

Institution: University of Birmingham		
Unit of Assessment: UoA27: English Language and Literature		
Title of case study: Improving care for women and families who have experienced miscarriage, stillbirth and elective abortion following a diagnosis of foetal anomaly		
Period when the underpinning research was undertaken: September 2016–July 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Periods employed by submitting HEI:
Prof. Jeannette Littlemore	Prof. of Applied Linguistics	Apr. 1999–present
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Dr Sarah Turner	Postdoctoral Fellow	Oct. 2016–Sept. 2018
Period when the claimed impact occurred: September 2016–December 2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact		
<p>Each year in the UK, there are approximately 250,000 miscarriages, 3,000 stillbirths and 3,000 terminations following a diagnosis of foetal anomaly. However, there is significant inconsistency in the level of care offered to, and the communication with, those who experience pregnancy loss. The research has impacted on policy and practice in four ways:</p> <ol style="list-style-type: none"> 1) We have improved bereavement care by shaping the newly created National Bereavement Care Pathway (NBCP); 2) We have informed new UK healthcare guidelines such that the key choices facing bereaved parents are communicated fully and in a non-coercive way; 3) We have transformed professional training standards by developing and implementing CPD training for midwives, registrars and funeral directors; 4) We have changed professional and public understanding of the manifold impacts of pregnancy loss and validated the experiences of those who have experienced such a loss. 		
2. Underpinning research		
<p>Between 2016 and 2018, the interdisciplinary 'Death before Birth' team at the University of Birmingham conducted an ESRC-funded study combining Linguistics with Legal Studies to investigate the following:</p> <ul style="list-style-type: none"> • how parents in England who have experienced pregnancy loss describe their experiences; • the advice they were given regarding the disposal and/or memorialisation of the remains of pregnancy (e.g., sensitive incineration, cremation, burial); • the extent to which the advice they received reflected guidance from the Human Tissue Authority; • the ways in which friends, colleagues and healthcare professionals communicated with them about the loss. <p>These investigations were carried out in partnership with major national organisations such as the Stillbirth and Neonatal Death Charity (SANDS), Miscarriage Association (MA), Antenatal Results and Choices (ARC) and the Human Tissue Authority (HTA).</p> <p>We conducted a series of interviews with women who have experienced pregnancy loss and those who support them, and analysed information leaflets, consent forms, hospital protocols and other forms of documentation. Our analyses focused on <i>what</i> was said and <i>how</i> it was said, paying attention to metaphor and other forms of figurative language, as these provide valuable insights into the ways in which people conceptualise difficult experiences. We found:</p> <p>RF1. More consistency is required in the range of information and support being offered to parents who have experienced pregnancy loss. Some Hospital Trusts do not offer the full range of disposal/memorialisation options because the Guidance produced by the HTA (2015) is somewhat unclear to them. Written and verbal communication of the choices available to bereaved parents is sometimes poor in both content and delivery. Many Trusts offered fewer choices than those outlined in the</p>		

Impact case study (REF3)

HTA 2015 Guidance and importantly tended not to offer information about choices that were not provided by the hospital directly (RO1, 2).

RF2. The language used to explain the options available to parents who have experienced pregnancy loss needs to be less euphemistic, vague and prescriptive. The unclear nature of the language used at present means that parents often lack crucial information about the choices available (RO2).

RF3. More consideration needs to be given to the wide range of attitudes that parents display following pregnancy loss, with some viewing what is lost as a 'baby' and others viewing it as a 'pregnancy', for example. These different views, which reflect different kinds of figurative thinking, do not map neatly onto stages in the gestational period. This means that legal and care-based assumptions should not be made about the levels and types of grief experienced by people at these different stages. Not all of these views are recognised in legislative procedures regarding memorialisation, registration and certification. The registration itself was reported as having been a very difficult process, often because of poor or insensitive communication (RO3).

RF4. A parent's world-view, as expressed through their use of metaphor, can be radically affected by the experience of pregnancy loss. When talking about the loss, they draw on conventional metaphorical scripts but supplement them with their own metaphorical experiences when they are trying to capture the individuality of their experience and their chosen memorialisation processes. The need to engage in memorialisation activities can occur with pregnancy loss at any stage of gestation. Rituals of memorialisation are often quite metaphorical and can constitute an important part of the grieving process. For women who opt for a cremation, the retention of the ashes is a particularly important outcome as it helps them retain a physical (albeit metonymic) attachment to their baby (RO6).

RF5. Parents who have experienced pregnancy loss sometimes develop paradoxical construals of time in which it is metaphorically displaced, expanded or experienced in other non-conventional ways, and this affects their decision-making processes (RO5, 6).

RF6. Parents who have experienced pregnancy loss use metaphor to report feelings of displacement and disorientation, a sense of a 'divided self' or 'mind-body separation' and a lack of 'ownership' over their thought processes. Communication by healthcare professionals that reflects an understanding of these feelings is a determining factor in shaping whether the parents report a positive experience of healthcare (RO4, 6).

3. References to the research

RO1. McGuinness, S. and Kuberska, K. (2017). [Report to the Human Tissue Authority on disposal of pregnancy remains \(less than 24 weeks gestational stage\)](#).

RO2. Austin, L., Littlemore, J., McGuinness, S., Turner, S., Fuller, D. and Kuberska, K. (2021). 'Effective communication following pregnancy loss: A study in England', *Cambridge Quarterly of Healthcare Ethics*. (Advance copy was made available online before the end of 2020). DOI: 10.17863/CAM.58668

RO3. Fuller, D., McGuinness, S., Littlemore, J., Turner, S., Kuberska, K., Austin, L. and Dixon, A. (2018). [Understanding, informing and supporting the choices made by people who have experienced miscarriage, termination, and stillbirth](#), report prepared for the Department of Health and Social Care Pregnancy Loss Review.

RO4. Littlemore, J. and Turner, S. (2020). 'Metaphors in communication about pregnancy loss', *Metaphor and the Social World* 10 (1): 45–75. DOI: 10.1075/msw.18030.lit

RO5. Turner, S., Littlemore, J., Burgess, M., Fuller, D., Kuberska, K. and McGuinness, S. (2020). 'The production of time-related metaphors by people who have experienced pregnancy loss.' In J. Barnden and A. Gargett (Eds.) [Producing Figurative Expression Theoretical, Experimental and Practical Perspectives](#), Amsterdam: John Benjamins, pp. 389–418. ISBN 978 90 272 6040 6.

RO6. Littlemore, J. and Turner, S. (2019). [What can we learn from the ways people talk about pregnancy loss?](#), *Frontiers in Communication, Health Communication* 4 (42).

4. Details of the impact

1) We have improved bereavement care by shaping the newly created National Bereavement Care Pathway (NBCP). Our evidence-based recommendations on how to communicate in a clear, non-euphemistic, more encompassing manner (RF1, 2, 3, 4) have directly contributed to the development of a newly created NBCP. In particular, from our work comes an emphasis on using clearer and more nuanced explanations of how to communicate sensitively and effectively with the bereaved, an emphasis on the need to present the different options available in a more balanced manner and making fewer assumptions about how people feel following a diagnosis of foetal anomaly. This contribution is attested by the UK lead on the NBCP who stated: “The recommendations set out in the Report brought our attention to the importance of sensitivity, clear communication with parents, consent and parental choice, and our need to focus on the language that we use in patient information leaflets around cremation. These insights have all had a beneficial impact on the Pathway” (S1).

The NBCP, launched in October 2017, was produced by SANDS, MA, ARC and other pregnancy loss charities in collaboration with the Department of Health and Social Care (DHSC) and the All-Party Parliamentary Group (APPG) on Baby Loss. **The NBCP has led to improvements in bereavement care and communication** for families suffering the loss of a baby through miscarriage, termination for foetal anomaly, stillbirth, neonatal death or sudden and unexpected infant death up to 12 months. **The NBCP has been implemented in 51 hospitals in England, and as a result, is systematically employed by healthcare professionals** working with families that have experienced pregnancy loss. That the change is significant is evidenced by an independent evaluation of the NBCP, which showed that it has led to a 76% improvement in bereavement care. Further, qualitative evidence attests to this change; for example, one Neonatal consultant states: “It has provided a valuable tool with a national benchmark which has been helpful to precipitate and initiate change, giving evidence and standards to management in making case for change” (S2).

2) We have informed UK healthcare guidelines such that the key choices facing bereaved parents are communicated fully and in a non-coercive way. We have brought about change in the national guidance produced by (a) the Royal College of Obstetricians and Gynaecologists and (b) the Royal College of Midwifery, and the implementation of guidance by the HTA on communicating available choices when people are deciding what to do with their baby’s body.

The HTA revised the online guidance that it provides to Hospital Trusts on the disposal of foetal remains and the need for clear, sensitive and consistent communication of options, meaning that the advice provided to families on the choices available following pregnancy loss has been improved (S3; RF1, 2, 3, 4). The Head of Regulation at the HTA states that our input into the HTA’s ‘Frequently asked questions’ section of the guidance ensured ‘clarity in our guidance and communications on this subject’ (S3). The Head of Regulation adds that our work ‘inform[ed] the advice and guidance we provide to the sector through enquiries we receive and inspections of HTA-licensed establishments,’ emphasising that this ‘includes advice and guidance we provide on the clarity and language in patient information leaflets and guidance’ (S3).

Specifically, we revised misleading euphemisms in the HTA documentation and introduced more subtle nuancing of the wording, thereby reflecting a wider variety of experiences of pregnancy loss. We also provided the HTA and its Regulation Managers with examples of language used in patient information leaflets that had been found to be confusing or coercive. This enabled the HTA to offer informed advice and guidance to HTA-licensed establishments on the language that they should use in patient information leaflets and other forms of documentation. In addition, we worked with HTA regulation inspectors to improve ‘their understanding of this important and sensitive subject and increase their confidence in having these conversations’ with hospital trusts and other stakeholders (S3).

We delivered this change via a report we produced for the HTA in 2017 on the disposal of remains of pregnancy (RO1; RF1). The foreword of the report was provided by the former HTA Head of Regulation, who stated that this report provided ‘the first reliable information we have about the take up of our guidance, and, I believe, for clinicians in this area’ (RO1), and this report instigated the changes outlined above. The report also received significant

media coverage (BBC, Huffington Post, Medical Xpress, Health Business, Med Page Today, October 2017); we were then invited to present its findings to the HTA (May 2017), at its Annual Open Meeting (June 2017) and at the HTA away-day in January 2019.

We have improved the national guidance documents provided by the Royal College of Obstetricians and Gynaecologists and the Royal College of Nursing on how to communicate the choices available to those who have been affected by pregnancy loss; this guidance is followed by all NHS Trusts in England (S4, 5). Our findings (RF1, 2) were cited in a paper, 'Surgical Management of Miscarriage and Removal of Persistent Placental or Foetal Remains' (Consent Advice No. 10 – Joint with AEPU) published by the Royal College of Obstetricians and Gynaecologists (S4). This paper advises clinicians on obtaining consent of women and explicitly draws on our work, stating that "The Death before Birth project recommends a standardised approach to provision of information about options for disposal of pregnancy remains" (S4). This is the first time that the RCOG has mentioned the disposal of pregnancy remains in its consent guidance. Similarly, our recommendation that choice be communicated more clearly and in a less coercive manner helped to shape the Royal College of Nursing updated guidance for nursing and midwifery practice on 'Managing the Disposal of Pregnancy Remains' (S5).

3) We have transformed professional training standards by developing and implementing CPD training for midwives, registrars and funeral directors. In partnership with key stakeholders, we developed new training packages for (a) midwives, (b) registrars and (c) funeral directors and crematorium technicians.

(a) We co-produced **two elearning modules with the Royal College of Midwifery**. One focuses on ways of communicating choice of what to do with the baby's body (and/or the pregnancy remains), and one focuses on ways of improving communication with parents when they are registering their baby's death, helping midwives to explain and facilitate this process. To date, these Continuing Professional Development modules are available to around 4,000 users (S6). The modules draw attention to the conflicting identities that people sometimes develop following pregnancy loss, the different ways in which people who have experienced pregnancy loss construe their experience through metaphor, their changing metaphorical relationships to time and the implications that these have for the care they require. These modules were launched in January 2020, and, in the first six months of availability, 50 midwives had taken the modules who found them to be "excellent and informative" (S6; RF3, 4, 5, 6).

(b) We co-produced an **online training package with the GRO and SANDS for registrars** on how to manage stillbirth registration and certification processes and how best to communicate with parents (RF4, 5, 6) to promote best practice and equip registrars to provide support for, and to communicate more effectively with, bereaved parents (S7). We did this following the presentation of our findings to the Department and Health and Social Care Pregnancy Loss Review (August 2017), particularly around the poor communication when registering death, such that some participants were not made aware that the certificate would be a certificate of 'stillbirth' rather than 'death'. Many found this wording distressing, reporting that they had "given birth", not "stillbirth" (RF3); the training packages enable registrars to mitigate the distress caused by this legal wording.

(c) We co-produced an **online training package in collaboration with the Federation of Burial and Cremation Authorities (FBCA)** which is available to members of the FBCA based across 236 crematoria (S8). The FBCA state that the training package is 'a completely new development for the Federation', which helps funeral directors and crematorium technicians to understand the metonymic relationship that parents have with their baby through their attachment to the ashes and why it is important for parents of stillborn babies to have the ashes of their baby returned to them (S8; RF4). The Federation goes on to say how it was 'only through having access to your research, guidance and input that we became aware of the central role of the ashes to many parents and the important role they play for many in a healthy grieving process' (S8).

In addition to these bespoke training materials, we have impacted upon other healthcare professionals, carers and people working in the funeral industry through various CPD events. These include two bereavement midwives forums (May 2017, June 2019); a

workshop for healthcare and support professionals (February 2018); a panel on best practice in care for bereaved parents at the International Stillbirth Alliance annual conference in Madrid (October 2019); and a plenary at the joint national conference organised by SANDS and Bliss, 'Transforming Loss' (November 2019). The feedback from these events contains numerous references to immediate planned changes in practice. For example, a medical professional reported a new awareness of the "importance of shared decision-making" and the "implications of the language I use"; another attendee developed a "realisation of the complexity" of these situations and an understanding of the fact that "the number of decisions and variables means that every family is unique" (S9).

4) We have changed professional and public understanding of the manifold impacts of pregnancy loss, and validated the experiences of those who have experienced such a loss. In addition to bespoke training courses we have sought to change professional and public understanding more broadly. For instance, we have sought to change practitioner understanding through publications in professional journals for Midwives (*Midirs*) and Funeral Directors (*SAIF Insights* and *Resurgam*; S10). These articles help professionals to understand the metaphorical thinking that underpins the rituals employed by the bereaved (RF3). We have worked with a Birmingham-based funeral director company (A Natural Undertaking) to extend the reach of our findings to other funeral directors and related industries through its social media channels. Through a series of workshops of different formats, we have promoted dialogue between families who have experienced pregnancy loss, healthcare practitioners, people who support them in other capacities (including religious leaders and people working for support organisations) and members of the public (RF3, 4, 5, 6). Feedback from these events shows that we gave those who have experienced pregnancy loss with a strong sense of validation (e.g., "I feel empowered as an advocate and representative of women in this situation ... [because] I trust more in my own feelings as a valid way of getting through this experience"; S9).

We guest-edited a Nursing Clio blog series on pregnancy loss (5,199 followers) and delivered two Facebook Live talks about pregnancy loss, one in collaboration with a funeral director. Our article on pregnancy loss in *The Conversation* was reproduced in *The Independent* with a combined readership of 11,930; this was then picked up internationally by Channel News Asia and Medical Xpress. The article was subsequently used by the US-based educational organisation 'Actively Learn' that promotes literacy and introduces teenagers across the US to contemporary issues. The content of the article now forms the basis for their online teaching materials that have been used by 15 teachers across the US reaching 200 teenagers, who have discussed the issue of pregnancy loss at length as a result of these materials (S11).

5. Sources to corroborate the impact

- S1.** Testimonial from UK lead on the NBCP (June 2020).
- S2.** Independent evaluation of the NBCP by Fiveways (May 2019).
- S3.** Testimonial from the Head of Regulation at the HTA (February 2021).
- S4.** Paper, 'Surgical Management of Miscarriage and Removal of Persistent Placental or Foetal Remains' (Consent Advice No. 10 – Joint with AEPU) (January 2018).
- S5.** RCN guidance for nursing and midwifery practice, 'Managing the Disposal of Pregnancy Remains' (2018).
- S6.** Testimonial from the Education Adviser at the RCM (December 2020).
- S7.** Testimonial from the Training and Learning Resources Manager at SANDS (November 2020).
- S8.** Testimonial from the Executive Officer of the FCBA (December 2020).
- S9.** Feedback from participants in practitioner-focused workshops and workshops attended by members of the public, healthcare professionals and support workers (2018-2019).
- S10.** Articles published in professional journals for midwives and funeral directors (*MIDIRS*; *SAIF*; and *Resurgam*) (2019-2020).
- S11.** Actively Learn report (November 2020).