate with their child's school in the future. For example, Mallarie highlighted how this would affect the way she advocates for her child:

> *"I'm just going to be a little more adamant that we do things the way that will work best for us...that I know my kid. And they're so sweet. But we know him best, and he has a therapist who really knows him well and is specifically trained in how to handle a kid like Darian, and that our way is actually really, really good. So we're just going to be really firm about that"* (Mallarie).

Navigating their role change and reaching acceptance required unimaginable effort by parents. Without readily available information and support, they sought help to best support their child amidst a pandemic enforced role change.

4.2 Parents' Coping Mechanisms for Navigating Role Change

After being suddenly *"thrown into"* (Shanice, Andrea) new support roles, parents needed information and strategies to provide a new level of care. Below we describe how parents coped while trying to meet their child's behavioral care needs. Specifically, we outline parents' adaptive coping mechanisms via three overarching themes: (1) seeking social support from practitioners, (2) seeking and providing emotional and esteem support online, and (3) seeking informational support online.

4.2.1 Seeking social support from practitioners. As the pandemic became their new normal, parents in our study shared that they contacted their child's special education teacher(s) and therapist(s) (i.e., speech and/or occupational) more than they ever had before for social support (i.e., informational, emotional, and esteem). However, the frequency and quality of communication with school practitioners during the quarantine varied greatly amongst parents in our study. Several parents, such as Paul, Andrea, and Lauren, also asked for documentation and in-person support, but were met with inaction.

Parents reached out to practitioners, asked questions about behavioral management and teaching, and requested resources and strategies that reflected their child's unique needs. Parents suggested that regular communication and responsiveness was especially encouraging. This social support was particularly helpful in times of serious behavioral challenges, or when parents were in the anger and bargaining stages. Eve, for example, shared that her son's special education teacher, general education teacher, and social worker all communicated with her daily, noting how helpful that was for her and her son.

> *"Trevor is in a special education class, so he was in...a resource room. They were very responsive. Just the smallest thing...a quick email...a quick phone call...they would always answer. I never had any issue. So, I communicated a lot with them, the social worker from school, and his actual general education teacher"* (Eve).

Many parents, such as Catherine, also explained how practitioners would tell them to *" 'email me if you need anything.' So, that was kind of my resource outlook if I needed anything I could just contact them."* Parents felt better knowing that if they needed anything, they were welcome to reach out, even if they were not ready to accept the help yet.

Parents in our study shared sentiments that group video calls (e.g., Zoom, Google Hangouts) were quite overwhelming and anxiety-inducing for their children, building on work by Zolyomi et al. [101] that video calls are also stressful for autistic adults. It was nearly impossible to get some children to attend to the call. Considering children's need to socially engage with peers or an adult, parents, such as Adrienne and Mallarie, asked for advice on how to help their children socially, with engagement and building social skills at home. Both of their sons' teachers suggested they schedule individual video calls with one friend or their teacher; this was a way they could socially engage with peers or an adult, yet avoid the taxing nature of group video calls. Adrienne took the teacher's advice and scheduled 30-minute Zoom calls for her son and his friend, but she said that they typically went longer as *"they talked about video games...It makes them happy, both of them."* These individualized recommendations provided Adrienne and Mallarie with a sense of relief and hope that things would get better.

When provided with informational support (e.g., training, individualized instructions, and real-time guidance), parents felt capable. Catherine, for example, continued to share how her daughter's occupational therapist (OT) was good at explaining how to physically help her daughter through the session and sent pamphlets with instructions for strength-building exercises. She also explained how the OT *"was providing me stuff to help out at home… during the meeting, we would do stuff together...she would sit there and instruct me."* Although the meeting was virtual, the togetherness encouraged her to facilitate therapy sessions.

4.2.2 Seeking and providing emotional and esteem support online. Numerous parents reported missing various kinds of support as they worked to provide individualized behavioral care for their child, so they looked online for emotional and esteem support. Specifically, many parents in our study sought and provided informal support with other parents via social media (e.g., Facebook groups) or synchronous virtual peer support groups. Others also sought formal support through individual or group therapy. For example, Blair found comfort in speaking with and listening to other parents in a peer support group, because other parents had shared lived experiences and could understand what she was going through. Blair articulates how she *"found a lot of help just by being able to talk to the other parents who kind of know. I have a couple of parent friends who I can vent to about stuff like that. I tend to seek that out... I ended up running the* [peer] *support group after a while."*

Andrea similarly joined several online groups, both related and unrelated to her son's diagnosis, because of the *"overlap with the disorders."* Even if she did not find help for herself or her son, she felt she could contribute and help other parents:

> *"I feel like all these other moms can help me out. They've been through it, they know what they're doing sort of. Or if they don't, they do the same thing I'm doing, just talking to people and seeing what works for them. It's been very helpful to have that support of people who have gone through it, or are going through it"* (Andrea).

4.2.3 Seeking informational support online. Parents suggested that they had a plethora of information needs related to their new role(s). To help them fulfill these needs, parents in our study looked to the internet for informational support (e.g., actionable strategies, resources, activities, ideas, and advice) related to their child's specific behavioral management, therapy, and teaching needs. Shanice, for example, sought behavioral activities *"to enforce sharing, incorporating tasks like taking turns"*,while Paul and his wife were *"constantly on the computer, looking at different ways to speak to, react to, and manage ADHD kids, kids with severe anxiety... on positive parenting websites."* Paul emphasized how they were *"always trying new and different things from Facebook groups"* since the content was *"very useful."*

For parents who lacked contact with practitioners, they found the internet to be a helpful starting point in understanding their children and how to best help them. For example, Shanice shared that she *"did not know where to even start"* to find answers to her questions, such as how to get her child *"to do certain things. How do I reward good behavior, but don't make it to be expected when she does something nice?"* Similarly, Talia sought resources and information about her son's diagnosis because she was unable *"to go to a doctor's office and get help from them...So, the only resource I know of is just to go online and try to see if I can find any help there."* Similarly, Catherine used the internet to understand how her daughter's behaviors align with her current diagnosis. She was doing her own research, as her daughter was on a waiting list for testing and it would *"take some time to fully grasp everything that she has."*

4.3 Unmet Information Needs during Role Change

Despite their best efforts to seek support in the process of role change, the parents in our study had several unmet needs, including (1) actionable information related to behavioral care, (2) validation of online resources, and (3) shared understanding of capacities, expectations, and progress. We describe each of these overarching unmet needs below.

4.3.1 Actionable information related to behavioral care. As discussed above, several parents wanted regular communication from their child's professional behavioral care team. They wanted actionable information (e.g., activities, behavioral management strategies) that could help them navigate the new tasks related to their role change, even if they were not tailored to their child's specific needs. However, many parents received information that was was too generic and thus, not suitable for their child's individualized needs. Equally, they wanted fewer "unimportant updates" about new assignments due or missing schoolwork. Rich, for example, explained how he received *"somewhere between 8 and 10 emails a day with various assignments and comments"* that were unrelated to the behavioral information that he requested from practitioners. Overwhelmed with information that was not useful, Catherine described how she stopped asking anyone for information because she *"was getting so much information from all of her teachers and her therapists at the time that I pretty much already had my head in water."*

At various stages of change, parents felt alone and suggested that receiving actionable information, such as strategies for managing their child's behaviors would have helped. For example, without even weekly contact regarding her daughter's behaviors, Shanice described how alone she felt:

> *"We are thrown into a situation that no one asked to be in with COVID-19. So I feel like [teachers are] learning also how to deal with providing behavior support. But at the same time, I would have liked for engagement, or not to just feel like I'm alone in the behavior part of her schooling and her changes, her adapting to this"* (Shanice).

Parents also expressed how they needed instruction to confidently facilitate therapeutic activities. For example, Rich explained how he would only facilitate speech therapy activities recommended by his daughter's speech therapist if he thought he *"could do them competently... It'd have to be a very dumbed down version of speech therapy to make sure I was doing it right."*

Additionally, parents expressed a need for guidance on behavioral management more quickly and perhaps directly from the practitioners who were familiar with their child (e.g., strategies for managing behaviors and detecting signs of an outburst). Paul, for instance, sought help with terminology when discussing behavioral incidents with his son. Paul's son's school-based social worker provided an approach to behavior management when he landed on *"a twofold perspective called expected behaviors and unexpected behaviors."* He noted how helpful this was for his family. Similarly, Mallarie asked her child's resource room teachers for *"different ways of reacting to [her* *son] when he would get in those moods."* However, since her request went unanswered, she looked to practitioners outside of school for behavioral management strategies. Because school support was so insufficient, several parents relied on other practitioners, who work with their children outside of school, for information. Vallerie, for example, asked questions in weekly parent sessions with her son's behavioral therapist. Whereas, Shanice, Mallarie, and Catherine gave up on contacting their children's school and texted their in-home behavioral therapists. Shanice shared that she contacted her daughter's behavioral therapist, instead of the school, because she was *"a direct line, a quicker response...[and] a more personal approach ...she sent out tips...*[She was] *more proactive and gave more tailored [behavioral] information."*

4.3.2 Validation of online resources. Parents often felt defeated when searching online for resources. It was time consuming, not always successful, and challenging because the subjects they searched (i.e., teaching, behavioral care needs, therapy, etc.) were not familiar to most participants. Trust was also a concern for many parents. When seeking information online, parents suggested they did not know what sources were reliable or trustworthy. Although it was helpful to have access to information online, Deja explained how unsure she really was: *"It's so much information out there, although I know that people say you can't believe everything that you read."*

Parents also wanted reassurance from practitioners that the resources they found online were appropriate for their child's behavioral needs. To meet this unmet need, some parents became resourceful, looking outside of their child's current behavioral care team for support. For example, Rich, without contact with his daughter's (school) speech therapist, found one on YouTube. Rich suggested he did this because his daughter's anxiety-induced behaviors worsened in quarantine. But he also talked about how unsure he was of this therapist's credibility and thus, waited weeks to watch the videos with his daughter until they were verified by her speech therapist:

> *"I was like, I wonder if I should do this? No, no, I should not listen to a random woman on YouTube...I poked around long enough to realize...I am out of my depth here. I have no idea if this is going to help or is this going to set up poor habits? I think this is a real speech therapist but I have no idea on whether this is entirely appropriate. At which point I set it aside and waited until we heard from the speech therapist....And then it turned out, that was the one that the actual speech therapist from school recommended"* (Rich).

Shanice also expressed similar concern and unease about the quality of the activities and strategies she found online:

> *"[they are] probably not the best because I Googled 'my child is experiencing this' and then it just takes me to a website. I'm not sure it was fully accredited...you get the good and the bad when you just go to Google. Maybe I didn't have the right method of doing it because I would just do a broad search"* (Shanice).

Their experiences with online search emphasize parents' unmet need for credible sources that are appropriate for their children.

4.3.3 Shared understanding of capacities, expectations, and progress. Most parents felt unable to meet the expectation of completing all assigned activities. With infrequent check-ins, parents and practitioners did not have a shared understanding of capacities, expectations, and progress. Parents felt that practitioners were unaware of their children's lacking behavioral progress. However, schools did not expect parents to teach their children nor did they expect they would provide them with behavioral services. Yet, as they experienced role conflict, some parents felt obligated to do so, to prevent their child from regressing. For many parents, this role conflict felt impossible to manage without guidance on what they were expected to facilitate and appropriate training on how to do so. Paige, for example, explained that if she needed to help her daughter *"in any way, I* *would like to be able to know what I can do and how to do it, because I'm definitely not a born teacher."* Eve echoed Paige's desire for training and resources on *"anything educational that's going to help the parent be able to teach the child."*

Almost all parents, except two, talked about how they received extensive assignment lists from their child's teacher(s), which were perceived to be unrealistic, especially considering their children's capabilities. Experiencing these unrealistic expectations during their role change, several parents reached out to their children's teachers in an effort to renegotiate and prioritize. They wanted to know which activities were most important and most appropriate, considering their children's skill-set and the parents' limited capacity to teach and provide behavioral care. Parents, such as Lauren, Mallarie, and Ryan, also discussed how they approached the practitioners working with their children with more confidence than before their pandemic-initiated role change. For example, Lauren explained how she did this because she knows what is best for her son:

> *"We would do it [a task] one time and then I would basically say, 'We're not going to stress out over this piece.' I'd much rather us work on holding his fork properly and eating...I would choose the things that I wanted, that I felt were better skills for him to work on. And there was never an issue. [His special education teacher] would just say, 'Okay, that makes sense to me' "* (Lauren).

After developing specific goals and a shared understanding of capacities, Lauren felt comfortable that her son was not falling behind and that he was meeting his IEP expectations. She explained how her son's teacher provided *"great"* instructions that were *"very specific 'This is all I'm asking for. I just want you to take a video of him doing these three things.' I didn't have to try to read into a lot of what their expectations were as far as meeting the standard on his IEP."*

Vallerie and Rich were the exception to the sea of parents unable to manage the workload. As teachers themselves, they liked having weekly assignment lists and easily adjusted without professional support, likely because they were familiar with lesson planning, pacing, and their children's needs and capacities. However, a vast task list was overwhelming for the remainder of the parents, who needed more specific and reasonable goals. Ryan described this struggle well:

> *"It's been a hard time during quarantine because he relies a lot on structure that the school provided and it was very hard to provide structure because of the work assignments... We would get an email at the beginning of the week from the school for the work assignments for that week...It was so long and detailed and I could not keep up, and could not give the time needed to adequately do my job here at home, trying to work full-time and teach him, especially when he doesn't want to be taught by me"* (Ryan).

5 DISCUSSION

We investigated how parents navigated pandemic-related school closures that precipitated a stoppage of professional behavioral care. We used the Kübler-Ross change curve to describe parents' experiences through the different stages of change (RQ1), explain how they adjusted their role and coped in order to maintain continuity in their child's behavioral care (RQ2), and identify their associated care-based information needs at each stage of change (RQ3). Our theory-driven and empirically-grounded insights can be applied to many types of change experienced by parents and children, including change related to the child's development or new diagnosis; transitions in family life (e.g., divorce, relocation, or loss of a family member); or external factors (e.g., natural disaster or political violence or instability). The COVID-19 pandemic required parents to adapt in their role with their child and in relation to the rest of their child's care team. We applied the Kübler-Ross change curve to illuminate parents' care-based information needs following a significant change in their lives.

Study findings can help us design appropriate tools that align with parents' information needs and coping mechanisms as they navigate change. We add to literature describing how parents can be supported through design for the care-based activities through which they manage their child's health [42, 84], which often requires seeking information online [3–5, 29], and collaborating with practitioners [2, 50, 63, 64]. Others have shown how various life transitions require different types of support to help meet a person's needs [4, 47, 72, 84], and we build on this body of work by showing how systems can be designed around the lived experience of change. Our work also has some similarities with Pollack et al.'s Knowledge, Resources, and Self-efficacy (KRS) Framework of Hospital Discharge [77]. A patient's discharge from the hospital is a change that can be expected and even planned for, yet the needs of patients and caregivers within that context are not unlike those of parents during the shocking COVID-19 pandemic. That is, in line with the KRS framework, parents needed knowledge about their child's condition or behaviors, resources to understand what their role was in caring for their child, and the self-efficacy to understand when what they were doing was enough to meet their child's needs. In contrast to Pollack et al.'s design opportunities specific to the hospital context, we explore possibilities for design across organizational and even systemic boundaries. Parents in our study were coordinating with practitioners available to them via the educational and healthcare systems, without shared health records, information systems, or communication channels.

In this section, we characterize two types of supports that can help parents as they navigate different stages of change: practitioner-initiated supports and parent-centered supports. We discuss how supports could be designed to accommodate a parent's capacity to accept and use help, and describe how supports can serve different functions throughout the experience of change. Although the stages of change cannot predict how a parent's experience will unfold, understanding how each stage affects them can help us anticipate the types of support they may need at different times. We found that support best serves parents when it is available as early as possible, in the moment they are experiencing change. If possible, support from practitioners should be visible from the onset of the change so that, once they are willing and able to accept help, parents know what supports are available and can feel comfortable enough to reach out.

5.1 Practitioner-Initiated Support to Meet Parents' Needs

If support is offered explicitly from the onset of role change, whether or not they are ready for it, parents can begin to recognize which care team members are willing to help, once they are ready to accept the help. Parents need their child's practitioners to be proactive by reaching out, listening, asking how they can help, and anticipating and offering resources. For example, Kübler-Ross describes how this type of proactive support can affect a person emotionally, even if they are not ready to accept informational or tangible help, such as when they find themselves in the Anger stage: *"A patient who is respected and understood, who is given attention and a little time, will soon lower his voice and reduce his angry demands. He will know that he is a valuable human being, cared for, allowed to function at the highest possible level as long as he can"* [52]. We discuss three ways that designing for the activities of practitioners can be informed by parents' experiences coping with change:

1. Conspicuous communication to establish and sustain emotional and esteem support
2. Coordinating tangible and informational support from multiple practitioners and via virtual agent
3. Scaffolding parent information seeking by validating sources, sharing personal resources, or facilitating peer support

5.1.1 Conspicuous communication to establish and sustain emotional and esteem support.

We found that practitioners' regular communication and openness to questions and feedback encouraged parents, helping them move through stages of change. Parents who felt most supported through change were able to air their concerns and frustrations to practitioners who had already opened up the space for that dialogue. We note that this communication can be effective whether it is one- or two-way. For instance, in the Anger stage, parents can benefit from sharing their frustrations one-directionally to practitioners who offer a sympathetic ear. Similarly, in the Depression stage, it can help for parents to hear from practitioners one-directionally, even if they do not say much in response. In contrast, when parents are in the Bargaining stage, they are more likely to engage in two-way communication.

Regardless of how much parents respond or engage, regular communication with their child's practitioners is vital across the stages of change because parents are in great need of emotional and esteem support. *Emotional support* involves actively listening to a person, expressing an understanding of what they are experiencing, and helping them feel hopeful instead of hopeless [23]. In our study, practitioners periodically checked in via phone call, text message, or email to parents with simple communication like *"I'm here if you need me."* This type of communication provides emotional support to parents by acknowledging the change they were experiencing and establishing dialogue. *Esteem support* promotes one's abilities, confidence, and inherent value, for example by reminding a person about their strengths or stating one's belief in them [23, 93]. Parents in our study benefited from reminders that they did not need to try to become their child's teacher or therapist, with assurance that they were doing enough and acknowledgment that fulfilling multiple roles was not sustainable. Esteem support also included practitioners validating parents' perspectives and emphasizing their intrinsic capacity to care for their child. This type of support also came from other parents, who shared their experience of change and therefore were uniquely positioned to provide validation.

In their efforts to navigate role change, some parents attempted to accomplish more than their capacity. The initial shock of role conflict, and the associated need to change, can be extremely overwhelming. Processing what is happening and moving past this initial shock can also be very challenging, taking up so much mental and emotional energy that the offer of information support may be more than parents can handle. For example, in the stages of Anger and Depression, some parents felt they needed additional training to provide behavioral care to their children. However, it was especially challenging to process so much new information. At these times, in addition to the informational support they requested (or even in lieu of it), parents were most in need of emotional and esteem support. We therefore complement recommendations for collaborative health tracking (e.g., [21, 73]) by suggesting that technologies should facilitate not only task-based and data-driven collaboration, but also more foundational communication that serves the function of relationship building. We also build on prior work showing that relationship building practices are critical for effective coordination on children's behavioral care teams [80].

For parents, technologies could help to make communication from practitioners more conspicuous. Regular communication from members of their child's care team that is conspicuous, and even becomes expected or routine, can establish that practitioners are accessible to parents throughout a time of change. Technologies could also help to facilitate practitioners checking-in with parents, making them more aware of how frequently they have been in contact with each parent. Such technological supports would make it easier to send parents electronic nudges without necessarily compiling personalized or detailed messages each time (e.g., through suggested language or light-weight non-text-based interactions). Even if the parent does not necessarily respond or engage each time, technologies can help practitioners establish communication channels, making it easier for the parent to reach out once they are ready. Such technologies can help parents to visualize and remember the amount of contact, encouragement, and reassurance they have received from practitioners, which in turn, can help them feel valued and less alone. Through regular check-ins, practitioners can also use technologies to prompt parents for information that can help them monitor the parent and child's progress. As Mishra et al. [73] note, if one collaborator lacks knowledge from another, the effects become more problematic over time. Thus, if practitioners continue to proactively gather and monitor some information, they can be more aware of the types of help either parent or child may need, enabling them to adjust therapeutic and educational supports to meet their capacities.

5.1.2 Coordinating informational and tangible support from multiple practitioners via a virtual agent. In our study, parents felt most supported when they could share their concerns and in return, receive informational and/or tangible support. However, we found this to be a largely unmet need, especially when parents were navigating the new tasks related to their role change. In Bargaining, for example, parents had a significant need for tangible or informational support that could help them understand how to take on the new roles required of them. In the Anger stage, as they struggled to renegotiate important tasks and shared goals for their child's behavioral and educational development, parents wanted tangible or informational support in order to feel more capable of managing their new reality. Receiving generic information that did not feel relevant to their child's specific behavioral needs only added to parents' frustration.

Massimi et al. [68] described how technology can facilitate group communication during life transition so that it is experienced as more consistent and satisfying. We similarly emphasize that *informational support* can be more satisfying for people undergoing role change if the information shared is prescriptive, as they may feel more confident and in control. Prescriptive information serves to teach or inform so that care team members can consistently deliver care across boundaries [80]. Building on Richards et al. [80], we argue that facilitating the exchange of prescriptive information to meet a child's needs is especially important during change, when prompt support is crucial for parents as they cope. *Tangible support* typically involves offering financial assistance, material goods, or services [23, 93]. With the loss of practitioner support, parents in our study needed tangible support that could help with their child's behavioral and learning goals, such as lesson plans and behavior management strategies. These materials, while readily available within the school context, are not typically shared with parents. To help parents adjust to the change, practitioners provided tangible support by supplying these materials, sometimes even bringing actual items to parents' homes (e.g., one practitioner dropped off a Velcro schedule and another dropped off recorded videos to replicate the school environment at home).

Despite the perceived necessity of prescriptive information and tangible supports, this was likely an unmet need for parents because it is challenging for practitioners to provide such individualized support. To reduce the amount of effort required from practitioners, technology could enable prescriptive information exchange by providing ways for parents to share concerns in an environment supported by a virtual agent. As parents describe challenges and make requests for tangible support (e.g., how to complete homework or decrease acting out behaviors), a virtual agent could scan for key words to which it provides immediate response with suggested resources previously validated by practitioners or from a school's larger resource database. As school practitioners prepare their materials, they could store and manage them in a way that makes it easier for a virtual agent to share them with parents as needed. Such technology could also facilitate material requests from parents to be fulfilled by multiple practitioners, to distribute and ease the effort of physically dropping off materials.

5.1.3 Scaffolding parent information seeking by validating sources, sharing personal resources, or facilitating peer support. In some stages, parents had greater need to find, process, and apply behavioral information for their child. Although the stages of change cannot be used to predict how a parent's experience will unfold, understanding how each stage affects them can help us anticipate the types of support they may need at different times. For example, in the Anger stage, frustration with having to navigate change as a whole caused parents to also experience significant frustration in situations when they asked a practitioner for guidance and did not receive a timely response. In the Bargaining stage, parents were most active in incorporating guidance they received. As a result, parents were more likely to seek information on their own.

Technology could function to scaffold the information seeking process, inserting the advice of practitioners when it is most needed. When parents did find behavioral strategies or therapeutic activities online, they were not comfortable adopting them with their child until they had an opportunity to confirm their validity and suitability with a practitioner. Unfortunately, this often left them dependent on receiving a response after reaching out to one of their child's practitioners, which could take days or weeks. A collaborative information system could facilitate the process of parents sending links to information or sources they would like validated, enabling an efficient response process from trusted practitioners who know their child, or even crowd-sourcing such tasks among local practitioners. To reduce this dependency, practitioners could also maintain a list of credible websites, organizations, and sources, or even recommended search terms, to share with parents who are making sense of what their new role means to them. Cloud-based document sharing, browser bookmarks, and other tools could enable some of these practices, but more research should explore their use in this collaborative context.

Finally, practitioners could anticipate parents' need for peer support as they grapple with change. Practitioners are in a unique position since they interact with a range of parents and are often aware of resources that have been useful to different parents and children. Thus, technology could support practitioners in facilitating connections to opportunities for peer support (e.g., social media-based parent groups, and in-person or virtual support groups). Sharing information on the availability, breadth, and wide use of parental support can help normalize their experiences. Work by Ammari and colleagues has emphasized the effectiveness of online support groups for parents with shared experiences such as their child's condition [5] or their transition into fatherhood [3]. Others have also discussed the need for parental peer support to connect to others in the parenting ecology [10, 97]. We extend this literature by highlighting that practitioners may be well-positioned to facilitate connections among parents for peer support. For example, teachers are increasingly using classroom management technologies to facilitate communication with parents of all of their students [6, 58]. Instead of using these technologies to more deeply surveil and scrutinize children's behavior [58, 59], they could potentially be used to support parents, including through peer support.

5.2 Parent-centered supports for meeting their own needs

Our findings also revealed that, as parents experienced role change, they had unmet information needs and focused their efforts on their child instead of on their own well-being (i.e., Depression). Since parents will likely have limited contact with practitioners at some point, technology could supplement the support they receive (or do not receive). Our findings emphasize the following potential technological supports for parents:

1. Seeking support and information online, and
2. Monitoring their own well-being.

5.2.1 Seeking support and information online. Scholars have established how caregivers seek support in online communities from other people who have a similar role [3, 5, 56, 57]. We confirm prior work that described online communities as places where unmet information needs could be satisfied in life transitions [67]. Parents in our study looked to social media to learn new strategies for caring for their child and to access social support from other parents of children with behavioral needs. Previous work outlined parent's support-seeking as mostly self-serving [3, 5]; however, we show evidence that parents went online and stayed in online groups to provide social support to other parents in online groups, in addition to obtaining support for themselves. Ammari and colleagues have shown that parents of children with special needs rely on both geographically related online groups and case-based groups for shared conditions when accessing information and social support [5].

Similarly, research has found that informal caregivers for older adults feel less alone when they obtain social support from peers online [94]. As expected, we found that parents trusted other parents who knew what they were going through for advice and support. In contrast to work studying the role change and transition into fatherhood [3], parents experiencing a role change did not express an interest in documenting or archiving their experience with caring for their child with behavioral needs.

We also show how parents did not share adverse experiences in seeking support from other people who have a similar role. Ammari et al. [5] pointed to the judgment and stigma that parents of children with special needs experience both online and offline (in-person) interactions as their reason for seeking support online or their reason for pseudonyms. Of all the challenges that parents in our study faced, judgment and stigma were not shared as concerns when they described their online and offline support-seeking. It is promising that parents could have received help from peers online without worrying about judgment and stigma. This presents an opportunity for future work to understand what aspects of online communities might enable their members to obtain non-judgemental social support, and what might account for the differences in experiences reported. For example, the nature of a parent's offline experiences and the catalyst that led them to seek social support online may affect their expectations for what responses they will get online. In the case of our study, the catalyst was role conflict resulting from a global pandemic, an external factor that may have helped parents feel less worried about judgement.

In line with previous research on health information seeking by parents [1, 49], parents in our study expressed concern regarding behavioral health information found online for their children. Parents would feel more supported if they received guidance when searching for health information. Design could support parents' online information-seeking by promoting validated academic or government sources through the use of tools such as a browser extension. Future work could explore whether parents would be interested in such a tool, or if they'd be interested in providing feedback on whether resources work for their child. Such data regarding valid or diagnosis-specific resources could be further disseminated in online groups.

5.2.2 Monitoring their own well-being. In thinking about the well-being of the children who are cared for, it is crucial to also recognize the importance of parent well-being. Research has shown that parents who are tired, depressed, or in need of health care services often sacrifice their own health and well-being to meet their child's care needs when support is lacking [18]. This effort took a toll on the physical health and well-being of the parents in our study. Given the many roles that caregivers were being asked to take on, as well as the external stress they may face, it is paramount that parents are given the resources to take care of themselves in addition to their children. Ensuring parents have the resources to take care of themselves would serve to mitigate stress at home and improve their capacity to meet their child's needs.

Plenty of HCI literature [4, 20, 47, 72] recommends design for parents or caregivers undergoing a role change or life transition. However, design does not all have to be focused on supporting actions in the process of providing care. Similar to recommendations by some researchers [20, 43], our findings suggest that design can aim to support caregivers' well-being and design can be unrelated to the act of providing care for their child (e.g., tracking developmental milestones and other health information [40, 51, 92], seeking information relating to caregiving [5, 29]). Like Chen et al. [20], we place emphasis on the social-emotion work of caregivers and their own need for reflection and learning. In our study, parents did not have to be actively engaging their child in an activity or intervention in order to help their child or themselves. Self-care and individual mental health support helped several parents, such as Mallarie, navigate their experience along the change curve.

Our findings suggest that technology might support parents by encouraging self-awareness through the stages of role change. Parents could use reminders to slow down, or remember that they are not expected to be an expert in their child's situation. Bosch and colleagues [13, 14] have found that caregivers of older adults benefited from toolkit-based self-reflective activities, which increased caregivers' awareness of their well-being, promoted capture of positive moments, empowered caregivers to seek social support, and provided caregivers reassurance with regards to their mental health. They also found evidence that providing reassurance about the caregivers' well-being promoted confidence in their ability to handle the situation [13]. We similarly found that parents in our study benefited from conversations with practitioners who assured them that they knew and were doing what was best for their child. Parents might benefit from self-care as well, as our findings showed how they often lacked confidence and spent time trying to do more than they were capable of or expected to do as non-experts. Thus, future work may consider the extent to which self-reflection positively impacts parents or other caregivers of young children. Our findings suggest that the strategies which help caregivers in typical situations may meet the same needs that caregivers have during the challenging experience of change—however, what is not clear is the appropriate mechanism through which to engage them in self-reflection during these times (e.g., the nature of the activities or toolkit).

Our contribution of applying the change curve to parents' information needs gives us a way to identify the appropriate timing, types, and level of detail of health-related information to be shared with parents. The change curve gives us new insights into parent needs with the understanding that helping parents navigate the experience of role change and increasing their awareness of what stage they are in might be helpful to them.

Future work might explore the timing, means, and method for self-reflection to be encouraged throughout the change curve. Future work might consider engaging parent caregivers in a diary study to assess their feelings and needs through the weeks following a role change. Hong et al. showed through a diary study that having parents and adolescents with chronic conditions assess their feelings helped them recognize, document, and share their physical and emotional experiences [41]. Design can help parents navigate the stages of their role change and help parents become aware of their needs as caregivers experiencing role change Parents in our study noted how they benefited when others reminded them that what they are feeling is normal, which could be validating for others, using self-reflective approaches.

5.3 Limitations and Future Work

The limitations of this study largely have to do with our sample. First, we conducted this research exclusively with parents who had access to communication technologies, as our recruitment strategies included Facebook, Reddit, and Nextdoor as well as our university's health research recruitment website. It will be critical to also understand the experiences of parents without access to or engagement with such platforms, especially since they may be the most affected by disruptions such as the COVID-19 pandemic. Our participants were also relatively educated. Between our selection of survey participants to interview and their self-selection in agreeing to be interviewed, our sample could have skewed toward those who are more communicative. Therefore, our study may not have included those parents who have the most trouble communicating with others about coordinating their child's care. Future work should aim to incorporate more diverse families, including families with lower socio-economic status, and families that have been marginalized or underserved, which may uncover unique barriers while navigating changes in their children's behavioral care.

Second, our findings represent the parent perspective, yet there are questions raised that can only be addressed from the perspectives of practitioners or children. Accordingly, our design recommendations reflect parent interests and do not thoroughly account for the interests or capabilities of other care team members or the care recipient themselves. Finally, regarding our findings in connection with the change curve, there was little evidence of denial found in conversations with parents. Typically, denial happens almost immediately and when the change is too unimaginable. Because our study was conducted 3-4 months after COVID-19 was declared a pandemic, our findings may not fully account for the experiences of parents in denial. It is likely that by the time we interviewed parents, their reality had already changed and their children's circumstances may have forced them out of denial. It is also possible that parents experiencing denial may have been less likely to self-select to participate in our study. Future work may look to confirm parents' information needs in denial following other external events (e.g., loss of a loved one, illness of a family member, natural disaster, etc.).

We suggest that future work explore the perspectives of practitioners in understanding how they might support parents through the stages of the change curve. Moreover, practitioners will have their own experiences of change and struggles to adjust their work activities. Understanding how they adjust their role as practitioners, and comparing this to our findings about parents, would give us a better understanding of how to mediate their differing needs. Conducting participatory design sessions with both parents and practitioners may improve our understanding of how tools can be designed for care coordination with respect to the needs of all stakeholders. Additionally, future work could explore the information gaps that exist with other kinds of practitioners, such as physicians, specialists, as well as coordination across multiple parents or caregivers in family life. Such future work would help us continue to broaden our understanding of how to design for care continuity across a range of stakeholders in children's health and wellness.

6 CONCLUSION

Many CSCW studies have considered information needs in the context of parenting, caregiving, and collaboration with clinicians. In this study, we apply role theory and the Kübler-Ross Change Curve to contribute an understanding of how parents navigate change in caring for their children. Using the COVID-19 pandemic as a case study, we focused on the school-based practitioners that provide accommodations and support for children with behavioral care needs. Through an in-depth analysis of 16 interviews with parents, we characterize how parents experienced changes to their child's care, and how they adjusted their role in an effort to maintain care continuity. To address their care-based information needs through the different stages of change, parents increased contact with practitioners, sought and provided social and emotional support from other parents online, and sought informational support online. Understanding the stages of change enables us to design with an appreciation for how practitioner-initiated and parent-centered supports can best suit parents' needs. As most parents face unexpected events that impact their parenting, we expect our findings and recommendations to have relevance for many types of change, and other kinds of individual needs that practitioners outside of the home support.

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