

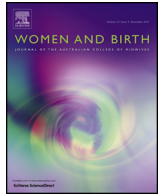


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ORIGINAL RESEARCH – QUANTITATIVE

Caring for parents at the time of stillbirth: How can we do better?

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ABSTRACT

Background: Many bereavement practices have become standard within maternity hospitals however little published evidence is available to confirm their benefit. We wanted to establish which aspects of care are valued, which could be improved and which, if any, cause distress.

Methods: This study aimed to survey parents who experienced stillbirth in a tertiary referral centre. There were seven question areas including receiving bad news, involvement of the multidisciplinary team, facilitation to grieve and have time with baby, autopsy communication process, post-discharge support and the importance parents placed on aspects of care. Mothers were contacted months following stillbirth to obtain verbal consent, before surveys were posted to both parents. Data were analysed using IBM SPSS Statistics version 22.0.

Findings: 70% ($n = 21$) of mothers and 51% ($n = 15$) of fathers responded. Responses between partners tended to agree. Predominantly positive replies to the survey suggested that our priorities in the provision of care were relevant but themes of dissatisfaction were identified regarding communication, written information, post-mortem information and post discharge follow-up. The overwhelming importance of caregivers' interactions with the parents was notable in terms of the extent to which the parents recalled and wrote in detail about these encounters.

Discussion: Parents place a great deal of importance on their interactions with caregivers. Staff education and training needs to reflect this to ensure that professionals relate unambiguously and knowledgeably while focusing on the quality of the connection so that care provided will be experienced as sensitive, empathic and attuned to each individual parent.

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Summary of relevance:

Problem or Issue

The lack of optimal care for bereaved families at the time of stillbirth impacts on the physical and mental health of parents, siblings, subsequent children and future generations.

What is already known

Modern bereavement theories have informed what have become routine and standard maternity practices at the time of

stillbirth but consideration must be given to parents' opinions to establish if they feel that their needs are being met.

What this paper adds

This paper supports the provision of many maternity hospital bereavement practices but identifies omissions and reprioritises aspects of care. It highlights that the manner in which staff interact with families is critical to their entire experience.

1. Introduction

Until the 1970s in Ireland it was common practice to remove a stillborn baby and sometimes sedate the mother before she could see her infant in an attempt to avoid attachment and therefore grief. Acknowledgement that there had been a baby was avoided

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and there were no rituals to say good-bye. The mother was encouraged to have another baby as if the one who died had never existed.¹ Current bereavement theory however, focuses on internalising the memory of the loved one,² the value of continuing bonds³ and making meaning⁴ of the loss which gradually enables the bereaved to integrate it as part of their life story.

While these theories have resulted in efforts to change practice in many high income countries, in low income countries where the vast majority of stillbirths occur, there continues to be a stigma of blame and shame attached to mothers and lack of recognition of the babies who are often disposed of without a funeral and seen as taboo objects.⁵ While education is needed to address these attitudes to stillbirth and prioritise it as global health issue, it is also necessary to be mindful of the differing cultural needs of our diverse populations within high income countries. Ireland has a traditional history of waking their dead i.e. friends and family continuously watch over their deceased from death to burial as they both celebrate their life and grieve their death. Irish families will generally see and hold their stillborn baby while many of our new immigrant parents have differing religious and cultural practices e.g. not wishing to see baby or have photographic images taken and preparing the baby for burial within a certain time in a certain way. It is important for us however not to make assumptions based on religion or culture but to sensitively offer choice and flexibility for each individual family.

To experience the death of one's child at the time of birth is a profoundly distressing bereavement. Stillbirth has been described as the invisible death⁶ as it occurs within the mother's body and her sense of grief may be disenfranchised as not publicly acknowledged.⁷ The baby's existence is denied and the mother's identity as a mother is lost.⁸ Subsequent morbidity including anxiety, depression, post-traumatic stress^{9,10} and relationship difficulties¹¹ are well documented. Additionally, attachment difficulties¹² in the next pregnancy and attachment disorders¹³ in children born subsequently are also reported. The surviving children at the time of the stillbirth experience double loss – their baby sibling and their parents as known to them prior to the loss.¹⁴ The emotional burdens they carry can have multi-generational repercussions as these adult children have families of their own.¹⁵ While there is an absence of high quality empirical evidence on best practice in supporting families following perinatal death in the literature what remains clear is the essential necessity of a "deep respect for the individuality and diversity of grief, respect for the deceased child and recognition of the healing power and resilience of the human spirit"¹⁶

2. Methods

2.1. Ethical approval

Ethical approval was sought and received from the Clinical Research Ethics Committee of the Cork Teaching Hospitals.

2.2. Setting

Cork University Maternity Hospital (CUMH) is a university teaching tertiary referral maternity hospital in the south of Ireland. In 2011, there were 30 stillbirths from a total of 8786 births, which equates to a stillbirth rate of 3.4 per 1000 births. The CUMH approach to bereavement care involves cohesion between hospital staff, the dedicated bereavement team and the bereaved families. The bereavement team includes representatives from obstetrics, midwifery, medical social work, chaplaincy, sonography, management and perinatal pathology. This group forms a committee, which meets regularly to review the service and implement new

initiatives. Good communication is central as team members liaise with each other regarding individual patient care. Patients have access to members of the team while in hospital and following discharge. A follow up appointment with a consultant obstetrician is standard practice within two to three months.

2.3. Study population

Of the 30 stillbirths in 2011, 26 experienced sudden unexpected intrauterine death, 2 of whom were subsequently diagnosed with a life-limiting congenital anomaly, while 4 mothers had received a life-limiting abnormality diagnosis antenatally.

2.4. Survey

A service evaluation questionnaire was designed to examine the extent to which the parents' needs were being met. Seven key areas were selected that reflected our assessment of parents' needs including; receiving bad news, involvement of bereavement team, facilitation of time with baby, communication regarding autopsy, care post hospital discharge, use of alert sticker and parents' assessment of the importance of specific aspects of care. Likert scales were used and free text fields invited comments on experiences of care which were particularly helpful or which caused distress, in order to measure the degree to which the parents felt their needs were being met through the care provided.

Initial contact was made by telephone to verbally explain our aim and obtain consent to post the questionnaires. Two copies of the postal questionnaire were sent to each home apart from one mother who was a single parent. It was made clear to parents that emotional support would be available if the questions triggered distress or unresolved memories. The bereavement midwives, who were known to the families, would provide this support. As the researcher was known to many of the participants, identifying demographic information was not collected and confidentiality assured at the initial telephone conversation.

3. Results

Of the 59 parents surveyed 61% ($n = 36$) responded; representing 70% ($n = 21$) of mothers and 52% ($n = 15$) of fathers in 2011. Here, the results of the Likert scale questions are presented along with examples of parents' written text responses to illustrate their experience.

3.1. Receiving bad news

The largest group that imparted the news of an intrauterine death or a lethal foetal diagnosis was obstetric consultants 44% ($n = 16$), followed by non-consultant hospital doctors 22% ($n = 8$) and sonographers 13% ($n = 4$). One fifth (20%; $n = 7$) of parents did not know who told them the news. The majority of parents (88%; $n = 32$) had their partner present at the time and 77% ($n = 28$) said they were given enough time, including time to ask questions. Almost three quarters of parents (72%; $n = 26$) said the news was delivered with sensitivity and 72% ($n = 26$) said it was given in privacy. Just over one third (38%; $n = 14$) received written information at this time.

The following comments display how parents recalled the experience of hearing the news in detail and the on-going emotion associated with the way in which it was given.

"I remember the serious look on the doctor's face. She told another doctor "There's no FH". That's how I knew my baby had died"

"They wouldn't tell me what was wrong until my boyfriend arrived. I was terrified but the ultrasonographer stayed with me. They were all really kind"

3.2. *The bereavement team*

Bereaved parents may access any relevant member of the bereavement team. We wished to identify which professionals met with the parents and how this facilitated their needs.

Following birth 47% ($n = 17$) of parents met their own obstetric consultant, 52% ($n = 19$) met another obstetric consultant, 25% ($n = 9$) met a paediatrician, 89% ($n = 32$) a chaplain, 58% ($n = 21$) a social work counsellor and 97% ($n = 35$) a bereavement midwife.

The importance of continuity of care from individual professionals is clear from these comments.

"I was hurt that my consultant didn't visit during the week that I was an inpatient until the last day at the request of the midwife on my behalf"

"Meeting the specialist bereavement midwife in advance and planning for the service and burial meant we could focus on our baby after birth. It was great to know we could also get in touch with her after discharge"

3.3. *Facilitation to grieve and spend time with baby*

While 72% ($n = 26$) of parents strongly agreed that they received sensitive care during labour, 89% ($n = 32$) were facilitated sensitively to have time alone together with their baby post birth. Support in parenting activities like dressing and bathing was experienced by 91% ($n = 33$), 86% ($n = 31$) were facilitated in introducing their other children and family members to the baby and 86% ($n = 31$) were supported with the creation of mementoes such as prints, photographs and clothing.

The comments relating to this area indicate the importance of staff sensitivity.

"The way the midwife made his little hand prints and foot prints is something I will hold forever in my heart, she showed such tenderness and respect".

"The amount of time that different people were coming in and out of our room for different services was a bit much at times when all we wanted was to be alone."

3.4. *Communication regarding autopsy*

When asked about the way in which information about post mortem was delivered 90% ($n = 31$) thought it was handled sensitively but only 58% ($n = 18$) said that it was explained clearly. Over three quarters (77%; $n = 24$) felt that they were given adequate time to decide but just 67% ($n = 21$) said it was addressed at an appropriate time. One quarter of parents (26%; $n = 13$) said that the information was not given by knowledgeable professionals and 26% ($n = 13$) said that they did not have adequate opportunity to ask questions.

The main difficulties experienced regarding autopsy involved clarity, timing, information and knowledge of the doctor who undertook the consent for the procedure, as comments here illustrate.

"I felt I was being pressured into getting a post mortem and at all the wrong times, i.e. at 8am in the morning when I was still resting after a long night of contractions and pain and it was the last thing I wanted to talk about at the time."

"There was no information provided on non-invasive post mortem tests. The doctor seemed confused in terms of what tests were performed."

Although a question had not been included in the survey on parents' experience of the retention of the baby's organs at the time of post mortem it was raised in the free text as a concern for many.

"We thought baby's heart and brain were both going to be kept. The brain only was kept. It would have been nice to know that we buried our baby boy with his heart inside him, but it is nice to know now that it was"

3.5. *Support and care post discharge*

Twenty-two percent ($n = 8$) of parents did not have any contact with the bereavement team or did not receive contact information and 25% ($n = 9$) were not aware that ongoing support was available. Over half of parents (55%; $n = 20$) felt that the follow up with their consultant obstetrician was timely and 86% ($n = 31$) were aware of receiving literature on patient advocacy and support groups.

The results on this area suggest that post discharge contact is vital to parents and improvements to timing, support and information should be made as seen in the following comments.

"It was very difficult to take in the information regarding support services/counselling. I feel that contact a few weeks after discharge would be beneficial."

"Being in contact with the bereavement midwife is great. Just to know, if I want, she is at the other end of the phone, is worth a lot".

3.6. *Use of an alert sticker for stillbirth records*

The hospital uses a green teardrop alert sticker on the front of patients' hand held records of the index pregnancy and in subsequent pregnancies. 72% ($n = 26$) agreed that this helped to improve communication, 8% ($n = 3$) said it was ignored and insensitive questions were asked by staff and 20% ($n = 7$) were unsure of its impact.

"Some staff including those at check in didn't know the meaning of the teardrop sticker. They asked awkward questions and were insensitive. This was very distressing"

"It was important to me to have the teardrop sticker on my records. It meant that staff knew I had lost my baby when they met me"

3.7. *Which specific aspects of care were most important to parents?*

In this category we asked parents to rate the importance of being kept informed, having control and choice, medical management, investigation of stillbirth, time with baby, creation of mementoes, support with funeral and burial, and the kindness and sensitivity of staff. Of the 36 replies, 89% ($n = 32$) rated time with baby, mementoes, investigation into cause of stillbirth and support with funeral arrangements as important. The medical management of the stillbirth was considered important by 83% ($n = 30$) of parents while having control and choice over their care and being kept informed were both rated as important by 75% ($n = 27$). The only field in the survey to rate a strong agreement from 100% of parents was the importance of the kindness and sensitivity of staff.

These comments show how parents valued these aspects of their care and the way in which the care was delivered.

“I will never forget the personal warmth and kindness that we received from all the staff we dealt with, right down from our wonderful obstetrician, through all the nurses, counsellors and even the lady bringing our meals”

“The sensitivity of the staff was absolutely fantastic and helping me to wash, dress and hold my baby girl meant an awful lot.”

4. Discussion

Midwives are in the unique position of having seen and/or known the dead baby¹⁷ and so intricately involved in the parents' story of their time with their child. Caelli et al.'s study of midwife managed care in Canada, identified the value of individualised compassionate midwifery care in perinatal bereavement.¹⁸ In our study we noted that the highest satisfaction was reported on the dedicated postnatal bereavement ward, where midwives are trained and experienced in perinatal bereavement. These findings identify the training and support needs in other areas of the hospital including the antenatal clinic or delivery suite where professionals may care for a mix of patients often moving from a healthy birth or an emergency situation to the delivery of a stillborn baby frequently within a short space of time.

It is telling that the only field in the survey to rate a strong agreement from 100% of participants was the importance of the kindness and sensitivity of staff, in keeping with Downe et al.'s study on bereaved parents' experience of stillbirth in UK hospitals.¹⁹ Our study also indicated that this applies to all staff including clerical, security, catering, medical, chaplaincy, midwifery and social work. Half of parents made it clear that not being visited by their consultant obstetrician at birth or afterwards and taking an interest in the baby was disappointing and hurtful, again indicating the need for training in this group. A hospital-wide culture of consideration and sensitivity must be established and midwives are particularly positioned to model and monitor this approach.

The experience of receiving bad news about their baby will stay with parents forever.²⁰ We noted that one quarter of parents in our study did not experience sensitivity, clarity, privacy or enough time to ask questions, and 20% did not know who the professional was who gave them the news. Only 38% of respondents agreed that they received written information. The diagnosis of intrauterine death or stillbirth is generally related by medical staff but as reported in Saflund et al.'s study²¹ “*caregivers should support parents in moments of chaos and at other difficult times*”. Midwife support and involvement at this time has the potential to make a difference in parent experience.

The level at which parents experienced being facilitated in their grief varied. The labour and delivery experience is central to all birth stories and we consider that it is perhaps more so when a baby is stillborn as it is one of the few aspects of parenting that remains to the parents. Over one quarter of parents did not experience very sensitive care in labour. This may be a reflection of the diverse patient presentations in a busy unit so that sensitivity to the needs of stillbirth patients is not always prioritised. This is in contrast to the greater number of parents who felt facilitated to spend time with and parent their baby, on the postnatal ward. Education and organisational planning are needed on the labour ward in establishing continuity of midwife which is identified by Fenwick et al.²² as making a difference to bereaved parents from midwives' perspectives, limiting numbers of staff and providing privacy so that care is sensitive and attuned to individual needs.

The majority of parents felt that their other children and extended family were facilitated in meeting the baby. Cacciatore et al.²³ identified lower maternal levels of anxiety and depression

post stillbirth when support was received by health professionals but even more particularly when supported by family. The children and other adult members of the family will be better placed to support the parents if they can share their memories of their time with the baby. Crawley et al.²⁴ report that the opportunity to share these memories is associated with improved mental health outcomes in mothers post stillbirth. Radestad recommended that midwives should create an atmosphere that is as natural and normal as possible for mothers to meet their stillborn baby.²⁵ McKenna and Rolls' study²⁶ describes undergraduate midwives' challenging experiences with stillbirth and neonatal death. Perhaps providing a supportive educational and clinical experience in bereavement for student midwives from the beginning of their training would help instil their intrinsic role at the time of stillbirth and better equip them as graduate practitioners.

Autopsy is the gold standard in the investigation of stillbirth but it is often difficult to broach with parents because of the popular media association with harsh clinical treatment of the body, parental inclination to protect their baby or because of prior attribution of cause.²⁷ While the experience of sensitivity was relatively high regarding receiving post-mortem information, satisfaction with other aspects was low. Parents reported that they did not experience unambiguous explanation, did not feel that the professionals were knowledgeable on the subject, were not given enough time to decide or opportunities to ask questions and many were approached at what they felt was an inappropriate time. Although the retention of organs at autopsy for further examination was not addressed in the questionnaire, parents highlighted concerns regarding this practice. They wished to know which organs were retained prior to burial and to have advance warning that they would be contacted subsequently when the organs were released. Flenady²⁸ suggests that maternity staff need to calmly and supportively “provide objective information while balancing guidance with parental autonomy in decision making” including decisions on autopsy and that education is needed to ensure competency for the provision of accurate and sensitive counselling.”

Parents felt strongly about the importance of contact and support following discharge and almost half felt they had to wait too long for a follow up visit to be informed of the investigation results. They talked about “*having their lives on hold*”. This can be understood in terms of Neimeyer's theory of the need of the bereaved to make meaning from their loss to enable them to integrate it into their life story.⁴ Parents will have differing degrees of social and family support, including newly immigrant families and so the provision of contact names and numbers may be all the more important. Both written and verbal communication needs to be addressed in this regard so that ongoing psychosocial support is available.

The majority of parents agreed with the seven specific aspects of bereavement care that we considered most important. Not all maternity units facilitate the creation of mementoes particularly those of a religious or spiritual nature²⁹ but our parents highly valued photos, videos, locks of hair, hand and foot prints and certificates of blessing from whichever faith they practised. Help with funeral arrangements also rated very highly. For parents practicalities such as organising the funeral can provide a practical distraction from the deep pain of the loss. Having control and choice and being kept informed though still high at 75–83% were rated relatively lower. Perhaps this is explained by parents' sense of vulnerability and shock and their need to rely on the professionals for guidance. The findings from our study suggest that the care being provided at CUMH was relevant in terms of content and to a degree, in the way it is delivered. A clear advantage in this hospital is the average length of stay in hospital of 2.5 days versus the shorter inpatient stay as in reported in a

recent UK report of 1.1 days.³⁰ This time allows for greater opportunity to provide psychosocial supports to the family, time to begin to accept the reality of the death, and time to build a store of memories. It also allows time for sensitive and empathic encounters with staff, which clearly leave a deeply felt, lasting impact.

The single highest rated finding throughout the survey was the importance of kindness and sensitivity from staff. Empathic care and sensitive communication from the bereavement team is not sufficient. The entire hospital must adopt a considerate and supportive approach towards the patients they encounter in the course of their work. The use of an identifier alert bereavement sticker on the cover of the hand held patient file has the potential to remind staff to be sensitive. Ideally the need for such an identifier would decrease as a culture of greater awareness of the critical importance of sensitivity develops throughout our healthcare systems.

The midwifery profession has a central role in advocating for the improved care and status of stillborn babies and their parents. We need to invest in the profession however in terms of education, training and support in this rewarding but demanding aspect of the work.

5. Limitations and strengths

5.1. Limitations

This study was based in a single site catering for a particular geographical demographic with a small homogenous sample. It lacks comparison with other units with differing practices and diverse populations.

The use of a postal questionnaire is a limitation in itself and because the fathers' copies were sent together with the mother and returned together, it is possible that the mothers acted as gatekeepers and affected the fathers' responses. This could possibly be a reason that the fathers responses concurred with their partners to a large extent and themes specific to individual experiences of fathers and mothers were not identified.

5.2. Strengths

There was a high response rate and the inclusion and use of open-ended questions elicited additional individual data. We suggest that research on a larger sample would be beneficial and conducting a qualitative study would elicit a deeper understanding of individual parent experience.

6. Conclusion

This survey has identified our bereavement practice as relevant and helpful to parents, including facilitating time and experiences with their baby, creating mementoes, instigating investigations including autopsy, support with siblings and with funeral arrangements. Parents also highlighted omissions including inadequate information regarding autopsy, untimely follow up consultation for results and a lack of written information when they first received bad news. The most significant finding however involves the critical importance of the quality of parents' interactions with staff. Caring for families with genuine kindness and sensitivity can instil loving and comforting memories, thereby helping to establish the baby's place in the family, assist with the grieving process and impact on wellbeing far into the future.

Conflict of interest

The authors have no conflict of interest to declare.

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