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# Edith Raap, Katie Lee Weille, Monique Flierman & Martine Jeukens-Visser

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# "The Attitude Is Essential" The Experience of Two Mothers with Differing Educational Backgrounds Receiving Post-Discharge Intervention after Very Preterm Delivery

Edith Raap (D<sup>a</sup>, Katie Lee Weille<sup>b</sup>, Monique Flierman (D<sup>c</sup>, and Martine Jeukens-Visser (D<sup>d</sup>

<sup>a</sup>Institute for Social Work, University of Applied Sciences Utrecht, Utrecht, The Netherlands; <sup>b</sup>Leiden. Independent practice, Webster University, Amsterdam, The Netherlands; <sup>c</sup>Amsterdam UMC, Department of Rehabilitation, Amsterdam, The Netherlands; <sup>d</sup>Amsterdam UMC, Department of Reproduction and Development, Amsterdam, The Netherlands

#### ABSTRACT

While the importance of professional support following very preterm delivery (VP) is established, the parental experience of support still warrants deeper understanding. Evaluation of a Dutch one-year post-discharge responsive parenting intervention following VP suggested that parents with lower educational levels benefitted less from the program. This idiographic phenomenological study investigated the lived experiences of two mothers with differing educational backgrounds receiving professional support during hospitalization and post-discharge. In-depth interviews with the mothers were analyzed using Interpretative Phenomenological Analysis.

We formulate three impressions: (1) How the mothers made sense of their experiences resonated with the findings of research on class differences in parenting. (2) The mothers valued professionals who struck a personalized balance between supporting their maternal agency and attending to their vulnerability and needs for help and perspective. (3) The mothers experienced greater trust in professionals who could suspend pre-conceived assumptions and take their personal characteristics into consideration. Practice suggestions are extrapolated for social work professionals.

The study has relevance to educational diversity and recommends an overarching sensitivity to positionality in professional work with parents.

#### **ARTICLE HISTORY**

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#### **KEYWORDS**

Parenthood; parental experience; very preterm infant; SEP; professional support; IPA

Becoming a mother in the neonatal intensive care unit (NICU) is different and more complex than carrying an infant to term and bringing it home. Parents of very preterm (VP) infants typically endure crises, uncertainty and powerlessness in their transition to parenthood (Russell et al., 2014). Negative experiences include struggling initially to feel like a parent (Hutchinson et al., 2012) or develop maternal feelings (Fernández Medina et al., 2018), as

**CONTACT** Edith Raap edith.raap@hu.nl Image: Institute for Social Work, University of Applied Sciences Utrecht, Padualaan 101, Utrecht 3584 CH, The Netherlands

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the reality of the birth is vastly different from one's expected path to parenthood (Adkins & Doheny, 2017). The medicalized context of the NICU may impact constructions of maternal identity and representations of the child (Spinelli et al., 2016). Coming home from the NICU with a vulnerable baby has been associated with difficulties in developing supportive relationships and finding affirming social environments (Gullino et al., 2017), and difficulties may last well beyond the event (Yaari et al., 2017). Many personal variables, from attachment to spousal support, mediate parents' development following premature birth (Taubman-Ben-Ari & Spielman, 2014), as do differences in degrees of prematurity (World Health Organisation, 2023). Mothers of extremely preterm infants "may take years to merge with the world of those mothers who parent healthy, term infants" (Wilson & Cook, 2018, p. 1627).

Studies on parental coping within the NICU show it is crucial for social workers and other professionals to develop intervention strategies that focus on the psychosocial needs and well-being of mothers (Lavallée et al., 2019), mitigating stress (Al Maghaireh et al., 2016), and increasing confidence after discharge (Adama et al., 2016). Good provision of information and communication are crucial (Labrie et al., 2021) as are sensitivity in recognizing parents' fear and confusion and helping them make sense of the experience (Gilstrap, 2021) – all of which may, in practice, be lacking (Lorié et al., 2021). But providing support in a setting characterized by existential threat is far from straightforward (Kraemer, 2006), requiring considerable support and education for staff (Turner et al., 2014). Initiatives such as Family Centered Care or Interdisciplinary Family Conferences have improved the NICU landscape by engaging parents more fully, for example in decision-making (Trujillo et al., 2017). However, even structural or policy changes may not ensure attuned care for NICU parents, as much remains to be understood about the breakdown of relationships between parents and NICU professionals (Steinberg & Patterson, 2017). One source of failure may involve positional differences, as parents with low socioeconomic positioning in the NICU experience distrust and stereotyping, with NICU clinicians viewing less educated parents as incapable (Sigurdson et al., 2020), and racial/ethnic and socioeconomic inequities in access to care persist (Sigurdson et al., 2018). In the Netherlands where healthcare is universally accessible, awareness of intersectional prejudice is nevertheless increasing (Stuij et al., 2020).

Following discharge from the NICU, preventive early intervention is important to support parental and infant resilience and provide enhanced developmental opportunities for infants (Van Wassenaer-Leemhuis et al., 2016). Here again, misunderstandings between parents and professionals may occur. Parents may be misconstrued as overprotective (Adama et al., 2016) which could be understood as hypervigilance (Fowler et al., 2019) in face of the daunting medical task of caring for a premature infant (Murdoch & Franck, 2012). Yet, there is overwhelming consensus on parents' ongoing needs for post-discharge support and contact (Granero-Molina et al., 2019), including individually attuned care (Davies et al., 2017).

#### **TOP Program: Psychosocial Support Following VP**

The TOP program is a Dutch, post-discharge parenting intervention for VP children (defined by the program as <32 weeks gestational age and/ or <1500 g birthweight). While the World Health Organisation (2023) defines VP as 28 to <32 weeks gestational age, and under 28 weeks is designated extremely premature or EP, the TOP program uses a single designation (VP) for both groups, who receive the same intervention. Using a strengths-based approach, the program aims to improve parental responsiveness and increase infant developmental outcomes (Jeukens-Visser et al., 2021). Other targets include parental understanding of the infant's behavior and parental well-being. The TOP program is a free, universally accessible service offered as part of routine care for VP babies and their parents in the Netherlands. It is carried out for one year post discharge by pediatric physical therapists with additional training in Infant Mental Health.

A randomized clinical trial of the TOP program showed positive results (Koldewijn et al., 2009; Van Hus et al., 2016), but did not answer the question of how parents experience professional support. Joining a broader trend in the science of parenthood (Van der Pas, 2003) the tendency of research to focus on the effects of parenting on child outcomes, rather than on the experience of being a parent, emphasizes the instrumental aspects of parenting, or the "outside in" perspective, rather than the "inside out" of parental experience (Weille, 2011). Even as research documents and quantifies the hardships, stresses, or traumatic effects of parental circumstances, the authors' experience is that this often misses the fine texture of the experience itself. In this context -The TOP program's interest in understanding the parental experience behind their statistics, and our own interest and engagement as researchers, teachers, and clinicians with parenthood "from the inside out" - the first and second author were invited to conduct this study. Given that earlier subgroup analyses carried out in the context of the program's evaluation research had shown less effect of the intervention on motor and cognitive development in children of mothers with lower educational levels (less than four years of post-elementary schooling) (Van Hus et al., 2016), a more specific question was raised along the general one about how this particular group of mothers might experience and make sense of their year in the TOP program, as well as what kinds of modification to the intervention might enhance engagement with this group of parents.

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# Parental Support and Positionality

As discussed earlier, access to and experiences with health-related care can be impacted by the many kinds of positionality subsumed under Galobardes et al.'s (2007) concept of SEP as a reference to "socially derived economic factors that influence what positions individuals or groups hold within the multiplestratified structure of a society" (p. 23), of which educational difference forms one such example. In a longitudinal ethnographic study exploring the intersections of race, class, and parenting, Lareau (2018) discerned significant differences in parenting values and practices based on class and education. Vincent and Maxwell (2016) underscore the fact that "although parenting is a personal, intensive and intuitive experience, it is also infused with classed behaviors, values, actions, and dispositions" (p. 269). Professionals are no less infused, as the history of social work in the USA (Lizzi, 2020) and its European counterparts (Ramaekers & Suissa, 2012) indicate, with examples of implicit middleclass bias permeating social welfare policies and programs and effectively stigmatizing the parenting practices of less affluent parents. This raises questions about how parents with lower SEP might experience and make sense of this stigma while interacting with the programs (and professionals) intending to help them as parents.

### **Current Study**

The review of prior research suggests there is still much to be understood about the parental experience of professional support, including the variations in experiences between mothers with differing educational positionalities. To gain insight into these questions, and contribute in some small way to the larger project of elucidating parental subjectivity more generally, we set out to explore the lived experiences of professional support of two mothers with differing educational backgrounds following very preterm birth and during the first year of support by the TOP program. We aimed to explore this question in the kind of granular, personal detail required for delving into subjective, lived experience while exploring broadly with an open mind around the full range of participants' experiences.

#### Method

#### Phenomenological design

A phenomenological design was employed. We used Interpretative Phenomenological Analysis (IPA), an idiographic approach that is well suited to accessing and providing detailed examinations of personal lived experience (Smith et al., 2022). IPA adds an explicitly interpretative layer to the subjective experiential focus characterizing phenomenological approaches (Smith, 2007). With its idiographic focus, IPA typically employs small sample sizes and aims to discover the complexities of contextual and other influences on a person's experience that become less perceptible with increasing numbers of participants or a nomothetic approach. In the analytic process a "hermeneutic circle" is employed that continually links part and whole, striking a "balance between individuality and commonality" (Nizza et al., 2021, p. 8). IPA produces an account of lived experience on its own terms rather than one prescribed by preexisting theoretical preconceptions (Smith & Osborne, 2008).

The choice of IPA as an analytic method was additionally based on its appropriateness for research into the domain of parental subjectivity. Where the predominance of research on parenting focuses on the developmental needs of children and positions parents as agents of their fulfillment (Weille, 2011), IPA shifts the focus to the subjective lived experience and sense-making of the parent. This analytic approach was chosen as the best operationalization of the research question and our broader view of parental subjectivity as a complex and profoundly personal experience in which contextual forces are strongly present and impactful. Making an "explicit commitment to person-in-environment and not just phenomenon-as experienced" (Quest, 2014, p. 43), IPA delves deeply into personal experience while considering social, cultural, and historical contingencies (Eatough & Smith, 2008). IPA is thus not "simply descriptive" but requires "double hermeneutic" interpretative work by the researcher making sense of the respondents making sense of their experience (Smith et al., 2022), all of which is specifically within their particular context (Noon, 2017).

While IPA is a flexible method that takes the position that "there is no right answer to the question of. . .sample size" (Smith et al., 2022, p. 46), the method sees merit in small sample sizes – including N = 1 or 2 (Smith, 2004; Smith & Eatough, 2006) - a perspective held more generally by phenomenological methods. Vasileiou et al. (2018) note that IPA studies stand out compared to other methods in "renouncing the notion of saturation" and advocating the value of small samples while problematizing large ones. IPA's idiographic and phenomenological commitments to the detailed examination of lived, subjective experience of one or a small number of individuals has the potential to yield insights or discoveries that might be missed by larger samples and/or more purely descriptive or less subjectivist approaches. In a comparative study, Spiers and Riley (2019) noted while performing two analyses on the same data, that certain findings "were not uncovered in the TA [Thematic Analysis] but only came to light during the subsequent IPA analysis" (p. 286). In order to do justice to the "the complexity of most human phenomena" (Smith et al., 2022, p. 46), sample sizes may be further bounded by the timeconsuming and labor-intensive "concentrated focus on a small number of cases" undertaken by IPA.

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This study was charged with the goal of exploring a fine-tuned question within the context of clear-cut "external," nomothetic findings from prior research: We wondered what we might discover in the process that could shed further light on the question, adding texture to the existing body of research, in which the "externality" of the phenomenon – the shock and strain on parents, the negative effects on children - had been well documented. Smith et al. (2022) note that by prioritizing the "detailed examination of a particular case ... it is possible to move to more general claims with IPA but this should be only after the potential of the case has been realized" (p. 3). The "particular" is thus prioritized above the "general" and any insights or claims arising from it are "bounded" by the sample size. Within these constraints, generalizability may as "an extension" be "considered through theoretical generalizability, where the reader of the report is able to assess the evidence in relation to their existing professional and experiential knowledge" (Smith et al., 2022, p. 3) as well as considering it in terms of the "claims in the extant literature" (Smith & Osborne, 2008). Vasileiou et al's distinction between "statistical generalizability" and "the ability of qualitative research to still be relevant beyond the sample studied" (Vasileiou et al., 2018, p. 14) describes the space inhabited by IPA: discovering something of relevance without either aiming or claiming to achieve generalization of the kind that may be achieved by larger sample sizes and other methodological approaches. Indeed, this study aimed to present a careful interpretative account that could be considered in relation to extant literature and theory, generating in the process insights, practice suggestions, and questions for further study.

# Participants

Two mothers were interviewed, both in their native language of Dutch. Their accounts were stripped of identifying information and assigned the pseudonyms Agatha and Bea. Agatha had a Master's level education and had worked for years as a practitioner and as an educator of new practitioners. Bea had a general education diploma, had worked in a supermarket, and had a history of chronic health issues. Both mothers were partnered with the fathers of their babies, and both were first-time parents. Bea's baby was born at 24 weeks and required a much lengthier hospitalization (220 days) than Agatha's child who was born at 31 weeks and required 28 days hospitalization. Both babies were boys. Agatha's child had a birthweight of 1990 grams, while Bea's child weighed 725 grams at birth. Both mothers were white, cis-gendered, Dutch speakers born and raised in the Netherlands. Agatha was interviewed 30 months after discharge and Bea 8.5 months after discharge. (Table 1). Consistent with IPA, purposive sampling was employed with the following inclusion criteria: Completion of the TOP program, language proficiency, and

interest/inclination to reflect on personal experience. The mothers were also

					Birth	Child's sex		Months	
Participant	Age	Partnership status	Level of education	Gestational weeks/days	weight (gram)	as designed at birth	Days in hospital	post discharge	First child
Agatha	37	Living together	University	31/0	1990	boy	28	30	yes
Bea	24	Living together	High School	24/4	725	boy	220	8.5	yes

Table 1. Participant Demographics.

selected for differing educational backgrounds. These criteria were assessed, and recruitment was carried out by the TOP interventionists who knew the mothers but were no longer engaged in a professional relationship with them. Two mothers were approached and ultimately selected for participation whom the TOP interventionists thought might be interested and inclined to reflect on their experiences of participating in the program.

#### Data Collection and Analysis

The research team consisted of two researchers, an IPA supervisor, and a TOP educator. All members of the working group, which combined Dutch and Dutch-American researchers, were fluent in spoken and written Dutch and English. All were middle-aged, middle-class, white professionals with combined backgrounds in clinical social work and developmental psychology, as well as specializations in research methods and the psychology of parenthood. The TOP clinician was a physical therapist with infant mental health training.

The Medical Ethics Review Committee of Academic Medical Center waived the need for ethical approval (Kenmerk W17\_239#17.277) stating that the Dutch Medical Research Involving Human Subjects Act (WMO) does not apply to this study given that only interviews were performed. Regarding privacy and research ethics, the study adhered to the Declaration of Helsinki (World Medical Association, 2018).

Both mothers signed an informed consent prior to the interview after being provided with verbal and written information regarding the aim and design of the study. The working group developed a topic list for the interviews. Semistructured interviews were conducted separately in private settings chosen by the mothers, lasting between 90 and 120 minutes. Interviews were conducted by E.R., who was not involved in the TOP program. The interviews were recorded with audio equipment and transcribed verbatim.

The analytic procedure followed Smith et al.'s (2022) multi-stage approach, starting with several close readings and an associative drawing out of themes, and proceeding further with a systematic, inductive thematic analysis of participants' texts, moving from emergent to higher-order themes. By moving iteratively between in-depth, detailed examination of each case and the cross-case analysis linking them in difference and commonality, the researchers

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engaged in the hermeneutic circle, finding relationships between part and whole.

The data analysis was performed by the first two authors. Audits of the data were conducted with the two other researchers at each stage of the analysis, and interpretations were discussed. Where there was disagreement, understanding and shared perspectives were sought through further discussion and thematic refinement. Translation of the material was not undertaken until the final stage of writing for international publication, having been delayed for as long as possible in order to remain close to the texture of the original text.

#### Assessing the quality of research

In keeping with emerging standards for evaluating qualitative research in psychology we applied Yardley's (2000) four principles for assessing the quality, adding to these a consideration of Nizza et al.'s (2021) recent discussion of what constitutes a good IPA study.

"Sensitivity to context" was established by the study's choice of methods, its idiographic commitment to understanding the mothers' experience in the context of their unique lives, ideas about motherhood and other particularities, and grounding analytic claims in verbatim accounts as well as generalizing only to the degree that befits an inductive, quasi case-study. "Commitment" and "Rigor" were ensured by careful listening during interviews followed by close readings of participants' material. The research group conducted regular discussions of the material and emerging analysis, checking it in relation to the experience of the TOP clinician. "Transparency and coherence" were demonstrated both by in-depth research team reflections and written notes as well as the detailed "trail" of analytic stages including successive developments and re-working of superordinate themes. Reflexivity was brought to bear on the theoretical and epistemological perspectives each member of the team brought to the research. A limitation in reflexivity at the early stages of the study emerged when, in the latter stages of the analytic process, as researchers we became increasingly aware of our unconscious middle-class bias and the degree to which this had permeated our research question and study design. We reflect on this issue in detail in the discussion.

#### Results

Three superordinate themes emerged that reflected the mothers' experiences of professional help in the context of their journey from pregnancy through the first year at home with their babies (Table 2).

The first superordinate theme followed the mothers' shock and disorientation during and after VP, tracing an unexpected and distressing loss of agency amidst an alienating institutional environment. The second and third superordinate themes elaborated on the women's personal journeys into motherhood and the vicissitudes of feeling supported and understood by professionals both in-hospital and post-discharge. While the first theme echoes prior insights into the shock and trauma following VP (O'Donovan & Nixon, 2019), we focus on the second and third themes as they deepen our understanding of the mothers' experiences of professional help and support our idiographic commitment to contextualizing these experiences within each of their stories (Table 3).

#### Agatha and Bea: Two Lives, Two Different Roads to Motherhood

In their respective journeys to motherhood, Agatha and Bea differed in their ideas and expectations of motherhood, how they thought about hospitals, professionals and their baby's development, and how they had each grown and changed through the transition to parenthood.

#### Agatha: leaving a career to find new meaning in motherhood

Before she had children, Agatha saw herself as a "happy butterfly" who "loved to travel" and live an unfettered life. In this, she "saw children as a real limitation", and hesitated "for a long time because I was afraid of losing my freedom". She was "really serious" about work, where she felt capable – "I could always do everything" – and very much in control. Agatha formulated her decision to have children as a shift of ideas about what makes life meaningful – perhaps work was not enough: "If this is my life in ten years . . . it feels empty". She described her decision to become pregnant as a rational weighing of pros and cons – "I'd have to make concessions, but I'd accept them. If I don't do it, I'll always think about what if I had done it".

#### Bea: blessed against all odds with a partner and a child

Bea came to motherhood in a different way. Like Agatha, she expected she would not become a mother, but this was not because she did not want to or was afraid to lose freedom or a career. Bea had been diagnosed with a chronic illness at the age of 16 years, and she (and her family) had "assumed that I'd never be able to have a boyfriend because who would ever accept that I couldn't do anything all day". Neither did she expect that childbearing would be

Superordinate Theme	Description
'It was like a spaceship in there'	Experiencing the shock and crisis of premature birth and the first period in the NICU.
Striking the right note versus 'they	The vicissitudes of feeling supported and understood, by family and
don't get it'	professionals, both in hospital and post-discharge.
'Bea and Agatha: Two lives, two	Tracing the women's personal journeys into motherhood and their
different roads to motherhood':	reflections on the experience as a whole.

Table 2. Superordinate themes in the study.

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Superordinate theme	Subordinate theme	Subordinate theme	Example
Two lives, two different roads to motherhood	Agatha: Leaving a career to find new meaning in motherhood Bea: Blessed against all		I feel so free [now, as a mother] because I'm worrying less. There's just us [her family surrounded by a little shell that's what matters, that's what I do it all for We actually didn't think very long about it,
	odds with a partner and a child Agatha: Expecting to feel capable and be		because I still lived with my motherbut I was already [pregnant] after a month! There was a particular method how you wer supposed to and [they said] "that is th
	listened to		way we work. We are going to do it this way and that way" And I thought . ??? I have a pedagogical background myse
	Bea: Used to not being heard; not taking anything for granted		The doctors said "let her wait in the waiting room" Well, I was crazy with the pain and I got something like, you know what, I'll ju fall down here on the floor, 'cause then you'll come. That's how it goes, if you fal down then all of a sudden they come.
	Both mothers: Who I have become		Agatha: It is just, yes, the ultimate feeling of happiness and freedom Bea: I have become, because of this perior I was always like: "Everything is ok and all fine;" but I have become tougher. Like: if I don't want it, then it won't happen. That and not for him: if he doesn't want it the he doesn't want it. Period.
Striking the right note vs they don't get it	They don't get it: Help that is not attuned	Help that is not negotiated or clear	Agatha: "We can help you we use this approachbut I had no request for help because you"I was so fed up with it." Bea: You get fed up with it. Everybody w comes interfering; I was thinking: get lost all of you!
		Disconnection and distrust	Agatha: I have to go back to the hospital, in r view for no reason but I have to see 5 specialists. Why? I get the feeling it is just i the graphs [statistics] Bea: Well, I didn't want him to go to [Hospital] B. I don't know why I didn't have a good feeling about it.
		Lack of agency	Agatha: "WE know how it works and you do what I say." That is how it felt to me Bea: In the hospital, it was always 'can I change him? Can I feed him? May I do th may I do that?"
	Striking the right note: How help can be attuned	Encouragement and support	Agatha: "Shall I come by again, or what do y think?" That: "what do YOU want," actual I really appreciated that. Bea: She [the therapist] said; yes, but if y look at this [adjusted chart for premies] h does really well. And then I thought: OK! If not like, he cannot do this and he cannot that. He does very well!
		Clear and credible expertise	Agatha: She was really professional. She kne what she was doing and what she was talking about. Bea: He [the pediatrician] talked straight talk I really appreciated the way he dew with it. Clear; and you know where you stand (Continu

Table 3. Summary of superordinate and subordinate themes.

(Continued)

Superordinate theme	Subordinate theme	Subordinate theme	Example
		Striking the right note	Agatha: I like the way she's been with me in my experience, she got more and more a place, like, next to me, next to our family. Bea: She [the nurse] said: what about laying down and kangaroo with him. "Uh? Can I still do that?" She said: yes, just enjoy it! Just lay down and take him to sleep with you. Well, I slept with him the whole afternoon!

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Tabl	2 2	(Continued).

possible, for medical reasons: With a ligamentary syndrome "*they said I'd have to do pelvic therapies and bla bla bla*". Bea was surprised to find a partner, and to find herself pregnant.

#### Agatha: expecting to feel capable and be listened to

Agatha expected her body, the pregnancy, and later the professionals and institutions to work as they were supposed to: "My body can do anything ... I can run the marathon ... I can travel if I want. I can learn if I want, so this [pregnancy] cannot be going wrong now!" Pregnancy ushered in a new insecurity about what she was feeling: "I noticed something was changing but I didn't know what.."She struggled to manage confusing emotions: when one of her twins died in utero, she described herself deciding to postpone grieving until the weekend when she would have time for it because she didn't have to work. Once in hospital with the baby in an incubator, she emphasized "This is not the way it is supposed to go. This is not OK".

As a professional herself, Agatha expected to be treated as an equal: "*I'm also a little bit in that world*". She felt entitled to her own opinion, was assertive and critical, punctuating with impatient expressions like "*come on*" and "*are you kidding*?" Unaccustomed to needing help, she "*had to get used to the role of asking for care*". She believed wholeheartedly in the developmental science paradigm employed by the TOP interventionist, recognizing elements this paradigm had in common with her own professional education.

#### Bea: used to not being heard; not taking anything for granted

Unlike Agatha, Bea didn't take for granted that anything – her body, doctors, experts, or her baby's development – would work well or as expected. She was "tough" on herself and did not ask for attention: "I never talk easily about [myself] ... I have pain every day ... that's the way it is ... I'm not gonna bother everyone with, 'I feel this and that". She did not assume that she had the right to criticize professionals, saying "I am very bad at that", and repeatedly using the phrase "bla bla" when quoting the information or perspective they had

conveyed. At times, this appeared to express a lack of understanding, as when she followed it with *"How should I know?!"* 

At other times "bla bla" seemed to convey ironic critical commentary, such as when Bea perceived a contradiction between two elements of a professional opinion, or between the professional opinion and her own sense of things. Where Agatha described her criticisms directly, Bea kept her annoyance to herself, certain that her perspective would not be taken seriously. She described arriving at the hospital in an acute state of premature labor where the doctors said "Let her wait in the waiting room". However Bea "was crazy with the pain and I got something like, you know what, I'll just fall down here on the floor, cause then you'll come. That's how it goes, if you fall down then all of a sudden they come".

Bea follows this painful contradiction between the presupposition of available help versus the reality on the ground, by drily recounting how her "water broke right at that moment ... so the doctor, everything and everyone were covered in it. Oh great ...". The specter of a typically invisible Bea dousing an entire medical team with amniotic fluid seemed to emphasize her awareness of transgressing a boundary while at the same time underscoring the doctor's error in not having understood the urgency of her condition.

#### Both mothers: who I have become

Both Agatha and Bea described changing and developing through their experience of VP and its sequelae in the transition to motherhood and experiences with professional intervention, most notably the TOP therapist.

Agatha described who she had become in this year: "I am a family". She spoke of moving from a primary focus on work and the drive to be in control and achieve goals, to a way of being in the world characterized by letting go and surrendering to the messiness of life. She described a reflection on this shift in priorities: "It was sunny ... I was walking with my buggy and he was sleeping peacefully. I thought, why do I actually have to travel to [some far flung location]? It's fantastic right here! I never experienced that before having kids".

In contrast to Agatha's easing up, Bea "became stubborn". Fighting for her child's needs had helped her to become more assertive: "I was always like 'everything's fine' but I got tougher. Like, if I don't want something, it won't happen". Being confronted with an extremely premature baby, Bea had also grappled with her own experience as a chronically ill person: "I have trouble accepting that I'm sick and so on, but with him, I don't have trouble with it ... it's a shame ... I wonder why does he have to get this? But yeah ... I can't change it".

What Agatha and Bea shared, despite differences, was a perspective of motherhood as having an intrinsic, existential value, and neither regretted having become a mother.

#### Striking the Right Note vs. "They Don't Get It"

In the second part of the analysis, we delved more deeply into the mothers' experiences of professional support. Coming into hospital with its plethora of staff and experts, and moving on to discharge and a longer term involvement with the TOP therapist, both mothers described professionals as variously more or less attuned. While some could really listen, understand and be capable of "striking the right note" others just "didn't get it".

#### They don't get it: help that is not attuned

There were three ways Agatha and Bea described professional help that did not feel helpful or understanding, together highlighting the importance (or lack) of negotiation, clarity, listening and trust, and agency.

Help that is not negotiated or clear: "I don't need help from you". Help that was not experienced as helpful began with professionals making unspoken assumptions about what the mothers needed, without first establishing a shared framework or agreement about what the mothers themselves felt they needed.

For Agatha, it wasn't yet clear what kind of help she needed. She first needed to get oriented: "that you . . . on your request, get someone who thinks with you, with your ideas about how you want to do things. Instead of 'we're going to help you'". She criticized a flyer about the TOP program because of its assumption: "We'll help you with your child's development" . . . and that approach . . . I was so done with that". It felt premature to push a particular version of what she needed before she had a chance to determine this for herself.

For Bea, the assumptions about what her child needed also felt like "*pushing*" when her hospital experiences had left her feeling overwhelmed and tired of having so many professionals "*meddling with your child* . . . *I was like: 'Get lost, all of you!*" She described her strong need to "*decide for myself*". "*It's my thing* . . . *if I put him in the highchair, I put him in the highchair. If I put him in the playpen, I put him in the playpen. So there*".

*Disconnection and distrust: "She doesn't listen to me".* Closely related to unclear or non-negotiated help were experiences of not feeling listened to or understood, and a resulting disconnection and distrust. When Bea's baby was moved to another hospital, she felt she had no say in the matter. Her reaction was

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detachment: "I didn't want him to go to Hospital B...I had a bad feeling about it ... then he went to Hospital B and yeah, whatever".

Both mothers experienced expecting their babies to be discharged, then hearing they needed to stay for further evaluation. Not trusting this advice, Agatha described how she "sat there, and thought, a 'test overnight'? Come on! We're just going home", and, "piss off...".

Equally, Agatha was put off by being referred for a dizzying array of services without any awareness on the part of the referring professionals of how taxing it was for her to attend so many appointments: "I had to go to all of them every month ... couples therapy as advised by the hospital ... the social worker, the physiotherapist, the pediatrician ... So many!"

Lack of agency: "I had to, I was not allowed to, I didn't dare to". Speaking about their time in hospital, both mothers used words like: I had to, I was not allowed to, I didn't dare to. They had entered a world of specialist expertise and terminology in which they felt dependent and helpless. As Agatha put it, "I didn't dare to do anything ...." THEY were the ones who knew everything. I didn't know anything". She described the staff as "bossy" saying "You have to do this and you have to do that". Bea spoke in a similar vein, saying "If someone came to tell *me what I had to do, then I became . . . actually mad, like what are you getting into* my business for? It was like ... 'you have to do it this way'". While both mothers understood they needed help, the feeling that staff was in control and mothers had to ask permission to care for their babies was dystonic: It seemed unnatural because it was *their* child – as Bea put it, "Can I change him? Can I feed him? May I do this? May I do that? May I sit with him ... when it's YOUR OWN CHILD!" This disjuncture contained a twinned sense of powerlessness and indignation. Right at the time when, as new mothers, they expected to take up a maternal position characterized by agency, both mothers felt instead disempowered.

# Striking the Right Note: How Help Can Be Attuned

Three themes emerged around the experience of help as sensitive and attuned, detailing the mothers' positive experiences with the post-discharge TOP therapist.

# Encouragement and support: "someone who focuses on what he can do"

Confronted with a premature baby lagging behind norms, both mothers appreciated a perspective tailored to their baby, rather than being confronted by the ways he was failing. For example seeing a growth chart calibrated for premature babies, or, "someone who focuses on what he can do". Agatha recalled the "one nurse" in the hospital "who sometimes put an arm around my shoulders ... and said, wow, you guys are really a super

team ... it's gonna be fine with [the baby]" This encouragement gave her "SO much relief".

Bea described a different kind of encouragement: She felt reassured by a doctor who acknowledged, understood, and normalized her difficulties feeling "like a mother", explaining that "you don't want to attach too much, because you don't know if he'll make it".

Finally, Agatha appreciated that her TOP therapist let her decide for herself what kind of support she needed: "She was very much of the approach: See what you need and give me a call ... and I knew that ... I could always call her". Being attuned to Agatha's own timing, but also generally available, gave Agatha a sense of "someone who is always there for you".

#### Clear and credible expertise: "She knows what she's talking about"

Both mothers reflected on what made expert knowledge feel attuned and trustworthy. Agatha felt her TOP therapist was "really knowledgeable" which she contrasted with her own lack of expertise "because for me it's all new". Making this knowledge more credible was the therapist's effort to get to know her: "She knew when I had to go to the hospital, who my doctor was . . . where I worked . . . how my child was developing". By coming to Agatha's home and connecting with her daily life, the expertise was grounded in practice – "She always looked at how I was doing things". This close knowledge of her situation made the therapist an ally: "Someone by my side . . . also in the communication with the hospital".

Bea valued clear, understandable perspectives. She recalled a good experience with a pediatrician who took initiative, was knowledgeable about her child, and had a clear plan and information about the condition of her child: in short, "clear, and you know what you're dealing with . . . cause I didn't understand anything of those x-rays". This doctor took charge in a way Bea appreciated and found trustworthy.

#### Striking the right note: "The attitude is essential"

Emerging from the nuances of attunement in both mothers' stories is the twinned importance of feeling seen and respected in their autonomy/competence, while at the same time being vulnerable and needing the professional's help and perspective, including the capacity to intervene judiciously in those areas where the mothers could not judge matters and/or operate entirely on their own. Here again, the *particularities and ways* in which each of the women's experience gives rise to this overarching thematic interpretation are highly distinct.

Initially, it was important for Agatha to feel safe being vulnerable, as she felt exposed: "Someone's there in your private business, it's intense. The first time I thought, maybe she's going to look under the sofa if there's dust". It helped that Agatha's privacy was respected, such as when she was 16 🔄 E. RAAP ET AL.

breastfeeding, and the therapist offered to leave and come back later. She appreciated the "*independent*" mind of the TOP therapist. Unlike in hospital where "*they all consulted with each other*", the TOP therapist could discuss matters without acquiescing to other professional opinions. Similarly, Agatha could sense the authenticity of the therapist, who sometimes said "*I don't know'* ... and that was just honest, not some kind of trick". Agatha could trust that if there were concerns, "*if it wasn't going well, she would tell me*"- Agatha could rely on honesty both in the sense of the TOP therapist being willing to admit to her own limitations and to confront Agatha about hers.

As time went on, after "spending whole days with my child", Agatha "began to notice ... I think I know this better. Because I know him much better ...". This sense of a growing understanding was mirrored by the TOP therapist who supported Agatha's increasing capacity for autonomy: "She gave me the control ... cause I was after all the boss, I was the parent. She said that too".

For Agatha, the TOP therapist was an approachable and trustworthy "compass", the "link in the whole" and "middle point" of the "premature predicament", connecting disparate professionals, information, and parts of her experience that might otherwise have fragmented. As a "kind of sounding board," the TOP therapist listened and watched closely; could be relied on to strike a balance between guiding and following; and grounded it all in equality – "we were on the same level".

For Bea, striking the right note involved a balance between the professional respecting and supporting her own, more naturalistic notions of what was best for her child, yet being directive at the times when she too felt that was what she needed.

When some doctors "came to the incubator and asked, 'how many people have been here" and Bea responded with a long list, she was relieved "they said: 'Ok, then we'll come back this afternoon.' Cause that is when I was finally sitting quietly". She was also happily surprised when a nurse insisted that she too should rest and lie down with her child – a directive that felt caring and attuned. Indeed, when Bea felt unable to attend to her own need for sleep, she welcomed another nurse's even more directive approach: "I had sat there the first two days and nights. . . and they said at a certain point, 'you're going to your room NOW and you're going to sleep. I don't want to see you before tomorrow morning". Intervention was welcome and supportive when Bea felt incapable of making her own judgment.

However, when Bea didn't instinctively agree with the professional's suggestion, it seemed more complicated to trust and accept influence while retaining her sense of autonomy. She wrestled with the TOP therapist's assertion that "he's a bit behind". To which Bea replied, "Yeah, so what ... he does it in his tempo, period". Then she described the therapist saying "Yeah but you should push him a little" to which Bea said, "No I'm not gonna do that" and characterized this as "then I'm being stubborn; I do it my way and [the baby] does it his way". Later, Bea noted that the TOP therapist also suggested stopping when the baby is tired: "She also says 'you know what, it's done ... you shouldn't push anymore".

We interpreted these differing accounts within Bea's interview as an indication of the complexity – for mother and professional alike – in seeking a balance between pushing and laying off. Ultimately, Bea seemed to feel supported in her emerging agency and competence by a combination of opening to influence *and* trusting in her own approach, both of which were aided by an attuned relationship with a trustworthy professional.

#### Discussion

In this study, we explored experiences of professional help following VP of two mothers with differing educational backgrounds, as well as differences in health history, age, and the degree of prematurity and length of hospitalization for their babies. We found the ways in which the mothers position and express themselves, and the kinds of examples that permeate their accounts strikingly distinct, yet also containing shared notions about what constitutes positive and negative experiences of professional help. In this discussion, we consider the findings in relation to extant literature.

#### Different Lives, Different Points of Departure

In the mothers' narratives, we noted overarching differences in the ways each related to the institutions and professionals charged with providing medical and psychosocial care in the event and aftermath of VP. While both experienced important growth and changes to their sense of self, it seemed instructive that one had to let go of the high degree of control she expected to enjoy, while the other became more assertive and found a sense of control she had previously missed. We were struck by how the mother with a stronger social and educational position who identified as a working professional reacted with indignation and criticism to perceived professional mis-attunements, while the mother with a lower SEP and a history of chronic illness seemed *accustomed to not being listened to* by professionals and responded with cynicism and resistance.

We made sense of this, first, with the interpretation that shifting from a background of professional-class identification with a good health status, to identifying as a "patient" needing "help" could be difficult in very different ways to the experience of coming from a background of minimal employment opportunities and living with chronic health issues since one's mid-teens. We imagined the latter might make a "patient" position feel uncomfortably familiar, and familiarly disempowered. Secondly, we imagined that sharing 18 👄 E. RAAP ET AL.

(identifying with) the "experts" knowledge framework would likely be experienced as ego syntonic and in line with expectations. Whereas finding oneself confronted with a contradiction between the expert paradigm and one's own instincts – in this case, developmental science versus "rest is best"- would be an uneasy and potentially stressful situation to navigate.

The differing ways the two mothers experienced the VP situation appeared to resonate with themes related to class- and education-specific positioning along with other elements of their biographies. In an earlier study finding that parents experiencing VP with higher educational levels perceived themselves, two months post-discharge, as "less competent parents" than did parents with lower educational levels (Olshtain-Mann & Auslander, 2008), the researchers hypothesized that more educated parents might be "more aware of the potentially difficult road that lies ahead with the uncertainty of their infants' normal development" (p. 305), and also wondered if these parents might simply "have higher expectations for themselves" (p. 306). For parents to have higher, or more professional-class, or expert-status expectations can be thought of in relation to Lareau's longitudinal study of parenting in relation to race, class, and educational differences (2018). Her study discerned two parenting styles based on SEP: "Concerted cultivation" in middle-class families describes the effortful (sometimes costly) promotion of children's development with emphasis on autonomy and leadership, as befits the goal of achieving highstatus positions in society. In poor and working-class families, however, parents subscribed to "natural growth" involving less monitoring and teaching, instead prioritizing respect for authority and conforming to norms - as befits the expectation of coping with a harsh and unfair, hierarchical world. While both approaches are purposeful styles of parenting intended to help children grow up and thrive in the kind of social world in which they are expected to belong and will need to survive, developmental science and much social policy strongly prioritize middle-class goals (Ramaekers & Suissa, 2012). This reflects the broader reality that parenting stressors are unfairly divided along socioeconomic, racial, cultural, and other positional lines (Karpman & Miller, 2020).

We see the differences discussed by Lareau (2018) and the other researchers (e.g. Ramaekers & Suissa, 2012) reflected in our findings both in the mothers' differing notions of child development *and* in their differing expectations about how much of a voice they could expect to have in the context of institutional or professional care. These complex and multi-layered differences weave positionality and personal biography together and are in some ways epitomized by the mothers' different responses to sudden changes of plan imposed on them by the professionals. Where the older and more socially privileged/empowered mother refused and said "*piss off*", the less positionally strong (less educated, younger, chronically ill) mother had a "*bad feeling*" but concluded "*whatever*". Only when it came to the crises of being in labor yet not

believed, or protecting her child from the intrusions of a model of developmental science to which she did not subscribe, did the less empowered mother rise up, shed her deference and throw her body to the ground or "become stubborn". Indeed "stubborn" was the empowerment that she spoke of in her reflections about "whom I have become". "Stubborn", a word laden with many meanings, also brings to mind a developmental phase of young adulthood, where psychological separation from one's family of origin and making one's way in the world as an individual form central tasks. We might consider this as an additional layer of meaning in relation to being younger (than the first mother) and still living with a parent, partly due to chronic illness and its impact on her capacity to work and earn a living. Whereas the first mother didn't share this fight - she after all agreed with the model and felt like she belonged - both positionally and emotionally, as a 'launched' adult - in the world of the experts. Rather, she had to grapple with what it meant to become a patient, a recipient of care, and, we can imagine, the regression she would likely have associated with this experience based on her foundational identification, in both personal and positional senses, as an autonomous person. Her final reflections had more to do with relaxing a critical-demanding need to be in control, learning to enjoy the present moment with her baby.

This complex multi-layering of personal and positional is reflected in Karpman and Miller's (2020) note about social class having "many meanings and components – economic, social, political, one's sense of identity, and how class intersects with other social identities" (p. 79). Positional differences between the mothers in this study intersected with age, health status, and the context of living in the Netherlands. Class differences in the Netherlands can be complicated to parse given the social welfare state and systems of access meant to flatten any sense of power difference between socioeconomic groups, even as inequities in health care are clearly present (Stuij et al., 2020). The mothers in this study did not mention class or reflect on privilege in their accounts, nor did the researchers make this explicit.

#### The Need for Support and Agency: a Common Parental Predicament?

Against the backdrop of tension between new motherhood and the loss of agency brought about by the VP crisis, both mothers experienced the need for professional help. Emerging at the core of "striking the right note" was the mothers' shared need to feel in charge and taken seriously by a professional who could stand back and hand over the reins, while at the same time feeling able to safely falter, fail, need more sleep, or crumble into an emotional heap. This required a professional who could respect and support the mother's personal agency while keeping her vulnerabilities in mind and, if necessary, intervene with an independent perspective. The TOP therapist emerged as precisely such a figure, accompanying and interacting with the mothers in ways that met both needs.

The need to feel supported as a competent maternal agent while also feeling safely contained in relation to vulnerability can be conceptualized in terms of what Van der Pas (2003), in a psychological theory of parenthood, proposes as the universal predicament of parenthood. Namely, the fundamental awareness of being responsible for a child, which implies the need to experience oneself as competent to care for the child's needs, while at the same time struggling with the profound vulnerability of never being fully capable of living up to that existential, ethical mandate. This vulnerability starts in new motherhood with the navigation of this major life transition with all its attendant anxieties and dangers (Stern, 2018) - which are greatly intensified by VP birth. With the baby's survival at stake, the mother's dependency on medical experts can disrupt her fragile sense of maternal agency, creating fraught psychological dynamics with nursing staff (Kraemer, 2006, Steinberg & Patterson, 2017). If we consider the tension between opposing needs for competence/agency and holding/support as constituting the psychological core of parenthood, we can make sense of how VP threatens to destabilize the balance between these two sets of needs.

#### The Need for Personalized Care: Parents as Unique Individuals

A second commonality to emerge regarding professional support, was the mothers' greater sense of trust when professionals could suspend pre-conceived ideas and practices and attend to them as unique persons. It was stressful to be viewed through various lenses that for different (and sometimes incomprehensible) reasons did not see the mothers as they were or understand what they needed because a generalized assumption was (mis)guiding the perspective of the professional and interfering with real contact or understanding. Here, the TOP therapists proved trustworthy and adept, both supporting the mothers' needs for both agency and help, and doing so in differentiated ways that suited the particularities of each mother. One therapist acted more as a "sounding board" - an equal who did her job well, helping and advising as needed while recognizing the mother's autonomy and supporting her in slowly taking up control. The other TOP therapist made contact by sensitively listening, not forcing a foreign model of development but rather slowly making the perspective intelligible so that the mother could discover for herself what part of it she deemed credible and useful. These findings underline the importance of individually attuned care (Davies et al., 2017), to which we would add "culturally agile" (Dodds et al., 2018) - that is, understood from multiple angles, ranging from intrapsychic to societal. In this way, personalized care may achieve shared understandings across positional and other gaps in perspective.

#### **Reflections on the Research Process: Limitations and Lessons Learned**

In the course of analyzing our findings, we became increasingly aware of hidden positional biases in the world, science, and ourselves as researchers Karpman and Miller's (2020) observation and clinicians. that a characteristic of privilege is a lack of awareness of privilege, applies to our professional stance at the start of the study: We followed the linear proposition that "lesser education" implied lesser capacity to benefit from the developmental psychological paradigm being offered as "help" to the mothers. Weise (2020) explores the experience of "unraveling many layers of class identity in relationship with others" (p. 42). We could relate to her uncomfortable discovery of the self-conceit of "magnanimity" in imagining herself to be helpful, and the fear of narcissistic injury when we, as researcher-practitioners, are confronted with possibly making wrong assumptions, or unwittingly committing harm. Here, the dry precision with which Bea laid bare the arrogance of the learned (professional), and her ironclad sense of "rest is best" in face of the pressure to provide "developmental stimulation," comes to mind. Her feisty resilience and pointed humor confronted us with the conceits of our professional knowledge and expert stance, and helped move class from its "hidden" status to a place in the forefront of our thinking. We can theorize this in terms of Del Mar Farina's comment that "clinical social work practice and particularly in psychodynamic clinical practice ... can be partially understood as a direct manifestation of the profession's compliance with dominant, sociohistorical discourses" (Farina, 2020, p. 54). The class bias of developmental psychology also relates to dominant social discourse, as does our unconscious compliance with it. This links back to the literature on middle-class bias stigmatizing the parental practices of less affluent groups (Ramaekers & Suissa, 2012, Vincent & Maxwell, 2016), leading to breakdowns of epistemic trust and unwitting harm through stigma and misunderstanding, precisely where help had been intended. Our expanding awareness in relation to the research spread to our clinical, supervisory, and teaching practices, leading to new perspectives and updated curricula, and colleagues, supervisees, and students who began to recognize class bias in their own work and lives.

Another theme we reflect critically on is race. While there was not a race-based rationale for selection but rather an educational one, as indicated by the study question and aims, the literature indicates many other intersectional positionalities of importance for parents, amongst 22 👄 E. RAAP ET AL.

which race is arguably the most central. In retrospect, we might have reflected more extensively on the inclusion/exclusion criteria of the recruitment process, particularly with regard to race, and their various possible impacts and relevance to the study. While this idiographic study may thus contribute to an enriched understanding of parental experience of VP and professional help in its wake, the experience of two white women leaves important positionalities unexplored, which are worthy of further study.

#### **Implications for Practice**

The journeys of the two mothers present common accounts of mastery, transformation, and professional support while significantly differing in the ways these are experienced. This underscores the urgency for clinical social work researchers, educators, and practitioners to consider the complex vicissitudes of parental subjectivity in the investigation, formulation and delivery of professional care for parents following VP. We make two recommendations for "idiographic practice", by which we mean practice that attends to the particular, while considering the general, and the personal as well as contextual and positional perspectives.

First, our findings suggest an approach to working with parents in the aftermath of VP in which awareness and curiosity about both the practitioner and the clients' positionality and other specificities are factored into thinking about how parents and professionals will read and make sense of each other. Along with conscious reflection on social class (Lesser, 2020), a broader consideration of "symptomatic aspects of norm conformity" (Del Mar Farina, 2020, p. 57) informs clinical thinking. More specifically, this approach might take the form of a more extended intake that explores a parent's implicit models of what developing babies need, or what constitutes good parenting in their eyes. Such an intake could benefit from a broader view of the parent as a whole person, and of the contours of their parental experience within the wider context of their life. This might include earlier encounters with professional help, as well as explicit negotiation of needs and preferences in working together.

Secondly, we recommend framing this approach within broadly shared principles of clinical social work practice with parents. This includes taking up a dual "parent guidance position" (Van der Pas, 2003) that supports parental agency while recognizing and attending to the vulnerability inherent to parenthood. For the practitioner, this means conceiving of the parent in two ways: On the one hand, as a fellow expert on the child, and on the other hand as an individual struggling to navigate the complexities and stresses of parenthood. As a *"fellow expert*," the professional collaborates in a manner

appropriate to the parent's consultative aims (supporting parental agency). As a "*struggling individual*," the parent may need more containment and holding from the professional, benefitting from feeling understood and supported in difficult times. By holding this dual framework in mind and using it as a clinical guide, the professional can chart a course through the tension between agency and vulnerability inherent to all parenthood, and quite acutely in the throes of the VP experience.

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#### ORCID

Edith Raap (D http://orcid.org/0000-0002-3660-0564 Monique Flierman (D http://orcid.org/0000-0002-1579-7011 Martine Jeukens-Visser (D http://orcid.org/0000-0002-7755-4509

#### **Geolocation information**

Amsterdam, The Netherlands

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