Concerns with the NICE guideline on seeing and holding a dead baby

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Prior to the 1970s it was likely that following a miscarriage, stillbirth or neonatal death, parents would not be allowed to see or hold their baby and would be told to forget about the baby and get on with their lives. From the 1970s onward, arising out of the anguish of those who had not been allowed to do so and reflecting wider societal change, with feeling being expressed rather than repressed, the practice of offering bereaved parents the opportunity to see and hold their dead baby was introduced.

As a chaplain, I am frequently involved in naming and/or blessing ceremonies for babies where parents both see and will often hold their deceased baby. I was, therefore, somewhat surprised to discover that the NICE clinical guideline, Antenatal and Postnatal Mental Health[1], contains the recommendation that women should not be encouraged to hold stillborn infants. The guideline consists of four documents that contain a number of different, but related, statements and recommendations varying in detail. The most comprehensive comment comes in the full guideline on clinical management and service guidance[1] which states that:

> 'A matched case-control study found that women who had been encouraged to have continued contact with their dead baby, for example, holding the baby, had increased rates of depression, anxiety and post-traumatic stress disorder symptoms than women who had either not seen the baby at all or who had not held the baby. This study also found that having a funeral or keeping mementoes was not associated with increased rates in morbidity, although since many of these women also held their baby, this is not straightforward to interpret. However, the findings of this suggest that women should not be encouraged to hold their dead baby if they do not wish to[1].'

This leads to the recommendation, repeated in the service guidance, that:

> 'Mothers whose infants are stillborn or die soon after birth should not be routinely encouraged to see and hold the dead infant[1].'

Rather more bluntly, the quick reference guide starkly informs staff:

> 'Do not routinely encourage mothers of infants who are stillborn or die soon after birth to see and hold the dead infant[2].'

While not included in any of the documents downloadable from the NICE website, the website itself, following campaigning led by Sands, the stillbirth and neonatal death charity, contains the following clarification statement:

> 'This recommendation is not intended to suggest that women should not be given the choice of seeing and holding their baby but rather that they should not be routinely encouraged to take up this choice if they do not wish to.
>
> 'In line with patient-centred care it is expected that treatment and care should take into account the woman's individual needs and preferences. Sensitive support will be required in offering this choice or other choices such as seeing or holding the baby with other family members present. Current evidence suggests that seeing and holding the baby is not beneficial for everyone and if women do not wish to see or hold their baby they should not be encouraged to do so[3].'

Sands was particularly concerned, quite rightly, about the removal of choice from parents. However, I would also wish to raise a number of further issues with the recommendation and the research that lies behind it. Please note that, although the numbers are relatively small, I am not questioning the statistical validity of the research or the methodological approach. Instead I want to highlight the possibility of the research being interpreted from a different perspective.

The research quoted by the guideline states that, among other things, the level of contact a parent had with a stillborn infant correlated with increased adverse outcomes. From this, Hughes et al speculate that:

> 'Seeing and holding the dead infant further traumatises a woman who is already intensely distressed and physically exhausted[4].'

In speculating in such a way, Hughes et al make a logical fallacy by inferring causation from correlation. Today, some pregnancy tests can tell within 14 days of conception that a woman is pregnant. From an early gestation, through discussion of names and making physical preparations such as decorating rooms, many parents will have invested emotionally, spiritually and materially in their baby, forming strong bonds of attachment. Consequently loss, at any gestation, can be experienced as a devastating shock. Given this, is it not entirely possible that parents who wish to see and hold their baby choose to do so because they have already

formed a stronger bond with their baby than those who decide not to see their baby? From this perspective, seeing and holding a baby is a sign of greater trauma rather than a cause. In support of this, it is worth noting anthropological evidence that, in places with high infant mortality, children may not be given names or recognised as a 'person' until it is more certain they will survive[5].

Alongside that, it is important to point out that the research compares outcomes between those who did see their baby and those who chose not to see their baby, rather than comparing outcome between those who wished to, but were not allowed to see and hold their baby. If the bluntness of the quick reference guideline is followed, it is likely that parents would be discouraged from seeing their baby. Based on qualitative evidence, Kohner and Henley describe how parents who did not mark their baby's life and death in some way:

> 'Find they can neither grieve as they want to grieve, nor allow their grief to rest[6].'

Hughes et al state that there is limited quantitative evidence as to the effect this may have. However, they do note that one limited study suggested:

> 'That there was higher anxiety three years from stillbirth when the mother reported she was not allowed as much time with the dead child as she wished[4].'

My second concern with the recommendation lies with the implicit understanding of grief that underpins the research. Most models of grief and bereavement tacitly use a medical framework. Construed in this way, grief is seen as analogous to illness. A bereaved person has been struck down with something but, given time and the appropriate care, the expectation is they will recover and return to how they were before. Such a framework can be seen behind the research of Hughes et al and the NICE guideline. The problems with this medical framework, as the anthropologist Douglas Davies describes, is that it ignores:

> 'Deep facts of existence, whether existential experiences lying at the heart of life, or religious experiences at the centre of faith. Some experiences influence human life so much that people are never the same again. They simply become different people through what has happened to them. To speak of recovery is to talk about a kind of backward change, an undoing of what has been done, an un-living of part of life[7].'

Traditional understandings of grief suggest that the longer someone lived, the greater the loss felt when they died. In contrast to this understanding, researchers working with bereaved parents have argued that, despite the shortness of life, parental grief:

> 'May be more intense and longer lasting than grief resulting from other bereavements[8].'

Those who have suffered the death of a child talk about never fully recovering but continuing to live with the hurt. As part of this they describe how painful memories and sensations continue to arise on key dates such as anniversaries of the due date or the actual delivery day – a phenomenon given the term 'shadow grief'[9]. Perhaps, more pertinently, parents also talk about not wanting to recover when that would imply that they have forgotten about their child. We see an example of this in the words of Richard Olsen, the founder of the US National Stillbirth Society, when he writes:

> 'I don't want to be well adjusted. I don't want to be accepting. I don't want to be healed. When healing is to be freed of feeling[10].'

Accordingly, it could be argued that, far from indicating anything wrong, the fact that in the immediate years following the death of her baby a mother continues to be affected, is entirely normal and indeed, should be expected.

Neither in interviews I have carried out with bereaved parents (as part of a research project investigating chaplaincy support following neonatal death), nor in other similar research, did any parent make reference to feeling traumatised by seeing or holding their baby. Instead, the comments made portray the direct opposite. For example, one parent in my study described how, when seeing their dead baby:

> 'We just had this quiet moment and the chaplain blessed him, and they gave him his name and everything...it was just really quiet and peaceful.'

Likewise, another described how:

> 'It made me cope with it better knowing that…she was settled and I knew when the chaplain blessed her…I just felt like…she's alright, she's gone now.'

In conclusion, with the proviso that clearly no parent who does not wish to see or hold their baby should be made to do so, contra to the NICE guideline, I believe that bereaved parents should routinely be offered the opportunity to see and hold their baby.

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