

## Lay Summary

### Dying at life's beginning: experiences of parents and health professionals in Switzerland

#### Project team

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## Background

The disclosure of a diagnosis during pregnancy of a congenital malformation of the baby incompatible with life normally comes completely unexpectedly to the parents. Instead of looking forward to the forthcoming child they are immediately confronted with the child's mortality and their own helplessness. Often they are faced with the difficult decision of whether or not to terminate the pregnancy illustrating the inevitability of loss.

Although parents are often in shock, termination of pregnancy after a diagnosis incompatible with life is associated with the idea of reducing their suffering and distressing experiences. Conversely, decisions to continue a pregnancy can be motivated by feelings of responsibility and bonding, or guilt in actively ending the child's life, hope of a wrong diagnosis or religious convictions. Various studies suggested that parents' willingness to undergo an abortion increases according to the severity of the diagnosis. Others show that well informed parents chose to continue the pregnancy following diagnosis.

Studies on the psychosocial consequences of late abortions compared with continuation generally have questionable value due either to the small number of participants, large numbers of confounders or potential influence of the political and social environment on results. Overall, studies indicate that a late abortion on the grounds of foetal abnormality is a major life-event and a source of psychological problems. Longitudinal studies carried out after abortions for foetal malformations show that psychological effects last for many years. Examination of perinatal palliative care programmes showed no notable maternal morbidity and families expressing positive feedback. However, it remains largely unknown if women who choose to continue their pregnancies to their natural conclusion exhibited negative psychological outcomes at different rates from those who choose medical termination. Some studies show an influence of loss upon succeeding pregnancies.

The few studies reported on parents' views showed that full information, empathy and understanding were essential for good care. The challenge for health professionals is simultaneously to be empathetic towards individual needs and coping strategies of the parents, communicate appropriate choices at this difficult time, involve the parents in decision making and provide ethical care. Feldhaus-Plumin's research concluded that the interface between medical care and psycho-social counselling for prenatal diagnosis in Germany is not well developed in contrast to the United States where some programmes allow children to be cared for by their families from the time of diagnosis until their death. These targeted access needs of affected families during pregnancy, birth and immediate newborn period.

While expert practice is supported by the international literature, there is little direct evidence generated in Switzerland. Guidelines have been published for antenatal diagnosis, for midwives working in situations dealing with loss, the inclusion of siblings in early death of a baby or the palliative care of neonates. Cignacco also reports the confusion experienced by midwives when caring for women experiencing termination of pregnancy. A recent publication reports from mothers who experienced perinatal loss of their children that less than 50% were satisfied with the care they received.

## Goals

This study aimed to illuminate contemporary treatment associated with a diagnosis in the antenatal period indicating an incompatibility with life for the unborn child and the subsequent death of the child regardless of whether parents make the decision to terminate or continue the pregnancy. Specific objectives were to explore the experiences of affected parents in terms of their response to the diagnosis and the remaining time they have with the child; capture the experiences of participating health and social care and other professionals in relation to their perceived impact; identify professional development opportunities which participating professionals could use to help affected families to come to terms with their loss.

## Methods

A qualitative design was selected. Participants were drawn from the German speaking part of Switzerland with command of the German language. Recruitment took place through a telephone counselling service and a major hospital. The main ethical issues were informed consent, autonomy, confidentiality and anonymity. As the interviews potentially could revive difficult memories and cause distress, contact details of a counsellor were given to participants for their use if required. Permission to undertake to study was given by the Ethics Commission for Zürich.

Data were collected by semi-structured interviews at a place of the participants' choice.

## Results

### *Sample*

Sixty one interviews were undertaken in 2013 and 2014 with 17 mothers, one father and seven couples who had experienced a lethal foetal diagnosis in the previous five years.

Twelve terminated their pregnancies, ten continued with the remaining three being unreported. Twenty nine health professionals; three nurses, one social worker, two psychologists, 15 midwives, five gynaecologists, two spiritual advisers and one funeral director were interviewed. Data were analysed by the entire team using thematic analysis.

The overarching theme of "temporality" dominated the results with four main time points: diagnosis, decision, birth/death and afterwards identified by the professionals.

Underpinning this were six major themes generated from parents which extended across the span from receiving the diagnosis until the interview: shock, choices and dilemmas, taking responsibility, still being pregnant, forming a relationship with the baby, moving on.

The themes identified arose both from parents and health professionals participating in the study. The time points identified from the professionals were given different emphases with obstetricians mainly being involved at the time of diagnosis while midwives' practice embraced the birth/death. However, data from parents showed gaps between these periods which were not articulated by the professionals. The periods between the diagnosis and the decision, from the decision until the birth/death and beyond the

birth, reflect critical points for the care of the participants. Such gaps between professionals' and patients' views of situations are not uncommon.

### *The first gap*

Diagnoses reflecting situations incompatible with life are often not made until approximately the 20th week of pregnancy. While the law in Switzerland allows abortion to be carried out at any time, it becomes more difficult after 22 completed weeks. The perceived pressure reported by the parents to make a decision were based on discussions they had with their doctors around the time of diagnosis. Similar findings were reported in other studies. It is noteworthy that none of the professionals spoke of an urgent need for decisions but suggested parents had time to decide for themselves.

Also relevant is that it was seldom mentioned what would happen if nature were to take its course where it is documented that babies with severe abnormalities will normally trigger premature labour. Rather, the prevailing feeling was that it needed to be put behind the parents so that they could move on. The decisions tended therefore to be made speedily, with some participants presenting themselves for their first dose of abortifacients within 24 hours of receiving a diagnosis. In contrast to the findings of Rapp and although all participants accepted the need to take responsibility for the decision, informed decision making was lacking amongst participants in this study.

In this first gap it appeared that little thought was given to the baby but rather that there was a severe problem in the women's bodies that, like a cancerous tumour, had to be removed or allowed to grow. This unresolved issue is in contrast to decisions concerning assisted suicide for which Switzerland is well known, and has a clear counselling process in place. Families of the affected person are also involved although ultimately the decision has to come from the person themselves. In the present situation only one area from which data were collected had a clear policy in place providing women with relevant information and in advocating for the baby.

### *The second gap*

This period, while experienced by all participants regardless of their decisions, was short but intensive for those who opted for abortion as appointments were always made quickly. This contrasts with other findings reporting lengthy waiting times. Unlike the cancer scenario mentioned above, for those participants who continued their pregnancies, this gap was longer and resulted in some positive consequences. This period gave the women more time to experience pregnancy. They participated in classes preparing them for birth so maintaining some degree of normality. Additionally they had time to form relationships with their babies as they felt them grow, move and become part of the family. By attending antenatal checks they were able to hear the heartbeat and sometimes see their babies and get photos of them on ultrasound scan. In all of these ways, while experiencing greatly conflicting emotions, these participants were giving themselves time to come to terms with their forthcoming loss and value the remaining time. However, what alternative resources such as counselling that they could access was very dependent on the insurance cover that they had with some packages not covering maternity leave before 22 weeks of pregnancy.

### *Birth and death*

This was a time when health professionals' and parents' views converged. Whatever option the participants had chosen was respected by hospital staff and empathetic care offered with a range of support services provided by the hospitals. Most hospitals offered a quiet room for reflection or prayer for the families' use in addition to the normal hospital room for their accommodation. Both Protestant and Catholic spiritual advisers were available 24 hours/day.

Participants welcomed this time in hospital where they were able to have their babies with them for as long as they wished. In addition to the feeling of this being a welcome child, this assisted in the grieving process. Hospital staff also offered help with many of the formalities surrounding burial or cremation and provided opportunities for return consultations with genetic counsellors or other appropriate staff.

### *Afterwards*

Following discharge from hospital, immediate postnatal care in Switzerland is usually arranged by the woman herself by contacting a midwife for which insurance would normally pay. For participants in this study this was the same situation. Several did not seek out midwives leaving them with no postnatal follow up. Likewise the possibilities for maternity leave were dependent on the insurance cover held by the participants as were opportunities for accessing counselling services. Several participants had gone on to have further pregnancies, none of which were problematic, but all had expressed great fears that the same issue would recur.

### **Significance of the results for science and practice**

Parents and health professionals agreed that receiving a diagnosis that an unborn child is incompatible with life is a traumatic life event with consequences that remain with the parents for the long term. While different areas of the country had different models of care, care provided to the parents was always as sensitive as possible, attempting to give them space to come to terms with their loss but fulfilling all the legal necessities required on such occasions.

A gap exists, however, in care between diagnosis and decision regardless of the time period involved with participants feeling pressured to make decisions regarding continuing or terminating their pregnancy although health professionals' testimony indicated otherwise. While the recollections of parents were very specific to their own experiences, it may be that the professionals tended to speak more generally thus indicating more of an ideal than reality.

The major gap, however, was to be found following the decision whether or not parents chose to continue the pregnancy. Abortions were carried out quickly while those continuing their pregnancies did so with their chosen health care provider or a tertiary hospital. No special palliative care packages were offered.

During the birth/death of the baby, care was always sensitive and appropriate but 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.

### *Recommendations*

All women on receiving a diagnosis that their unborn children are incompatible with life be given an appointment within 24-48 hours to discuss next steps and possible options. Ideally this should be with an independent person such as a health advocate. A multidisciplinary group, including the proposed advocate, discusses each case prior to a care package being offered.

Individual care packages are put in place for each woman regardless of her choice.

National guidelines are developed for professionals by a multi-disciplinary group so that women can be given full information about further care, maternity leave provisions, laws and options for burial of the baby and follow up care to include planning for the future.

A palliative care programme for women who choose to continue their pregnancies is implemented and evaluated in one centre.

A longitudinal study be carried out comparing the effects of this situation on women who had abortions with those who continued their pregnancies.

References are available on request

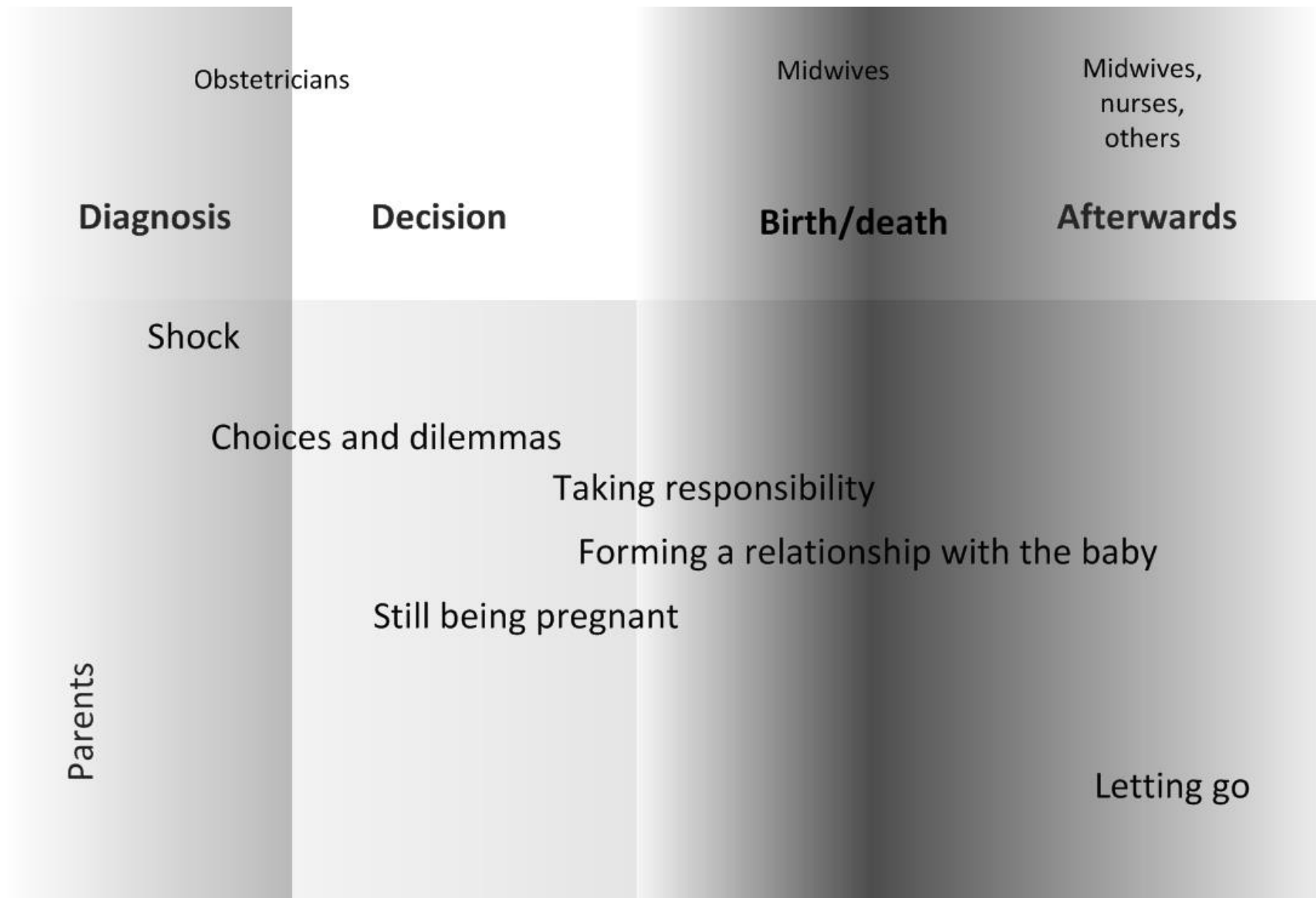


Figure 1: major themes