

Care associated with stillbirth for the most disadvantaged women: A multi-method study of care in England

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Abstract

Background: Most research on women experiencing stillbirth relies on online user group surveys or qualitative interviews. The objective of this study was to investigate the experience of women who are at a higher risk of stillbirth, living in areas of greatest deprivation, and are commonly not well represented.

Methods: This study used birth and death registrations in 2012-2013 to identify a sample of mothers whose babies had died as a result of stillbirth. These women were sent a survey 6-9 months after the stillbirth. We undertook descriptive analysis of quantitative data and used binary logistic regression with the Index of Multiple Deprivation as a measure of disadvantage. We used thematic analysis to describe free text responses.

Results: The survey response rate was 30% (N = 473). Ethnic minority, younger age, and single parenthood were associated with disadvantage. Women residents in the most deprived areas perceived care more negatively: during labor they were significantly less likely to be spoken to by medical staff so they could understand (73% compared with 90%, adjusted odds ratio [aOR] 0.33 [95% confidence interval {CI} 0.18-0.65]), or treated with respect by midwives (79% compared with 90%, aOR 0.41 [95% CI 0.22-0.77]). The qualitative themes identified were: "Difficulty in accessing care," "More could have been done," "Ineffective communication," and "Cared for and not cared for" which support the quantitative findings.

Conclusion: Women living in the most deprived areas reported poorer experiences of care compared with more advantaged women. All women need compassionate and sensitive care around the time of a stillbirth.

KEYWORDS

disadvantage, maternity care, stillbirth

1 | INTRODUCTION

The emotional pain and trauma associated with stillbirth is well recognized.^{1,2} In the United Kingdom, stillbirth occurred at a rate of 3.87 per 1000 births in 2015.³ However, women residents in areas of greatest social deprivation in the United

Kingdom are more than 50% more likely to have a stillbirth compared with women residents in areas of greatest affluence with rates of 5.05 and 3.00 per 1000 births, respectively.³ Reasons for this may relate to nutrition, health behavior such as smoking, access to health care, social support, and other factors.⁴ It has also been suggested that disadvantaged

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women may feel constrained by their circumstances, have difficulty accessing and understanding information, and that they have little control and power over their care.⁵ Stillbirth is thus strongly associated with the adverse socioeconomic determinants of health and therefore stigmatized.⁶

Studies of the maternity care experienced by women with surviving infants in different socioeconomic groups indicate that those residents in areas of deprivation are significantly less likely to be spoken to so they could understand or to be treated with respect.⁷ They also experience significantly more antenatal anxiety and depression,^{8,9} and are less likely to receive support for antenatal mental health problems or be asked about their mental health in the postnatal period.¹⁰

In general, women suffering the tragedy of a stillbirth report being treated well, with respect and kindness.¹¹ However, a significant proportion of women have reported being cared for in inappropriate environments, close to laboring women and crying babies, and in areas where their partner could not stay with them.¹¹ While good, sensitive care cannot remove the pain of the loss, poor and insensitive care can add to the distress felt and affect parents' recovery.^{12,13}

Few research studies, to our knowledge, have examined the perceptions of care provided before, during, and after stillbirth specifically focussing on those women most at risk of stillbirth, those living in the areas of greatest deprivation. The aim of this study was therefore to examine the perceptions of care before, during, and after stillbirth occurring in women from the most deprived quintile using both quantitative and qualitative data from the *Listening to Parents* study. The quantitative data provide the numerical framework regarding how women perceived their care; the qualitative data add detail and richness and help to explain some of the reasons for women's perceptions.

2 | METHODS

The *Listening to Parents* study was a cross-sectional study carried out in 2013 in England. It was developed in association with the stillbirth and neonatal death charities Sands¹⁴ and Bliss.¹⁵ The Office of National Statistics identified all women aged 16 years and over who registered a stillbirth or neonatal death between January and March 2012 or between June and August 2012 in England. These periods were chosen for pragmatic reasons, to avoid sending questionnaires during holiday periods, while avoiding birthdays and anniversaries. The women, 1668 of whom had suffered a stillbirth and 893 whose baby had died as a newborn were sent an initial letter, followed by another letter, information sheet, and questionnaire between 6 and 9 months after the stillbirth or neonatal death. An information sheet in 18 non-English

languages gave a Freephone number for contacting the team and getting help in completing the questionnaire, through an interpreter if required. A single reminder was sent to nonrespondents after 4 weeks. Women could call or email at any point and opt out of the study. Return of a blank questionnaire was treated as opting out. In recognition of the potential for distress caused by the survey, the information leaflet gave details of support services offered by Sands, Bliss, and other organizations.¹¹ The research reported here focuses on women's experiences associated with stillbirth, defined in the United Kingdom as a baby born dead after 24 weeks' gestation. In the United Kingdom, almost all maternity care is provided by the National Health Service which is free at the point of use.

Structured closed-end questions were used to ask about sociodemographic characteristics, about events and care during the pregnancy, at the time of the baby's death, labor, birth, and the postnatal period with a range of response options ("agree," "disagree" and "not sure" [latter 2 categories combined]; and "yes," "to some extent" and "no" [latter 2 categories combined]) for statements about care. The Office of National Statistics provided information about women's marital status, age group, and Index of Multiple Deprivation in quintiles, an area-based measure of deprivation based on income, employment, health, and disability.¹⁶ The questionnaire also included space for free text comments at the end of each section and at the end of the survey.¹² The exact wording of the open questions was: "Is there anything else you would like to say about your antenatal care?"; "... care around the time that you found out that your baby had died?"; "... care during labor and the stillbirth of your baby?"; "... in the maternity unit (or hospital) after your baby was stillborn?"; "... about your postnatal care after your discharge home?" There was also an open question at the end of the questionnaire: "If there is anything else you would like to tell us about your care while you were pregnant or since your baby died, please add your comments here:"

2.1 | Quantitative analysis

The experience of women in the most deprived Index of Multiple Deprivation quintiles was compared with that of women in the 4 less deprived quintiles. Raw percentages, cross-tabulations, and chi-square statistics were used to test for associations between the dependent variables which measured perceptions of care quality, and the independent variable, social deprivation. Binary logistic regression was then carried out adjusting for age, ethnicity, and parity to determine the independent effect of social deprivation. Missing values were handled using listwise deletion. Age at leaving full-time education was not included in the model as it was highly correlated with Index of Multiple Deprivation. Results were considered statistically significant if *P* was less than .05 or 95% confidence interval (CI) excluded 1.00. Quantitative

data were analyzed using STATA 13 SE (StatCorp, College Station, TX, USA).

2.2 | Qualitative analysis

Qualitative data from women in the most deprived quintile were analyzed in an iterative process by both researchers independently, coding themes and subthemes as they arose, using a thematic content analytic approach.¹³ Differences in coding and interpretation were resolved by discussion. Deviant cases which ran counter to the dominant themes were sought. Qualitative data were further coded as positive, negative, or neither/both to allow for triangulation with quantitative data on satisfaction.

This was used to test the credibility and trustworthiness of the analysis.¹⁷ Qualitative analyses were carried out using SQR nVivo 10 (QSR International, Melbourne, Australia).

2.3 | Ethics

NHS Research Ethics approval for this study was obtained in July 2012 from the National Research Ethics Service Committee South Central—Oxford A. Consent was considered implicit in completion and return of the questionnaire. Questionnaires were completed anonymously, stored in locked filing cabinets, and data stored on a secure network. Women could opt out at any point.

TABLE 1 Demographic characteristics of women residents in the most deprived areas compared with other women, England 2014

	Less deprived quintiles (N = 366) No. (%)	Most deprived quintile (N = 106) No. (%)	Total (N = 472)	
			No. (%)	P
Parity				
Total	364 (100)	105 (100)	469 (100)	.710
Primiparous	211 (58.0)	63 (60.0)	274 (58.4)	
Multiparous	153 (42.0)	42 (40.0)	195 (41.6)	
Ethnicity				
Total	363 (100)	105 (100)	468 (100)	<.001
White	329 (90.6)	79 (75.2)	408 (87.2)	
Asian	21 (5.8)	12 (11.4)	33 (7.1)	
Black	7 (1.9)	11 (10.5)	18 (3.8)	
Mixed/Other	6 (6.1)	3 (2.9)	9 (1.9)	
Maternal age (y)				
Total	366 (100)	106 (100)	472 (100)	0.065
16-19	17 (4.6)	7 (6.6)	24 (5.1)	
20-24	47 (12.8)	23 (21.7)	70 (14.8)	
25-29	78 (21.3)	29 (27.4)	107 (22.7)	
30-34	131 (35.8)	28 (26.4)	159 (33.7)	
35-39	69 (18.9)	14 (13.2)	83 (17.6)	
40 or more	24 (6.6)	5 (4.7)	29 (6.1)	
Age left full-time education (y)				
Total	360 (100)	101 (100)	461 (100)	0.001
16 or less	48 (13.3)	28 (27.7)	76 (16.5)	
17 or more	312 (86.7)	73 (72.3)	385 (83.5)	
Single mother				
Total	366 (100)	106 (100)	472 (100)	<0.001
Yes	21 (5.7)	24 (22.6)	45 (9.5)	
No	345 (94.3)	82 (77.4)	427 (90.5)	
Free text comments at some point in questionnaire	307 (83.8)	87 (82.1)	394 (83.5)	0.996

Missing values vary and ranged from 2 to 11.

TABLE 2 Antenatal and labor and delivery care experienced by women with a stillbirth in the most deprived quintile compared to others, England, 2014

	Less deprived quintiles (N = 366)	Most deprived quintile (N = 106)		Binary logistic regression
	No. (%)	No. (%)	P	Adjusted for parity, ethnicity, maternal age, odds ratio (95% CI)
Care before death of baby				
Midwives...				
talked so that they could be understood	332 (92.0)	82 (78.8)	<.001	0.35 (0.18-0.65)
showed respect	326 (90.3)	81 (79.4)	.003	0.41 (0.22-0.77)
were kind	330 (91.4)	83 (80.6)	.002	0.41 (0.22-0.77)
listened to concerns	262 (72.8)	68 (65.4)	.143	0.69 (0.42-1.13)
Doctors...				
talked so that they could be understood	295 (89.7)	69 (73.4)	<.001	0.33 (0.18-0.62)
showed respect	289 (88.1)	76 (82.6)	.167	0.60 (0.30-1.17)
were kind	282 (86.2)	76 (81.7)	.278	0.67 (0.35-1.29)
listened to concerns	239 (72.9)	64 (68.8)	.443	0.84 (0.49-1.42)
Care at the time of stillbirth				
Felt listened to	204 (70.3)	54 (63.5)	.233	0.81 (0.47-1.39)
Taken seriously	211 (72.8)	52 (60.5)	.029	0.60 (0.36-1.02)
Informed	214 (72.1)	62 (69.7)	.661	0.96 (0.56-1.66)
Involved in decisions	166 (57.0)	47 (56.0)	.859	0.93 (0.55-1.57)
Confident in decisions made	160 (55.9)	46 (54.1)	.766	0.98 (0.58-1.66)
Health professionals...				
were kind	276 (89.6)	75 (79.8)	.012	0.50 (0.26-0.96)
were sensitive	263 (85.4)	76 (79.2)	.147	0.71 (0.38-1.31)
showed respect	259 (84.6)	72 (77.4)	.105	0.62 (0.34-1.13)
Care during labor and birth				
Staff generally communicated well	323 (90.5)	84 (80.8)	.007	0.41 (0.22-0.77)
Midwives...				
talked so that they could be understood	339 (95.0)	90 (85.7)	.001	0.34 (0.16-0.73)
showed respect	333 (93.0)	89 (85.6)	.018	0.45 (0.22-0.91)
were kind	336 (93.9)	88 (84.6)	.003	0.36 (0.17-0.73)
listened to concerns	309 (86.1)	80 (76.2)	.016	0.51 (0.29-0.90)
Doctors...				
talked so that they could be understood	297 (88.9)	70 (72.9)	<.001	0.29 (0.16-0.54)
showed respect	292 (87.7)	71 (74.7)	.002	0.36 (0.20-0.67)
were kind	285 (85.3)	72 (75.8)	.028	0.53 (0.29-0.96)
listened	278 (83.2)	67 (69.8)	.004	0.44 (0.26-0.77)

Missing values ranged from 8 to 53 (some women did not receive care from medical staff).

CI, confidence interval.

3 | RESULTS

The response rate to the *Listening to Parents* survey was 30% (473 women who experienced a stillbirth). Index of Multiple Deprivation was available for all women except

one. Two women completed the survey with an interpreter, with verbal consent. There was significant underrepresentation of women born outside the United Kingdom, those aged <30, and those living in more deprived areas

TABLE 3 Postnatal care and overall satisfaction with care of women with a stillbirth in the most deprived quintile compared to others, England, 2014

	Less deprived quintiles (N = 366)	Most deprived quintile (N = 106)		Binary logistic regression
	No. (%)	No. (%)	P	Adjusted for parity, ethnicity, maternal age, odds ratio (95% CI)
Postnatal care in hospital				
Women cared for...				
away from crying babies	179 (49.9)	44 (42.7)	.201	0.67 (0.42-1.07)
away from laboring women	175 (48.7)	32 (31.1)	.001	0.46 (0.28-0.76)
where partner could stay	306 (85.2)	74 (71.8)	.002	0.39 (0.22-0.69)
After baby was stillborn...				
saw baby	342 (94.5)	94 (88.7)	.007	0.43 (0.19-0.96)
held baby	310 (86.1)	84 (79.2)	.037	0.61 (0.34-1.11)
Women offered...				
quiet room	314 (88.2)	83 (81.4)	.073	0.60 (0.31-1.14)
blessing	289 (83.0)	82 (80.4)	.536	0.89 (0.49-1.60)
help with funeral	309 (85.6)	86 (83.5)	.597	0.84 (0.45-1.57)
information about support groups	344 (95.3)	86 (85.1)	<.001	0.26 (0.12-0.56)
written information	326 (91.1)	79 (78.2)	<.001	0.32 (0.17-0.59)
advice about breastmilk	238 (69.4)	59 (58.4)	.039	0.60 (0.37-0.98)
counselling	268 (74.9)	72 (70.6)	.386	0.72 (0.43-1.21)
Postnatal staff...				
talked so that they could be understood	342 (95.0)	91 (87.5)	.007	0.34 (0.15-0.76)
showed respect	337 (93.6)	90 (86.5)	.019	0.40 (0.19-0.85)
were kind	338 (93.9)	91 (87.5)	.030	0.42 (0.19-0.91)
listened to concerns	317 (88.1)	76 (74.5)	.001	0.39 (0.22-0.70)
treated woman as an individual	323 (89.7)	85 (82.5)	.046	0.59 (0.31-1.13)
Postnatal care after hospital discharge				
had confidence and trust in midwives	299 (83.1)	72 (69.9)	<.001	0.30 (0.16-0.57)
last visit later than 3 weeks	137 (38.1)	31 (31.3)	.217	0.86 (0.52-1.42)
had as many postnatal visits as wished	260 (74.7)	62 (64.6)	.026	0.76 (0.45-1.27)
met consultant to discuss case	338 (93.4)	88 (86.3)	.021	0.55 (0.26-1.19)
able to ask questions	266 (72.9)	62 (59.0)	.007	0.58 (0.36-0.94)
had postmortem	231 (63.1)	51 (48.1)	.006	0.55 (0.35-0.88)
Overall satisfied with...				
antenatal care	241 (66.2)	54 (52.4)	.010	0.52 (0.33-0.83)
intrapartum care	297 (82.0)	77 (74.0)	.071	0.61 (0.35-1.05)
postnatal care	250 (68.9)	67 (65.0)	.463	0.86 (0.53-1.39)

Missing values vary and ranged from 4 to 22.
CI, confidence interval.

(responders vs nonresponders were 20.8% vs 35.3% for women born outside the United Kingdom, 43.0% vs 53.1% for women aged <30 years, 23.3% vs 37.3% for women residents in the most deprived quintiles). The questionnaires were generally well-completed with missing values

ranging from 2 to 53. High numbers of missing values were for data relating to contact with a doctor during their care which not all women experienced. There were no substantive differences in rates of missing values between the two comparison groups.

TABLE 4 Themes and subthemes identified in the survey responses of women with a stillbirth living in the most disadvantaged areas, England, 2014

Themes	Subthemes and examples
Difficulties in accessing care	<p>The need for midwifery care “I never saw the same midwife twice...I think that the size of my baby and little movement may have triggered a response earlier if I had been able to build a relationship with the same midwife.”</p> <p>Sent home or not admitted “...after 38 weeks my blood pressure started to increase, I was sent to the hospital from where I was sent back home each time. I was told at the hospital that my b.p. is not high enough for them to keep me in (ie, not to their threshold level).”</p>
More could have been done	<p>Recognizing risk “Everyone I spoke to was more worried about my weight/bmi than my baby.” “I was classed as high risk pregnancy, saw different doctors at every appointment...only seemed to take notice when it was too late.”</p> <p>A need for checks and monitoring “The hospital failed to check me, because they were busy.” “It was terrible. All warning signs were ignored.” “I do not believe that I was a ‘low risk’ category.”</p>
Ineffective communication	<p>Not listened to “If they had just listened to me and treated me on an individual basis things could have been different.” “...my concerns were not dealt with. I was made to feel foolish.” “I didn’t feel as though my concerns were taken seriously, even when I went in a few hours before my baby’s death.”</p> <p>Inappropriate information-giving “Did not read my notes and therefore did not explain scan properly.” “We felt like when consultant explained the problems he didn’t take into consideration she was our baby.”</p>
Cared for and not cared for	<p>Kept waiting, left alone “I was completely neglected left to my own device, the hospital failed to check me, because they were busy.”</p> <p>Really cared for “The midwife told us what to expect and answered all of our questions. She took great care of me and my son.”</p> <p>Contrasts in care “I only really felt supported in my pregnancy once it had gone wrong.” “I can’t fault the care we received AFTER our baby had died.”</p>

3.1 | Quantitative results

Those in the most deprived quintile were significantly more likely to be of Asian or Black ethnicity (21.9% vs 7.7%), to have left full-time education aged 16 years or less (27.7% vs 13.3%), and to be single mothers (22.6% vs 5.7%) (Table 1).

The perception of women residents in the most deprived areas was that they were treated more poorly at each stage of their maternity care (Tables 2 and 3). They were significantly less likely to feel spoken to in a way that they could understand, to be shown respect, treated with kindness or listened to during pregnancy, labor, and birth, and in the postnatal period (eg, aOR [95% CI] for being spoken to by midwives in a way that they could understand during labor and birth 0.34 [0.16-0.73]). At the time that their baby died, these women were less likely to feel that their concerns were taken

seriously, although after adjustment, this was no longer statistically significant.

After stillbirth, while still in hospital, the care taken for this group of women was a cause for concern: they were significantly less likely to be cared for in an area away from laboring women (aOR [95% CI] 0.46 [0.28-0.76]), and where their partner could stay with them (aOR [95% CI] 0.39 [0.22-0.69]). After adjustment, these more disadvantaged women were also significantly less likely to see their stillborn baby or to be offered information about support groups or written information or advice about managing their breastmilk and other issues of importance. Similarly, after hospital discharge, they were significantly less likely to have confidence and trust in their midwives, less able to ask the questions they wanted, and their baby was significantly less likely to have a postmortem. Overall, women residents in the most deprived areas were significantly less satisfied with their care (aOR [95% CI] 0.52 [0.33-0.83]).

3.2 | Qualitative results

The focus in this section is on the free text responses of women who had experienced a stillbirth and were living in the most disadvantaged areas. A total of 78 of the 106 women in this group responded with free text responses to one or more of the open survey questions. They gave rich and detailed descriptions of their care. Four key themes were identified: “Difficulties in accessing care,” “More could have been done,” “Ineffective communication,” and “Cared for and not cared for” (Table 4). The quotes included here came from 22 different women in the most deprived quintiles. The themes and related subthemes are described separately.

3.3 | Difficulties in accessing care

Access to care was a key issue for many women living in the most disadvantaged areas. A basic need for midwifery care was identified as a subtheme. This theme arose in relation to all phases of care and could take the form of a lack of response from midwives or of delays in doing what women felt was needed, particularly in the antenatal period and as labor approached.

Could never get hold of my midwife even when I was told she would contact me.

Had bleeding at about 24 weeks and contacted midwife team who informed me I should call doctors as their budget didn't cover me.

“Sent home or not admitted” was a second subtheme in relation to accessing care in the context of raising concerns or identification of early or established labor. This was seen as critical:

On 8th I went to hospital and told them I think my waters were going slowly, they said my waters hadn't gone and sent me home. The last time I went into hospital 13/14 July I had been having contractions 12 days and BEGGED her to help me. I was refused and sent home.

Even when care was available, women described delays in decision-making and intervention:

I feel my care was taken too long, the day my baby died the community midwives were taking too long to make decisions, they couldn't find my baby's heartbeat, was just getting my pulse all time, took far too long.

3.4 | More could have been done

“Recognizing risk” and “a need for checks and monitoring” are the two subthemes under this heading. Women’s concerns about the effective identification and recognition of risk status for them and their babies were evident:

I felt I wasn't listened to about my headaches and other problems.

I just feel angry and let down. I feel more could of been done. I feel like my baby's life could have been saved if they had considered my family history and given me another scan after 20 weeks.

If I would have seen a specialist it is likely my condition would not have threatened my life—as a result my baby died.

Many women referred specifically to the need for more monitoring and insufficient checks on themselves and their babies, particularly in late pregnancy and possible early labor.

Midwife did not follow procedure. When baby's growth stopped after 3 weeks we should have been sent for scan. While this may not have changed the outcome, questions will always remain.

There was a failure to recognise that I had experienced a slow rupture of my membranes...I feel what happened was completely avoidable.

The detection of fetal movement changes was recognized as important by many mothers, after which they felt checks should have been made. However, some felt inadequately informed about the type and frequency of movement about which they should have been aware and that later scans and checks could have made a difference:

The midwives ask me if I'd been having movement and I said yes because I had. I didn't know you should be feeling at least 10 movements a day which I know I wasn't.

3.5 | Ineffective communication

“Not listened to” was a significant subtheme in relation to communication among the responses of many mothers living in the most disadvantaged areas.

The greatest sadness of all is that this could have simply been avoided if the midwives had

listened to me and spotted the obvious signs that were there to see such as the infection in my water and my slow rupture of membranes.

This was key in terms of how they felt things might have been different:

I feel what happened was completely avoidable. I feel I was put in a bracket with everyone else, but everybody is different. If they had just listened to me and treated me on an individual basis things could have been different.

Where women felt their concerns were not acknowledged, but interpreted to be a function of their lack of experience or knowledge, they felt this affected the care provided and may have contributed to the outcomes for their baby.

Before my baby died, I didn't feel as though my concerns were taken seriously, even when I went in a few hours before my baby's death.

I felt because it was my first pregnancy, the doctor didn't think I know what I am talking about, even after I knew something was wrong, in the end but they just ignore me.

Feeling belittled by staff or made to feel foolish in their concerns disempowered women in this context, making them feel even more powerless in retrospect.

While some women may not have been listened to, staff may not have given adequate or effective explanations about care and checks. "Inappropriate information-giving" was the second subtheme in relation to communication:

It was appalling. Not bothered midwives. Just a number. Did not read my notes and therefore did not explain scan properly. I feel if this had been better I would have had a better chance catching my placenta problems and my baby could have been saved.

We were cared for by three midwives the day I lost my son and each gave different information. It was not until the third midwife were told I was to go home and return to hospital 3 days later to be induced.

3.6 | Cared for and not cared for

This theme reflects the mismatch between what women had expected and the care received. Several subthemes were

identified: "Kept waiting, left alone," "Really cared for," and "Contrasts in care."

Feeling they were being kept at a distance and denied appropriate care contrasted with what was due:

When first called hospital to say baby wasn't moving, couldn't hear heartbeat and needed to come in, midwife on phone just said 'oh I'm not worried, ring tomorrow if no change'. We said no and went straight through. Found out baby died and my BP was 177/107, was told I was at risk of a stroke.

Even after admission, women found that care was not as anticipated. Being kept waiting and left alone made these women feel of less account:

When I informed the hospital that my baby movement had reduced. I was kept waiting in the waiting room for hours...the hospital failed to check me, because they were busy.

The midwife was very insensitive she couldn't care less as she never attended to me all throughout the night. I was admitted and never put one on a heart monitor either even though my waters had broken the night before.

The midwives at the hospital were very slow in dealing with me when I got there, took their time finding machinery, other midwives/doctors. I constantly asked for pain relief, and to know what was going on, it took roughly an hour for them to actually tell me.

Even after giving birth, some mothers were left alone:

After they took him they never said nothing to me until 10-15 mins later. I felt alone and left out with what was happening.

Once discharged from hospital, some women felt abandoned:

I had very little support once leaving hospital. I wasn't given any information on who to contact. Two midwives appeared the day after I left hospital. Neither of them were aware of the situation and were very insensitive. It took 2 1/2 months for the bereavement midwife to contact me, due to holidays and no cover provided.

No-one bothered to contact us afterwards just the bereavement midwife by phone.

Midwife stayed 10 minutes, had never met us before and was clearly uncomfortable.

Other disadvantaged women felt really well cared for, a subtheme that ran counter to the dominant narrative:

I had the same three midwives care for me over a two day period. This was really good as I knew them when the shifts changed and they understood the situation without me having to tell them. All were excellent in their care for me.

The two midwives we had were amazing. They looked after us and made a hard situation bearable. They were a credit to their profession and instilled a great belief in the nursing system. I can't thank them enough and will always be grateful.

Some women observed what they felt were differences in the quality of care, highlighting contrasts in care, before and after, and between the different places in which they received care:

It was tragic that I only really felt supported in my pregnancy once it had gone wrong. I would have liked that empathy in the 3rd trimester instead of feeling like cattle once I had got past 20 weeks. Individually people were nice but on a whole it felt very cold and routine.

The care I received after I found out my baby had died was fine, they were helpful, understanding, and sensitive. One of the midwives even gave me a hug when she came to give us more information and it got a little overwhelming for me. I can't fault the care we received AFTER our baby had died.

I was in two hospitals. My local hospital care was very good. The staff were kind and considerate. After 11 days I was moved a different hospital. No midwife visited. I was put in a ward and I don't recall any of the nurses acknowledging I had had a baby, they were just concerned with getting me out as quickly as possible.

3.7 | Triangulation between quantitative and qualitative findings

The identified themes concur with the quantitative findings described for women who participated in the *Listening to Parents* study.¹¹ The quotations about their care from women

who had experienced a stillbirth and resided in the most deprived areas in England support this view; while 30% of disadvantaged women who included free text were entirely negative in their comments, 61% were both positive and negative. The subthemes "Really cared for" and "Contrasts in care," in reflecting more positive experiences, provide a balance to the quantitative differences and other qualitative themes reported.

4 | DISCUSSION

The quantitative findings of this study indicate that women residents in the most deprived areas were more likely to be multiply disadvantaged. In addition to having the highest rates of stillbirth, they perceived their care more negatively than other women. They were significantly less likely to be spoken to, so that they could understand, or treated with kindness and respect by both the medical and midwifery staff, at each stage of their care. Their own descriptions of the care they received and their reflections on this in their own words provide expressive and powerful examples. After the identification of stillbirth and thereafter they were significantly less likely to be offered information and advice, to feel listened to, to be cared for away from laboring women or where their partner could stay, and reported less confidence and trust in the midwives seen after their discharge. Their views based on the quantitative data are well illustrated by the free text comments which highlight difficulties in accessing care, feeling that more could have been done, both clinically and in an interpersonal way, the ineffective nature of communication at times, and the dismay and disregard that some described when they were not listened to or cared for as they would have hoped.

The findings of this study are consistent with previous research on women's experience of care in relation to stillbirth in the United Kingdom and other high-income countries and more broadly in emphasizing the importance of appropriate training for health professionals and care and support for women and partners after being discharged.¹⁸ However, mothers from more disadvantaged areas in this study reported that they experienced poor care before, during, and after stillbirth, particularly in terms of communication and interpersonal aspects of care. Many of those living in the most deprived areas were from ethnic minority groups (25% compared with 9% in less deprived areas in this study population). Other factors may have contributed, including staff attitudes^{19,20} and language difficulties, with some women having limited spoken and written English and needing more time for their care than other women.²¹ Data on women and partners in low- and middle-income contexts suggest that negative societal and provider attitudes do affect care and support.^{21,22} Some research has indicated that, in an underresourced service, some midwives

resent the additional time necessary to appropriately care for women with limited English.²³ It is possible that the association between socioeconomic disadvantage and perceptions of poor care are also mediated through maternal education which differs between disadvantaged women and care providers and could be a barrier to effective and compassionate care.²⁴ Research on the maternity experiences of women with a live born baby has also shown that women residents in the most deprived areas have a poorer perception of their care, particularly with respect to health professionals speaking in a way that they could understand and treating women in a respectful manner.⁷ Interventions to help women from disadvantaged communities through doula support and additional care facilities have proved effective in improving these experiences of women and perceptions of maternity care.^{19,25} However, for all women, especially those experiencing a stillbirth, the best quality care is needed to address their needs,^{1,3,20} no matter what the differences in their background and culture.

4.1 | Strengths and limitations

This study was based on a large survey of women who had a stillbirth in England and more than 400 women responded in the months after experiencing a stillbirth. However, with the 30% response rate, there was significant underrepresentation of women born outside the United Kingdom, those aged <30, and those living in more deprived areas¹¹ and the findings may therefore be less generalizable to the wider population. In addition, women who had a more negative experience may have been more or less likely to respond. However, it is rare to carry out this type of population-based study in which one is able to fully describe both respondents and nonrespondents and to make comparisons. The Index of Multiple Deprivation¹⁶ is a robust measure of socioeconomic position which relates well with other characteristics such as ethnicity, education, partnership status, and being born outside the United Kingdom,^{7,22} but it may fail to capture the complexities of disadvantage at an individual level.

The data were not weighted for nonresponse as, with this proportion, to do so could give undue and inappropriate weight to the views and perceptions of a relatively small number of women in underrepresented subgroups.²⁶ The questionnaires were returned on average 9 months after the stillbirth experience (99% within 12 months), to allow time for some adjustment so as to recall events that may have been affected. However, there is evidence that salient events are accurately remembered^{17,18} and the profound and life-changing impact of giving birth to a stillborn baby is well recognized in whichever country it takes place.^{27,28} The qualitative study material was exclusively from the women's free text written responses in the questionnaire and lacks the depth and richness of interview data. However,

a large proportion of respondents from the most deprived quintile responded in this direct way.

4.2 | Conclusions and implications for practice

This study shows that the perceptions of care among women who have suffered stillbirth are worse among women residents in the most deprived areas compared with more affluent women. This is likely because of a range of factors, including the treatment of minority ethnic groups who are also at significantly increased risk of stillbirth. Maternal concerns and perceptions associated with their care and experience of stillbirth need to be addressed through more compassionate and sensitive care, better access for disadvantaged women, appropriate training of health professionals, and use of interpreters with effective acknowledgment of different cultural contexts.

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