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# How do parents frame their engagement experience in early intervention? A grounded theory study

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## ABSTRACT

**Purpose:** Parent and therapist engagement and partnership are critical in early intervention physiotherapy and occupational therapy for infants with cerebral palsy to improve outcomes. The main aim of this study was to understand how parents perceive their engagement experience in early intervention over time.

**Methods:** Grounded theory methodology was used. Twenty parents of diverse backgrounds participated in 22 interviews (including some repeated longitudinally) to reflect on their engagement experience within the context of early intervention community services provided in the UK NHS.

**Results:** The findings highlight how parents' perspectives of their engagement in EI change according to critical circumstances, including their preceding neonatal trauma, the at-risk CP label, firmer diagnosis of CP and their child's response to intervention. We theorise that this disrupted transition experience to parenthood becomes part of parental framing (or sense-making) of their engagement in EI. Overlapping frames of uncertainty, pursuit and transformation capture and explain nuances in parents' engagement patterns within EI over time.

**Conclusion:** This theorising has implications for early intervention therapists in how they engage in the lives of families and partner with parents to support healthier parental transition, wellbeing and subsequent improved infant outcomes.

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## > IMPLICATIONS FOR REHABILITATION

- New insights are provided into how recent advances to prognostic practices for infants with cerebral palsy affect parental perspectives and their engagement experience in early intervention
- The paper's organising concepts support a clearer understanding for early intervention practitioners of this complex parent experience
- Early intervention practitioners are encouraged to reflect upon their practice as they engage in families' lives and partner with parents during this challenging period to optimise outcomes

## Introduction


Cerebral palsy, the most common childhood neurodevelopmental disability with an incidence of two per 1000 births, is associated with neonatal risk factors, including extreme prematurity and hypoxic ischaemic encephalopathy (HIE) [1,2]. Prognostic assessments support early identification of infants as 'at risk' of CP and timely communication with families [3]. Research is needed to understand how these recent advances affect parental engagement experiences in EI [4].

Parental engagement and learning are critical components in early intervention physiotherapy and occupational therapy (EI) to improve outcomes for infants with cerebral palsy (CP) and the wider family [5,6]. Engagement has layers of overlapping meaning with other concepts such as involvement, participation, enablement and empowerment [7]. King et al. [8, p. 2] outline parental engagement as a co-constructed 'multifaceted state of affective, cognitive, and behavioural commitment or investment' in their role over time.

Pre-existing and changing contexts are proposed to shape parental engagement response to EI and subsequent outcomes [9]. For example, relating to the impact of neonatal intensive care experience on parental self-efficacy. However, additional exploration of the intersection between parental experience and engagement is needed during this distinctive period of the infant's first two years [10].

A key aspect of the changing context over time involves the parental transition, which occurs when families partner with EI services. Transition is a passage from one life phase or status to another [11] by 'linking change with experienced time' [12, p. 239]. Through an internal affective process, transition connects external change with personal development [13]. There are close links between transition and grief theory [14], and grief theory application in CP rehabilitation is well established [15,16]. However, further study of how parents' experience shapes their engagement approach is required in EI contexts.

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This research comes from the first phase of the Optimise EI study. This paper aims to present theorising around two exploratory research questions:

1. What are parents' experiences surrounding their engagement in EI for an infant with CP?
2. How does the 'changing context' affect how parents perceive their engagement in EI over time?

## Methods

### Design

We applied grounded theory with Straussian roots in constructivism and pragmatism to promote an in-depth understanding of how parents perceive their experience around engagement in EI [17–19]. These paradigms support theorising through the non-hierarchical intersubjective reasoning of stakeholders and assume knowledge is changeable over time and place. Grounded theory provides transparent connection between participants' accounts and more abstract theoretical construction [20]. The approach aims to explore phenomena afresh, *avoiding* a 'verificationist' approach where data is collected to fit and confirm existing theoretical frameworks.

### Participants

Twenty parents (six fathers, 14 mothers) from 15 families participated in 22 interviews. Four parents participated in two interviews as a couple; five parents provided longitudinal follow-up interviews. Thirteen were first-time parents.

Parents varied in ethnicity, educational and socioeconomic status and the medical history and age of their child receiving EI (Supplementary Appendix 1 – demographic information). Household incomes ranged from three families on low incomes (<£20000) to three with high household incomes (>£80000). Five parents had left school at 16 years old, one at 18, and the remaining parents had completed degrees or higher. All parents were heterosexual and married or in marriage-like relationships. Parents were aged in their 30's, except one father (50) and one mother (18).

Participants came from four inner-London boroughs of three NHS Trust sites. Each site provided community EI services and represented typical urban settings in their diversity. Sites followed evidence-based integrated (acute and community) high-risk neurodevelopmental follow-up pathways, including predictive assessments of CP [3].

### Data collection

Grounded theory's sampling strategy is symbiotic with analysis [20]. The initial sampling was purposive, selecting parent participants for characteristic variation. Theoretical sampling began early (fourth interview), as analysis informed subsequent sampling to expand, refine and ultimately exhaust the conceptualisation process [21]. For example, fathers were approached more explicitly for recruitment to probe different parental perspectives. Deviant cases were embraced to ensure robust analysis [22]. Data saturation was observable around the 14<sup>th</sup>-15<sup>th</sup> participant interviews and confirmed with participant 17, which only added 'in a minor way to the many variations of major patterns' [19, p. 292].

Data were collected through in-depth interviews with the parents of infants with CP using a semi-structured topic guide (Supplementary Appendix 2). Open questions were used to explore the subject broadly and theoretical sensitivity supported

probing [21]. Guide development was supported by the project's parent advisory group (PAG) and literature review. Interviews lasted for approximately one to two hours, were audio recorded and transcribed verbatim by a third-party company.

### Procedure

This paper shares theorising from phase one of the Optimise EI study (Health Research Authority ref: Z6364106/2018/11/78), which has full ethical approval granted by the Bloomsbury NHS Research Ethics Committee (REC; no.19/LO/0298). Locally assigned clinicians identified eligible families (Table 1). Parents were approached by their treating therapist. Parents were provided an information sheet explaining the research rationale and ethical considerations, including; confidentiality (participant pseudonyms are used), data protection and their right to withdraw. Informed consent was agreed before participation.

Interviews were performed with parents individually or as a couple, in person or online, according to Covid-19 restrictions. Sensitive interviewing techniques were used because of the risk of causing emotional trauma in parents revisiting traumatic events.

### Analysis

Data analysis was managed systematically using NVIVO 12. Analysis began with immersion, where verbatim interview transcripts were read several times. Initial codes were applied line-by-line to text. These open codes often denoted 'actions' or verbatim (in-vivo) quotes [23]. Focused coding refined the analysis to support more precise conceptualisation. Constant comparative analysis and iterative cycles were performed at every analytical level to establish similarities and differences in data. As theoretical sensitivity grew around significant concepts, constant comparison involved returning to previous data samples for reanalysis [21]. Later, axial coding supported connecting categories [19]. Despite these steps being presented linearly, the analysis was iterative and circular in practice. In addition to this inductive approach, a process of abduction was used whereby connection to relevant extant theories from interdisciplinary fields supported theoretical sensitivity and development, a practice asserted as essential in GT [17,19].

### Trustworthiness

Various strategies were used to support trustworthiness following guidance from Morse [24] using different triangulation strategies, including close attention to varied member checking practices [25]. Another researcher (DG) separately analysed the first three transcripts to compare code and theme development to ensure the analysis reflected the raw data [24]. Disagreements were

Table 1. Participant inclusion and exclusion criteria.

Inclusion	Exclusion
<b>Infant</b>	
<ul style="list-style-type: none"> <li>• MRI confirming at risk of CP</li> <li>• Predictive assessment confirming at risk of CP</li> <li>• Age &lt;24 months</li> <li>• Receiving regular EI NHS services</li> </ul>	<ul style="list-style-type: none"> <li>• Under child safeguarding</li> <li>• Under palliative care services</li> </ul>
<b>Parent</b>	
<ul style="list-style-type: none"> <li>• Aware their infant is at risk of CP</li> <li>• &gt;16 years old</li> </ul>	<ul style="list-style-type: none"> <li>• Mental health difficulties that impair ability to participate</li> <li>• Learning difficulties preventing informed consent process</li> </ul>

discussed, and consensus established for developing the coding framework. Analytical development was discussed with the research team (PH, DG, JB and AB), and the PAG provided sense-checking using their lived experience. Transcripts were offered to participants to check for accuracy and offer a prompt in follow-up interviews to review meaning, which three parents found useful. In later follow-up interviews, primitive analysis was shared to elicit challenge and extension to the formative analysis.

A reflective diary promoted self-awareness of the situational context and relevant non-verbal observations (e.g., body language) during interviews [18]. The interviewer (PH) was conscious of how their social characteristics, which include being white; professional; middle-class; father and physiotherapist may have influenced participants' perception and the subsequent interaction (Ibid.). For example, these characteristics may have encouraged some fathers to participate and talk more openly [26]. Memo writing promoted reflexivity to support and justify analytical decisions, including critical reflections on preconceptions and ongoing perspectives during data collection and analysis were developed [18]. Recorded action points guided theoretical sampling and topic guide development, thus, providing an audit trail [20]. For transparency, the final codebook is provided (Supplementary Appendix 3).

## Results

We used data to theorise how the changing context of parents' disrupted transition (including grief) becomes part of their framing (or sense-making) of their engagement in EI. 'Framing' is understood as the organisation of experience, in how contexts structure a person's perceptions of social situations and guides their actions [27–29]. Framing is also explained by Goffman [28] in how individuals ask themselves, explicitly or tacitly, 'what is going on here?' and, in any situation, there may be multiple layers of frames. More broadly, it is through parents' dominant early experiences we propose that they interpret (or frame) their engagement in EI.

Transition to parenthood is commonly a shared social experience with family and friends and an opportunity to forge new social networks. However, parental participants' experience is disconnected from the social norms of this life transition.

"...me and my best friend, we had the babies, like, literally four days apart ... we've been friends since we were ten and now we don't even hardly see each other. When I'm around her I get upset because I'm thinking my son could be doing this stuff." (Kala)

This quote emblemises the disruption and separation from the usual rites of passage (e.g., sharing developmental progress) that usually help parents process the liminality of early parenthood [11].

Three parental frames of engagement associated with parents' transition will be presented; uncertainty, pursuit and transformation. These frames are outlined discretely in linear, chronological form for clarity. However, triangulation with participants and the PAG indicated that these frames (uncertainty–pursuit–transformation) resonated but challenged their linearity. Instead, they highlighted a significant flux in framing of EI over their transition, comparable to a 'swirly whirly lolly pop' (PAG). Further reflective memos, theoretical sampling and abduction, most notably with Bergson's philosophy of process time, led to understanding 'experienced time' as quite different from a chronological, scientific spatial, concept of time [30,31]. Process time does not break down present moments into the linearity of measurable time but considers time as experience unfolding into the future. As such, in our analysis, a specific frame will occasionally be emphasised then subside, and at other

times multiple frames overlap in equal and sometimes paradoxical measure, which was grounded in numerous parents' narratives.

### Uncertainty framing

#### *Confusion – the affective impact of circumstances out of control*

Then it all went to shit... (Liz)

Each parent's traumatic early experience leading up to their infant being identified as 'at risk' of CP is unique and consequential to their subsequent engagement in EI. Traumatic neonatal circumstances are thrust upon families, creating a sense of a loss of control. Mothers particularly hold guilt over the circumstances of an 'unsafe' delivery and events that unfold to cause their infant's CP development.

...you feel guilty about every single aspect ... how he was born, the fact that he was born so early, you couldn't keep him in longer, the fact that his brain bleed got worse ... I mean the guilt is all encompassing. (Aneeta)

Within the early period following discharge from NNU, uncertainty influences parental framing of their engagement in EI. Trauma and guilt, described as an "extra layer of stress and confusion", dominate a parent's affective state for a prolonged period, which underpins their uncertainty. The described trauma can disrupt parental connection with their infant, which may challenge engagement in therapy for some parents.

These [emotions] are ... lasting. It's stuff I can tap into quite easily because the legacy of that emotion at the time, which was very new obviously, [and] is still there when I'm with him [infant] (Warren)

Coming home is significant, where anticipated family bonding, disrupted by the neonatal unit (NNU) experience, can (re)commence. However, despite acknowledging this emotional pain, many parents compartmentalise these feelings, stating that they "haven't let it" affect their interaction and relationship with their infant, including within an EI context. Other parents feel their shared trauma with their child only deepens their connection and paternal protective instinct.

#### *"It's said but not said" – misalignment of knowing*

The 'at risk' label of CP is expected to support open communication with parents. However, this (often one-off) initial disclosure is not always interpreted as intended. Parents interpret the 'at risk' label as an "if scenario", hoping "maybe they're wrong", while considering the "brain is just recovering", to the point of ignoring it.

No-one wants to hear that, so I just brushed all that back...we tried to ignore that (Dorothy)

Some parents acknowledge avoidance and denial of future difficulties in light of complex medical concerns and care burdens post-NNU. Parents seek a recovery period for the infant and themselves when first home. This situation means early communication does not connect fully with parents.

I found it very traumatic being in the hospital where it had all happened ... I just thought I can't be here anymore ... looking back I wish I'd gone, 'Are you sure?' (Alice)

Early movement difficulties are not always readily observable, aptly named the 'latent or silent period' [3, p. 2]. Without discernible visual evidence for parents, their concerns do not align with clinicians'.

Maybe the confusion came when I got home, I didn't know what to expect. I'm a bit confused thinking, 'Okay, she looks fine, she's only a baby, how can he [doctor] even tell; ... she's going to get better, she's only a baby;' (Haleema)

The uncertainty of the formative 'at risk' label can constrain parental focus in intervention, especially when they perceive their infant to be doing well.

I feel like if you are diagnosed with something you deal with it ... you know, 'okay this is what I've got, this is the treatment', but because he's so small, it's still a bit questionable ... he's doing so well (Bonnie)

Parents can also have a vague understanding of the prognostic general movements assessment.

... when he was three months corrected ... he had videos taken ... I think at that point in my head fidgety movements was a bad thing and I don't think I really [understood] that him having ... a lack of fidgety movements was actually a bad thing. (Aneeta)

The prognostic ambiguity of 'at risk' labelling creates an "it's said but not said" limbo for parents. These mismatched perspectives between parents and professionals significantly increase parental confusion and uncertainty. Confusion is compounded by the sudden influx of concerned professionals, with therapists at the forefront. Intervention is perceived as preventative, supported by an "if" or "just in case" rationale.

At the beginning, because I didn't realise she needed it, or hoped she didn't need it, I was a bit, 'All these appointments are stressing me out.' (Liz)

However, initial parental avoidance of "hoping nothing was wrong" becomes untenable when parents sense their understanding is misaligned with professionals', provoking a response.

It was quite confusing because every time I went to an appointment, I would ask questions and it was like, I felt that the doctor knew something but wasn't letting on anything. (Nicole)

Perceptions of a lack of transparency with professionals talking together "behind closed doors" creates mistrust from a sense of "What are you saying that I can't hear?." Information appears guarded and sensitively disclosed at a time when professionals decide it is best for parents to know, which some parents perceive to be "about power."

...they veer on the side of only giving what information they [professionals] absolutely have to give. And if the parent asks more, then answer those questions, but other than that, don't go too much, because they don't think that the parents can handle it. (Jay)

In contrast her partner, Victor believes, "they probably gave it to us in pieces so we could process it." Nevertheless, this paternalistic information sharing becomes counter-productive as proactive parents take it upon themselves to "piece things together."

...it's not good enough to say, 'Well go home and love him and see how he turns out.' Because we knew already from the MRI. (Alice)

The confusion triggers a wrestling for control through information seeking, where parents work towards greater transparency to align their knowledge of the situation with the professionals.

... we couldn't really tell. We couldn't see... I was trying to put them [consultants] under a little bit of pressure to tell us one way or another [about CP prognosis]. (Alistair)

The quest for alignment is seen as a "puzzle to be solved." It involves some parents picking up fragments of information from different sources (e.g., conversations with therapists) until it

becomes possible to press practitioners for clarity with their evidential knowledge.

... piecing everything together what people had said. Then I came here for an appointment and said, 'Oh, this is what X have said,' and it was like, 'Hmm.' So, when they agreed, I was like, 'Oh, my God. Maybe people have known this for a while and not said it explicitly. (Liz)

Parents also acknowledge the sensitivities of sharing uncertain prognostic information, and many parents perceive this differently in hindsight. However, the potential of a "trust erosion" with the team involved in their child's care can cross-contaminate parent and therapist relationships, as therapists are seen as complicit in the system of information guarding.

... the physio hadn't probably explained what had happened because they're probably thinking it's the doctor's thing [to disclose diagnosis]. (Victor)

Therapists are constrained in being able to openly share CP prognostic/diagnostic information due to diagnostic procedures (where consultants hold responsibility for prognostic-diagnostic information sharing). Nevertheless, this condition means that therapists spend much of this early period in EI, consciously (and often uncomfortably) residing in an 'asymmetry of knowing' with parents. As therapists have much earlier knowledge of diagnosis than parents due to the therapist's expert observations and shared knowledge with the healthcare team. This asymmetry, or misalignment ("it's said but not said") is deepened with significant talk in therapy sessions of concepts related to CP (e.g., muscle tone) but which circumnavigate its actual naming. In contrast, some parents differentiate the relationship with therapists versus the medical team, as they perceive less conflict around information sharing of CP and greater relational equality and communication with their child's therapist.

### *Begrudging engagement*

Therefore, parents' engagement response in EI at this time can become "begrudging", as they prefer to avoid engaging when the family want to recover and bond.

At the beginning ... I didn't want to engage, I didn't want to do much, then they would call and say, 'Oh, we're coming for a visit,' and I thought, 'Why are you coming?' You know? (Dorothy)

Parents want what is best for their child, but what is best is not yet clear, and this is in tension with what they consider to be best for themselves, that is, their wellbeing and their family's.

It's hard because if there's something wrong, you want early intervention, but that's linked to confusion. 'Why are you here? Why do you need to see me so often?' (Liz)

The conundrum appears irreconcilable for parents. In this 'if' situation, EI is proposed as the best opportunity to ameliorate the impact of a brain lesion whose effects they cannot fully observe in the present. Yet, what might be the consequences 'if' they do not take on the support? The conclusion is that parents have little choice, begrudgingly they must engage as they "wouldn't want to look back and feel guilty ... 'Oh I should have.'" Interestingly, despite feeling this early begrudging engagement, some parents reflected later that they were glad they did engage.

### *Relieved engagement*

In contrast, other parents respond with relief from the reassurance in the presence of a therapist, for the sense of control that the therapist's knowledge can bring in their frame of uncertainty.



I was very, very reassured that we were getting support ... we ... came out of this bubble of hospital where you had that medical support around you all the time, to then coming home and having to just get on with it yourself. (Aneeta)

This reassurance is particularly valued when parenthood preparation has been disrupted by unexpected preterm birth. Therapists can help reduce anxieties related to early infant development, as parents reflect, "I wouldn't know what to look for" and "you don't know what you don't know."

However, this reassuring therapist's presence might not enable parents to understand their infants' underlying prognosis fully. Instead, following therapy guidance in a perceived preventative approach (the 'if' scenario) can lead to complacency because of inadequate information sharing, parental receptive misinterpretation, or a mixture of both.

I think there was an element of complacency that I think had set in after we got a bit comfortable at home that maybe wouldn't have happened had we known there was some other things [going on] (Aneeta)

If complacency persists, it can create parents' reliance upon professionals for direction and motivation, with information seeking also diminishing over time.

### **Pursuit framing**

The pursuit framing represents parental perception of their engagement in EI with a new sense of purpose and intensity, created by multiple factors but most notably a firmer diagnosis.

### **Diagnostic trauma, facing reality and grieving**

While parents desire earlier transparent diagnostic disclosure to answer unanswered questions, relieve guilt and share understanding with professionals, they also compare the initial "crash" of emotional trauma of disclosure to "an out-of-body experience." This generates a secondary grieving process, layered upon the loss of a typical neonatal experience. Interactions with others contribute to confronting this painful reality.

People say to me, 'So, how do you feel if it is cerebral palsy?' It is what it is. I'll have to deal with the complications that come with it. If he doesn't walk, I'll carry him. I'll do the things for him. (Nicole)

Parents begin to realise "that our lives are going to be more difficult" than their imagined shared future with their envisioned child. Although a variable process, parents grieve the loss of parental identity and associated roles they anticipated.

[I] slowly started processing it in my head, but not straight away ... oh my gosh it was going to be a lot, and I was like ... it's going to be so much to do. (Haleema)

These altered roles extend to taking on unexpected roles in EI therapy long-term, which can be an overwhelming prospect and evidently can become conflated with an affective response.

... we were so early on in our understanding ... of what we were dealing with ... I was just very afraid of what the future might hold, so doing the physio would sometimes feel like a very proactive thing, and sometimes would feel like a very frightening thing, where I had to confront what had happened to him. (Alice)

Parents struggle with expectations to partner with therapists in EI at times when they are emotionally vulnerable. Hence, emotional support from a wider social network and EI therapists with whom they have built a trusting relationship is mitigating in these circumstances. However, not all is equal regarding social support

between parents. For example, the younger mother's (Camila, 18) circumstances of social isolation, combined with an early morning part-time cleaning job and attendance at college, created barriers in her ability to invest intensively relative to other parents with more social support. Camila has intentionally not revealed to others that her daughter has CP because she feels that "they would not be able to help her", so there is "no point." She also describes how she feels stigmatised within her ethnic-cultural community for being a young mother, that people judge her as a 'bad' mother because she is young. Nevertheless, she asserts a strong and proud parental identity, as she contends that age does not define a 'good mother', but that her care and love for Emily is what matters most. In the face of these apparent multiple social challenges and demands placed upon her, she presents as a resilient, resolute and bright individual while remaining devoted and accepting of her small child with an early CP diagnosis.

### **The turning point: neuroplasticity discourse and the 'sand timer effect'**

For many parents, the diagnostic process signifies a "turning point" in their transition experience and framing of engagement. In an example of a follow-up interview, Victor describes his response to recent confirmation of a CP diagnosis, which aligns with other parents experience.

... emotionally it has changed ... for me because having such a black and white ... label for it. You can say what it is ... it helps me compartmentalise that now ... and I can focus on just that.

Parents are enabled to "know what they are dealing with now", meaning they can concentrate knowledge assimilation upon CP, which is also essential to grief processing. Early intervention is "intrinsically motivating" because it represents "doing something proactively" about CP while also "getting to know their child better", thereby offering a sense of control. The CP label provides a foundational symmetry of knowing between parents and therapists for open information sharing and observation of the child's therapeutic needs. Information can be individualised to the parental need and generalised to the natural history of CP. Yet, uncertainties persist despite information seeking as an uncomfortable and painful unfolding reality is uncovered with changing practical concerns of everyday life.

The "turning point" contrasts parental begrudging engagement in uncertainty with a refocused and intensive commitment. A strong motivator is the immediate shift of conversation to the hope of neuroplasticity.

[Knowing] it is definitely cerebral palsy ... got our minds focused onto the fact that there's something going on. We then turned the conversation to neuroplasticity ... that was really important to know ... I think it was a case of it was a shock but we're really glad ... we can now do as much as we can to do something about it ... you're ... doing it with a new sense of focus ... feeling like every single thing you're doing could have a real positive effect on him going forward so you're definitely much more likely to be a bit more militant (Aneeta)

The neuroplasticity discourse becomes a significant driver of parental affective and cognitive engagement change processes towards states of hope and conviction [8] within the pursuit frame.

... the brain is more or less like plastic so if you give it what it needs now, it could potentially just redirect and do what it needs to do to make him stronger. (Bonnie)

However, neuroplasticity's 'critical window' dictates a perception of limited time for optimising motor outcomes. This time-critical perspective (reinforced with mothers on maternity leave) has a counter-effect of creating pressure.

I ... describe it ... like one of those *sand timers* ... you feel time's essentially running out. And every day that passes, if you're not trying to learn about his condition or do something about it, you've lost a day. (Rohan)

We conceptualise the 'sand timer effect' to explain the dualistic tension between hope and motivation in neuroplasticity versus the pressure felt. Parents accept they have "a big part to play" and invest fervently in an active role, grounded on "leaving no stone unturned" and "wanting no regrets." They sacrifice to prioritise therapy and "put the hard yards in." Many parents recognise the importance of "not placing all of your hope on the therapist and feeling like they're the ones that are going to fix this" (Aneeta), consolidating their role's significance.

We can't have every time physiotherapists around him. We have to support the baby when they're not here. We have to take responsibility for doing these things. (Shoaib)

Nevertheless, therapists' conveyance that neuroplasticity is the foundational reasoning for therapeutic activities sustains parental beliefs in working to "fix" an underlying "issue." Parents, explicitly and implicitly, express a desire to "fix", "find a cure", or "sort out the problems of prematurity." Beliefs in neuroplasticity can interact with grief and guilt as parents see an opportunity to "make better what I didn't do right" (Alice).

Therefore, conversely, while parents accept responsibility for being actively involved in EI, they simultaneously grapple with the accountability pressure of the role. Parents face the reality that "it's all on me to do it, is it?" to provide the expected intensity.

I felt ... this pressure...if I didn't do it, I wouldn't fix her. (Liz)

Parents feel accountable for outcomes while asking themselves, "am I doing enough?"; "am I capable of doing this effectively?" and "if I don't do this is s/he not going to get better?" Parents perceive it as "overwhelming" to meet an expectation "to learn how to be a physio [or OT]" while they are "in a very vulnerable state" (Alice). Some parents express they feel "useless" at "what [they are asked] to do" (June). Their low self-expectancy heightens the pressure, causing some parents to prioritise therapist-led intervention delivery more.

When the infant's prognosis is still uncertain, parents want "to maximise his [or her] opportunity to be as normal as possible" (Alistair), and there is pressure in not knowing how much intervention is enough to meet unknown effects.

If it was a case of saying that ... 'if you put another two and a half hours in every day ... for the next fifteen years ... and he will turn out normal' Or... he'll have exactly the same life chances by the time he gets to that point ... it just doesn't work like that. And that's the real pressure ... We don't know ... how much ... early intervention is going to help him, we definitely know that it does help him ... (Warren)

This ambiguity can create a feeling of not knowing when to stop in the pursuit and achievement of milestones. Goals are described as "a double-edged sword" and a "red herring" as if unachieved accountability pressure is intensified.

I feel like if he didn't [achieve goals] it wouldn't be on him, it would be on me. I'd feel like bad about it ... I just feel like maybe I should've done more. (Melody)

Likewise, parents perceive therapists to be "engaged by milestones" and society's "oppressing obsession" with them, while for parents counting down to critical developmental milestones is "scary" and anxiety provoking. Thus, a further sense of isolation from parenthood norms is created, with no time to celebrate milestones in the pursuit of the next.

You're never able to really sit and celebrate anything without being like, okay great he's done that but now we need to move on to make sure he can do the next thing. (Rohan)

One parent compares this phenomenon to when "you've just binged a TV show on Netflix, one season ends and you just plough into the next season" (Warren) to compensate for lost time.

Therefore, pursuit framing can generate such an intensive investment that it negatively impacts parental wellbeing and identity formation.

Our whole attention and focus is on him and everything just becomes an opportunity crossroads where I could go out to the pub and meet friends ... or I could ... do some research, or read a few articles about what I could do. So you ... make that trade-off which isn't, I'd say, healthy to do all the time. (Rohan)

Enjoying typical parent-child interactions is challenging in a pervasive parent-led delivery at home. Time spent with the child is overshadowed by thoughts of constantly making therapeutic adjustments, inadvertently causing relational development to become more transactional and functional.

We had some expectations about what becoming parents would be, but now we know that can sort of no longer happen organically, it feels like every moment, every day is a lost day unless you're not doing something. (Warren)

The essential requirement for parents to learn to observe their child using a therapeutic professional lens, inevitably becomes intertwined with their transitional parental identity development.

In contrast, some parents see the benefit of pressure, viewed within a productivity ethic, completing tasks is purposeful and goal achievement satisfying.

It's been really rewarding ... I really like setting targets ... and seeing her meet the targets is really satisfying. (June)

There is added satisfaction in pleasing the therapist they respect and trust, indicating the motivation and accountability parents gain from the relationship. Parents can enjoy learning and applying therapeutic principles, particularly those interested in physical activity and self-improvement.

I've always been very active ... I've always had regimented training sessions ... so I'm aware of some of the exercises that you need to do (Alistair)

Nevertheless, parental engagement and outcome expectancy within pursuit framing is tempered with impatient anxiety as parents wonder, "...when is this going to start working?" When progress takes longer and is difficult to observe, ongoing motivation can be affected, for example, in infants with greater impairment levels.

I feel like we are not actually getting anywhere at the moment. (Nicole)

A feeling of hopelessness may cause some parents to revert to uncertainty framing and begrudging engagement. For others, pursuit framing persists longer.

... it's an endless pursuit, it's not a frivolous one by any means but ... there's no end in sight. (Warren)

Parents acknowledge that framing in 'pursuit' can be related to difficulty accepting their child's long-term disability. Alternatively, parents begin to reframe their expectations through transformation.

While a shift to a frame of pursuit was the dominant pattern, accompanied by intensive investment, there were exceptions. One

mother reported that she felt more intensity and pressure around engagement before diagnosis because she wanted the intervention to prevent CP, following the receiving the 'at risk' label. Other parents whose children were initially identified as high-risk infants due to prematurity but were eventually not diagnosed with CP (e.g., Dina) did not report such a "turning point" in their engagement. And they became encouraged and affirmed in their engagement in EI by observing their infant's developmental progress.

### **Transformation framing**

The transformation frame marks a new beginning in the disrupted parental transition. Parents reorganise the meaning of their experience and reframe the meaning of their engagement in EI through adjusting and affirmation.

### **Adjusting**

After facing reality and continuing knowledge acquisition and internal processing, parents begin to make sense of and accept the new reality.

I've come to accept the diagnosis. It is what it is. (Jay)

There is a subtle but significant perspective shift, encapsulating the latter stage of the grieving process: adjusting to an altered future, mourning the loss of their anticipated child, and accepting parenting a child with a life-long disability. Neuroplasticity and EI remain motivating, but they are considered an opportunity for their child to reach their potential.

I don't think any therapy in the world is going to completely cure this, that's these words that I felt at the time. We've just got to do it as much as we can as often as we can to make the best that she can do with what she can do. That felt a bit more reassuring. (Liz)

This transformation frame releases parents from the accountability pressure experienced in the "endless pursuit" to fix and supports a healthier shaping of parental identity and engagement in EI. Parents recalibrate to embrace parenting a child with a disability positively.

This is a great opportunity for him, and ... we're going to give him every opportunity possible that we can ... I think to get from that emotional period when suddenly you're told that the little boy ... wasn't what you'd hoped. You need something to transition into the positive attitude (Alistair)

As parents proceed further in their transition experience, they tend to express more adjustment, although one parent, Bonnie, deviated from this pattern. At an early stage (infant four months old) she received firm disclosure of CP, yet she already expressed a frame of transformation in her self-concept as a parent of a child with CP and perspective of engagement in EI. Despite being a first-time mother, she had extensive experience caring for younger relatives. Her pre-existing experiential knowledge from her Early Years special education vocation gave her "familiarity" and "patience" in her expectations for her son's development, priming her parental self-efficacy and early adjustment. Resonant with other parents, she felt accountable to her child because of his resilient "fight", traits she wanted to mirror, including rejecting narratives of pity presented in encounters with professionals.

Nevertheless, most parents expressed continued difficulty adjusting with internal emotional processing, suggesting it is too simplistic to consider adjustment as a final state. Parents often feel a need to present a (public) face of resilience to others, to fulfil expectations around being a 'good parent' of a child with a

disability [32]. These expectations impose that they must cope in the face of this adversity. So, the projection of a state of adjustment partially appeases societal expectations, as a social 'normality' presented for the comfort of others.

A lot of people was like, 'You're strong.' I'm like, 'Yes and no.' You still have your times when you think, 'Oh my God. This is too much,' but you just bounce back up and you deal with it. (Nicole)

Therefore, adjusting in the transformation framing infers a continuing process, where parents handle difficult emotions while developing a new sense of parenthood in the face of an altered present and future while "settling into a [new] norm."

### **Affirmation**

The parental engagement experience within EI can be affirming for parents. Parents' observation of new movements or achievement of goals or milestones validates their investment in therapy, particularly where progress is attributed to their input. The child's agency, emerging character and relational development with the parents, particularly when nurtured in EI, can help transform parental self-concept while also affirming parental engagement in EI. Parents observe their child's readiness and 'eagerness' as they engage and take control within therapeutic settings. Parents learn to share responsibility and accountability with their child.

I think he's taking control most of the time now. So, he's doing my job, basically (Dina)

Parents understand the place and value of EI while appreciating a healthier balance between 'doing' and 'being' with their child. Engagement and learning within therapy session make parents feel "contained" and "grounded" as anxieties are met with reassurance and practical advice.

I've come to really enjoy physio, because it's a space where I can ... share my worries and I usually get an answer or some reassurance. I can also share all the good things that happen. (Aneeta)

Progress is no longer overlooked within the "Netflix binge" of pursuing the next goal, but parents become "grateful" for milestones met. Therefore, achieving milestones or therapy goals takes on different meanings as parents share the view of helping their child to reach their developmental capacity.

... it is still at the point of coming to terms with it and it is more, 'What does the future hold?' because you just don't know. All we can do is try and get her to the best version of her that she can be, you know? (Dorothy)

Where a child's progress may be slower, parents cope by developing a more hopeful perspective, where patience is learned for future development while accepting the child they are in that moment.

I can see he is delayed but then ... I haven't given up hope. Like, even if it does take two years to turn over, I don't mind. What can I do? It's ... not in my hands.... He's loved. He's eating. He's with me. He's smiling. He's a happy little boy. That's all I want. (Kala)

Parents learn to celebrate their child's incremental steps in their own time. In doing so, they are "letting go" of typical parental rites of passage, such as celebrating textbook milestones more socially. Instead, adjusted milestones are celebrated with the therapist and close family.

I really need to learn to be better about celebrating [her] achievements ... friends are kind and friends want to hear the news ... but do they really appreciate if I sent them a text going, 'oh my gosh, Grace is trying to turn a page with her fist', would they really understand the gravity and how amazing that is. (Liz)



Such examples of how parents are affirmed in their relationship with their child and through engagement in EI provide a counter-normative social perspective that can enable positive adjustment of parental identity. As a sense of confidence in their identity as a parent of a child with a disability grows, so does parental advocacy as parents “anticipate” having to explain to other “people not understanding her disability” (Dorothy). Overall, parents reframe their expectations for their child as they understand them better, including the individualised nature of their emerging abilities despite an uncertain prognosis.

## Discussion

Our paper adds new insights into how the changing context of parents’ transition experience frames their meaning-making in all facets (affective, cognitive and behavioural) of their engagement in EI [8,9].

Inconsistencies in communication of the prognostic at-risk CP label signifies the emerging nature of this evidence-practice translation [33]. Our study highlights that at times parents still report being “fobbed off” as “worried parents.” At other times they are not deemed ready by professionals to receive prognostic-diagnostic information (e.g., “go home and love him”), highlighting ‘epistemic injustice’ in practice [34,35]. Epistemic injustice refers to the unfair distribution of knowledge or the inability of certain groups to access or contribute to knowledge [34]. Our study provides new evidence that alignment of understanding between parent and practitioner is not only an ethical issue but also has implications for parental engagement in EI [4,36].

Research on ‘uncertainty’ highlights different behavioural responses to *approach* or *avoid* a situation, guided by negative or positive cognitive and affective perceptions of the circumstances and intervention [37]. Early intervention may offer parents support and reassurance, but misalignment in prognostic understanding creates confusion regarding its rationale, producing begrudging engagement behaviours. Some parents may disengage entirely as an avoidance coping mechanism [38], which may involve families with more significant intersecting social stressors [39].

Firmer labelling of CP triggers secondary grieving to the primary neonatal trauma, but it can represent a turning point for parents, eliciting conviction in their engagement state. The ‘neuroplasticity sand timer effect’ explains a dualistic tension. Parents might intensively engage because of a ‘concrete hope’ in the coherent restitution and mechanistic messaging of neuroplasticity as a potential to ‘fix’ errant circuitry within the critical developmental window [40]. An unintended consequence of this linear perspective is the pressure it creates, potentially negatively affecting parental wellbeing and identity formation. Therefore, some parents resist this narrative and reframe their perspective to be more transformative, resonating with other sociological literature [41,42]. In transformative framing, ‘losses continue to be mourned but the emphasis is on gains’ [40, p.128]. Orientation is on the present, as the unpredictability of the future is accepted, hope becomes transcendent, with openness to making new meaning through unfolding experience [41].

Our paper highlights how parental adjustment within their transition is interdependent with their engagement and learning experience in EI, building on previous grounded theory with parents of slightly older children with CP within a different context [16]. The practical wisdom of our theorising asserts that true partnership involves therapists first engaging in parents’ lives. This practice involves attending to parental framing of engagement

in EI to understand their beliefs and expectations before sensitively supporting a healthy transition. Expectations on parental engagement cannot be imposed, and therapists need awareness of existing parental pressures. Early interventions should encourage joy in the parent-infant relationship to develop positive parental identity and self-efficacy [9,43].

Therefore, a variety of parental and parent-infant relational goals will offer balance against child-focused activity/impairment goals to support parental enjoyment and fulfilment in the relationship [44]. The application of the ICF’s participation construct (defined as ‘involvement in life situations’) is under-considered in the context of the parent-infant dyad in EI [45–47]. Supplementary to EI, a recently co-designed education programme, ENVISAGE (Enabling visions and growing expectations), shows promise in supporting healthy early parental transition [48]. Of course, therapists’ influence on parental transition will always be partial, as it converges with existing processes of growth and development in parents’ lives [49]. Personal factors, as well as social support, will also be highly influential on the family’s wellbeing [50–52].

Our theorising in this paper simplifies the complexity of the parental experience in EI but it is incomplete. There remains a question as to what extent meaning making is pre-defined by parents from their broad experience and how meaning might become (re) defined in new interaction encounters with the therapist within an EI context. In the future publications, we plan to present analysis around how the interactive partnership between parents and therapists shapes engagement and learning. Yet, as Goffman himself states, ‘The first issue is not interaction but frame’ [28, p. 127].

## Limitation

This study had limitations. Data collection was conducted before and during the Covid-19 pandemic, which may have influenced typical service delivery and parents’ perceptions of their circumstances. Interviews conducted online compared to in-person might have altered data quality. However, as with other researchers, this was not reflected in our practice [53].

At the time of their participation, parental characteristics varied in numerous areas, such as ethnicity, but there were limited data that directly addressed the influence of culture. Reflections through memos explored how some parents’ culture potentially created a more fatalistic orientation to accepting that circumstances and the future is out of their control, “we can’t do anything about it” (Shoaib). Furthermore, one mother discussed her partner’s difficulties in accepting their child’s CP label because of the stigmatisation of disability in their community. Different ethnic cultural beliefs are known to affect parents’ perceptions of their child with a disability [54], which warrants further exploration to support clinicians’ cultural competency for the development of relational practice within EI.

In other areas, there was less variation. For example, most parents were in their 30’s, which reflects a trend in the UK similar to other developed countries, where parents often delay parenthood due to personal career and economic considerations [55]. There was also a higher proportion of parents with a higher education status (70% with degrees), which may have influenced their perspectives, for example, concerning expectations of parenthood [56,57].

Longitudinal interviews were possible with some participants (n=5). Other participants preferred to undertake interviews at one time-point, which allowed retrospective perspectives of change but limited the understanding of change over time. However, the triangulation of the data between all participants and the PAG strengthened the robustness of theorising.

Finally, we recognise that we extend Goffman's initial 'framing' conceptualisation that he applies to social interactions, in how we considered that parents' personal experience becomes part of their engagement framing in EI. Regardless, Goffman too would acknowledge that people draw on their experience and subsequent perceptions to enable sense making of new situations [28].

## Conclusion

This paper has expounded upon the changing context for parents surrounding their engagement experience in early intervention for infants with cerebral palsy. It conceptualises how the early disrupted parental transition experience creates fluctuating framing of their engagement beliefs, expectations and behaviours in therapy. This theoretical development provides an organising schema through which service providers and parents can understand this complex area of practice. For early intervention practitioners, the implications reflect a need for more sensitive engagement in families' lives and partnering with parents during this challenging time.

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