DOI: 10.1111/j.1471-0528.2012.03357.x
www.bjog.org

A difficult conversation? The views and experiences of parents and professionals on the consent process for perinatal postmortem after stillbirth

AEP Heazell,[a] M-J McLaughlin,[a] EB Schmidt,[a] P Cox,[b] V Flenady,[c] TY Khong,[d] S Downe[e]

[a] Maternal and Fetal Health Research Centre, Manchester Academic Science Centre, University of Manchester, Manchester, UK [b] Department of Perinatal Pathology, Birmingham Women's Hospital, Birmingham, UK [c] Mater Medical Research Institute and University of Queensland, Brisbane, Queensland, Australia [d] University of Adelaide, Adelaide, South Australia, Australia [e] Faculty of Health, University of Central Lancashire, Preston, UK

Correspondence: Dr Alexander Heazell, Clinical Lecturer in Obstetrics, Maternal and Fetal Health Research Centre, Manchester Academic Health Science Centre, St Mary's Hospital, Oxford Road, Manchester, M13 9WL, UK. Email alexander.heazell@manchester.ac.uk

Accepted 17 March 2012. Published Online 16 May 2012.

Objective To describe the experiences, knowledge and views of both parents and professionals regarding the consent process for perinatal postmortem.

Design Internet-based survey.

Setting Obstetricians, midwives and perinatal pathologists currently working in the UK. Parents who have experienced a stillbirth in the UK in the previous 10 years.

Sample Obstetricians, midwives and perinatal pathologists registered with their professional bodies. Parents who accessed the Sands website or online forum.

Methods Online self-completion questionnaire with both fixed-choice and open-ended questions.

Results Responses were analysed from 2256 midwives, 354 obstetricians, 21 perinatal pathologists and 460 parents. The most common reason for parents to request postmortem examination was to find a cause for their baby's death; the prevention of stillbirths in others also ranked highly. Perinatal pathologists possessed greatest knowledge of the procedure and efficacy of postmortem, but were unlikely to meet bereaved parents. The majority of professionals and parents ranked emotional distress and a lengthy wait for results as barriers to consent. The majority of staff ranked workload, negative publicity, religion and cultural issues as important barriers, whereas most parents did not. Almost twice as many parents who declined postmortem examination later regretted their decision compared with those who accepted the offer (34.4 versus 17.4%).

Conclusion Emotional, practical and psychosocial issues can act as real or perceived barriers for staff and bereaved parents. Education is required for midwives and obstetricians, to increase their knowledge to ensure accurate counselling, with due regard for the highly individual responses of bereaved parents. The contribution of perinatal pathologists to staff education and parental decision-making would be invaluable.

Keywords Autopsy, consent, counselling, perinatal death, postmortem, stillbirth.

Please cite this paper as: Heazell A, McLaughlin M, Schmidt E, Cox P, Flenady V, Khong T, Downe S. A difficult conversation? The views and experiences of parents and professionals on the consent process for perinatal postmortem after stillbirth. BJOG 2012;119:987–997.

Introduction

In the UK over one in 200 babies are stillborn after 24 weeks of gestation.[1] Concern about stillbirth rates has recently been highlighted by the analysis of 35 high-income countries, in which the UK is ranked 33rd.[2] Despite advances in maternity care, the incidence of stillbirth in many high-income countries, including the UK, USA and Australia, is similar to two decades ago. Inadequate knowledge regarding the underlying causes hinders progress in reducing national stillbirth rates. Even when modern classification systems are used, approximately 20% of stillbirths remain 'unexplained'.[3] The lack of explanation for stillbirth is exacerbated by falling rates of perinatal postmortem examination. Postmortem examination provides information that changes the primary cause of death in 9–34% of

stillbirths,[4–7] and confirms the clinical diagnosis in 48.9–58%.[4,5] This compares favourably with histological examination of the placenta alone or maternal blood tests, which yield information included in the classification of stillbirth in 47 and <15% of cases, respectively.[8,9] Therefore, postmortem examination is the single most useful investigation to provide information for parents regarding the cause of their child's death.[10] International guidance is clear that high-quality postmortem examination should be offered to all parents after stillbirth.[11]

The proportion of parents consenting for postmortem examination of their stillborn infant in the UK has decreased from 54.7% in 2000 to 42.4% in 2007, and is lower than in Scandinavian countries (58–95%), which have also noted a reduction in their stillbirth rates.[12] Although cause and effect cannot be assumed in these data, the falling acceptance of perinatal postmortem investigation in the UK merits further investigation. Although parental consent for postmortem fell, the proportion of parents being offered postmortem examination increased from 88.8 to 93.4%.[13] We hypothesised that the consent process for postmortem contributes to the falling acceptance of postmortem. Counselling and the consent process is a complex interaction between parents, family members and a multitude of professionals. We aimed to describe the experiences, knowledge and views of parents and professionals regarding the consent process for perinatal postmortem, to identify factors that can be modified to improve counselling and the consent process for postmortem after stillbirth.

Methods

Because of the unexpected nature of stillbirth and the emotional turmoil that occurs when a baby dies, it is ethically and practically difficult to directly study interactions between professionals and parents in this area. Using an internet-based approach has proven to be an effective route for studying sensitive topics, as it offers participants the opportunity to remain anonymous and to maintain control over their level of disclosure.[14]

A cross-sectional national survey of perinatal pathologists, obstetricians and midwives was undertaken, accompanied by a purposive sample of parents using the Sands (the Stillbirth and neonatal death charity) forum. For the professionals, we selected the most appropriate national organisation for each group we wished to study (the British Paediatric Pathology Association, the Royal College of Obstetricians and Gynaecologists, and the Royal College of Midwives). The questionnaires for practitioners were designed to address questions in five main areas: (1)their practice regarding consent for postmortem examination; (2)education and support for staff in consent for postmortem examination; (3)perceived barriers to postmortem examination consent; (4)knowledge about postmortem examination; and (5)views about postmortem examination. An example of the professionals' questionnaire is shown in Appendix S1. The parents' questionnaire was designed to ask related questions, but sections (1), (2) and (4) were removed and replaced with questions regarding parents' experience and satisfaction with their care after stillbirth. The questionnaires contained fixed-answer questions, with either binary or five-point Likert scale responses, and a single text box for open responses at the end; the questionnaire for parents is shown in Appendix S2. This article focuses on answers to the fixed-answer questions. For the professional surveys, face and content validity was checked by experts in the field, and reliability was established by oral interview of ten respondents after the completion of the survey, in which the survey questions were repeated; the variance between written responses and the interview data was 0.9%. Where appropriate, the questionnaire was amended to ensure clarity. For the parental survey, face and content validity, ease of completion and comprehensibility were checked informally by five parents who had experience of stillbirth.

Following ethics committee approval (Tameside & Glossop Local Research Ethics Committee, ref. 09/H1013/3), an electronic link to an online survey was sent to practitioners registered with their respective professional colleges/organisations: this resulted in a potential sample size of approximately 10 000 registered midwives, 1136 consultant obstetricians and 40 perinatal pathologists. Following approval from the University of Manchester Research Ethics Committee, parents were contacted via an internet forum hosted by Sands. The number of parents regularly using the Sands forums is 813, with approximately 6000 registered users. Data were analysed using SPSS 16.0 (SPSS Inc., Chicago, IL, USA) and STATISTICS TO USE (www.physics.csbsju.edu/stats).

Results

Response rates

The effective response rates from professionals were 2256 midwives (23%), 354 obstetricians (31%) and 21 perinatal pathologists (53%). Initial response rates were higher, but cases were excluded from analysis if they were not in a relevant area of clinical practice or if their survey response was less than 50% complete. The effective number of parental responses was 460, although 732 parents in total answered the survey. Parents' responses were removed from analysis if their most recent stillbirth occurred before 2000, if the pregnancy lost was less than 24 weeks of gestation, if the stillbirth did not occur in the UK or if less than 50% of questions were completed.

Table 1. Sociodemographic characteristics of respondents to the questionnaire by group: professionals and parents

Staff group	Characteristic	Mean (range) or number (%)
Midwives (*n* = 2256)	Experience (years)	11 (1–40)
	Number of births in unit per year	3909 (20–10 000)
	Main area of work	
	Antenatal care*	868 (38.5)
	Delivery suite*	1479 (65.6)
	Postnatal care*	810 (35.9)
	Community*	656 (29.1)
	Specialist bereavement role	58 (2.6)
Obstetricians (*n* = 354)	Experience (years)	17.7 (1–40)
	Number of births in unit per year	4,123 (600–10 500)
	Main area of work	
	Antenatal care*	330 (93.2)
	Delivery suite*	338 (95.5)
	Postnatal care*	282 (79.7)
	Other* (University/Fetal Medicine)	13 (3.7)
Pathologists (*n* = 21)	Experience (years)	15.0 (1–30)
	Number of postmortem examinations in unit per year	221 (60–500)
	Perinatal pathologist	14 (66.7)
	Paediatric and perinatal pathologist	4 (19.0)
	Paediatric and gynaecological pathologist	1 (4.8)
	General pathologist with interest in perinatal pathology	2 (9.5)
Parents	Respondents age	33 (18–47)
	Parity	2 (1–9)
	Gestation at stillbirth (weeks)	35 (24–42)
	Which pregnancy affected by stillbirth	
	First	261 (56.7)
	Second	109 (23.7)
	Third	56 (12.2)
	Fourth	15 (3.3)
	Fifth or more	9 (2.0)
	More than one pregnancy affected	10 (2.2)
	Geographical location (%)	
	East Anglia	34 (7)
	London	50 (11)
	Midlands	50 (11)
	Northern Ireland	33 (7)
	North-East England	46 (10)
	North-West England	63 (14)
	Scotland	59 (13)
	South-East England	61 (13)
	South-West England	38 (8)
	Wales	26 (6)
	When did baby die	
	Before labour	379 (82.4)
	In labour	79 (17.2)
	Unsure	2 (0.4)
	Had postmortem examination	283 (61.5)
	Had no investigations	23 (5.0)

*Numbers do not total 100%, as respondents could work in more than one area.

Participant demographics

The demographic details of participants are shown in Table 1. Responses came from professionals with a range of experience from 1 to 40 years. The majority of obstetricians (95.5%) and midwives (65.6%) worked on the delivery suite; 2.6% of midwives identified themselves as specialist bereave-

ment midwives. All pathologists worked in specialist units, which performed 60–500 perinatal autopsies annually.

For the parents' survey, the majority of respondents were mothers. Most parents had experienced a stillbirth within the last 2 years (80.4%), and 2.2% of parents had experienced more than one stillbirth. The geographical distribution of parents was similar to nationally reported data.[1] The gestation at stillbirth ranged from 24 to 42 weeks of gestation; 95% of respondents were white, although responses were also received from Pakistani, Indian, Afro-Caribbean, African and mixed-heritage parents.

The proportion of parents consenting to autopsy was 61.5%, a rate greater than that reported nationally (42.4%).[1] Only 5% of parents reported having no investigations at all after their stillbirth. Therefore, this sample may over-represent parents who chose autopsy. The majority of respondents stated that the reason for any investigation was to find a reason for their child's death (Table 2). Altruistic motives including research and prevention of further stillbirths were important for approximately half of respondents. Professional advice affected parents' decision to have an autopsy in 22.2% of cases. The majority of parents (69%, 95% CI 64.8–73.2%) remained satisfied with their decision to have or to decline an autopsy. Of the 21% (95% CI 17.3–24.7%) who were not satisfied with their decision, the majority (90%, 95% CI 80.3–93.7%) would have liked more investigation. In this sample, parents who did not have an autopsy were more likely to be dissatisfied with their decision than those who did (OR 2.43, 95% CI 1.53–3.87, $P < 0.001$).

Clinicians' practice when counselling about autopsy

The majority of pathologists (61.9%) reported never seeing parents to discuss autopsy (Table 3). Obstetricians most frequently counsel parents for autopsy, with 95% reporting always or often seeing parents to discuss autopsy, compared with 71.2% of midwives. In contrast, parents reported most frequently discussing autopsy with midwives (93%) and obstetricians (70.9%).

Table 2. Parents' reasons for having a postmortem examination

Reasons	Yes	No	Missing
Professional advice	102 (22.2%; 18.4–26.0)	350 (76.1%; 72.2–80.0)	8 (1.7%; 0.5–2.9)
Cause for child's death	336 (73.0%; 68.9–77.1)	116 (25.2%; 21.2–29.2)	8 (1.7%; 0.5–2.9)
Reduce other babies dying in future	228 (49.6%; 45.0–54.2)	224 (48.7%; 44.1–53.3)	8 (1.7%; 0.5–2.9)
Research	197 (42.8%; 38.3–47.3)	255 (55.4%; 50.9–59.9)	8 (1.7%; 0.5–2.9)

Percentages with 95% confidence intervals shown in parentheses.

Table 3. Reports from professionals and parents on the frequency of interactions discussing postmortem examination

	Always	Often	Sometimes	Rarely	Never	Missing	*P**
Pathologist	0 (0%; 0)	0 (0%; 0)	2 (9.5%; –3.0 to 22.0)	6 (28.6%; 9.3–47.9)	13 (61.9%; 41.1–82.7)	0 (0%; 0)	Pathologist vs midwife, $P < 0.001$
Midwife	1302 (57.7%; 55.7–59.7)	304 (13.5%; 12.1–14.9)	317 (14.1%; 12.7–15.5)	209 (9.3%; 8.1–10.5)	113 (5.0%; 4.1–5.9)	11 (0.5%; 0.2–0.8)	Pathologist vs obstetrician, $P < 0.001$
Obstetrician	299 (84.5%; 80.7–88.3)	37 (10.5%; 7.3–13.7)	13 (3.7%; 1.7–5.7)	5 (1.4%; 0.2–2.6)	0 (0%; 0)	0 (0%; 0)	Obstetrician vs midwife, $P < 0.001$

	Obstetrician	Midwife	Bereavement midwife	Pathologist	Chaplain	Bereavement counsellor
Parents	326 (70.9%; 66.7–75.1)	428 (93.0%; 90.7–95.3)	147 (32.0%; 27.7–36.3)	22 (4.8%; 2.8–6.8)	246 (53.5%; 48.9–58.1)	59 (12.8%; 9.7–15.9)

Percentage with 95% confidence intervals shown in parentheses.
**P* values determined by Fisher's exact test.

The time at which professionals reported their first discussion with parents regarding autopsy varied between different groups and parents. Most professionals reported initiating discussion of autopsy when they first met parents after diagnosis. The majority of obstetricians (55.1%) initially raised autopsy at the time of diagnosis. In contrast, one-third of midwives initially raised autopsy when women were admitted for the birth (32.9%), although a similar proportion waited until a few hours after the birth to discuss autopsy (Table 4). Parents' recollection of events differed from professionals, with the largest group (42.4%) recalling discussion a few hours after birth or the following day (28%) (Table 4). Parents often recalled only one discussion (39.3%; Table 4). Verbal communication was used to convey information about autopsy more than written resources, with 88.9% of professionals using verbal communication compared with 50.9% for written information (Table 5). Approximately 2% of professionals had no written information to give parents. The majority of professionals and parents were satisfied with the written information available.

Perceived barriers to counselling for autopsy

The perception of barriers to counselling for autopsy differed between professionals and parents (Table 6). Although the most frequent responses are highlighted, responses were most often spread throughout the Likert scale, ranging from strong barrier to no barrier. It was unusual for over 60% of individual groups to agree on any given barrier, highlighting the importance of individual professional or parental opinions (Table 6). Overall, staff more than parents perceived a lack of rapport as a barrier to consent: 70.0% of parents stated that lack of rapport was no barrier. Likewise, staff workload was felt to be a significant barrier by midwives and pathologists, but not by the majority of parents. All groups recognised emotional distress as a barrier to discussing autopsy. Negative press coverage regarding perinatal autopsy was felt by the majority of professionals to be a significant barrier, but 76.3% of parents indicated that this factor had little influence on their decision. Religious and cultural issues were felt to be a significant barrier to consent by obstetricians and midwives, but less of an impact was perceived by pathologists or parents. Service-based factors, such as the time to get results or the need to transfer babies, were insignificant barriers according to most professionals. However, parents' views were spread throughout the scale, with 32.8% describing this as a significant or strong barrier.

Professionals' education, training, knowledge and views about autopsy after stillbirth

A total of 26.1% of midwives and 12.4% of obstetricians had no training regarding counselling for autopsy consent. A further 32.9% of midwives and 10.7% of obstetricians were dissatisfied with the training that they had received. Additionally, 36.3% of midwives had low levels of confi-

Table 4. Timing of first discussion and frequency of discussions about postmortem examination. Only two pathologists regularly counselled parents. The most frequent response in each group is shaded

	At diagnosis	On admission for birth	At the time of birth	A few hours after the birth	The next day	2+ days later	Missing	*P**
Midwife	407 (18.0%; 16.4–19.6)	742 (32.9%; 31.0–34.8)	21 (0.9%; 0.5–1.3)	701 (31.1%; 29.2–33.0)	199 (8.8%; 5.8–11.0)	10 (0.4%; 0.1–0.7)	176 (7.8%; 6.7–8.9)	Midwife vs obstetrician, $P < 0.001$
Obstetrician	195 (55.1%; 49.9–60.3)	79 (22.3%; 18.0–26.6)	2 (0.6%; 0.0–1.4)	43 (12.1%; 8.7–15.5)	31 (8.8%; 5.8–11.8)	0 (0%; 0)	4 (1.1%; 0.0–2.2)	Midwife vs parents, $P < 0.001$
Parents	117 (25.4%; 21.5–29.4)	62 (13.5%; 10.4–16.6)	22 (4.8%; 2.8–6.7)	141 (30.7%; 26.4–34.9)	90 (19.6%; 15.9–23.2)	27 (5.9%; 3.7–8.0)	1 (0.2%; 0–0.6)	Obstetrician vs parents, $P < 0.001$

	Once only	1 or 2 times	3+ times	Missing	*P**
Midwife	403 (17.9%; 16.3–19.5)	1385 (61.4%; 59.4–63.4)	280 (12.4%; 11.0–13.8)	188 (8.3%; 7.2–9.4)	Midwife vs obstetrician, $P = 0.053$ Midwife vs parents, $P < 0.001$
Obstetrician	69 (19.5%; 15.4–23.6)	255 (72.0%; 67.3–76.7)	26 (7.3%; 4.6–10.0)	4 (1.1%; 0–2.2)	Obstetrician vs parents, $P < 0.001$
Parents	181 (39.3%; 34.8–43.8)	186 (40.4%; 35.9–44.9)	78 (17.0%; 13.6–20.4)	15 (3.3%; 1.7–4.9)	

Percentage with 95% confidence intervals shown in parentheses.
*P values determined by Fisher's exact test.

Table 5. Reported means of giving/receiving information regarding postmortem examination and satisfaction with local written information about postmortem examination

	Verbal	*P*	Written	*P**
Midwife	2005 (88.9%; 87.6–90.2)	Midwife vs obstetrician, $P = 0.0002$	1579 (70.0%; 68.1–70.9)	Midwife vs obstetrician, $P = 0.95$
Obstetrician	336 (94.9%;92.6–97.2)	Midwife vs parents, $P = 0.10$	249 (70.3%; 65.5–75.1)	Midwife vs parents, $P < 0.0001$
Parents	421 (91.5%;89.0–94.0)	Midwife vs pathologist, $P < 0.0001$	234 (50.9%; 46.3–55.5)	Midwife vs pathologist, $P < 0.0001$
Pathologist	1(4.8%;0.0–13.9)	Obstetrician vs parents, $P = 0.07$	5 (23.8%; 5.6–42.0)	Obstetrician vs parents, $P < 0.0001$
		Obstetrician vs pathologist, $P < 0.0001$		Obstetrician vs pathologist, $P < 0.0001$
		Parents vs pathologist, $P < 0.0001$		Parents vs pathologist, $P = 0.02$

	Very satisfied/ satisfied	Neutral	Dissatisfied/very dissatisfied	None available	No response	*P**
Midwife	1322 (58.6%; 56.6–60.6)	635 (28.1%; 26.2–30.0)	209 (9.3%; 8.1–10.5)	55 (2.4%; 1.8–3.0)	35 (1.6%; 1.1–2.1)	Midwife vs obstetrician, $P = 0.75$ Midwife vs parents, $P < 0.05$
Obstetrician	240 (67.8%; 62.9–72.7)	75 (21.2%; 16.9–25.5)	25 (7.1%; 4.4–9.8)	7 (2.0%; 0.5–3.5)	7 (2.0%; 0.5–3.5)	Midwife vs pathologist, $P < 0.0001$ Obstetrician vs parents, $P < 0.008$
Parents	220 (47.9%; 43.3–52.5)	117 (25.4%; 21.4–29.4)	65 (14.2%; 11.0–17.4)	52 (11.3%; 8.4–14.2)	6 (1.3%; 0.3–2.3)	Obstetrician vs pathologist, $P < 0.0001$ Parents vs pathologist, $P = 0.0001$
Pathologist	6 (28.6%; 24.5–32.7)	2 (9.5%; 6.8–12.2)	0 (0%; 0)	0 (0%; 0)	13 (61.9%; 57.3–66.3)	

Percentages are of all respondents in that group. Percentage with 95% confidence intervals shown in parentheses. * Determined by Fisher's exact test.

Table 6. Perceived barriers to consent for postmortem examination

Perceived barrier	Strong/ significant	Somewhat	Slight/none	No response/ uncertain	*P**
Lack of rapport with staff					
Midwives	1334 (59.5%; 57.5–61.5)	561 (24.9%; 23.1–26.7)	320 (14.1%; 12.7–15.5)	34 (1.5%; 1.0–2.0)	Midwife vs obstetrician, $P = 0.22$ Midwife vs pathologist, $P < 0.001$
Obstetricians	159 (45.0%; 39.8–50.2)	116 (32.8%; 27.9–37.7)	72 (20.3%; 16.1–24.5)	7 (2.0%; 0.5–3.5)	Midwife vs parents, $P < 0.001$ Obstetrician vs pathologist, $P = 0.01$
Pathologists	6 (28.5%; 9.2–47.8)	11 (52.4%; 31.0–73.8)	4 (19.1%; 2.3–35.9)	0 (0%; 0)	Obstetrician vs parents, $P < 0.001$ Parents vs pathologist, $P < 0.001$
Parents	58 (12.6%; 9.6–15.6)	35 (7.6%; 5.2–10.0)	322 (70.0%; 65.8–74.2)	35 (9.8%; 7.1–12.5)	
Emotional distress					
Midwives	1404 (62.2%; 60.2–64.2)	546 (24.2%; 22.4–26.0)	267 (11.9%; 10.6–13.2)	39 (1.7%; 1.2–2.2)	Midwife vs obstetrician, $P = 0.008$ Midwife vs pathologist, $P < 0.001$
Obstetricians	140 (39.6%; 34.5–44.7)	120 (33.9%; 29.0–38.8)	87 (24.5%; 20.0–29.0)	7 (2.0%; 0.5–3.5)	Midwife vs parents, $P < 0.001$ Obstetrician vs pathologist, $P = 0.004$
Pathologists	8 (38.1%; 17.3–58.9)	6 (28.6%; 9.3–47.9)	7 (33.4%; 13.2–53.6)	0 (0% 0)	Obstetrician vs parents, $P = 0.30$ Parents vs pathologist, $P = 0.003$
Parents	204 (44.3% 39.8–48.8)	62 (13.5%; 10.4–16.6)	164 (35.7%; 31.3–40.1)	30 (6.5%; 4.2–8.8)	
Staff workload					
Midwives	979 (43.4%; 41.4–45.4)	529 (23.4%; 21.7–15.1)	702 (31.1%; 29.2–33.0)	46 (2.0%; 1.4–2.6)	Midwife vs obstetrician, $P = 0.02$ Midwife vs pathologist, $P = 0.61$
Obstetricians	89 (25.2%; 20.7–29.7)	82 (23.2%; 18.8–27.6)	176 (49.7%; 44.5–54.9)	7 (2.0%; 0.5–3.5)	Midwife vs parents, $P < 0.001$ Obstetrician vs pathologist, $P < 0.001$
Pathologists	11 (52.4%; 31.0–73.8)	5 (23.8%; 5.6–42.0)	5 (23.8%; 5.6–42.0)	0(0%; 0)	Obstetrician vs parents, $P = 0.002$ Parents vs pathologist, $P < 0.001$
Parents	70 (15.2%; 11.9–18.5)	39 (8.5%; 6.0–11.0)	320 (69.6%; 65.4–73.8)	31 (6.8%; 4.5–9.1)	
Time to get results					
Midwives	745 (33.0%; 31.1–34.9)	667 (29.6%; 27.7–31.5)	800 (35.5%; 33.5–37.5)	44 (2.0%; 1.4–2.6)	Midwife vs obstetrician, $P = 0.09$ Midwife vs pathologist, $P = 0.16$
Obstetricians	91 (25.7%; 21.1–30.3)	69 (19.5%; 15.4–23.6)	187 (52.8%; 47.6–58.0)	7 (2.0%; 0.5–3.5)	Midwife vs parents, $P = 0.004$ Obstetrician vs pathologist, $P = 0.29$
Pathologists	5 (23.8%; 5.6–42.0)	6 (28.6%; 9.3–47.9)	10 (47.6%; 26.2–69.0)	0 (0%; 0)	Obstetrician vs parents, $P = 0.17$ Parents vs pathologist, $P = 0.001$
Parents	124 (27.0%; 22.9–31.1)	59 (12.8%; 9.7–15.9)	239 (51.9%; 47.3–56.5)	38 (8.3%; 5.8–10.8)	
Religion/culture					
Midwives	1472 (65.3%; 63.3–67.3)	450 (19.9%; 18.3–21.5)	289(12.8%; 11.4–14.2)	45 (2.0%; 1.4–2.6)	Midwife vs obstetrician, $P = 0.64$ Midwife vs pathologist, $P = 0.16$
Obstetricians	198 (55.9%; 50.7–61.1)	89 (25.1%; 20.6–29.6)	57 (16.1%; 12.3–19.9)	10 (2.8%; 1.1–4.5)	Midwife vs parents, $P < 0.001$ Obstetrician vs pathologist, $P < 0.001$
Pathologists	2 (9.5%; 0–22.0)	1 (4.8%; 0–13.9)	15 (71.4%; 52.1–90.7)	3 (14.3%; 0–29.3)	Obstetrician vs parents, $P < 0.001$ Parents vs pathologist, $P = 0.03$
Parents	15 (3.3%; 1.7–4.9)	8 (1.7%; 0.5–2.9)	406 (88.3%; 85.4–91.2)	31 (6.8%; 4.5–9.1)	
Negative press					
Midwives	914 (40.5%; 38.5–42.5)	622 (27.6%; 25.8–29.4)	663 (29.3%; 27.4–31.2)	57 (2.5%; 1.9–3.1)	Midwife vs obstetrician, $P = 0.92$ Midwife vs pathologist, $P = 0.003$
Obstetricians	157 (44.3%; 39.1–49.5)	80 (22.6%; 18.2–27.0)	107 (30.2%; 25.4–35.0)	10 (2.8%; 1.1–4.5)	Midwife vs parents, $P < 0.001$ Obstetrician vs pathologist, $P = 0.006$
Pathologists	13 (61.9%; 41.1–82.7)	5 (23.8%; 5.6–42.0)	3 (14.3%; 0–29.3)	0 (0%;0)	Obstetrician vs parents, $P < 0.001$ Parents vs pathologist, $P < 0.001$
Parents	33 (7.2%; 4.8–9.6)	42 (9.1%; 6.5–11.7)	351 (76.3%; 72.4–80.2)	34 (6.4%; 4.2–8.6)	

Table 6. (Continued)

Perceived barrier	Strong/ significant	Somewhat	Slight/none	No response/ uncertain	*P**
Child moved to a different unit					
Midwives	439 (19.5%; 17.9–21.1)	381 (16.9%; 15.4–18.4)	828 (37.9%; 35.9–39.9)	581 (25.8%; 24.0–27.6)	Midwife vs obstetrician, $P = 0.04$ Midwife vs parents, $P < 0.001$
Obstetricians	37 (10.5%; 7.3–13.7)	35 (9.9%; 6.8–13.0)	202 (57.1%; 51.9–62.3)	80 (22.6%; 18.2–27.0)	Obstetrician vs parents, $P < 0.001$
Pathologists	–	–	–	–	
Parents	151 (32.8%; 28.5–37.1)	40 (8.7%; 6.1–11.3)	228 (49.5%; 44.9–54.1)	41 (7.8%; 5.3–10.3)	

Table 7. Obstetricians' and midwives' knowledge regarding the postmortem examination procedure (midwives had significantly less knowledge than obstetricians regarding the postmortem procedure), and change in midwives' and obstetricians' knowledge regarding postmortem examination dependent on exposure

Question	Don't know/incorrectly answered % (95% CI)		*P**
	Obstetricians	**Midwives**	
Specific consent for organ retention	1.3 (0.1–2.5)	13.6 (12.2–15.0)	<0.0001
Brain can be adequately examined and returned to body immediately	30.3 (25.5–35.1)	72.0 (70.1–73.9)	<0.0001
Blocks and tissues are disposed of after one year	54.9 (49.7–60.1)	89.6 (88.3–90.9)	<0.0001
A magnetic resonance scan offers as much information as a postmortem exam	22.8 (18.4–27.2)	65.6 (63.6–67.6)	<0.0001
	Don't know/answered incorrectly (%)		
	Seen PM	**Not seen PM**	
Specific consent for organ retention	6.4 (3.6–9.2)	13.8 (12.4–15.2)	0.0002
Brain can be adequately examined and returned to body immediately	59.3 (53.6–65.0)	79.2 (77.5–80.9)	<0.0001
Blocks and tissues are disposed of after one year	51.9 (46.1–57.7)	74.5 (72.7–76.3)	<0.0001
A magnetic resonance scan offers as much information as a postmortem exam	47.2 (41.4–53.0)	65.0 (63.1–66.9)	<0.0001

**P* values determined by Fisher's exact test.

dence in their abilities to counsel parents regarding autopsy investigation. This lack of confidence may arise from a lack of exposure and knowledge for midwives, as only 5% of midwives had witnessed a perinatal autopsy. Professionals had variable knowledge of the autopsy procedure (Table 7). Disposal of tissue blocks or examination of the brain were areas in which knowledge was the weakest. Professionals who had seen a perinatal autopsy had better knowledge of the procedure (Table 7). A substantial proportion of midwives (35.4%) and obstetricians (31.7%) underestimated the value of autopsy, reporting a likelihood of ≤20% that useful information will be obtained (Figure 1), in contrast to at least 48% likelihood reported in published data.[4]

Discussion

These data represent the largest study of the experiences, knowledge and views of parents and professionals regarding the counselling and consent process for perinatal postmortem examination in the UK. The response rate of one-third of professionals is consistent with current trends for social science surveys administered through the internet.[15] In the absence of primary observational studies, this provides the most comprehensive description of the interaction between professionals and parents discussing postmortem examination after stillbirth. These data demonstrate that there are striking differences between parents and profession-

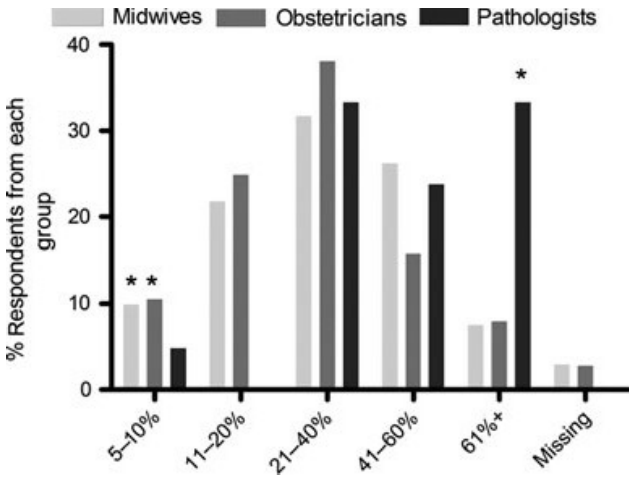

Figure 1. Perceived likelihood that postmortem examination would provide useful information. Midwives and obstetricians had a significantly lower expectation than pathologists that a postmortem would provide useful information ($P < 0.001$, Fisher's exact test).

als regarding perceptions of counselling for perinatal postmortem; these different perceptions may contribute to the falling rates of postmortem examination after stillbirth.

The reasons parents consented to a postmortem examination are similar to those reported by Rankin et al. in 2002.[16] In both studies parents' primary desire was to find a reason for their child's death, with the second most common reason to enable research to prevent stillbirth affecting other parents. Importantly, in both cohorts parents who did not consent to a postmortem examination were approximately twice as likely to regret their decision compared with those who chose to have this investigation performed. Thus, the benefits of postmortem examination may not be simply diagnostic, but also emotional. Rankin et al.[16] describe a group of parents who consented to postmortem examination to enable emotional closure, on the basis that they had then explored every potential cause. Despite the reported physical and psychological value of postmortem examination, it is clear from this study that a significant proportion of midwives and obstetricians underestimate its value.

In 2006, a study of 60 UK neonatologists described six reasons why consultants did not offer postmortem examination to parents: the availability of a perinatal pathologist (35%); concern that it might upset parents further (20%); the (then) new consent form for postmortem examination (15%); the recent cases of organ retention (9%); being uncomfortable with the postmortem process themselves (4%); and concern that the result might question their professional judgement (2%).[17] Some of these concerns are reprised in this study, particularly the wish to avoid further emotional distress and the media coverage of cases of organ retention. In particular, all professional groups in the current survey ranked the cases of organ retention as a significant barrier. This was not echoed in the responses from parents. Staff education could usefully challenge the professional assumptions in this area.

Perceptions of counselling for postmortem examination and knowledge regarding the postmortem procedure differed between professional groups and, most importantly, between parents and professionals. This study has identified factors that, if addressed, may improve the counselling and consent process for perinatal postmortem, including: education regarding the details of the postmortem procedure and its effectiveness; engagement with parents, and an understanding of their needs; interaction of perinatal pathologists with parents and staff; and the provision of good-quality information.

Responses from professionals indicate that in practice the nature of counselling for perinatal postmortem varies, and this is echoed in parents' experiences. There was variation in the timing and frequency of discussions about postmortem examination, with most obstetricians discussing this at the first time of meeting parents after the diagnosis of fetal death, whereas the timing of discussions by midwives was more variable. The origin of this variation in practice was not determined in this study, but may either reflect professionals responding to the individual nature of each case or a lack of evidence to direct a specific practice. This issue merits deeper exploration, ideally by direct interviews with professionals to determine the reasons underlying individuals' practice and to identify areas that could benefit from further research.

The means of giving parents information was most commonly verbal, although a significant minority relied on written communication alone, and a small group of parents received no information at all. The quality of information about perinatal postmortem was reported by 25% of parents to be unsatisfactory. Although this represents an improvement from 1995, when only 29% of parents were satisfied with the information they received after their baby died, there are opportunities to improve the delivery of information.[18] The quality of verbal information given to patients is affected by practitioners knowledge.[19] Here, midwives, the professional group most frequently involved in counselling for postmortem examination, were the least well informed about the process of postmortem, the least likely to have seen a postmortem and the most likely to underestimate its value in determining the cause of stillbirth. This study is in agreement with other studies that have demonstrated a need for midwives to be educated in perinatal care after stillbirth.[20–22] In other fields, comprehensible, tested written information combined with verbal information improves patient knowledge and satisfaction.[23] Given the emotive nature of perinatal postmortem, written information needs to be developed with service users, professionals and evaluated before widespread introduction.

Currently, perinatal pathologists who have expert knowledge regarding the perinatal postmortem examination, and positive views regarding its value, rarely see parents. As midwives' and obstetricians' knowledge of postmortem examination is incomplete, increasing the availability of perinatal pathologists to either see parents or educate other professionals, and restricting postmortem counselling to trained individuals, may provide a viable strategy to increase the uptake of perinatal postmortem examination. Pathologists, who have traditionally had limited contact with parents, may require preparation and training for conversations about postmortem. However, specific units who have adopted this approach reported an improved uptake of perinatal postmortem.[16,24,25]

Although this study is the largest investigation of maternity service providers and bereaved parents carried out in the UK, it has some important limitations. First, the majority of respondents to this questionnaire were of white British origin, were conversant in English and had access to the internet. This may account for some differences in responses regarding barriers to postmortem examination: for example, midwives and obstetricians perceived religion and culture to be a significant barrier to counselling for postmortem examination, whereas parents in this study did not. In addition, fathers were also under-represented in this study, which may reflect their lower use of internet support groups. Focused studies are needed to determine the views and experiences of specific groups of parents who may not access internet-based forums, members of different ethnic groups or those for whom English is not their first language. The use of this survey in other high-income countries (such as Australia, New Zealand and the Republic of Ireland) may also facilitate our understanding of different social and cultural responses to counselling for postmortem examination.

In addition to a different ethnic profile to that reported nationally, the parents contributing to this study had a higher rate of postmortem than is found in the population, which may have produced a responder bias. This was minimised by the introduction to the questionnaire, which did not specifically mention postmortem examination, so that parents who did not have investigations would not be dissuaded from participating. We have followed-up this questionnaire study with a qualitative study, purposively sampling parents who elected to have or decline a postmortem, and who were satisfied and dissatisfied with their choice. Interviews with parents will provide deeper insights into parents' decision making and the influence of the professionals caring for them. Further studies are also required to include responses from specific ethnic minorities or marginalised groups (e.g. parents who have misused drugs or asylum seekers) that experience a higher prevalence of stillbirth. Because of social exclusion, such studies will need to focus directly on these groups.

Conclusion

Given the range of parental beliefs and experiences, the uptake of postmortem investigations for stillbirth is unlikely to ever reach 100%.[26] However, the very low rates currently obtained in the UK limit a sophisticated understanding of the causes of stillbirth, and this, in turn, might be linked to the relatively high rates of stillbirth in the UK, as noted in the recent Lancet stillbirth series.[2] Current guidelines stress that parents should be supported and encouraged to think about what is the best thing to do after a stillbirth.[10,27] Parents' needs include impartial, accessible and objective information delivered by empathic and sensitive caregivers, so that they can make choices consistent with their values.

To provide accurate information, witnessing a postmortem examination of a stillborn baby is an important component of training for maternity professionals. Education that includes up-to-date facts about the nature and contribution of the postmortem examination is also vital for midwives, obstetricians and other professionals interacting with parents, such as hospital chaplains. Involving perinatal pathologists in this training would be ideal. Engaging bereaved parents themselves in the training might increase professionals' capacity to understand parents' perceptions of the counselling process. As parents report that their primary contact is with midwives, this group is particularly important. Adopting these approaches may improve the counselling process for perinatal postmortem examination.

Disclosure of interests

The authors have no conflicts of interest to report.

Contribution to authorship

AEPH and SD devised the study and obtained funding. AEPH, PC, TYK and VF developed the questionnaire for professionals. MJM. and AH analysed the responses from professionals. AEPH and SD devised the questionnaire for parents. EBS, AEPH and SD analysed responses from parents. All authors contributed to the formulation and writing of the article.

Details of ethics approval

Ethical approval for this study was given by Tameside & Glossop Local Research Ethics Committee, ref. 09/H1013/3 and the University of Manchester Research Ethics Committee.

Funding

This study was funded by Tunbridge Wells SANDS, which was made possible by Eden Financial plc.

Acknowledgements

The authors would like to thank all of the parents, midwives, obstetricians and perinatal pathologists who gave their time to complete the questionnaire. The authors would like to acknowledge the questionnaire development team of the Australian and New Zealand Stillbirth Alliance: Katie Day, David Ellwood, Adrian Charles, Dell Horey, Emma McLeod, Liz Conway and Ros Richardson. The authors would like to thank Claire Storey, Chris Wildsmith and Glen Cooper who helped in the development of the questionnaire for parents.

Supporting information

Additional Supporting Information may be found in the online version of this article:

Appendix S1. Questionnaire for obstetricians regarding views, knowledge, experience and practice of counselling for postmortem examination and other investigations after stillbirth.

Appendix S2. Questionnaire for parents regarding their view and experience of counselling for postmortem examination.

Please note: Wiley-Blackwell are not responsible for the content or functionality of any supporting information supplied by the authors. Any queries (other than missing material) should be directed to the corresponding author. ■

References

1 Confidential Enquiry into Maternal Child Health. *Perinatal Mortality 2008: England, Wales and Northern Ireland*. London: Centre for Enquiries into Maternal and Child Health, 2010.
2 Cousens S, Blencowe H, Stanton C, Chou D, Ahmed S, Steinhardt L, et al. National, regional, and worldwide estimates of stillbirth rates in 2009 with trends since 1995: a systematic analysis. *Lancet* 2011; 377:1319–30.
3 Gardosi J, Kady SM, McGeown P, Francis A, Tonks A. Classification of stillbirth by relevant condition at death (ReCoDe): population based cohort study. *Br Med J* 2005;331:1113–7.
4 Faye-Petersen OM, Guinn DA, Wenstrom KD. Value of perinatal autopsy. *Obstet Gynecol* 1999;94:915–20.
5 Kock KF, Vestergaard V, Hardt-Madsen M, Garne E. Declining autopsy rates in stillbirths and infant deaths: results from Funen County, Denmark, 1986-96. *J Matern Fetal Neonatal Med* 2003;13:403–7.
6 Cartlidge PH, Dawson AT, Stewart JH, Vujanic GM. Value and quality of perinatal and infant postmortem examinations: cohort analysis of 400 consecutive deaths. *BMJ* 1995;310:155–8.
7 Saller DN Jr, Lesser KB, Harrel U, Rogers BB, Oyer CE. The clinical utility of the perinatal autopsy. *JAMA* 1995;273:663–5.
8 Heazell AE, Martindale EA. Can post-mortem examination of the placenta help determine the cause of stillbirth? *J Obstet Gynaecol* 2009;29:225–8.
9 Heazell AE, Byrd LM, Cockerill R, Whitworth MK. Investigations following stillbirth – which tests are most valuable? *Arch Dis Child* 2011;96(Suppl 1):Fa135.
10 Royal College of Obstetricians and Gynaecologists. *Green-Top Guideline 55 - Late Intrauterine Fetal Death and Stillbirth*. London: Royal College of Obstetricians and Gynaecologists, 2010.
11 Flenady V, Middleton P, Smith GC, Duke W, Erwich JJ, Khong TY, et al. Stillbirths: the way forward in high-income countries. *Lancet* 2011;377:1703–17.
12 Holste C, Pilo C, Pettersson K, Radestad I, Papadogiannakis N. Mothers' attitudes towards perinatal autopsy after stillbirth. *Acta Obstet Gynecol Scand* 2011;90:1287–90.
13 Confidential Enquiry into Maternal and Child Health. *Perinatal Mortality 2007: England, Wales and Northern Ireland*. London: Confidential Enquiry into Maternal and Child Health, 2009.
14 De Vaus DA. *Surveys in social research*. 5th edition London: Routledge, 2002.
15 Frippiat D, Marquis N, Wiles-Portier E. Web surveys in the social sciences: An overview. *Population* 2010;65:285–311.
16 Rankin J, Wright C, Lind T. Cross sectional survey of parents' experience and views of the postmortem examination. *BMJ* 2002;324:816–8.
17 Rose C, Evans M, Tooley J. Falling rates of perinatal postmortem examination: are we to blame? *Arch Dis Child Fetal Neonatal Ed* 2006;91:F465.
18 Crowther ME. Communication following a stillbirth or neonatal death: room for improvement. *Br J Obstet Gynaecol* 1995;102:952–6.
19 Moret L, Rochedreux A, Chevalier S, Lombrail P, Gasquet I. Medical information delivered to patients: discrepancies concerning roles as perceived by physicians and nurses set against patient satisfaction. *Patient Educ Couns* 2008;70:94–101.
20 Chan MF, Lou FL, Zang YL, Chung YF, Wu LH, Cao FL, et al. Attitudes of midwives towards perinatal bereavement in Hong Kong. *Midwifery* 2007;23:309–21.
21 Roehrs C, Masterson A, Alles R, Witt C, Rutt P. Caring for families coping with perinatal loss. *J Obstet Gynecol Neonatal Nurs* 2008;37:631–9.
22 Khong TY, Turnbull D, Staples A. Provider attitudes about gaining consent for perinatal autopsy. *Obstet Gynecol* 2001;97:994–8.
23 Johnson A, Sandford J, Tyndall J. Written and verbal information versus verbal information only for patients being discharged from acute hospital settings to home. *Cochrane Database Syst Rev* 2003;4:CD003716.
24 Stock SJ, Goldsmith L, Evans MJ, Laing IA. Interventions to improve rates of post-mortem examination after stillbirth. *Eur J Obstet Gynecol Reprod Biol* 2010;29:epub ahead of print.
25 Becher JC, Laing IA, Keeling JW, McIntosh N. Restoring high neonatal autopsy rates. *Lancet* 2004;364:2019–20.
26 Rempel GR, Cender LM, Lynam MJ, Sandor GG, Farquharson D. Parents' perspectives on decision making after antenatal diagnosis of congenital heart disease. *J Obstet Gynecol Neonatal Nurs* 2004; 33:64–70.
27 Henley A, Schott J. The death of a baby before, during or shortly after birth: good practice from the parents' perspective. *Semin Fetal Neonatal Med* 2008;13:325–8.