Abstract

Pregnant women in Switzerland expect safe and healthy birth outcomes for themselves and their babies. However, in 2018 691 died in infancy with gaps identified in the provision of services to parents in such circumstances.

Our study aims to illustrate these gaps and how, from participants' perspectives, they were addressed.

A hermeneutic method was employed to analyze three cases: one from each major language region. was via primary health care providers. A thematic analysis was carried out with individual participants followed by a cross case comparison which showed a hermeneutic of rupture, the juxtaposition of time and reshaping the family.

This article shows the unique journeys experienced by parents whose baby dies before or shortly after birth in one country where neither the language nor experience is shared. The derivation of three hermeneutic themes may resonate with other parents or health professionals.

Introduction

The central European country of Switzerland is constantly ranked amongst the highest of the world's wealthiest countries with residents enjoying a high quality of life (World Bank, 2018). The country's political system consists of a national government and 26 cantons, each of which acts autonomously in matters such as schools, local taxes and some aspects of health. The country is renowned for its direct democracy where voters participate in several referenda per year on issues concerning society and which can be recommended by individual citizens. Individual cantons may also hold their own referenda as required. National as well as regional and community elections take place every four years to elect members of the national parliament (Ch.ch, 2020).

There are three major language regions in the country, German being the main language of 19 cantons, French of four, and Italian of one. Two are bilingual. A fourth official language, Romanish, is the main language of 0.5% of the population and is spoken in a small part of one canton (Federal Council, 2017).

It is the national government that determines health policy but the health system's infrastructure is decentralized with each canton determining what public hospital facilities it makes available. However, many services are operated by private companies and access is dependent on an individual's insurance cover. All women have access to gynecological services from their teenage years with some gynecologists also providing maternity care. Women who become pregnant can access services from their own gynecologist, from another, from public hospitals, from a midwife or a combination thereof. In such a context, pregnant women expect safe and healthy birth outcomes for themselves and their babies (Shaw et al, 2016). However, even in Switzerland not all pregnancies lead to the birth of a healthy child. In 2018 87,851 babies were born alive and 381 were stillborn and a further 310 infants died in the first year of life (Bundesamt für Statistik, 2019). Both the stillbirth and perinatal mortality rates have remained stable since the beginning of the century.

The loss of a baby is a traumatic event, with potentially significant and lasting emotional impact (Benute et al, 2016), making caring for such families complex (Williams et al, 2002). While the body of published literature on the subject remains small, as highlighted in a ground breaking review (Sandelowski & Barroso, 2005), this review has sparked the interest of other researchers. Previous studies in Switzerland showed a gap experienced by parents whose babies have been diagnosed as having a condition “incompatible with life” (Frank et al, 2016, Meier-Magistretti et al, 2014). Examination of perinatal palliative care programs showed no notable maternal morbidity and families expressed positive feedback. According to Lotto et al (2016) the sensitivity of the issue has potentially contributed to the small volume of literature available, with a recent review of 24 qualitative studies agreeing but failing to throw any more light on the subject (Blakey et al, 2019).

There is a larger body of literature in relation to stillbirth and early neonatal death with Seppanen et al’s (2019) study providing guidelines for specialist palliative care while several address the devastating effect on families (Martinez-Serrno et al, 2019; Watson et al, 2019) with one specifically considering the experiences of men who lose a child (Obst & Due, 2019).

Despite these studies, the evidence available generally has highlighted the lack of practical guidelines which could support affected families, as well as provide direction to clinicians (Rice et al, 2019; Lotto et al, 2017). Small-scale studies suggest that there is an opportunity to provide carefully targeted care and support for the baby and family from the time of diagnosis. However, variations in care provision in Switzerland suggest that not all families are able to access the care they require (Fleming et al, 2016). Meier-Magistretti et al (2019) in a study, which provided a thematic analysis of 20 bereaved parents' journeys, supported this and developed a complex pathway of care. However, limitations to reporting of this study meant that it was not able to present some of the contrasts experienced within the one, fairly small country. The present study thus aims, through the generation of three hermeneutic case studies, to illustrate some of the gaps in care provided to parents whose babies are given a diagnosis incompatible with life while in utero and who continue the pregnancy, who experience an intrauterine death resulting in stillbirth, or whose babies die within the first month of life. Specific objectives were to define what palliative and bereavement care was provided to parents of affected babies and to identify gaps in care provision.

Method

Gadamer's (1960/1990) hermeneutic framework, which draws on history and tradition, provides a foundation for the present research as he suggests both allow understandings or meanings to emerge accordingly. To translate Gadamer's philosophy into a research method we have utilized the framework of Fleming et al (2003). This five step approach begins with defining the research question, which has been discussed in the previous section. Stage two calls upon the researchers to identify their pre-understandings. These were initially influenced by their life experiences, which for three of the authors have taken place in clinical settings where they have provided care for parents whose babies have died. The fourth author is a psychologist. Two of the authors are parents, one of whom has experienced the loss of a baby. All are fluent in English and at least one other of the languages used in this study. Further stimuli have come from the academic literature, the most influential of which has been discussed in the previous section. Our pre-understandings have been taken with us consciously or unconsciously, into the research process. Gadamer (1060/1990) notes that it is only by consciously assimilating them that we can avoid “the tyranny of hidden prejudices that make us deaf to the language that speaks to us in tradition” (p. 239). This first stage of a reflexive process has led to continued reflexivity at all stages of the research, some of which we report in our reflexive stop offs, thereby increasing the validity of the method.

The third stage of the method involves dialogue with participants, providing an opportunity to challenge our pre-understandings to reach a new level of understanding (Malpas et al, 2002). In a phrase that draws together many lines of his thought, Gadamer warns that “understanding a text and reaching an understanding in a conversation” appear to be very different (Marshall, 2004, p.131). In conversation, knowledge is not something fixed; it is an aspect of a process arising out of interaction. Our dialogue with the participants is presented by means of a thematic analysis of each person‘s story, allowing the participants’ own words to be given voice.

A further important issue in this study is the languages used. Each participant was interviewed in their own language by a member of the research team who was fluent in that language. The transcription was also made in the original language with coding being done in English and checked independently by two members of the research team. The ultimate themes were determined in the same way with three of the authors agreeing on them.

The fourth stage invokes the researcher to engage in dialogue with the data. Here we question the text and listen to its answers so bringing them to life. At this stage our pre-understandings are subjected to dialogue with those of the participants’ accounts. As Freire and Shor (1988) note, this mediation between the text and its interpreter is an essential stage leading to the fusion of the horizons of each party and so gaining understanding. In this section the three cases were juxtaposed with each other to reach a fusion of horizons between each of their views and ours. This involved us entering the hermeneutic circle and engaging in a backwards and forwards movement between the parts and the whole texts as each part gives a sense of the whole, and to understand the significance of the parts we need to have an appreciation of the whole. Similarly, we took our understandings which changed after analyzing each interview to the next one until we reached a fusion of our horizons.

The final stage of our method is to ensure trustworthiness of the study. We have achieved this by using a case study approach where each participant's "story" is clearly spelt out, using each participant's own words whenever possible. The researchers' voices have been utilized to generate themes in a systematic manner so bringing the data to a cohesive whole. The hermeneutic grounding of these themes is explained in the appropriate section. Finally, each case has been interspersed by our own reflexive thoughts so paving the way for the in depth hermeneutic merging of the themes. We have indicated above how we dealt with the language issues so ensuring that we remained faithful to the participants' original meanings, this being paramount.

Ethical approval and access

The main ethical issues in this study were acknowledged as the right to confidentiality and anonymity and the potential distress that data collection might invoke. To alleviate the latter, all interviewers were chosen for their experience in dealing with such situations. Additionally, we advised potential participants that recording could be stopped at any time and should they require it, details of counsellors could be given. To deal with the issues of confidentiality and anonymity, we ensured that all identifying details were removed during transcription. We also changed locations and other immediately identifying detail but advised potential participants that despite such precautions there was a possibility that they may be identified. They accepted this risk, one person stating that their story was not secret and they were sharing it in other ways. We gained permission to carry out the study from the Ethics Commission of Lucerne.

Access to participants was via doctors' surgeries and midwives' clinics.

Selection of participants

We opted for a case study approach to present this study in order to articulate the unique nature of the participants' journeys as in the parent study the thematic analysis of 20 participants showed a diverse range of experiences (Yy et al, 2019). Yin, a major proponent of case study research, argues that the individuality of the case study provides an empirical inquiry about a contemporary phenomenon, especially when the boundaries between a phenomenon and its context are not clearly evident (Yin, 2009). According to Flyvberg (2006) case studies provide a means of investigating complex social units consisting of multiple variables of potential importance in understanding the phenomenon. By their grounding in real-life situations, case studies will give rise to rich data, and so offer insights that have the potential to expand the horizons of their readers thus they are totally in keeping with Gadamer's philosophy. The benefit of such an approach in the present article allows for both the diversity and commonalities of the participants' understandings, to be presented.

We utilized multiple case studies to include deliberately contrasting cases, so providing greater confidence in findings; each case aiming to examine a complementary facet of the main research question. Taking into account, the decentralization of services in Switzerland and the three major languages, we chose one case from each of the Italian, German and French speaking regions of Switzerland. The selection of the cases was made by the two authors who had been involved in the study from its inception and were deliberately chosen for the depth of responses by each participant and the differences they revealed while all experiencing the same phenomenon in the same country. Each interview was audio-recorded, transcribed verbatim and coded. Codes, all of which were data driven, were then grouped into themes; thus each individual case study contains its own unique themes. Cross case comparison was then undertaken by two of the authors who, dialoging with the data carried out a cross case comparison seeking similarities and seeking to address the research question. Through this process of engaging with the hermeneutic cycle, moving from the whole (the three interviews) and the parts (each code and theme) they reached a fusion of horizons, with three hermeneutic themes identified and discussed.

Findings

Case 1: Italian speaking woman

This participant and her husband have two young children but later lost two babies, one at 38 weeks of gestation and the other at 14 weeks. The couple is from Italy and moved to the Swiss canton of Ticino prior to having any of their children. This case focuses on the loss of the baby at 38 weeks. Three themes emerged from the interview: “Facing the reality of the baby’s death”, “The need to be close to the child” and “You learn to live with it”.

Facing the reality of the baby's death

This theme describes the woman's experience not only from when she first learned of the baby's death in the womb but to the time following the birth when she had to tell individuals such as neighbors or shopkeepers what had happened. However the most intense and confused feelings arose at the time of being informed of the situation and the time immediately following the birth. She describes the feeling of being in a dream following the news that after an apparently normal pregnancy the baby's heart was not beating:

> *An ultrasound was done and the heart wasn't beating anymore. I didn't know what to say. I could tell from the face of the gynecologist that something was wrong. I was shocked and didn't have words...I couldn't grasp it. And when I asked him what it meant that it was not beating. He said the heart was not beating anymore. But what do I do then. What can you say? I was well three days ago at the last visit. I asked was it not possible to repair the heart. My husband and I were incredulous that they said it was not possible. You say it is not true. It is a bad dream and I am dreaming.*

Both the woman and her husband were shocked and confused by the news that the baby's heart had ceased beating and found it hard to grasp the reality of their baby's death. After thirty eight weeks of pregnancy she was expecting to give birth to a live baby as she had done twice before: *"I remember having asked the midwife how the birth would be, that I had imagined a pink baby who would cry. Would I see him?"*

The fact the baby would not cry contributed to the feelings of unreality and of being in a bad dream that continued after giving birth with the depth of the despair being evident:

> *I remember a thing the day after when I woke up. I had the strange idea that there was a window in the room. The department is on the third floor and I remember*

> *looking at the handle...and the desire to leave through the window is truly so much...I was in the room on my own only because my husband had gone to get something to eat.*

Whilst this suicidal feeling was transient in this participant it is something to be aware of when caring for a woman in this situation. In addition, this participant was alone only for a very short while on the day after the birth. Her husband was present during the birth and other family members arrived soon after.

Following discharge from the hospital facing the reality that the baby had died involved unhappiness not only for the woman but individuals with whom she came into contact in her day to day life: "*It is bad for everyone, it is a bereavement for everyone. I remember the first time that I was at the butcher's and he asked if the baby had been born. I replied that unfortunately he was dead and the butcher began to cry".*

While this type of situation is upsetting and made more difficult by having no words to describe it, they help the mother face the reality of the baby's death.

The need to be close to the child

Like the above theme the need to be close to the child is something that is both immediate and longer term. The woman and her husband were able to spend the night with the baby following the birth but the woman would have liked to spend longer with him:

> *I wanted perhaps to cuddle him more. I was frightened to break him, he was cold. They told me that they would take him tomorrow. I had all the time to look at him, watch him. I asked where they would put him, in a fridge? They said no, that is absurd. They didn't want to say where they put him but I wanted to know. Because he was becoming blue? He was only blue in the face, his body was perfectly pink*.

She had concern for where the baby would be taken after he was removed from her and both the midwives and the participant appear unhappy that he would in fact be put in a fridge. It is perhaps reflective of the difficulty in coming to terms with the death of the baby and the knowledge that she would not be taking a live baby home. However a continued feeling of closeness to the baby was promoted by having a photograph of him: "*I am really happy that they took a photo of Alessandro. It is black and white because Alessandro had started to go blue"*.

This was not important only for the short term but for the future as "*It is absolutely vital (to have a photo) as there are going to be no birthdays or other things"*.

It is also important to this woman that her first two children have a photo of the baby as he is their little brother and "*I prefer that they keep in mind the image of the little brother that they have seen (in the photo). It is not important how they imagine him. They have the photo if they want to see him".*

In this way she is reinforcing that he is part of their family and through this is feeling a closeness to the baby. The need for closeness to this child is also met by the woman and her husband visiting his grave:

> *We had him cremated and put him in a little tomb near to where my mum is buried. The stone is pink. We sometimes go there [the cemetery] in the evening and water the flowers. It is a place where I feel fine. It is peaceful, you are alone. I asked the psychologist why I feel well when I go to the cemetery. He said that it is because I am with him at this time and have the need to dedicate time to him.*

These things help the woman and her husband to learn to live with the fact that they have lost a child.

You learn to live with it

As stated above maintaining the feeling of closeness to the baby helps the woman to learn to live with her loss. This theme identifies three other factors that help the woman to learn to live with the situation. The first of these, in the case of this participant, was the support of a psychologist and it is interesting that he suggested that she should not try to get over the pain of loss but should in fact learn to live with it:

> *I saw him [the psychologist] on the first day and saw him the day after before going. I had appointments once every two weeks and then once a month for the whole year after Alessandro. He has been very good, he would say to me you don't ever get over this pain, this emptiness. You learn to live with it.*

Whilst the support of a psychologist was pivotal in helping this woman to learn to live with her loss, not all women will either require or wish to have this support. A more transferable issue is perhaps the support of the family. In this woman's case she mentions the benefit she has gleaned from her two young children:

> *I have perhaps had the good luck to have two marvelous children so I could not become too depressed...Unfortunately things have happened but the two other children have helped their mum to recover. The wonderful thing about the children is they are little and have thousands of questions that don't allow you to mourn. You have to respond to the children's' questions good or bad.*

Having young children and having to deal with the sometimes difficult questions children ask encourages the woman to deal with the situation by helping her children understand and accept the situation. The third thing that helped this woman to learn to live with her loss was the recognition that she and her husband were not the only ones to have suffered such a loss:

> *I found the group on Facebook 'Dead children' very helpful. It is in German because it is a big thing in Austria and Germany. There are ten or twenty stories every day [on this site]. And you say 'I am not the only unlucky one'. You read the stories and you feel that they help when it has only just happened. You feel better reading the stories of the others and when you tell yours it gives you comfort.*

The sharing of such stories does not only help the woman to accept the situation and realize that she is not alone but it helps her maintain closeness to the baby which was seen to be important in the previous theme.

> Reflexive stop off, new understandings:
> Whilst I appreciated that the loss of a baby would be devastating to parents, dialogue with the data made me appreciate that the loss was of a new family member and their absence would be felt by the couple possibly for the rest of their lives.
> Analyzing data in a language other than English made me aware in a very practical way of the importance of the Gadamerian concept of language. I was concerned at each step of the analysis that I may misunderstand something the woman said or misrepresent it. The support of a native Italian speaker is gratefully acknowledged here as it limited these risks.
> Finally I recognise the importance of van Manen's claim that it is of value for the researcher to collect their own data as I would have liked on occasion to ask the woman a question to clarify a point. However opposing this is the fact that the interviewer enabled the woman to tell her story in a way I could not and asked questions that may not have occurred to me.

Case two: German speaking couple

This couple were expecting their second baby and very much looking forward to it. At about the 9th week of pregnancy, during a routine antenatal appointment, their doctor found that something was abnormal in the baby's heartbeat and wanted to refer them for further tests. Subsequent referrals lasted a further 12 weeks and the baby was eventually born at 22 weeks' gestation. This case study, taken from an interview with both parents, revealed four major themes: "Seeking help while living with the doubts", "creating their individual journey", "integrating the baby into the family" and "experiencing support from health professionals throughout the journey".

Seeking help while living with the doubts

This period of the journey lasted approximately 12 weeks, from the initial hints in the ninth week that something was not right to reach the point at 22 weeks at which they realized that the baby had no chance of life. The parents thought that their referral meant an ultrasound scan and agreed but instead were referred to a base hospital for a further consultation which resulted in "*being sent here and there and then sent away from the consulting room*". Following this the parents sought a second opinion resulting in further tests by mutual agreement. A detailed ultrasound scan showed that the baby had severe abnormalities and the consultant made it clear that "*he could not do anything to save the baby and he doubted that it was possible anywhere*". The couple made the decision to continue with the pregnancy. This made the health professionals even more proactive in their efforts to find a solution and further tests were done but it made no difference until eventually the neonatologist said there was nothing else that could be done "*there was no light at the end of the tunnel, at least there was an end even with nothing positive*".

Creating their individual journey

A period of relative calm followed although the couple had to justify their decision to continue the pregnancy several more times "*I had this feeling that I had to fight.....to fight for our ethical decision, against the doctors*". Despite the couple's clear decision there were more consultations and the couple had to fight for their will to be done and eventually received the support they needed from their own obstetrician. “*I thought I can discuss it further, but I do not want to*” (and finally the consultant accepted this. Termination was mentioned to them by one doctor who “*knew our thoughts on it but didn’t want to accept them while there was the possibility of a termination saying it was his duty*”. The parents had the baby with them the short time she lived, still “*hoping for a miracle*” but accepting her death and keeping her with them for a few hours thereafter. Additionally they took the baby home for a few days being “*extremely thankful for that opportunity*”. They said their goodbyes in two steps. In the first, all friends and family were invited to an evening in the family home a week after the birth and death of their daughter. For the parents it was important and encouraging “*to see how many people came…from the neighborhood and the church*”. The burial followed later in a smaller circle. After the burial the couple could take some time for themselves and this they felt was vital for mourning.

Experiencing support from health professionals throughout the journey

Having gained the support of their second obstetrician, the couple also found professional support forthcoming from their midwife. She “*supported the decision to continue the pregnancy from the beginning and made contact with other parents in similar circumstances as we lacked experience*”. She put the parents in contact with a professional agency whose personnel helped with “*things that we couldn’t work out ourselves, how they all went together*”.

The birth was a good experience with “*few interventions except where it was necessary*” and the couple tried natural remedies. The hospital staff were well informed about the situation and provided appropriate and supportive care throughout labor.

Following the birth of their daughter, who lived for nine hours, everything possible was done, the hospital staff providing space for the parents to be with the baby "*and fed her with a spoonful of milk every three hours*". The parents never "*felt alone. There was no vacuum. And that was so valuable*" with such good support from health professionals, family and friends as well as their church. In the postnatal period the midwife was also very supportive giving "*tips for the burial and beyond*".

Integrating the baby into the family

For this couple it was vital to integrate the baby into their family and particularly with their son. In the antenatal period this meant going to appointments together and "*watching the baby growing*". Being able to take the baby home meant that their two year old son could begin to understand that he had a young sister which was "*very different from the 70s where you couldn't even have a photo*". In their own experience naming the baby, having her footprints and photos all contributed to her inclusion in the family. Finding closure was an important issue but here also friends have become closer and through their church and their faith they were also helped.

Reflexive stop off: new understandings

These parents seemed to go through a living hell in the first part of pregnancy, going from doctor to doctor, seeking a definitive diagnosis. Everything was shared with them but the different parts of the health service didn't seem to talk to each other. Why? Was it a cultural thing as Gadamer may suggest? And why did it take such effort on this grieving couple's part to get the doctors to agree to them continuing with the pregnancy? Surely such a wish is not unusual?

Case three: French speaking man

The interview took place with the husband of a woman who experienced the loss of their first baby around the fifth month of pregnancy. They had had a feeling that something was not right following a routine detailed ultrasound scan at the mid-point of pregnancy, and it was at the next routine checkup that they learned that the baby was dead. This couple experienced a series of errors in the health system resulting in the loss of the baby's body, for which, to this date, they still have no explanation. Three major themes emerged from this interview: suspending time, strong impressions and importance of external relationships.

Suspending time

Timing was very important to the couple's experience and influences the other themes. The couple first had the impression that everything was taking too long and that the succession of steps, which should have been straightforward, was longer than expected. The feeling of unease started at the ultrasound scan around 22 weeks when "*the scan itself did not go well, the pictures were not very good, apparently the midwife was not satisfied with what she could see."* It was 10 days later that they received the news that their baby was dead: *they explained to my wife she would have to give birth the next day. Well they didn't say that, the date was ours to decide, but we talked and thought it as better to get it over as soon as possible*"

The woman experienced a bad labor and birth when "*the baby arrived in the middle of the night in Pentecost weekend*". The postmortem of the baby took another three weeks. The couple initially *“were scared to see the baby, which is apparently a usual reaction. We should have been told that it is recommended and that it is not horrible, but this discussion did not take place”*. Following discussions with various people they changed their minds but were “*bounced around*” from one place to the next. Lack of information during that time about the possibility of seeing the body even if the analyses were not complete prevented the couple from moving on rather than “*just waiting*”. Between visits to the hospital they experienced lonely times being “*left to fend for ourselves*”, which were hard to live through. At the beginning of the grief process, contact with professional organizations was described as negative: “*they insisted we were separated for counseling interviews, and there were other things that were such as ‘ how can you go home when you live at the 8th floor and might jump out the window ?’”.* This impression changes along the way, as they gradually come to peace with the event: *“we were told this was not our fault, we didn’t really have the impression it was our fault but maybe we needed to hear it too”.* The couple described some organizations they encountered later in their journey as “*comforting*”, or “*meeting someone who understands*”. In the aftermath of the events, moving on is what describes best their experience as opposed to “*recovering*”, “*getting better*”, or any other term suggesting some kind of healing. This is best described when the father says that he “*learns to live with it and digest what happened*”.

Living the horror

Strong feelings of disbelief of reality, fear, failure of the system, and rejection were experienced. Rejection was first directed towards the baby, the mother refusing to see him, and closing up her feelings. Then, anything that might remind them of their suffering, expressed as “*unbearable pain*” and “*raw suffering*” was also rejected. They described that time as “*going from one mistake to the next*”. There were always excuses as to why they could not see the baby: “*we were told maybe it’s no such a good idea, the body stayed in the tummy for a long time, it is all red and mangy, not pretty to see”*. Finally they were told to return the next day when a doctor told them “*we are very sorry but we have lost the body*”. This prevented them from organizing a real funeral [with the body] which may have been a milestone that helped: a before and after moment. During the first three weeks, encounters with organizations that were supposed to help were viewed as unhelpful at best, if not worsening *“from average to catastrophic*”, the woman feeling “*close to jumping out the window*”, and the man describing his wife’s state as “completely and utterly washed out”. The participant used strong words to describe events that took place: movements of the baby just before it died are described as “*violent*” and they expected the baby to look like “*a vision of horror*”. The contact with the pregnant sister of the father was reported as “*tripling the trauma*”. The second source of disbelief is then linked to the loss of the body: *“there, my wife was in a terrible state, she had to stay two days in the hospital with sedatives”* The loss of the body is a crucial aspect of this experience, and is described as due to a failure of the system, worsened by practitioners’ reactions: “*one of the psychiatrists found nothing better to tell her but than to say ‘oh but your baby is not lost, he was just incinerated with all the other hospital waste, it’s normal.”* Despite finding excuses linked to the logistics of it happening at night, and on a holiday week-end, they still are dumbstruck: “*we couldn’t believe they had incinerated the body without even telling us!”* One of the recurring themes in this interview is fear of their feelings. Facing their feelings is an ordeal that they try to avoid in many ways. The fear of seeing the body is also clearly expressed as “*expecting a vision of horror*”. Fear of being confronted by others and their interpretation of an experience they know nothing of is also present: “*we lost touch with a lot of people who* *were not able to accept my wife in the state that was hers then"*. Fear of this event happening again is also described when talking about the future pregnancies: "*we expected to be very stressed at the anniversary date of the first pregnancy"*.

Importance of external relationships

The external relationships were referred to as both helpful and hurtful depending on nature, timing and context. Family was described by the father as helpful when referring to his parents, especially his father who is a doctor and helped understand the medical process and environment. The relationship with his sister was problematic due to her pregnancy and his wife refusing to see her and experiencing trauma seeing her soon after birth and even later on: "*she has been though such terrible moments, moments when she felt close to jumping out the window just to suppress the pain. She was too afraid she'd relapse if she saw my sister"*. The situation was hurtful to the participant who was torn by the impossibility of having a normal relationship with his sister but also had to respect his wife's feelings. He himself had "*mixed feelings*" towards his sister and "*At the beginning it was hard to see my sister's boy. I love him but I simply cannot talk about it with my wife, even today."* He explains the importance of having outside support from friends and relatives while pointing out the difficulty of truly sharing with somebody who has not had this experience, sometimes finding certain forms of advice or reactions hurtful: "*some people were shocked by the fact that my wife had maternity leave when she did not have a baby, there is such a taboo around this that people are not well informed and are scared. At first, my wife would talk about it openly and was ready for social interaction but people ran when they saw her pretending they had an appointment or something"*. This justifies the importance for him of support groups where people know the suffering and where they are strong enough to hear it. However, help they received from the regular pathways of support offered by the insurance was insufficient, sometimes dilatory and led them to seek other forms of help such as support groups, the personal initiative of writing a book and the organization of the ceremony replacing the funeral, helping them in their reconstruction: *"whatever the reasons of people losing touch, we had the feeling that everything needed to be built from scratch again"*.

Reflexive stop off: new understandings

This interview struck me by its intensity, which I would expect of any experience of loss of a loved one, all the more in the case of a child. The failure of the system and loss of the body appeared to worsen the experience, experience that was already unacceptable as such. This made me feel some extent of guilt, on behalf of my profession (midwifery), at the thought that these parents did not get all the opportunities of support they should have had to help overcome this event

Dialogue with the data

The cases we have presented in the previous section have given rise to three hermeneutically derived themes: rupture, juxtaposition of time and reshaping. Stage four of the research method develops them further, bringing together the individual experiences through a deeper engagement with the hermeneutic circle, taking into account the pre-understandings each of us brought to the project and the reflexive stop offs those of us analyzing the data experienced.

Rupture

A “hermeneutic of rupture,” initially identified by Ratzinger (2005) describes a negative experience and influence. In each of the three cases there is no doubt that the moment of diagnosis initiated that rupture. However, the form of rupture was different in all three cases, as shown above. The participant from the Italian speaking region experienced this as an immediate and complete rupture, coming without warning in late pregnancy, while for the French speaking participant a 24 hour period of anxiety and uncertainty followed initial concerns before that rupture finally occurred. For the German speaking couple, rather than an instant definite rupture, it was more akin to a small hole in a tooth, which can be picked at until it eventually reaches the point of no return. The case of the German speaking couple may be seen as being parallel to the ideas espoused by Ratzinger in which he describes the rupture as occurring after a period of discontinuity and discontent. He also alludes to the potential to counter it through a hermeneutic of reform, again this reflects this couple’s attempts to make sense of and if possible change the outcome for their baby. Likewise, it is supported by studies throughout the developed world. Where parents are forced into unwelcome decisions despite the inevitable rupture (Byar, 1997; Balkan et al, 2016; Hodgson et al, 2016) The Italian speaking woman described the situation like being in a bad dream and for her explanations after the event were the most important. This resonates with Höglund et al’s (2019) and Rempel et al’s (2014) published work both of which also describe this as a neglected area although there have been signs that health professionals are addressing this issue by working with affected parents to achieve joint decisions (Frank et al, 2018). The French speaking case has less grounding in the literature, with fathers’ experiences in such circumstances being almost absent from the literature despite a plea from Locock and Alexander (2006) to include them but perhaps the idea of a health advocate mooted in one study could have come into play here in an attempt to cause less distress and confusion (Fleming et al, 2016).

Juxtaposition of time

The hermeneutic expressing a juxtaposition of time derives from the original hermeneutic of time posited by Heidegger (1927/2006) who spoke of the flexibility of time and its molding to situations. Similarly, Gadamer describes time as being “pushed and pulled” by situations. Each of these analogies could describe the situation of the participants in this study as they are pushed and pulled by the health care facilities and in turn push and pull themselves in attempting to make sense of the situation. For each of these participants, time has lost any sense either dragging on interminably or moving so fast they just had to go along with it. The uniqueness of each “case” is seen at the different periods of pregnancy at which events occur. For the French speaking participant, the juxtaposing of time, after a protracted 24 hours immediately around the period of diagnosis, mainly takes place after the birth. At this time, the parents are trying to make sense of the situation, not wanting to see the baby and then changing this and experiencing further reality shock when the body could not be located. For the German speaking couple the 12 weeks between the first suspicions of problems and the final diagnosis represented an interminable period while, from the acceptance of the diagnosis until the baby’s birth some 16 weeks later, time seemed to go extremely quickly. The Italian speaking participant and her husband were overtaken by events and had no time to come to terms with the reality of their baby’s death before his birth. This contributed to the period of time after the birth where they sought reasons for the death after an apparently normal pregnancy. Other authors such as Watson et al, (2017) have described similar findings and again the uniqueness of each situation comes to the fore.

Reshaping the family

The final hermeneutically derived theme that we identified was “reshaping the family”. Kubler Ross’ (1969) stages of grief identified half a century ago does not use this but instead refers to “acceptance”. However, in the present study each of the participants took this further and became proactive in trying to change their own or others’ trajectories. In this present study we did find some elements of acceptance especially in the German speaking couple’s experience where after seeking alternative diagnoses and potential cures they acknowledged the situation for what it was and decided to continue with the pregnancy. While they cited their religious beliefs as the reason for continuing, it is possible that they were still hoping for a miracle. When their baby lived for nine hours and died in their arms it provided the way towards moving on and reshaping their family without her immediate presence resonating with the study by Martinez-Serrano et al (2019). The French speaking participant tried to live normally at first following his daily routine but as time has passed he has reshaped his life and that of his family by writing a book about the experience and so bringing a subject acknowledged by other researchers as taboo into the public domain (Kelly & Trinidad, 2012; Lotto et al, 2016). Finally the Italian speaking participant has learned to live with the death of the baby at least partly through having to deal with the questions her two children ask about the little brother who is not with them. In addition she feels a closeness to the baby through having a photograph and a grave that the family can visit which offers comfort to her and her husband. This has brought her to the stage that she can now offer support to couples who find themselves facing life after the death of a much-wanted baby. As identified in the introductory section the sensitivity of this topic is what has perhaps prevented researchers from discussing it in detail. The parents in this study, however, all were thirsty for information and the French speaking couple especially wanted to shake off the taboos which have been identified in previous studies (Lotto et al, 2016).

Conclusions and limitations

This paper has shown the unique journeys experienced by parents whose baby dies before or shortly after birth. Inevitably this research comes with limitations. Although we have obtained rich, thick description and analysis of the phenomenon some readers may find it too long or detailed, while other may feel it lacks information. We have taken the advice of Stake (2005) and reported what we feel provides the story rooted in a credible and well tested research method but accept that the final article is rooted not only in the data from participants but in our own pre-understandings. In an attempt to make these transparent we have included reflexive stop offs at the end of each of the cases.

That the parents share a country but not a language or an experience has been brought to the fore through their individual journeys. Some words do not exist in all languages we acknowledge that so there may be different ways to express a common experience. Additionally, as we coded the interviews in English, each researcher already interpreted the text before even analysing it. Gadamer notes that in such circumstances the gap between the spirit of the original words and that of their reproduction must be taken into account. We acknowledge that such a gap that may not have been completely closed.

As with all qualitative research, there is no attempt to generalize from these cases and we believe that the uniqueness of each case will provide health professionals working in the field with opportunities to reflect on the services they provide and, where possible, tailor it to meet the individual needs. Neither does this research does offer any solutions to the problems encountered on these journeys but is presented in a way that remains faithful to them and which may offer guidance to professionals working with affected parents throughout the pregnancy continuum and in years after the event.

As noted in the introduction, the Swiss health system is highly decentralized as well as highly medicalized, thus three stories from the same language region may have produced results similar to each other. However, as we had noted a gap in health service provision in our previous report, our aim was to highlight the individual journeys of the participants in an effort to advise health professionals that it is parents who most often are in the best position to determine their own pathways at times such as this. This study has shown three unique journeys and these may resonate with other parents' or health professionals' experiences but, as with all health care at this time the uniqueness of each participant must be acknowledged.

In such situations, it may be inevitable that questions are raised about the pathway of care, but what is important here is that while a rupture was common to all, its nature was very different in each case. The diverse experiences of each participant have nonetheless led to the derivation of three hermeneutically derived themes: those of rupture, juxtaposition of time and reshaping. Future studies in such sensitive areas should also consider the uniqueness of individuals rather than be adopting methods that seek to generalize such experiences.

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