JOURNAL OF OBSTETRICS AND GYNAECOLOGY, 2017
VOL. 37, NO. 7, 931–936
http://dx.doi.org/10.1080/01443615.2017.1316710

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ORIGINAL ARTICLE

Assessing the quality of bereavement care after perinatal death: development and piloting of a questionnaire to assess parents' experiences

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ABSTRACT

Understanding parents' experience of care is essential to develop high-quality perinatal bereavement services. This study aimed at developing a questionnaire to identify parents' needs and record their experience of care. The patient experience questionnaire was developed by professionals and parents, and piloted in a tertiary maternity unit. Responses were received from 58 parents. Sensitivity and kindness of staff and time spent with their baby were ranked as 'very important' by 95% of parents. Care in these areas largely met their needs (90%), although 5% of respondents stated that partners could have been more involved. Between 8% and 15% of respondents did not feel that language used at the diagnosis of fetal death was sensitive, clear and unambiguous. Parents did not always receive written information about their care (5%) or post-mortem (13%). Analysis of bereaved parents' responses identified areas for improvement including greater involvement of partners and a need for timely information.

IMPACT STATEMENT

- **What is already known on this subject?:** Good quality bereavement care after perinatal death reduces the negative emotional, psychological and social effects for parents. Description of parents' experiences is a potential means to improve the quality of perinatal bereavement care.
- **What do the results of this study add?:** Parents' needs and experiences of care after perinatal death were recorded using a patient-experience questionnaire designed by a multi-professional team and parents. Staff behaviour, particularly sensitivity and kindness was highly valued by parents. Giving both verbal and written information could be improved. Training is needed for professionals, particularly those who come into contact with bereaved parents less frequently.
- **What are the implications of these findings for clinical practice and/or further research?:** Description of parents' priorities and views can be used to identify areas for improvement in perinatal bereavement care. Parents' views should be regularly sought and used to develop local services in an iterative process.

KEYWORDS

Stillbirth; perinatal death; grief; bereavement support; questionnaire; pilot study

Introduction

Globally, 2.6 million stillbirths (Lawn et al. 2016) and 2.9 million neonatal deaths occur each year (Lawn et al. 2014). Despite evidence that many perinatal deaths are preventable, and some of the negative emotional, psychological and social consequences of these deaths can be addressed by high-quality postnatal care (Heazell et al. 2016), stillbirth and neonatal deaths are not seen globally as a priority to be tackled and effectively managed. The effects of perinatal death are not only confined to emotional distress resulting from the death of the baby, but also have biomedical and psychological implications for future pregnancies which frequently require additional care (Mills et al. 2014). In 2014, there were 3252 stillbirths and 1381 neonatal deaths in the UK placing a significant burden on the National Health Service (Office of National Statistics 2016).

Perinatal death shares similarities with other forms of bereavement and also has important differences from the death of an adult or an older child. One intrinsic difference is that in stillbirth, bereaved families have neither had a chance to meet the deceased nor form tangible memories. Also, there may not be an anticipatory period of grief and mourning, especially in apparently uncomplicated pregnancies, because death usually happens unexpectedly (D'Agostino et al. 2008). In common with other forms of bereavement, parents bereaved in the perinatal period may experience shock, disbelief, confusion and guilt (Cacciatore et al. 2013). In addition, they may also exhibit grief-related behaviours such as disturbed sleep, denial, avoiding or prizing objects or

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places which remind them of their baby, for instance, the nursery or a baby blanket (Holland et al. 2013).

A systematic review did not identify any randomised clinical trials to inform care of bereaved parents and families following perinatal death (Koopmans et al. 2013). Therefore, care is based on descriptions of parents' experiences of care; several studies have described the needs of bereaved parents including: sensitive delivery of information, enough time to retain and understand information and time to make decisions (Malm et al. 2011; Flenady et al. 2014; Redshaw et al. 2014). The majority of published studies suggest that parents need to be supported to see and spend time with their child and create mementoes (Kingdon et al. 2015). Whilst grieving, parents also need to consider whether to have investigations such as autopsy and chromosomal analysis (Heazell et al. 2012), and make other decisions regarding their care and funeral arrangements (Royal College of Obstetricians and Gynaecologists 2010). During this period, health care professionals need to ensure that whilst providing information to parents, they do not advise parents based on their own personal values or ideology but remain objective and allow the parents to come to their own decision independently, ensuring that patient autonomy is maintained (Flenady et al. 2014).

Critically, appreciation of the underpinning evidence needs to be augmented with understanding of parents' experience for the development of high-quality bereavement service and local needs should be appreciated (Redshaw et al. 2014). This study aimed to develop and pilot a patient experience questionnaire that complements existing tools, such as the Sands Audit Tool, to assess perinatal bereavement services (Henley & Schott 2011), to describe what parents deemed to be important aspects of their care and to ensure that care provision met parents' needs.

Materials and methods

To describe parents' experience of care following a perinatal death on the delivery unit (this included parents whose babies died before labour, during labour or shortly afterwards), a questionnaire was developed by a multidisciplinary team (including Bereavement Midwives, Obstetricians, Perinatal Pathologists, Mortuary Staff, Chaplains (Religious Leaders) and other Bereavement Support Staff including counsellors and staff from the Family Support Service). The questionnaire was developed referring to several sources: an existing resource from a tertiary maternity service in Cork, Ireland (O'Connell et al. 2016), guidelines for the management of stillbirth published by the Royal College of Obstetricians and Gynaecologists (Royal College of Obstetricians and Gynaecologists 2010), parents' experiences documented in the Listening to Parents Report (Redshaw et al. 2014) and recent qualitative studies of parents experiences of perinatal bereavement in the UK (Downe et al. 2012; Murphy 2012). Components of bereavement care that were recommended by professional bodies or were common themes in the literature were used to formulate questions. The questionnaire was then sent to five bereaved families for their feedback; changes were made to question wording and content in accordance with comments from service users. The final parent experience questionnaire (PEQ) included 30 questions which were a mixture of open and closed questions and Likert scales (Supplementary material).

The questions addressed topics identified as important themes from published reports, including: the diagnosis of fetal death (Rådestad et al. 2014), care after diagnosis (Trulsson & Rådestad 2004), during labour and delivery and postnatally including the provision of mementos (Downe et al. 2012; Redshaw et al. 2014), contact with the baby (Kingdon et al. 2015), discussion about investigations (Heazell et al. 2012) and lactation suppression (Cole 2012). The PEQ asked respondents to rank the importance of different aspects of care to ensure that the evidence-based recommendations were applicable to the local population. Respondents were then asked to describe the quality of care they received. Optional questions regarding demographics were included at the end of the PEQ. In accordance with recommendations from the UK Health Research Agency, this programme of work is identified as description of patient experience which does not require evaluation by research ethics committee. The project was registered and approved by the Patient Experience Department of the host institution, a part of the Division of Clinical Audit. The Patient Experience Department specifically aims to record the views and experiences of service users, as opposed to Clinical Audit which assesses care quality based upon specific indicators.

The PEQ was sent to all parents who had experienced a perinatal death on the delivery unit at St Mary's Hospital, Manchester, UK, over an 18 month period from 2014 to 2015. This is a large tertiary maternity unit in the North-West of England, where there are ~9000 births per year. The stillbirth rate in the unit was 5.4 per 1000 births and the neonatal death rate was 3.5 per 1000 births in 2014–2015. The PEQs were sent out to each family ($n = 144$) who had a stillbirth or neonatal death on the delivery unit 3–6 months after the stillbirth or death of the baby. Parents were able to complete the questionnaire on paper or online; parents could complete the questionnaire together or individually. No identifiable data were collected. Anonymised responses were collated on an online tool (www.surveymonkey.com, Palo Alto, CA). Quantitative data were exported to Microsoft Excel. Descriptive statistical analysis was performed calculating the proportion of respondents responding to each question. Qualitative data were analysed using thematic analysis by two investigators (EA and AH); the free-text data were read by both investigators independently and emerging themes were identified and relevant quotes were extracted.

In addition to the PEQ, elements of care were assessed using the audit tool developed by Sands which comprised 120 questions grouped into 18 themes regarding the provision of care for parents whose babies die in the perinatal period (Henley & Schott 2011). Information was gathered by interviewing key members of the perinatal bereavement team including: Bereavement Midwives, Perinatal Pathologist, Consultant Obstetrician and by consulting the

local guideline for the management of stillbirth and neonatal death.

Results

Characteristics of respondents

During the time frame of the study there were 144 perinatal deaths, all of which were sent a PEQ. There were 58 responses from parents, giving a response rate of 40%. Respondents included those from female and male parents. The largest group of respondents were aged 31–35 years of age, but ranged from less than 20 years to over 41 years of age. The largest ethnic group of respondents was White British women (67%), although responses were received from Black African, Black Caribbean and Asian parents. Only one parent identified themselves as having a disability (Table 1).

Parents' assessment of the importance of aspects of care

Most parents (95%) rated sensitivity and kindness of staff, provision of mementos and time spent with baby as very important. In contrast, the importance of practical issues such as the quality of medical management (84%) and lactation suppression was not ranked high (41%). The sensitivity and kindness of the staff was frequently identified as a very important aspect of care, and is summarised by the quotes: 'Everyone was very respectful and showed us compassion', 'Building a lovely relationship with the midwives caring for us was important as was allowing my husband to stay throughout my entire hospital stay' and 'The midwife was extremely sensitive and supportive, couldn't have done it without her'.

Table 1. Demographic characteristics of respondents.

Demographic	Subset	Number of participants (%)
Gender	Male	2 (3.4%)
	Female	47 (81.0%)
	No response	9 (15.5%)
Age (years)	<20	1 (1.7%)
	21–25	7 (12.1%)
	26–30	11 (19.0%)
	31–35	17 (29.3%)
	36–40	11 (19.0%)
	Over 41	2 (3.4%)
	No response	9 (15.5%)
Disability	Yes	1 (1.7%)
	No	48 (82.7%)
	No response	9 (15.5%)
Ethnicity	White British	39 (67.2%)
	White Other	1 (1.7%)
	Black African	2 (3.4%)
	Black Caribbean	1 (1.7%)
	Asian	3 (5.1%)
	Mixed	1 (1.7%)
	No response	9 (15.5%)

Evaluation of parents' experience of care

All parents felt supported in aspects of care which they reported as very important including: caring for their baby, spending enough time with their baby and being offered mementoes. All parents were offered photographs and most (95%) were offered mementos such as a memory box and hand and footprints (Table 2).

Bereaved parents encounter some staff groups more often than others, including Consultant Obstetricians, labour ward Midwives, Bereavement Midwives, Chaplains (Religious Leaders) and Bereavement Support Officers (Table 3). The majority of experiences of staff interactions were positive, although rarely some parents reported negative experiences (2%). A sticker applied to the notes did not prevent communication difficulties such as staff being unaware of their bereavement in 10% of cases. Negative interactions were predominantly with staff who had not received specific training to care for parents after perinatal death such as administrative staff or anaesthetists. Other staff who received such training or who have had more advanced role-specific training such as Bereavement Midwives, were rated as very helpful by almost all of those who met them.

Over half of respondents had complications in their pregnancy prior to the death of their baby. Almost half of the parents (47%) were informed of their baby's death by a consultant obstetrician. Other members of staff delivering the diagnosis included sonographers and midwives, 14% of parents did not know the grade or profession of the staff member who informed them their baby had died. The majority of respondents felt that the diagnosis of fetal death was delivered sensitively in a private space. Some respondents (3.6–5.5%) did not feel that the language used was sensitive, clear and unambiguous, and they felt they had insufficient time. Almost 14% of parents who had a stillbirth were not given written information with contact numbers after fetal death was diagnosed (Table 4). Forty-eight parents (83%) discussed post-mortems with a member of staff. Of these, six parents (13.6%) were not given written information. Nevertheless, the verbal discussion was interpreted as sensitively and clearly explained, and with adequate opportunity for parents to ask questions (Table 5).

Fifty-one parents (87.9%) met the bereavement team in hospital and 54 (93.1%) were contacted after hospital discharge. Fifty-four parents (93.1%) felt adequately supported

Table 2. Respondents' perception of the quality of care they received in hospital.

Please indicate your agreement with the following statements about the care you received in hospital.

Answer Options	Strongly agree (%)	Partly agree (%)	Neither agree or disagree (%)	Partly disagree (%)	Strongly disagree (%)	Response Count
I had sensitive care during labour and delivery.	48 (84.2%)	3 (15.8%)	0 (0%)	0 (0%)	0 (0%)	57
I had enough time together with my baby after the birth	47 (85.4%)	2 (3.6%)	6 (10.9%)	0 (0%)	0 (0%)	55
I had support to hold and care for my baby.	53 (96.3%)	0 (0%)	0 (0%)	2 (3.6%)	0 (0%)	55
I was asked whether I wanted footprints, photos and mementos	55 (96.4%)	2 (3.5%)	0 (0%)	0 (0%)	0 (0%)	57
Other children or family members were included appropriately.	44 (86.2%)	1 (2.0%)	6 (11.8%)	0 (0%)	0 (0%)	51

Percentages of respondents are shown in parentheses.

Table 3. Respondents' interactions with and experience of the helpfulness of staff.

During the time you were in hospital and after you were discharged home, did you find the services of the following members of the team helpful?

Answer options	Helpful (%)	Neither helpful/unhelpful (%)	Unhelpful (%)	Did not meet them (%)	Response Count
Your obstetric consultant	36 (75.0%)	3 (6.3%)	0 (0%)	9 (18.8%)	48
Another obstetric consultant	22 (46.8%)	6 (12.8%)	0 (0%)	19 (40.4%)	47
Your baby's neonatologist/paediatrician	12 (25.5%)	6 (12.8%)	0 (0%)	29 (61.7%)	47
Another neonatologist/paediatrician	5 (12.2%)	8 (19.5%)	0 (0%)	28 (68.3%)	41
Junior doctor	13 (30.2%)	8 (18.6%)	0 (0%)	22 (51.2%)	43
Labour ward midwives	47 (92.1%)	2 (3.9%)	0 (0%)	2 (3.9%)	51
Bereavement midwife	51 (94.4%)	0 (0%)	0 (0%)	3 (5.6%)	54
Chaplain	35 (72.9%)	1 (2.1%)	0 (0%)	13 (27.1%)	48
Mortuary staff	16 (47.1%)	3 (8.8%)	0 (0%)	15 (34.9%)	34
Bereavement support officer	40 (72.7%)	2 (3.6%)	0 (0%)	13 (23.6%)	55
Anaesthetist	25 (49.0%)	6 (11.8%)	1 (2.0%)	19 (37.3%)	51
Secretaries/Admin staff	21 (46.7%)	6 (13.3%)	1 (2.2%)	17 (37.8%)	45
Answered question					54
No response					4

Percentage of respondents is shown in parentheses.

Table 4. Parents' experience of the manner in which diagnosis was given.

When you were told that your baby had died, did you feel that this was …

Answer options	Strongly agree (%)	Partly agree (%)	Neither agree nor disagree (%)	Partly disagree (%)	Strongly disagree (%)	Response count
Delivered with sensitivity?	37 (67.3%)	9 (16.4%)	6 (10.9%)	0 (0%)	3 (5.5%)	55
Clear and unambiguous?	44 (80.0%)	9 (16.4%)	2 (3.6%)	1 (1.8%)	1 (1.8%)	55
Given in private space?	47 (85.4%)	7 (12.7%)	1 (1.8%)	0 (0%)	0 (0%)	55
Given in a way that you felt could ask questions?	38 (69.1%)	10 (18.2%)	5 (9.1%)	1 (1.8%)	1 (1.8%)	55
You were given enough time?	39 (70.9%)	8 (14.5%)	5 (9.1%)	2 (3.6%)	1 (1.8%)	55
Given with written information and contact numbers?	33 (64.7%)	4 (7.8%)	7 (13.7%)	2 (3.9%)	5 (9.8%)	51
With the option of having your partner or another person present?	43 (86.0%)	4 (8.0%)	2 (4.0%)	0 (0%)	1 (6.0%)	50
Answered question						38
No response						1

Percentages of respondents are shown in parentheses.

Table 5. Respondents' experience of post-mortem discussions.

If the post-mortem discussed was it?

Answer Options	Strongly agree (%)	Partly agree (%)	Neither agree nor disagree (%)	Partly disagree (%)	Strongly disagree (%)	Response count
Accompanied by written information?	25 (56.8%)	8 (18.1%)	5 (11.4%)	2 (4.5%)	4 (9.1%)	44
In a kind and sensitive manner?	42 (89.4%)	5 (10.6%)	0 (0%)	0 (0%)	0 (0%)	47
Explained clearly?	37 (77.8%)	8 (16.7%)	2 (4.2%)	1 (2.1%)	0 (0%)	48
At an appropriate time?	32 (71.1%)	7 (15.6%)	2 (4.4%)	2 (4.4%)	2 (4.4%)	45
With adequate opportunity to ask questions and have them answered?	38 (80.9%)	5 (10.6%)	2 (4.3%)	2 (4.3%)	0 (0%)	47
With enough time to think it over?	37 (78.7%)	5 (10.6%	0 (0%)	3 (6.4%)	2 (4.3%)	47
By health professionals who were clearly knowledgeable?	39 (83.0%)	4 (8.5%)	2 (4.3%)	2 (4.3%)	0 (0%)	47
Answered question						48
No response						10

Percentages of respondents to the question are shown in parentheses.

for as long as they needed and only two parents said they were not supported for long enough. All parents who met the bereavement midwives found them helpful. A common theme in free text responses was the role of interactions with staff to form positive memories as illustrated by the following free-text responses to the survey. 'Although you can't bring our babies back you do make life without them easier', 'Receiving a memory box was unexpected and very kind … Without her (the Bereavement Midwife) we wouldn't know how important creating memories of our baby boy were …' and, 'The care received during delivery was exceptional'.

Assessment of care using a national audit tool

Of 120 standards in the Sands audit tool, bereavement care in the institution under study met 110 (92%). The standards that were not met largely involved members of the staff who were not directly a part of the clinical staff involved in the parents' care such as interpreters (Table 6). Half of the unmet standards related to staff training, whereas others were not within the remit of the hospital, i.e. the use of a shared grave and lockable cover (within the remit of local councils).

Discussion

This project has developed and piloted a PEQ to assess parents' needs and experiences of perinatal bereavement services. In doing so, we have confirmed that our service meets parents' key needs such as sensitivity and kindness of staff, provision of mementos and facilitating parents to spend time with their baby. Responses from the PEQ have also identified areas for improvement, particularly information giving

Table 6. Breakdown of audit themes showing number and percentages achieved.

Theme	Number of questions	Number of standard achieved (%)
Training and support for staff	4	4 (100%)
Ultrasound scans and antenatal care	12	11 (92%)
Care in life-threatening or lethal abnormality in progressing pregnancy	6	6 (100%)
Internal hospital communication	4	4 (100%)
External hospital communication	5	5 (100%)
Care on labour ward	19	19 (100%)
Care after birth	8	8 (100%)
Taking baby home	3	3 (100%)
Post mortem examinations	9	9 (100%)
Death registration	2	2 (100%)
Funerals	12	10 (83%)
Leaflets	4	3 (75%)
Post-natal check-up appointments	3	3 (100%)
Care in subsequent pregnancies and births	5	5 (100%)
Care in language barriers	11	7 (64%)
Care for parents with disabilities	7	5 (71%)
Seamless process of care	4	4 (100%)
Reviewing care	2	2 (100%)

and involvement of partners. The PEQ compliments existing audit tools to optimise perinatal bereavement care.

Although the importance of good quality bereavement care after perinatal death is established, as it reduces pathological grief (Kersting & Wagner 2012), there have been few other attempts to measure patient experience for quality improvement in this area (O'Connell et al. 2016). Consequently, there is no existing model of improving bereavement services for stillbirth. The PEQ developed here can be incorporated into a model of improving bereavement services for stillbirth which is informed by parental involvement (Figure 1). Parental involvement was important in the development and refinement of the PEQ in collaboration with a multidisciplinary team. Bereaved parents' responses to the PEQ have enabled specific improvements to be made to the care pathway, which can then be re-evaluated in the future.

This pilot study of the PEQ showed that parents' needs in this diverse tertiary maternity population were largely in line with expectations from published data. For example, the higher importance ascribed to psychological and emotional needs, rather than physical needs, is in agreement with the findings of systematic review of 43 studies describing interventions that were associated with positive experiences of care after a stillbirth. In that review, the majority of included studies (40/43) identified the importance of emotional support, in which interactions with health professionals were critical (Heazell et al. 2016). Elements of tangible support including seeing and holding their baby and making mementos were also ranked as highly important by parents in this study, providing further impetus to implement these evidence-based practices (Kingdon et al. 2015).

Although some guidelines recommend that bereavement care should be evaluated every two to three years there is no instruction about the format this should take (Henley and Schott 2011). The Sands Audit Tool largely focuses on the availability of elements of training, elements of care and organisational structures. The combination of the audit tool and PEQ allows units to ensure that the correct facilities and

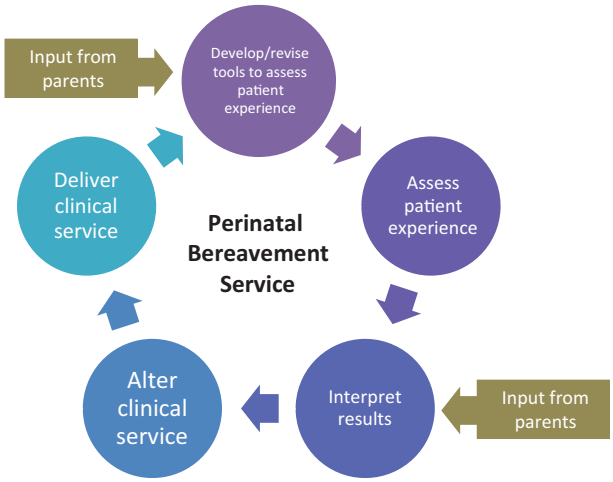

Figure 1. Cycle for the development and improvement of perinatal bereavement services showing focus for parents' involvement.

structures are in place and to ensure that individual parents experience is optimal. This information has enabled the perinatal bereavement service to develop by making specific changes to clinical guidance and services, e.g. involvement of partners/fathers, making information simpler and direct, training of staff groups with less exposure to bereaved parents, e.g. administrative staff, anaesthetists. The impact of these amendments can then be assessed, and care improved in an iterative manner in a continuous cycle of improvement (Figure 1).

Descriptive studies of this nature are important, as facets of care such as kindness and sensitivity of staff which rated highly in this survey and are consistently valued in published studies, are not amenable to randomised clinical trials. The qualitative data from this survey provides a rich source of information, which gives insights into parent's perspectives on their care in particular the importance of authentic relationships with staff. This is important as parents' and professionals' perspectives often differ, with professionals consistently overestimating parents' satisfaction with bereavement care (Flenady et al. 2016). The PEQ highlighted the importance of communication between professionals and parents. Critically, over half of the standards in the national audit that were not achieved (8%) were related to barriers in communication, such as access to trained interpreters, which for 18% of respondents was important, as English was not their first language. Thus, another area identified for improvement is the provision of training regarding care after stillbirth for interpreters that regularly work on maternity units.

The development and pilot of the PEQ provides novel insight into perinatal bereavement care. However, data to compare different perinatal bereavement services or models of care are scarce. The findings of this study may be generalisable, as parents answers reflected wider UK practice, such as 46% of respondents reported that a Consultant Obstetrician informed them of their babies death (Redshaw et al. 2014). However, other practices differed, respondents received more written information than reported by O'Connell et al. from Ireland, who reported that 38% parents received leaflets compared to 92% of the respondents here (O'Connell et al. 2016). Currently, this study is limited by the

number of respondents and the location in a single maternity service. However, it is of a comparable size to similar studies (D'Agostino et al. 2008; Downe et al. 2012; Horey et al. 2014). Although the sample largely consisted of white British women, the women from ethnic groups were represented in approximately similar proportions compared to the demographics of women experiencing a stillbirth at the unit. The 30-item PEQ may be perceived by some parents to be too long to complete, and restrict completion to parents who are fluent in English. In addition, the volume of data generated by the questionnaire may be excessive for healthcare professionals to collate and analyse. The utility of the PEQ needs to be assessed by further studies in a variety of other maternity units. In common with other studies, fathers were underrepresented in this study (Downe et al. 2012; Avelin et al. 2013; Cacciatore et al. 2013; O'Connell et al. 2016). Therefore, future iterations of the quality improvement cycle also need to consider specific methods to engage with fathers' or partners' views and respondents from minority ethnic groups.

This study describes the development and initial use of a PEQ which identified areas for local improvement to ensure high-quality perinatal bereavement care in a tertiary UK maternity unit. Further work is needed to establish whether this tool can facilitate improvements in other settings and in other groups (e.g. women from minority ethnic groups, fathers). Nevertheless, the additional information obtained from parents enabled additional focus to be placed on emotional and tangible support as well as devising methods to give information to parents. It is anticipated that perinatal bereavement care can be developed and reassessed using these tools after an appropriate interval following the introduction of changes to facilitate ongoing development.

Disclosure statement

The authors report no conflicts of interest

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References

Avelin P, Rådestad I, Säflund K, Wredling R, Erlandsson K. 2013. Parental grief and relationships after the loss of a stillborn baby. Midwifery 29:5.

Cacciatore J, Erlandsson K, Rådestad I. 2013. Fatherhood and suffering: a qualitative exploration of Swedish men's experiences of care after the death of a baby. International Journal of Nursing Studies 50:6.

Cole M. 2012. Lactation after perinatal, neonatal, or infant loss. Clinical Lactation 3:94–100.

D'Agostino NM, Berlin-Romalis D, Jovcevska V, Barrera M. 2008. Bereaved parents' perspectives on their needs. Palliative Supportive Care 6:8.

Downe S, Schmidt E, Kingdon C, Heazell AE. 2012. Bereaved parents' experience of stillbirth in UK hospitals: a qualitative interview study. BMJ Open 3:11.

Flenady V, Boyle F, Koopmans L, Wilson T, Stones W, Cacciatore J. 2014. Meeting the needs of parents after a stillbirth or neonatal death. BJOG: An International Journal of Obstetrics & Gynaecology 121(Suppl 4):3.

Flenady V, Wojcieszek AM, Middleton P, Ellwood D, Erwich JJ, Coory M, et al. 2016. Stillbirths: recall to action in high-income countries. The Lancet 387:691–702.

Heazell AE, McLaughlin MJ, Schmidt EB, Cox P, Flenady V, Khong TY, et al. 2012. A difficult conversation? The views and experiences of parents and professionals on the consent process for perinatal post-mortem after stillbirth. BJOG: An International Journal of Obstetrics & Gynaecology 119:10.

Heazell AE, Siassakos D, Blencowe H, Burden C, Bhutta ZA, Cacciatore J, et al. 2016. Stillbirths: economic and psychosocial consequences. The Lancet 387:604–616.

Henley A, Schott J. 2011. The Sands audit tool for maternity services: caring for parents whose baby has died. London. Stillbirth and Neonatal Death Charity.

Holland JM, Futterman A, Thompson LW, Moran C, Gallagher-Thompson D. 2013. Difficulties accepting the loss of a spouse: a precursor for intensified grieving among widowed older adults. Death Studies 37:18.

Horey D, Flenady V, Conway L, McLeod E, Khong TY. 2014. Decision influences and aftermath: parents, stillbirth and autopsy. Health Expectations 17:10.

Kersting A, Wagner B. 2012. Complicated grief after perinatal loss. Dialogues in Clinical Neuroscience 14:7.

Kingdon C, Givens JL, O'Donnell E, Turner M. 2015. Seeing and holding baby: systematic review of clinical management and parental outcomes after stillbirth. Birth 42:206–218.

Koopmans L, Wilson T, Cacciatore J, Flenady V. 2013. Support for mothers, fathers and families after perinatal death. Cochrane Database of Systematic Review 6:CD000452.

Lawn JE, Blencowe H, Oza S, You D, Lee AC, Waiswa P, et al. 2014. Every newborn: progress, priorities, and potential beyond survival. The Lancet 384:189–205.

Lawn JE, Blencowe H, Waiswa P, Amouzou A, Mathers C, Hogan D, et al. 2016. Stillbirths: rates, risk factors, and potential for progress towards 2030. The Lancet 387:587–603.

Malm MC, Rådestad I, Erlandsson K, Lindgren H. 2011. Waiting in no-man's-land: mothers' experiences before the induction of labour after their baby has died in utero. Sexual & Reproductive Healthcare 2:51–55.

Mills TA, Ricklesford C, Cooke A, Heazell AE, Whitworth M, Lavender T. 2014. Parents' experiences and expectations of care in pregnancy after stillbirth or neonatal death: a metasynthesis. BJOG: An International Journal of Obstetrics & Gynaecology 121:943–950.

Murphy S. 2012. Reclaiming a moral identity: stillbirth, stigma and 'moral mothers'. Midwifery 28:476–480.

O'Connell O, Meaney S, O'Donoghue K. 2016. Caring for parents at the time of stillbirth: How can we do better? Women Birth 29:345–349.

Office of National Statistics. 2016. Deaths Registered in England and Wales, 2014. Available from http://www.ons.gov.uk/ons/rel/vsob1/death-reg-sum-tables/2013/sb-deaths-first-release–2013.html#tab-Stillbirths.

Rådestad I, Malm MC, Lindgren H, Pettersson K, Larsson LL. 2014. Being alone in silence: mothers' experiences upon confirmation of their baby's death in utero. Midwifery 30:e91–e95.

Redshaw M, Rowe R, Henderson J. 2014. Listening to parents after stillbirth or the death of their baby. Oxford: University of Oxford. p. 57.

Royal College of Obstetricians and Gynaecologists. 2010. Green-top guideline 55: late intrauterine fetal death and stillbirth. Available from: www.rcog.org.uk/globalassets/documents/guidelines/gtg-55-31072013.pdf.

Trulsson O, Rådestad I. 2004. The silent child-mothers' experiences before, during, and after stillbirth. Birth 31:189–195.