Dying at Life’s Beginning:
an invisible tragedy.

Study objectives

- Experiences and needs in perinatal-neonatal loss;
  - Affected parents,
  - Participating health and social professionals;
- Existing health- and social-care practices:
  - Pregnancy, birth and puerperium,
  - Palliative care of the child;
- Development opportunities and concepts of inter-professional collaboration
Effects on parents

• Devastating loss and bereavement:
  ➢ Facing the diagnosis (Sandelowski & Barroso, 2005),
  ➢ Limited access to health care system (Büro Bass, 2011),
  ➢ Immediate impact on parents (Kersting et al 2005, Korenromp et al. 2005);

• Chosen loss / lost choices:
  ➢ Decision whether to continue or to end the pregnancy (Wool 2011),
  ➢ Long term impact of choices (Myer-Witkoff et al 2006).

Effects on professionals

• Insufficient emotional assignment or support:
  ➢ affects psychological well-being of involved health professionals (Cignacco, 2004; Roehrs et al. 2008);

• Uncertainty in health practices and support situation (Gund & Maurer, 2010);

• Experts in the provision of care are not always expert in understanding the cultural needs of other groups (Stülb, 2010, Mertion & Gari, 2014).
Birth statistics in Switzerland 2014

- Stillbirths (368) 4.8/1000;
- Perinatal mortality: 7.6/1000;
- Abortions: total 10,249;
  - Before 12th week 9,804;
  - After 12th week 445;
  Reasons ??
- Live births 85,287


Methods

- Audio recorded qualitative interviews with affected parents and relevant health professionals;
- Verbatim transcription;
- Thematic Analysis (Braun & Clarke, 2005).
Data collection

Sample

- Inclusion criteria:
  - Health or social care professionals involved during pregnancy, childbirth, postpartum or beyond,
  - Parents experiencing a diagnosis incompatible with the life of their unborn baby during pregnancy in previous five years;

- Strategy:
  - Gatekeepers:
    - Institute for Miscarriage & Perinatal Loss (FpK Bern) and Zürich University Hospital,
  - Snowballing.
Data collection

- Initial questions:
  - Health- and social-care professionals:
    - Please tell me about your experiences in caring for parents confronted with a diagnosis incompatible with life in their unborn child;
  - Affected parents:
    - Please tell me about your experience related to your child’s loss.

Participants

32 parents
- 7 couples,
- 17 mothers,
- 1 father.

29 health/social care professionals
- 3 nurses,
- 1 social worker,
- 2 psychologists,
- 15 midwives,
- 5 doctors,
- 2 spiritual counsellors,
- 1 funeral director.
Breakdown of the parents

- 10 non-Swiss mothers and one father
  - 1 Italian
  - 1 German
  - 2 Kosovar (1 Stateless)
  - 2 Sudanese
  - 1 Indian (father)
  - 1 Cambodian
  - 2 Congolese
  - 1 Sudanese (Stateless)

Births in Switzerland 2014

<table>
<thead>
<tr>
<th>Country</th>
<th>Births</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Switzerland</td>
<td>60707</td>
<td>71.2</td>
</tr>
<tr>
<td>Other Europe</td>
<td>19569</td>
<td>22.9</td>
</tr>
<tr>
<td>Africa</td>
<td>1910</td>
<td>2.2</td>
</tr>
<tr>
<td>Americas</td>
<td>917</td>
<td>1.1</td>
</tr>
<tr>
<td>Asia</td>
<td>1681</td>
<td>2.0</td>
</tr>
<tr>
<td>Oceania</td>
<td>70</td>
<td>0.1</td>
</tr>
<tr>
<td>Stateless</td>
<td>433</td>
<td>0.5</td>
</tr>
<tr>
<td>Total</td>
<td>85287</td>
<td>100</td>
</tr>
</tbody>
</table>
Our sample compared with live births 2014

<table>
<thead>
<tr>
<th>Country</th>
<th>Live births %</th>
<th>Our sample %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Switzerland</td>
<td>71.2</td>
<td>65</td>
</tr>
<tr>
<td>Other Europe</td>
<td>22.9</td>
<td>12</td>
</tr>
<tr>
<td>Africa</td>
<td>2.2</td>
<td>15</td>
</tr>
<tr>
<td>Americas</td>
<td>1.1</td>
<td>0</td>
</tr>
<tr>
<td>Asia</td>
<td>2.0</td>
<td>3</td>
</tr>
<tr>
<td>Oceania</td>
<td>0.1</td>
<td>0</td>
</tr>
<tr>
<td>Stateless</td>
<td>0.5</td>
<td>3 (1 Somali, 1 Kosovar)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Data Analysis

- Five stages (Braun & Clarke, 2005):
  - Stage 1 through listening and reading,
  - Stages 2 & 3 with computer-assisted analysis (MAXQDA),
  - Stages 4 & 5 through discussions and refinement in team.
First period: diagnosis to decision
Shock

• Everything was going so well and I never thought there would be something wrong. It was clear: I’d become pregnant, no problems, the baby and then this (Mother 12).

Choices and dilemmas

• And because of the stage of my pregnancy everything was pressured and we had to decide right away, we’d only a couple of days and didn’t know what to do (Mother 12);

• It depends if it’s early or already too late. It becomes more and more difficult. I can’t wait until it’s 28 weeks….it’s theoretically possible but…….(HP28).
Taking responsibility

• Our midwife said that such decisions can never be right or wrong…and that took the pressure off us. And let us know we were able to make the decision. Because really you have the feeling that you’re not capable of making such decisions (Parents 15);

• It’s a bit strange for us because we are the parents and until the 12th week we could decide to have an abortion regardless of the reason…and now in this terrible situation it has to go to an ethics committee. I just don’t understand (Mother 23);

• It’s not easy to do an abortion according to Swiss law, and there comes a time where you can’t do it without a certificate (HP 15).

Taking responsibility: the difficulties

• We didn’t have any orientation any more. What did it mean now? He lets us out with such a diagnosis and we’ve no idea what we need to do now (Parents 3);

• I’d never heard of such a topic before. It’s taboo and it’s just not talked about but it affects a lot of people but we don’t really have family here to ask (Mother 24).
Second period: decision to birth/death

Terminating the pregnancy

• We had to make the decision and in our case it was very quickly clear what we had to do. Because the baby couldn’t live, I couldn’t go on any further waiting and waiting until it died. That would have been awful for me (Parents 14);

• The experience shows that people really want the birth behind them because then they can begin the process of letting go and look to the future (HP 18).
Still pregnant

- When the baby is so, so sick I believed God would take him. But I went to the hospital and my baby was still alive so I said “don’t take the baby away”. He always said the baby would come dead and he said it would be better to take it. But I said he couldn’t because of my beliefs (Mother 18);

- …to talk to someone who could tell me exactly how the birth would go. We also said we wanted it to take its own time…..and the midwife encouraged us not to be frightened (Parents 25);

- If the diagnosis is confirmed we offer them grief counselling in the hospital. And they could use this contact to work out the next steps. And that’s an offer we have for them all (HP 7).

Ante natal care

- The gynaecologist said “nature’s decided….” I found such a small sentence really important (Parents 24);

- The midwives even made listened to the heartbeat. They treated me like a normal pregnant woman. And that gave me a good feeling instead of being pushed away because the baby would die (Mother 7).
Sources of support

• They knew what was happening and I don’t think we missed out on anything. We always knew what options we had and we asked a lot too (Mother 12);

• I don’t know how we would have managed without our faith. We hope, through Jesus, that we’ll see our daughter again (Parents 25).

Forming a relationship with the baby

• We could take a family photo and now we’ve got a footprint of [the baby] beside our son’s. We’ve got memories and we can show him that he had a sister (Parents 25);

• It’s up to the individual parents. They can have the spiritual advisers or the priests if they’re religious. They can dress the baby in their own clothes or ours. We’ve also got a room for them to say goodbye… or they can also take their baby home. What we always do is to take photos of the baby in the labour ward and sometimes midwives take hand or footprints or cut a lock of hair...whatever the parents want (HP 29).
Third period: Afterwards

Immediate issues

• At first it was a bit difficult... then after about quarter of an hour my wife wanted to hold the baby and we did and we all fell asleep together (Father 21);

• After the birth the psychologist or spiritual advisers can visit and the mother or child can be blessed and the whole family strengthened (HP 21).

• They told me “your baby is too small to be cremated, it’ll fall through the grate”. That is a terrible thing to say, it is so bad (Mother 13).
Moving on: longer term (1)

- For me the exercise class was extremely important. Only that I went to something where every woman who’d given birth goes, to acknowledge that I’d given birth (Parents 15);

- I found it really good to be in a meeting with other parents who’d had more or less the same experience. I can recommend that, it really helped (Mother 26).

Moving on: longer term (2)

- We also invite them for a discussion after six weeks and they usually come…we’ve also got a book where they have a page dedicated to them and mostly they look at it. Six weeks is an important time for the parents to take some time to think where they stand, how it’s all going (HP 19);

- I wanted to get pregnant as soon a possible. However, we had time to prepare so that I could enjoy a second pregnancy and not panic before every scan. In hindsight it’s good that it took 13 months for the second pregnancy so that I had time to prepare. (Mother 23).
The first gap

- Few professionals spoke of an urgent need for decisions but suggested parents had time to decide for themselves;
- Prevailing feeling from professionals was that it needed to be put behind the parents so that they could move on;
- Confusion from the parents who didn’t always understand;
- The perceived pressure by parents to make a decision;
- Truly informed decision making lacking amongst participants.

The second gap

- This period, short but intensive for those who opted for abortion as appointments were always made quickly;
- Participants who continued their pregnancies experienced longer gap with some positive consequences:
  - This period gave the women more time to experience pregnancy and come to terms with their situations,
  - They were able to speak with family in their own countries as well as with their communities in Switzerland,
  - They had time to form relationships with their babies as they felt them grow, move and become part of the family.
Conclusions 1

• This study has highlighted an important area previously neglected in much of Europe;
• Parents and health professionals agreed that receiving a diagnosis that their unborn child is incompatible with life is a traumatic life event;
• While different areas of the country had different models of care, care provided to the parents was always as sensitive as possible, attempting to allow them to come to terms with their loss but fulfilling the legal necessities required on such occasions.

Conclusions 2

• A gap exists in care between diagnosis and decision with parents feeling pressured to make decisions regarding continuing or terminating their pregnancy although health professionals’ testimony indicated otherwise;
• The major gap for parents was to be found following the decision whether or to continue the pregnancy;
• Many parents were not fluent German speakers and failed to grasp what was happening and the choices they had to make so allowed themselves to be talked into things.
Conclusions 3

- Another gap manifested following discharge from hospital, depending on insurance cover with many parents not having follow up care other than a routine postnatal appointment with the main health care provider;
- No special palliative care packages were offered;
- During the birth/death of the baby, care was always sensitive and appropriate.

Limitations

- While the recollections of parents were specific to their own experiences, the professionals spoke more generally thus indicating more of an ideal than reality. A hermeneutic approach to this study may have elicited more in depth information in this area;
- Although this study uses a robust qualitative approach it is by nature small.
Recommendations 1

• All women on receiving a diagnosis that their unborn children are incompatible with life be given an appointment within 24-48 hours to discuss possible options;

• Ideally this should be an independent person who understands the cultural beliefs and practices of the bereaved parents;

• A multidisciplinary group, including the proposed advocate, discusses each case prior to a care package being offered.

Recommendations 2

• Guidelines are developed for professionals by a multidisciplinary group so that immigrant women can be given full information about all aspects of care leading to informed decision making;

• A culturally sensitive palliative care programme for women who choose to continue their pregnancies is implemented and evaluated;

• A longitudinal study be carried out comparing the effects of this situation on immigrant women with Swiss women.