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Dying at life's beginning: Experiences of parents and health professionals in Switzerland when an 'in utero' diagnosis incompatible with life is made



Valerie Fleming, RM, B Div, PhD (Professor)*, Irina Iljuschin, MA (Research Assistant),
 Jessica Pehlke-Milde, RM, Dr Rer Cur (Professor),
 Franziska Maurer, RM (Midwifery and Perinatal Loss Consultant),
 Franziska Parpan, lic. Phil. (Research Fellow)

Zurich University of Applied Sciences, Switzerland

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ABSTRACT

Objective: The disclosure of a diagnosis during pregnancy of a fetal malformation, which is incompatible with life, normally comes completely unexpectedly to the parents. Although a body of international literature has considered the topic, most of it comes from the United States and little has been generated from Europe. This study aims to illuminate the contemporary treatment associated with such diagnoses, regardless of whether parents decide to terminate or continue the pregnancy.

Design: a qualitative design was used with data collected by semi-structured interviews and subjected to a thematic analysis.

Setting: the research was conducted in the German speaking areas of Switzerland with data collected from participants in places of their choice.

Participants: 61 interviews were conducted with 32 parents and 29 health professionals.

Findings: the theme of 'temporality' identified four main time points from the professionals: diagnosis, decision, birth/death, and afterwards. However, in contrast to these, six major themes in this study, primarily generated from parents and extended from receiving the diagnosis until the interview, were identified: shock, choices and dilemmas, taking responsibility, still being pregnant, forming a relationship with the baby, letting go. Although there was concurrence on many aspects of care at the point of contact, parents expressed major issues as gaps between the points of contact.

Conclusions: care varied regionally but was as sensitive as possible, attempting to give parents the space to accept their loss but fulfil legal requirements. A gap exists between diagnosis and decision with parents feeling pressured to make decisions regarding continuing or terminating their pregnancies although health professionals' testimonies indicated otherwise. A major gap manifested following the decision with no palliative care packages offered. During the birth/death of the baby, care was sensitive but another gap manifested following discharge from hospital.

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Introduction

The disclosure of a diagnosis during pregnancy of a fetal congenital malformation, incompatible with life, normally comes completely unexpectedly to the expectant parents. Instead of

looking forward to the forthcoming baby they are immediately confronted with the child's mortality and their own helplessness; while the loss is inevitable, they are faced with the difficult decision of whether to terminate the pregnancy or allow it to reach its natural conclusion (Sandelowski and Barroso, 2005; Wool, 2011).

Although parents are often in shock, abortion after a diagnosis, incompatible with life, is sometimes considered to be aimed at reducing their suffering and distressing experiences (Marteau et al., 1994). Conversely, the decision to continue pregnancy can be motivated by feelings of responsibility and bonding, guilt in actively ending the child's life, hope of a wrong diagnosis, or religious convictions (Sandelowski and Barroso, 2005). Various

* Correspondence to: Institut für Hebammen, Departement Gesundheit, ZHAW Zürcher Hochschule für Angewandte Wissenschaften, Technikumstrasse 71, CH – 8401 Winterthur, Switzerland.

E-mail addresses: flem@zhaw.ch (V. Fleming), ilju@zhaw.ch (I. Iljuschin), pehl@zhaw.ch (J. Pehlke-Milde), Franziska.maurer@bluewin.ch (F. Maurer), parp@zhaw.ch (F. Parpan).

studies suggest that parents' willingness to undergo an abortion increases according to the severity of the diagnosis (Schechtman et al., 2002; Feldhaus-Plumin, 2005; Meyer-Wittkopf et al., 2006; Gottmann, 2007). Others show that parents who have sought more information chose to continue the pregnancy following diagnosis than those who made the decision quickly (Calhoun et al., 2003; D'Almeida et al., 2006).

Studies on the psychosocial consequences of late abortions compared with continuation generally have questionable value due to several factors: the small number of participants, large numbers of confounders, or potential influences of the political and social environment on the results. Overall, studies indicate that a late abortion on the grounds of fetal abnormality is a major life-event and a source of psychological problems such as post-traumatic stress syndrome and grief (Kersting et al., 2004; Feldhaus-Plumin, 2005; Kersting et al., 2007, 2009; Korenromp et al., 2009; Kersting et al., 2010; Wool, 2011). Longitudinal studies carried out after abortions for fetal malformations show that some psychological effects last for many years (Kersting et al., 2005; Korenromp et al., 2007). Examination of perinatal palliative care programmes showed no notable maternal morbidity and families expressed positive feedback. However, according to Sandelowski and Barroso's (2005) review it remains largely unknown if women who choose to continue their pregnancies to their natural conclusion exhibit negative psychological outcomes at different rates from those who choose medical termination. Some studies show an influence of loss upon women who become nervous, not only during the first half of succeeding pregnancies but even following a detailed scan revealing no life limiting abnormalities (Cote-Arsenault and Mahlangu, 1999; Hughes et al., 2001; Bergner et al., 2008).

The few studies reporting parents' views showed that full information, empathy and understanding were essential for good care (Lalor et al., 2007; Henley and Schott, 2008; Einlaudi et al., 2010). 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 (2005) research concluded that the interface between medical care and psycho-social counselling for antenatal diagnosis in Germany is not well developed. In contrast, the United States offers some programmes which allow children to be cared for by their families from the time of diagnosis until their death. These programmes targeted access needs of affected families during pregnancy, birth and the immediate period after birth (Calhoun et al., 2003; D'Almeida et al., 2006; Munsen and Leuther, 2007; Kobler and Limbo, 2011).

Although expert practice is supported by the international literature, there is little direct evidence available in Switzerland, where this study was carried out. Here, pregnancies can be terminated at any gestation for major abnormalities though different cantons (administrative areas of Switzerland) have different guidelines regarding the decision making. In one canton a committee comprising obstetricians, midwives, neonatologists and spiritual directors makes all decisions concerning abortion after the 12th week of pregnancy whereas in others it is less formal. Midwives are generally involved only after the decision has been made, and their role is to accompany women through labour. There is no 'conscience clause' in Swiss legislation enabling professionals to opt out of provision of abortion care. Guidelines have been published for antenatal diagnosis, (Hürliman et al., 2008; Dialogue Ethik and PLANes, 2010) for midwives working in situations dealing with loss (Maurer and Gassmann, 2006), the inclusion of siblings in early death of a baby or the palliative care of neonates (Gund and Maurer, 2010). Cignacco et al.'s (2004) qualitative study reports the confusion experienced by midwives

when caring for women experiencing termination of pregnancy. A recent publication (Meier-Magistretti et al., 2014) reports from 22 mothers who experienced perinatal loss of their children that less than 50% were satisfied with the care they received.

This study aimed to add to the research evidence generated in Switzerland by illuminating contemporary treatment associated with receiving a diagnosis in the antenatal period that indicates 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:

1. Explore the experiences of affected parents in terms of their response to the diagnosis and the remaining time they have with the child.
2. Capture the experiences of participating health and social care and other professionals in relation to their perceived impact.
3. 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 and were expected to have command of the German language. Recruitment took place through a telephone counselling service available to anyone with interest or experience in the area of perinatal loss and a major hospital. The main ethical issues were informed consent, autonomy, confidentiality and anonymity. As the research 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 (KEK-ZH-2010-0141).

Data were collected by semi-structured interviews at a place of the participants' choice. Interviewers were experienced, female researchers and prior to commencing this project participated in refresher courses on conducting semi-structured interviews. Both were native Swiss-German speakers. The project leader, fluent in German, though not in the local dialect, also carried out some interviews, but only with the professionals, as to ask a potentially distressed participant to speak in High German would have been unethical.

Interviews were transcribed verbatim using the programme F4 and analysis was carried out in accordance with the method of Braun and Clarke (2005). Transcripts were entered into the MaxQDA software package from which codes were initially generated from each interview. These were grouped firstly within each interview and then between interviews but within the interviews of parents or professionals. Next these were combined, seeking common themes and differences. Finally manual analysis by the team was carried out discussing both the similarities and differences to generate the final themes. Translation of the quotes used in this article was undertaken by the first author.

Findings

Sample

Sixty one interviews were undertaken in 2013 and 2014 with 17 mothers, one father and seven couples who had experienced a lethal fetal diagnosis in the previous five years. Twelve terminated their pregnancies and 13 continued them until their natural conclusion. Twenty nine health professionals: three nurses, one social

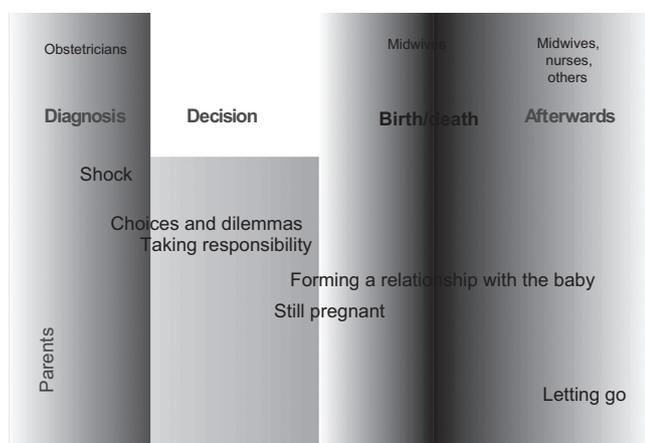


Fig. 1. Main themes.

worker, two psychologists, 15 midwives, five doctors, two spiritual advisers and one funeral director were interviewed. Interviews lasted from 40 minutes to 1.5 hours.

The overarching theme of ‘temporality’ dominated the results. Four main time points were clear in the interviews of the professionals: diagnosis, decision, birth/death and afterwards. However, underpinning this were six major themes generated from parents: shock, choices and dilemmas, taking responsibility, still being pregnant, forming a relationship with the baby, letting go. Not only did these extend across the span from receiving the diagnosis until the interview but they also highlighted gaps between the definitive time points presented by the professionals. The results are therefore presented as a continuum rather than focusing on each time point but embracing the gaps as illustrated in Fig. 1.

Diagnosis to decision

Shock

Whether or not the pregnancy was planned, the sense of shock was described vividly by all parents.

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

We had an appointment at 11 and afterwards we came out of the surgery. We stood on the street, walked to the car. We had no idea. **What does it mean? They let us out with this diagnosis and we had no idea where to go** (Parents 3).

For the health professionals it was important during this time to speak directly with the parents as this doctor explained.

But I always say to them **right at the beginning**. Listen, this isn't a routine scan, it's not baby watching. But we've got to make a diagnosis or, if there's already a provisional one, confirm or reject it. And for me it's really important that we say this clearly (HP13).

Choices and dilemmas

Following the diagnosis, participants were confronted with the issue of whether or not to continue with their pregnancies. Often they saw themselves as being pushed into making decisions as soon as possible. One reported:

Und we only had that chance to decide **before the end of the week** because I was in the 24th week. After that you're not allowed to have an abortion in Switzerland. So we had to

decide whether to induce labour or wait until it happened itself (Mother 13).

Another reported:

And because of the stage of my pregnancy everything was pressured and we couldn't take several weeks to decide, we'd only a couple of days. Because medically induced abortions were only allowed until the end of the 24th week (Parents 15).

During the diagnosis the main professionals involved were obstetricians who saw things from a different perspective:

It depends how late it is. It [becomes] more difficult so I can't wait until it's 28 weeks. It's technically possible and you can wait. Now the doctors are beginning to say it just depends on the case (HP 28).

We guide the parents. When something shows in the diagnosis we discuss it. Really we need to make sure they get the message so that they can find out a bit and decide.....but they need to know they can have time, they don't need to hurry (HP11).

Taking responsibility

Parents realised it was their responsibility to make decisions. In order to help them they employed a number of different strategies:

Our midwife said that such decisions can never be right or wrong...and that took the pressure off us. And [it] 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).

I only wanted someone to say you must do his. But that wasn't possible. The decision was simply shoved elsewhere....to me. They made that clear...it is **your** decision. (Mother 12).

For one family, the information they received was very different:

Finally we were told there was no chance of life, and we went home relieved that there was an answer and to know where things stood. But then they sent us from [one region] to [another] because we had to go through another ethics committee and it would decide whether we were allowed to terminate the pregnancy or not because we were past the 12th week. That was really strange for us because we're the parents and up until the 12th week, we could decide regardless of any major reasons. But now because of an accident we can't say 'I want to terminate the pregnancy'. We can't make our own decisions but have to let an ethics committee make them for us (Mother 23).

For the professionals, responsibility was also important with regard to the legal position of abortion.

According to Swiss law it's not easy to do an abortion and after a certain time you need to get a certificate from a cardiologist or psychiatrist (HP 15).

Occasionally a woman booked for an abortion comes to us and then changes her mind at the last moment. That's absolutely fine, it's her right. But by the time they get to us [labour ward] a lot has already happened (HP 21).

Despite careful planning some parents felt abandoned and helpless as in seeking support to make decisions it was often difficult to have open dialogue. Often they turned to the internet for such help, especially if they were unsure as to what professional help would be covered by their insurance policies.

There's hardly any forums where people exchange information about things like that [weeks of paid maternity leave] or dare to ask the ethical questions. How you come to a decision. You hardly find them (Mother 9).

Decision to birth/death

Having reached a decision, the pathway was more clearly defined. For parents who chose to terminate their pregnancies, health professionals felt that speed was once more vital as they sensed parents wanted the experience behind them.

The experience itself is usually easy, the parents want this birth behind them because they feel they can start again by saying farewell and then looking to the future....and a chance to have a healthy child (HP 18).

And when someone hears that it's not so bad they can have an abortion right away, they don't need to have pain or suffer any more...it makes other options impossible (HP 7).

Still pregnant

Speed was less important at this time for participants who decided to continue with the pregnancy as nature would take its course. One woman with strong religious beliefs emphasised this:

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 God had put it there and only God could take it (Mother 18).

Others looked around for birth options

[I wanted] to talk to someone who could tell me exactly how the birth would go. We also said we were not in a hurry....and the midwife encouraged us not to be frightened (Parents 25). If the diagnosis was 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).

Appropriate antenatal care was essential for both parents and health professionals

I think the regular antenatal checks ensure we continued the contact and if she said she wanted to hear the heartbeat again it was fine. And so we experienced a lot together (HP 1).

The midwives even 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).

One doctor said to us 'ok nature has decided'. And I found that so reassuring and **really** important. It also gave us a bit of peace (Parents 24)

Preparation for the birth and death was also vital.

The first questions are more focused on the labour, just like normal. Not specifically focusing on what comes after. The shock has mostly gone and it's always about the labour regardless of the outcome (HP 28).

She prepared us for the birth so well, just we two and her. So really I had a normal birth preparation, what is labour, how does it go and [we] only later [talked] about our specific situation and what we could do (Parents 3).

Support was also an issue for all parents. In many cases they got this from health professionals

I found the information and care was very, very good. 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).

Religious beliefs often provided extra support

I believe Jesus brought us through this time...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).

Support from family and friends was also vital. For some this was a positive issue whereas for others it was less so as the topic was somewhat taboo and make family and friends feel uncomfortable.

I didn't really look for outside support. We could talk about it a lot in the family. And we shared the grief and cried together (Parents 14).

We had a wide circle of friend to call on. That was really great (Father 21).

I'd never heard of such a topic before. It's taboo and it's just not talked about but it affects a lot and you don't know the legal stuff or anything (Mother 24).

Forming a relationship with the baby

Regardless of their decision, all participants formed relationships with their babies.

We mostly had him in the room. We always talked to him as if he were living. To talk to our son was the first step to the separation (Parents 15).

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 have a mourning room for newborns where they can also have remembrance services or leave mementos. 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).

Afterwards

Letting go

Having got to know the baby, parents then had to say goodbye and move on. Hospital personnel were able to help with extra support in the immediate postnatal period.

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).

However when women were discharged from hospital they did not always have follow up postnatal care and in some cases had to return to their work as their insurance companies did not provide for maternity leave before 22 weeks.

You know, it was really difficult for me. To know how someone could help me. You've been to hell and back and now after five weeks in the hospital there is no one to help (Mother 10).

It would have been good to have the whole maternity leave because you could use it. But because of the law I only was entitled to eight weeks (Mother 20).

Another complication experienced by some parents was with the burial or cremation as expressed by this mother:

They said to me 'your baby is too small to cremate as it'll fall through the grate'. They said that to me on the phone, you

wouldn't believe it, especially when you're already in a traumatic situation. That was so bad....really bad (Mother 13).

Normal postnatal courses were important

For me, the exercise course 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).

However special courses in which affected parents could mix together were also valued:

I found it really good to be in a course with other parents who'd had more or less the same experience. I can recommend that, it really helped (Parents 14).

The longer term was also important

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).

We had time to prepare so that I could enjoy a second pregnancy and not panic before every scan. ...in the first pregnancy we did our best and it didn't end well. But in the second pregnancy I accept it's not in our hands but in nature's and we have to leave it to nature (Mother 23).

Once or twice each year we have a big memorial service. All the parents who were affected are invited and also those whose babies died in the neonatal unit. They find it really helpful and one or two midwives from the labour ward go along and some of the team from the antenatal clinics as well as some of the doctors (HP 29).

Discussion

The themes identified arose both from parents and health professionals participating in the study. The time points acknowledged by the professionals were given different emphases with obstetricians mainly being involved at the time of diagnosis whereas midwives' practice embraced the birth/death. However, data from parents showed gaps between these periods which were not always visible to or acknowledged by the professionals. The periods between the diagnosis and the decision, from the decision until the birth/death and afterwards, reflect critical points for the care of the participants. Such gaps between professionals' and patients' views of situations are not uncommon (Feldhaus-Plumin, 2005; Gottmann, 2007). For midwives, and other professionals working in this area these gaps are highly relevant.

The first gap

Diagnoses reflecting situations incompatible with life are often not made until approximately the 20th week of pregnancy. Although the law in Switzerland allows abortion to be carried out at any time, permission for this becomes harder to obtain as pregnancy continues. 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 and showed a general lack of understanding of the legal position. Similar findings were reported in other studies (Sandelowski and Barosso, 2005). It is noteworthy that none of the professionals spoke of an urgent need for decisions but suggested parents had time to decide for themselves.

It is also relevant although seldom mentioned what would happen if nature were to take its course where it is documented

that babies with severe abnormalities will trigger premature labour (Feldhaus-Plumin, 2005). 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 (2000) 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. Families of the affected person are also involved although ultimately the decision has to come from the person themselves thereby supporting the findings of Sandelowski and Jones (1996) Redlinger-Gross et al (2002). In the present situation only one area from which data were collected had a clear policy in place providing women with all relevant information outlining the clinical situation that would be the likely result of terminating or continuing the pregnancy.

The second gap

This period, although 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 (Rillstone and Hutchison, 2001) 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, largely unreported in other research although touched on by Redlinger-Gross et al. (2002) 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, 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 and as outlined by Cignaaco (2002). 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 (Redlinger-Grosse et al., 2002). 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 whom 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 although some were able to access postnatal classes offered by independent health care providers. 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.

Conclusions, limitations and recommendations

This study has highlighted an important area previously neglected in much of Europe and, as shown in the introduction, in the rest of the world. It has therefore illuminated an area of care that has been little addressed in previous studies and thereby fills a gap in existing evidence. Midwives, although not the major caregivers in the antenatal period, have a strong role to play during labour and birth.

Parents and health professionals agreed that receiving a diagnosis that their unborn child is incompatible with life is a traumatic life event although it may be alleviated with good care. Although 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 and fulfil the legal necessities required on such occasions.

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

The major gap for parents was to be found following the decision whether or not parents chose to continue the pregnancy. Abortions were carried out quickly, whereas those continuing their pregnancies did so with their chosen health care provider or a tertiary hospital. The time available to undertake this study meant that this was not explored in further detail. No special palliative care packages were offered.

During the birth/death of the baby, care provided by the midwives was always empathetic 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.

Limitations and recommendations

Although this study uses a robust qualitative approach it is by nature small and cannot be generalised. Likewise it was carried out in one specific language region of Switzerland. And thus although previously unpublished results have been shown, it may be that even within the same country different regions would yield different results. The choice of a thematic analysis was made due to the time constraints. It may have been that a grounded theory or hermeneutic approach would have yielded richer data or more in depth information.

The undernoted recommendations are made

Due to the differences in care provision at the time of diagnosis, all women on receiving a diagnosis that their unborn babies are incompatible with life be given an appointment within 24–48 hours to discuss possible options. Ideally this should be with an independent person such as a health advocate who may have a midwifery background. A multidisciplinary group, including the proposed advocate, discusses each case prior to a care package being offered.

National guidelines are developed for professionals by a multidisciplinary group in which midwives participate so that women can be given full information about all aspects of care including maternity leave, laws and options for burial of the baby and planning for the future.

A palliative care programme for women who choose to continue their pregnancies is implemented and evaluated in one centre. Midwives with an interest in the area are ideally placed to provide a major part of such a programme.

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

Concluding statement

Although care for individual parents who experience a lethal fetal diagnosis is in line with legal and professional guidelines, difference between parents' and different professionals' views need to be addressed. Likewise the gap between decision and birth/death of the baby needs to be tailored to individuals' needs while maintaining safe practice. At present with the decentralised provision of health care in Switzerland, policy making remains fragmented.

Conflict of interest

None.

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References

- Bergner, A., Beyer, R., Klapp, B.F., Rauchfuss, M., 2008. Pregnancy after early pregnancy loss: a prospective study of anxiety, depressive symptomatology and coping. *Journal of Psychosomatic Obstetrics and Gynecology* 29, 105–113.
- Braun, V., Clarke, V., 2005. Using thematic analysis in psychology. *Qualitative Research in Psychology* 3, 77–101.
- Calhoun, B., Napolitano, P., Terry, M., Bussey, C., Hoeldtke, N., 2003. Perinatal hospice. Comprehensive care for the family of the fetus with a lethal condition. *Journal of Reproductive Medicine* 48, 343–348.
- Cignacco, E., 2002. Between professional duty and ethical confusion: midwives and selective termination of pregnancy. *Nursing Ethics* 9, 179–191.
- Cignacco, E., Stoffel, L., Raio, L., Schneider, H., Nelle, M., 2004. Empfehlungen zur Palliativpflege von sterbenden Neugeborenen (Recommendations for palliative care of dying neonates). *Zeitschrift für Geburtshilfe und Neonatologie* 2008, 155–160.
- Cote-Arsenault, D., Mahlangu, N., 1999. Impact of perinatal loss on the subsequent pregnancy and self: women's experiences. *JOGNN-Journal of Obstetric, Gynecologic and Neonatal Nursing* 28, 274–282.
- D'Almeida, M., Hume Jr., R.F., Lathrop, A., Njoku, A., Calhoun, B.C., 2006. Perinatal hospice: family-centered care of the fetus with a lethal condition. *Journal of American Physicians and Surgeons* 11, 52–55.

- Dialog Ethik, PLANes, 2010. Psychosoziale Beratung bei vorgeburtlichen Untersuchungen. Anleitung für die Beratungspraxis ergänzt mit interdisziplinärem Fachwissen (Psychosocial advice for ante natal examinations. Introduction for advisers and multidisciplinary teams). AZ Druck, Zürich.
- Einaudi, M.A., Le Coz, P., Malzac, P., Michel, F., D'Ercole, C., Gire, C., 2010. Parental experience following perinatal death: exploring the issues to make progress. *European Journal of Obstetrics, Gynecology, Reproductive Biology* 151, 143–148.
- Feldhaus-Plumin, E., 2005. Versorgung und Beratung zu Pränataldiagnostik. Konsequenzen für die psychosoziale und interdisziplinäre Beratungsarbeit (Care and advice in ante natal examinations. Consequences for psychosocial and interdisciplinary advice). V&R unipress GmbH mit Universitätsverlag Osnabrück, Göttingen.
- Gottmann, A., 2007. Psychosoziale Beratung bei Pränataldiagnostik in Abhängigkeit von der diagnostizierten fetalen Anomalie (Psychosocial advice for antenatal diagnosis in relation to fetal abnormalities) (Dissertation). Medizinische Fakultät der Universität Bonn, Bonn.
- Gund, K., Maurer, F., 2010. Trauernde Geschwister. Orientierung und Unterstützung zum Begleiten von Kindern beim frühen Tod eines Babys (Grieving siblings. Orientation to and support for those accompanying children during the death of a baby): Fachstelle FpK und Schweizerisches Rotes Kreuz Bern-Oberland.
- Henley, A., Schott, J., 2008. The death of a baby before, during or shortly after birth: good practice from the parents' perspective. *Seminars In Fetal and Neonatal Medicine* 13, 325–328.
- Hughes, P., Turton, P., Hopper, E., McGauley, G.A., Fonagy, P., 2001. Disorganised attachment behaviour among infants born subsequent to stillbirth. *Journal of Child Psychology Psychiatry Allied Disciplines* 42, 791–801.
- Hürlimann, D.C., Baumann-Hölzle, R., Müller, H., 2008. Der Beratungsprozess in der Pränatalen Diagnostik. Bern Peter Lang AG.
- Kersting, A., Reutemann, M., Ohrmann, P., et al., 2004. Grief after termination of pregnancy due to fetal malformation. *Journal of Psychosomatic Obstetrics and Gynecology* 25, 163–169.
- Kersting, A., Dorsch, M., Kreulich, C., et al., 2005. Trauma and grief 2–7 years after termination of pregnancy because of fetal anomalies—a pilot study. *Journal of Psychosomatic Obstetrics and Gynecology* 26, 9–14.
- Kersting, A., Kroker, K., Steinhard, J., et al., 2007. Complicated grief after traumatic loss: a 14-month follow up study. *European Archives of Psychiatry Clinical Neuroscience* 257, 437–443.
- Kersting, A., Kroker, K., Steinhard, J., et al., 2009. Psychological impact on women after second and third trimester termination of pregnancy due to fetal anomalies versus women after preterm birth – a 14-month follow up study. *Archives of Women's Mental Health* 12, 193–201.
- Kersting, A., Kroker, K., Steinhard, J., 2010. Psychiatric morbidity after termination of pregnancy for fetal anomaly. *American Journal of Obstetrics and Gynecology* 202, e6–e7.
- Kobler, K., Limbo, R., 2011. Making a case: creating a perinatal palliative care service using a perinatal bereavement program model. *Journal of Perinatal and Neonatal Nursing* 25, 32–41.
- Korenromp, M., Page-Christiaens, G., van den Bout, J., et al., 2007. A prospective study on parental coping 4 months after termination of pregnancy for fetal anomalies. *Prenatal Diagnosis* 27, 709–716.
- Korenromp, M.J., Page-Christiaens, G.C., Mulder, E.J., Visser, G.H., 2009. Adjustment to termination of pregnancy for fetal anomaly: a longitudinal study in women at 4, 8, and 16 months. *American Journal of Obstetrics and Gynecology* 201, 160, e161–167.
- Lalor, J.G., Devane, D., Begley, C.M., 2007. Unexpected diagnosis of fetal abnormality: women's encounters with caregivers. *Birth* 34, 80–88.
- Marteau, T., Drake, H., Bobrow, M., 1994. Counselling following diagnosis of a fetal abnormality: the differing approaches of obstetricians, clinical geneticists, and genetic nurses. *Journal of Medical Genetics* 31, 864–867.
- Maurer, F., Gassmann, M.-C., 2006. Der perinatale Kindstod-Hebammenarbeit in Verlustsituationen. In: Cignacco, E. (Ed.), *Hebammenarbeit: Assessment, Diagnosen und Interventionen bei (patho) physiologischen und psychosozialen Phänomenen*. Hans Huber, Bern.
- Meier Magistretti, C., Rabhi-Sidler, S., Villiger, S., Luyben, A., Auerbach, S., Varga, I., 2014. Wenn die Geburt der Tod ist (When birth is death) (Report). Hochschule Luzern, Soziale Arbeit, Lucerne.
- Meyer-Wittkopf, M., Stanimirov, O., Haupt, J., Wallwiener, D., 2006. Bedeutung des Aufklärungsgesprächs bei der Feststellung eines unerwarteten Ultraschallbefundes zur Entscheidungsfindung über den weiteren Schwangerschaftsverlauf (The meaning of the explanation of an unexpected ultrasound result and its effects on the pregnancy). *Ultraschall in der Medizin-European Journal of Ultrasound* 27, 390.
- Munson, D., Leuthner, S.R., 2007. Palliative care for the family carrying a fetus with a life-limiting diagnosis. *Pediatric Clinics of North America* 54, 787–798.
- Rapp, R., 2000. *Testing Women Testing the Fetus: The Social Impact of Amniocentesis in America*. Routledge, New York.
- Redlinger-Grosse, K., Bernhardt, B., Berg, K., Muenke, M., Biesecker, B., 2002. The decision to continue: the experiences and needs of parents who receive a prenatal diagnosis of holoprosencephaly. *American Journal of Medical Genetics* 112, 369–378.
- Rillstone, P., Hutchison, S., 2001. Managing the re-emergence of anguish: pregnancy after a loss due to anomalies. *Journal of Obstetrics, Gynecologic and Neonatal Nursing* 30, 281–298.
- Sandelowski, M., Jones, L., 1996. "Healing fictions" Stories of choosing in the aftermath of the detection of fetal anomalies. *Social Science and Medicine* 42, 353–361.
- Sandelowski, M., Barroso, J., 2005. The travesty of choosing after positive prenatal diagnosis. *JOGNN: Journal of Obstetric, Gynecologic and Neonatal Nursing* 34, 307–318.
- Schechtman, K.B., Gray, D.L., Baty, J.D., Rothman, S.M., 2002. Decision-making for termination of pregnancies with fetal anomalies: analysis of 53,000 pregnancies (Erratum appears in *Obstetrics and Gynecology* 2002 Apr;99(4):678). *Obstetrics and Gynecology* 99, 216–222.
- Wool, C., 2011. Systematic review of the literature: parental outcomes after diagnosis of fetal anomaly. *Advances in Neonatal Care* 11, 182–192.