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Parental Experiences of Perinatal Loss with a Focus on Hospice Provision: A Thematic Analysis

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Table 3: - Participant quotes arranged by theme.

Theme	Exemplar Quote	Quote Number
Theme 1: “The phrase that sticks”	<i>“It was these mixtures of language, and especially at that time we were so sensitive to language.” (Interview 4)</i>	Q1.1
	<i>“The phrase that one of the doctors used to us which really sticks with me. And it was, this this baby isn’t viable... I imagine she wanted to be more compassionate than she came across but that’s the way it was used. And the impact on us... it sticks with me today that phrase.” (Interview 11)</i>	Q1.2
	<i>“And then eventually... that was when I did fight, I had to put in a complaint to get an appointment with her in the first place, it was just couldn’t get any support from her.” (Interview 2)</i>	Q1.3
	<i>“I think the doctors may have assumed that the previous consultant had told us outcomes and things and finds that haven’t been communicated with us.” (Interview 9)</i>	Q1.4
	<i>“In the meantime, we went out to a private foetal medicine consultant... we just struggled with not having a diagnosis and everyone telling us they didn’t know what it was, and they’d never seen this before.” (Interview 7 - father)</i>	Q1.5
	<i>“I’ve said, “Oh, I knew it, we’ve been to see a private consultant and that’s one of the things I asked him” and then her whole demeanour just changed; “You’re welcome to take your care elsewhere.” (Interview 1 - father)</i>	Q1.6
	<i>“There was one occasion when [Consultant] spent it felt like all night with us. There didn’t feel like any rush and they answered our questions, it made such a difference. We felt like we actually understood what was happening and could trust them.” (Interview 10)</i>	Q1.7
	<i>The doctor was careful... he said, ‘Hopefully everything is going to turn out fine, but they will support you either way.’” (Interview 8)</i>	Q1.8

Theme 2: “Why were we not offered this three weeks ago?”	<i>“He said look, they do look after people who are palliative, young people who are palliative, but they also look after people who, you know, you just, your baby is very poorly and you need the extra support and hopefully everything is going to turn out fine, but they will support you either way regardless... so he explained it really well to me and that’s why I accessed [hospice].” (Interview 2)</i>	Q2:1
	<i>“Then the midwife just said, “You can see [hospice]. Someone from [hospice] can come. [Husband] was beside himself, you know, ‘It’s a hospice, our baby’s going to die. What do we do?’ (Interview 3)</i>	Q2:2
	<i>“I actually said to her, “why were we not offered this three weeks ago?” and you just get told, “Well, parents don’t take kindly to it,” I’m like, “Well your paternalistic viewpoints are taking that choice away from people, it’s not your decision to make.” (Interview 7 - Mother).</i>	Q2:3
	<i>“They [hospice staff] came over quite frequently... I suppose at first when you hear that they’re from a hospice you kind of think, you know, but I think they probably visit more parents with very, very premature babies, but I do think they visit nearly all of them there... When we’d had the talk about palliative care, and [hospice staff] was one of the first people that I rang. You know, her and [hospice staff] knew [baby], so they were already familiar with us.” (Interview 8)</i>	Q2:4
	<i>We just thought that [hospice] were there just to support us. Just because of the situation. I never thought about palliative care, or that he was going to pass away.” (Interview 14)</i>	Q2:5
	<i>“It felt like [Claire House] was the only time I’d had any support. Even after finding out about the heart condition, my midwife didn’t even say... ‘here’s what you can do.’ She was still awful.” (Interview 2)</i>	Q2:6
	<i>“When they say where they’re from... people are like, ‘Oh my god, is my baby dying?’ But we never thought that... we just thought they were there to support us.” (Interview 1 - Mother)</i>	Q2:7

Theme 3: “Everyone’s different and [needs] something different”

Talking to wife: “You really get a lot of help from it, but I find it’s a lot of the same conversations if you know what I mean. Like people are dealing with the same issues. And it’s good for them, they can get it off their chest. But, for some of us a bit introverted like me, I don’t really contribute that much.” (Interview 6 - Father)

Q3.1

“Because when I had counselling, I didn’t feel like I needed it. But, I said, I probably will do in the future.” (Interview 1)

Q3.2

“Yeah, I am sure many dads feel that, feeling a bit spare, I think, sometimes. Like I say my main and only focus was [wife] and [baby], so yeah, it was very much not in my thinking about how I am doing, that sort of thing.” (Interview 5)

Q3.3

“You do feel really it’s a bit chauvinistic, but you do feel responsible for your wife as a husband. I know you shouldn’t, you know these days, but that’s just the way we feel. And to have to see what she’s managing well, is a big relief.” (Interview 12)

Q3.4

“We were talking about there’s pros and cons, because we never actually got any time to grieve alone, because the kids were off school for a couple of weeks afterwards... I was careful how I said it, because I was conscious they didn’t have other children and they would have loved that distraction.” (Interview 2)

Q3.5

“Most of them have still got one child left, which is my only criticism. Because you are mixed with people who have still got children around.” (Interview 1 - mother)

Q3.6

Theme 4: "Common ground builds relationships"	<i>"It just becomes a community. It's like a family that you are part of, you don't want to be in it, but you are." (Interview 11)</i>	Q4.1
	<i>"Relationships have also struggled in our family, people who can't quite understand what we're going through and the fact that time doesn't massively heal things." (Interview 8)</i>	Q4.2
	<i>"The bereaved parents in the room, it's like speaking a language that you're familiar with and of course if you're outside of that circle, whether it be family or friends, they're very sympathetic but they can't truly understand." (Interview 14)</i>	Q4.3
	<i>"So, it's just far better for us having these conversations, with likeminded people here than trying to have this, expect friends and families to come up with the goods." (Interview 9)</i>	Q4.4
	<i>"So they never held him... Because it's strange because we were in the hospital with him. And we shared pictures and things. It's like it sort of didn't happen." (Interview 1)</i>	Q4.5
	<i>"Initially family were supportive. It's just sometimes... Family [dynamics] can be a bit negative sometimes. And thinking that we should be over it by now, and stuff." (Interview 7 – mother)</i>	Q4.6
	<i>"My cousin blurts out last week that she thought we should be getting over it. So, yeah, it's kind of... it does set me back a bit." (Interview 13)</i>	Q4.7
	<i>"It's nice to come once a month... because we are like friends now, aren't we? And friends who don't say things [like family sometimes do]." (Interview 8)</i>	Q4.8
	<i>"It's people who understand. You don't need to say anything to them half the time because clearly, they already know." (Interview 10)</i>	Q4.9
	<i>"People said, 'You should be over it by now.' It's not supportive; it's judgmental and sets you back." (Interview 11)</i>	Q4:10

Theme 5: "Their names are going to be everywhere"	<i>"They make it lovely, they do painting with him, they do everything with him, family come to visit and just like play with them and they have a pool and everything. So he thought it was like Butlins."</i> (Interview 4)	Q5.1
	<i>"I feel like, he felt in ways, although he passed away, he felt more mine. Because I could pick him up whenever I wanted to. And I could sit and cuddle him, there wasn't the tubes, and the struggling to move. It was a proper cuddle."</i> (Interview 6 - mother)	Q5.2
	<i>"Doing the abseiling. I'm collecting all my money in this week. I've raised about £550. So it's a lot it's just to give the children a day to make memories, a day out, just to give their parents something to keep."</i> (Interview 10)	Q5.3
	<i>"I love it when people say their names, I love it when people talk about them but I understand some people find it hard but it's when people just don't acknowledge."</i> (Interview 3)	Q5.4
	<i>"We take the [bears] with us when we go away somewhere... That they both had, didn't they? After they had passed away."</i> (Interview 6 – mother)	Q5:5
	<i>"We're going to [names town] on Sunday. Because we have put their names on the side of... the wheelhouse of the lifeboat."</i> (Interview 1 – mother)	Q5:6
	<i>"We had posters on the wall about 30 of us... a sponsored walk. And some parents from here... We raised over £4,000 in just that."</i> (Interview 5)	Q5:7
	<i>"We've got stars named after them. Their names are going to be everywhere."</i> (Interview 7 – mother)	Q5:8
