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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.


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 bonds[3] and making meaning[4] 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 death[6] 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 difficulties[11] are well documented. Additionally, attachment difficulties[12] in the next pregnancy and attachment disorders[13] 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 sonographers13% ($n = 4$). 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"