

# MAKING A DIFFERENCE; EXPERIENCES OF REPRODUCTION AND LOSS

**Report of the symposium and workshop 18<sup>th</sup> January 2007.**

The above symposium and workshop – funded by *The Foundation for the Sociology of Health & Illness* – was convened by the Birth and Death Study Group, Faculty of Health & Social Care, The Open University. The Symposium aimed to bridge the gap between the sociology of human reproduction on the one hand, and the sociology of death, dying and disposal on the other, drawing together these areas of study to explore aspects of both divergence and commonality. In doing so, the symposium also aimed to develop the sociological study of reproduction and loss. Furthermore, to create an opportunity for those involved in working and researching within this field to share their knowledge and practice with each other and with those who have themselves experienced reproductive loss, a range of groups and individuals were invited to attend. These were:

- key stakeholders in policy and practice;
- practitioners, including midwives, nurses, health visitors and counsellors;
- researchers and academics in the sociology of health and illness, in particular those with an interest in reproduction and loss and
- service users.

Two service users, **Suzanne Tibbenham and Nick Thompson, from SANDS**, began the day with extremely thought and emotion-provoking accounts of reproductive loss. They gave the audience powerful insights into the experience of losing a baby at birth. These accounts set the scene for consideration of what might be perceived as best practice as well as challenging both academics and practitioners' perceptions of care. The next presentation was delivered by **Debbie Komaromy & Jane Gick, from the Metabolic Team, Guys Hospital London**, who explored the care of families and their dying babies from a professional perspective.

There are still a number of diseases that can be diagnosed where treatment or 'cure' is not yet available. Their presentation considered the journey faced by families from diagnosis to the death of a child and beyond, and highlighted the lack of day-to-day provision of care for families in this situation. In the final presentation before lunch (entitled *A time to be born? A time to die?*) **Professor Jenny Hockey, from The University of Sheffield**, asked whether thinking about issues of time and timing during the dying trajectory might provide new insights into reproductive experiences which result in termination, miscarriage, stillbirth or infant death. She suggested that one starting point was to consider the role of medical science in shoring up the taken-for-granted status of numerical age and the quantification of bodily processes. As a result, life course events and transitions can become standardised in ways which not only give weight to the idea of medical control but also sideline the importance of other kinds of 'time'.

After lunch, symposium attendees were invited to work within interdisciplinary groups to discuss one of the following issues:

- Policy and practice on reproductive loss
- Education, training and reproductive loss
- Researching reproductive loss
- Reproductive loss; knowledge transfer and dissemination

The first workshop, led by Dr Carol Komaromy, took a professional perspective on the development of policy and practice. The group discussed their experiences of the existence of protocols about 'what to do when a baby dies'. The group noted the following concerns and issues for professional practitioners involved with the care of women at this time of loss:

- The wide variation in the range of skills and experience among midwives in managing stillbirth and neonatal loss.
- The gaps in research-based evidence on effective support and effective training.

- The reality that giving birth in a labour ward setting might not be appropriate given the sounds associated with birth from other labouring women and the bustle and different 'culture of care'.
- The amount of paperwork that the named midwife needs to complete can mean that she is not able to be with women for long enough after a stillbirth or neonatal death.
- The need for feedback (on how well she handled the situation), supervision and support for midwives at this time.

The group discussed the way that all policy changes needed resources and that sharing good practice and guidelines in this newly formed Birth and Death Study Group could be an efficient way of working. The group agreed to try to meet the challenges to better support women at this time through actions that were not heavily resource-dependent and some of which could happen through the study group meetings and web communication in the following ways:

- the quality of evidence for evidence-based practice;
- sharing experiences as part of that evidence;
- sharing good practice and
- revising policy and guidelines in the light of the above.

Participants in the second workshop considered issues around education and training and this was chaired by Dr Pam Foley. Participants discussed the extent of existing training and the importance of experiential knowledge in the field of reproductive loss. A number of delegates noted how education and training varied across the U.K. as well as within Europe. It was agreed that the Birth and Death Study Group could play an important role of bringing together these variations in experience and identifying good practice. The importance of peer support in education and training in this field was also noted. The group agreed that:

- sharing of academic, professional and experiential knowledge was vital;
- the development of cross-boundary networks to facilitate scholarship and research should be a priority and

- key stakeholders should be involved in future education and training in reproduction and loss.

The third workshop was led by Dr Cathy Lloyd and participants considered particular areas of research in the field of reproductive loss that delegates felt should be highlighted. A range of research methods was considered, with input from a range of disciplinary backgrounds. The midwives in the group stressed the importance of participatory research, whereas others present reminded the group of the usefulness of quantitative data, often as a basis or rationale for carrying out more in-depth or qualitative research. The dilemmas involved in conducting research were discussed including ethical considerations and the problems of researching the experiences of bereaved parents at such a difficult time. The participants noted the lack of resources for research in this area and the few funding bodies who would consider supporting studies of this kind. The importance of service-user involvement on both the design and conduct of research was identified as a priority. The Birth and Death Study Group was identified as an important arena within which to collaborate; to discuss research and develop study protocols.

Dr Sarah Earle chaired the fourth workshop, which focussed on knowledge transfer and dissemination. The launch of the Birth and Death Study Group was welcomed by all those present, both lay people and professionals. The participants noted the wider membership of the study group and agreed that a further conference was vital. One important way of disseminating information was through the study group's website and there was a consensus that this should continue to be developed as it could be an important resource. Given the Open University's strong links with the BBC the delegates agreed that this would represent a further means of dissemination. The BBC series *Desperate Midwives* had already been produced in conjunction with members of Birth and Death Study Group. The study group was also in the process of publishing a three-part series in the professional journal, *The Practising Midwife*, and would also be editing a special edition of the online journal *Surveillance and Society* in 2007/8.

The symposium closed with a plenary at which the ideas discussed within each workshop were presented. Delegates agreed that this symposium had been an exciting, thought-provoking one, and that a further conference should be a priority.

Cathy Lloyd

20<sup>th</sup> June, 2007