Histories of fetal losses told by women: research qualitative study

Alba Lúcia Dias dos Santos, Cornélio Pedroso Rosenburg e Keiko Ogura Buralli†

Departamento de Saúde Materno-Infantil da Faculdade de Saúde Pública da Universidade de São Paulo. São Paulo, SP, Brasil

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Abstract

Objective
To recognize the significance of fetal loss for women who have experienced it, starting from an understanding of the pregnancy process, based on their reports.
Methods
This was a qualitative analysis study based on the histories of seven women who experienced fetal loss in the town of Arujá, State of São Paulo, between July 1998 and June 1999. The women were identified from the death certificates of stillborn infants born within the study period, which were obtained from the Civil Registry Office of Arujá. The methodological procedures involved the utilization of the techniques of oral history-taking to gather data and content analysis to evaluate the material collected. The interviews were recorded, fully transcribed and subsequently prepared for analysis.
Results
The findings were analyzed as two points: the circumstantial context of the pregnancy and the impact after the loss, with the adoption of specific thematic categories. The first of these encompassed the woman's perception of the pregnancy, her awareness of the coming of the new baby, health problems up to the time of the loss, and the health service attendance. The significance of the loss for the women in this study was made evident along three central lines: the loss of a part of herself, attribution of the fatality to divine intervention and changes in attitude towards life. The social support network for these women was built on two pillars: family and church. Support from the health services was practically nonexistent. Finally, they all expressed their will to live and the need to work, study and even have another pregnancy.
Conclusions
There needs to be a change in general concepts in the mission to attend to such women. The attendance provided by the healthcare services needs to be humanized. The need for multiprofessional follow-up of healthcare service users who suffered fetal loss was very evident. The importance of a support network for women who have gone through this problem was also shown.

INTRODUCTION

The majority of scientific work on the subject of fetal loss, within the field of public health, has involved population or single-institution studies. These have taken a quantitative approach along classical lines, seeking to investigate the biological causes and the social or psychosocial risk factors that are associated with fetal loss. In essence, these studies have considered the problem of fetal loss from the viewpoint of an outsider trying to discover the factors that may have influenced this occurrence.

Correspondence to:
Cornélio Pedroso Rosenburg
Departamento de Saúde Materno-Infantil
Faculdade de Saúde Pública da USP
Av. Dr. Arnaldo,715
O1246-904 São Paulo, SP, Brasil
E-mail: cprosen@usp.br

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There have also been some studies performed medical school obstetric clinics that were undertaken with a qualitative approach towards women who suffered fetal or perinatal loss while interned (Luz et al,[9] 1989; Popim et al,[14] 1990; Martins et al,[10] 1998). These studies were linked to preoccupations within nursing, psychological and medical attendance for comprehension of the genesis and dynamics of the mothers' feelings when faced with fetal or perinatal loss.

According to Bogdan & Biklen[4] (1982), in qualitative methodology, the researcher should especially focus on the significance that people give to events and their lives. In the opinion of Meihy[11] (1998), the basis for an oral history is the recorded testimony and, according to Denzin[8] (1973), the oral history presents the experiences and definitions that a person lives through.

Minayo[12] (1994) considered that "content analysis is the method most frequently utilized in the field of healthcare for undertaking the data treatment of a qualitative investigation" and, according to Bardin[2] (1977), "thematic analysis consists of discovering the core meaning that makes up a communication, and the presence or frequency of such meaning may signify something within the chosen analytical objective" (p.105).

With the aim of contributing towards deepening the knowledge of this matter, the present study had the objective of obtaining a comprehension of fetal loss through the eyes of those who have suffered the experience: having gone through the process of pregnancy within the context of their lives, confronting problems of various kinds, they ended up losing their children and afterwards suffered the consequences of this loss.

METHODS

This was a qualitative study performed in the municipality of Arujá, State of São Paulo. The subjects for the study were identified from the death certificates of stillborn infants born between July 1998 and June 1999, which were obtained from the Civil Registry Office of the municipality.

The objective was to comprehend these women's perceptions within their real circumstances of having gone through the problem of losing their babies. For this, certain initial questions were put to them, and these questions informed the whole investigative process:

- How did the woman realize she was pregnant?
- What were the alterations felt in her body?
- How was the news that she was going to have a baby received?
- When and how did she seek out the healthcare services?
- What were the circumstances of the loss of the baby?
- What reactions did the woman have, following the loss?
- What significance did the loss of the baby have, in the context of her life?

Out of the total of fifteen women identified, eleven were located. Of these eleven women, seven were interviewed while four were not. The reasons why these four were not interviewed were the following: two did not show up at the agreed location, even though they had been visited at home three times; one moved away from Arujá after being located; and one did not agree to participate in the interview. The interviews were held in the women's homes, after they signed a statement of consent.

Data collection was performed by means of the *oral history-taking technique* and the reports from the interviews with the women were analyzed by means of the *content analysis technique* and, in particular, *thematic analysis*.

The first two stages cited by Bardin[2] (1977) were utilized for the thematic analysis, i.e. pre-analysis and exploration of the material. The interviews were recorded and then fully transcribed, with correction of the Portuguese. To obtain a text for analysis, the transcription rules from Preti[15] (1997) were utilized. The thematic categories for the study were selected subsequently.

For the analysis, two points in the process experienced by these women were chosen. These were named the circumstantial context of the pregnancy and the impact after the loss.

— Circumstantial context of the pregnancy: for this, the reports of the pregnancy process up to the time of loss were considered, including the attendance for the delivery, utilizing the following categories:

- the woman's realization that she was pregnant;
- the coming of the baby;
- health problems up to the time of the loss;
- the attendance by the healthcare services.

— Impact after the loss: for this, the reports of the process experienced by the women after the loss were considered, from the time of their arrival back home without the baby, until the time of the interview, utilizing the following categories:

- the reactions presented;
- the memories of the baby;
- the significance of the loss;
- social support networks;
- messages for other women;
- prospects.

Profiles of the women and analysis of their histories

Interviews were held with seven women who suffered fetal loss, between four and thirteen months after the loss of the baby. From their sociodemographic profiles, the interviewees belonged to lower social classes. They were aged between 17 and 38 years; five had a stable partner and two were single (no partner). They had all become pregnant without prior planning, and therefore the pregnancy had an unexpected character. Six of them had previously had one or more pregnancies, and this was the first pregnancy for only one of the women.

The first analysis point – the circumstantial circumstances of the pregnancy – was obtained by recalling the circumstances that surrounded the process for these women, from the moment they realized they were pregnant until the loss, including the attendance for the delivery.

The women realized that they were pregnant at around three months of gestation in six cases, and in the remaining case (an adolescent), it was at five months of gestation. For three of the women the diagnosis was given by a doctor. From the time of confirmation of the pregnancy, all these women underwent prenatal examinations, mostly in public healthcare services. *"I was three months pregnant, so I had to face up to this situation."* (Ane)

For the other four women, the realization that they were pregnant came from the presence of evident symptoms such as late menstruation, changes in the body, nausea and headaches. In this group, the realization came earlier – at around three months of gestation – and was by the women themselves. *"It was easy to realize, because for me [my period] is never late, and it was a week late, so it was a sign of pregnancy."* (Marilsa).

In the analysis of the second category (the coming of the baby) two opposing reactions were observed: on the one hand happiness, and on the other hand, rejection. *"They were six and a half months of great joy, you know, because to discover I was pregnant after so long... I was happy, really I was happy."* (Mariana).

In the other group of women, whose reaction was rejection, the circumstances of life that surrounded them at that time could be recognized from their histories. For them, pregnancy did not appear to have been something they wanted. *"I was desperate, I told myself it couldn't be pregnancy."* (Ane)

It was very striking in this group that, despite the initial feeling of rejection that was common to all of them, the most dramatic reactions were presented by the single women, which may be a reiteration of the cultural, social, historical and affective meaning of pregnancy and the symbolic meaning of marriage, as revealed in the studies by Paim[13] (1998) and Brioshi & Trigo[6] (1989).

It is worth emphasizing that no subject in the present study reported a desire to have an abortion.

Despite the initial rejection, all the women subsequently shouldered the burden of the pregnancy, according to their reports. This may also be an expression, from a sociocultural point of view, of the value placed on the role of being a mother, as a fundamental component of female identity, which was well defined by Stasevskas[18] (1999).

In the category of health problems prior to the loss, the women in the study detailed the process leading up to the outcome, highlighting health problems that they had to face up to. *"It's just that what happened was... when I was six and a half months pregnant, I started to realize that really I was very fat; I saw that my feet had started to swell. I came here to the emergency service... the doctor said that I needed to take the medicine* [Aldomet]*, because I had high pressure... when I told my gynecologist that the baby wasn't moving, he interned me immediately."* (Mariana)

This report gives an idea of health problems perceived during the pregnancy that led the women to seek healthcare services. The evolution of the health problems described allows the recognition of two sequential points in time: the first, when the evident symptoms were swelling, pains in the legs, bleeding, fever, pain, dizziness and vomiting; and the second, when most of the women said they had realized that the baby had stopped moving.

For these women, this realization that the baby had stopped moving was the crucial moment of death of their children. This occurred between the second and third three-month period of the pregnancy.

The correct description of symptoms could be rec-

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ognized from the reports given by the interviewees. In some cases, these symptoms preceded the medical diagnosis of the loss of the baby. These data put into question the myth that people of low income belonging to low social classes are incapable of correctly communicating their symptoms and understanding diagnostic explanations. Such reasoning is alleged by many healthcare professionals to justify not giving out information correctly to service users under these conditions.

With regard to the category of attendance by the healthcare services, the reports reveal that all the women in the study mentioned that they underwent prenatal examinations as soon as the pregnancy was confirmed. They were all attended by the public healthcare services, except for one woman who utilized a private health scheme service. For the majority of the women, prenatal care began at around three months of gestation, and it began at five months for only one woman.

The women's words give evidence of serious criticism of the quality of prenatal attendance received in some cases: *"Now, speaking like this about doctors... I think the prenatal care isn't very good... I think it needs improvement. I notice these things, I went through all this, and who wouldn't notice? I did two prenatal tests and, well, I think that the high pressure, this business of the* [high-risk] *pregnant woman just once a month, I think it's not right. I think it should be once a week... I think, because it really needs care, like in that poster saying that pregnancy requires care."* (Mariana)

Others directed their complaints towards the quality of prenatal consultations, particularly the lack of adequate physical examination during the consultation.

With regard to hospital attendance, they referred to the disorganization of the hospital, in relation to family members seeking information about the situation of patients.

There were other criticisms in the reports, regarding doctors' attitudes, especially concerning the doctor-patient relationship and the attendance within the hospital environment. In the women's testimonies, they attribute blame and responsibility to the doctors who attended to them, in relation to the procedures accompanying the delivery, as in the following: *"I just thought he was very cold, because for a doctor, OK, the doctor doesn't have to be cold, but not to the point of going up to the mother and saying: 'we're going to take out your baby because it's dead'... I don't think it's right like that, no. I could even blame the doctor, but... there's no point in blaming something because I've got no proof, I can't say it was just his mistake... I did my bit, when he kept me in hospital, I think he had to do something, he knew the baby was dying... and I was expecting to have normal contractions... like always. Not everything's normal... not all deliveries are the same. I thought he would have to do a cesarean, taking the baby out earlier."* (Marilsa)

With regard to the hospital attendance, side-by-side with the criticisms, some women (Rosângela and Cristina) had praise for the nurses and doctors. *"The one who released me from hospital was my doctor, he passed by on the next day and released me. I asked them to call him, because I did the prenatal tests with him, and he explained everything: it didn't work out this time, you've got to keep calm, you're going to get another baby and so on, he said the right things to me like that. He said that the baby was very young, six months, it's difficult... because the little lungs are still green... "* (Cristina)

Defey et al[7] (1985) showed that the confirmation of fetal loss is experienced by doctors and nurses as a failure of medicine, which produces a feeling of frustration and impotence because of their difficulty in controlling the situation.

In addition to the criticisms directed towards the prenatal care and hospital attendance, there was also questioning of the healthcare services regarding the lack of follow-up after delivery in cases of loss of the baby. *"You know, I don't have anyone to accuse of anything... because I know I wasn't well. And another thing that's very important... the pregnant woman after the pregnancy. Hey, guys, how important that is after the delivery! In my case, for example, I had no support - none. This is what I think... the family must be prepared, given advice for such, such a situation. I think that a comforting place, she really needs it."* (Mariana)

The majority of the attendance by the healthcare services frequented by these women revealed the asymmetry of the doctor-patient relationship during the consultation, in concordance with the study by Boltanski[5] (1979). According to this study, the guidance for patients becomes less significant, the lower the patient's social stratum is, with the justification that low-stratum patients have difficulty in comprehending the scientific language utilized by doctors.

The present study contradicts this myth, as already observed earlier, through the reports by these women, with the richness of detail regarding their bodies, the

evolution of diseases, perception of serious symptoms and knowledge of the need for supplementary tests. Such facts give an indication of greater incorporation of medical knowledge by the general population today.

The second analysis point – the impact after the loss – considered the process experienced by these women from the time of the news of the loss of the baby in the hospital until the time of the interview, which took place between four and thirteen months after the event, as mentioned earlier.

From a psychological point of view, the fact the baby was stillborn represents what Defey et al[7] (1985) called "a truncation of the natural order and a rupture of the expectations placed on this project for life", implying greater difficulty for the woman to accept it.

The reactions presented by the women in the present study constituted a long pathway of suffering and pain that began in the hospital, by means of the doctor's cold news, and continued upon arriving back home, in being confronted by everything that would have been for the baby: cradle, shawls and baby clothes. This moment was identified as the time when the reality of the absence of the baby struck home. *"Ah, it's hard to have to face up to the truth, arriving back home and seeing all the baby's things, seeing the cradle made up, seeing the baby clothes... resting for eight months for nothing... it was all in vain... it makes me resentful... but we have to accept it... it's very painful for me."* (Marilsa)

The reports show that, as the woman went on becoming aware of the loss of the baby, many feelings took hold of her, revealed verbally and non-verbally: frustration, disappointment, resentment, sadness, guilt and tearfulness. *"What I want to say to you... in spite of... the loss [she cries], I still cry..."* (Mariana)

According to our interpretation, Mariana also reported perceived feelings of hallucination and Cristina expressed the wish to die, as in the following reports: *"I remember that, I think this is important, I remember that my whole body, it was as if it had erupted into pimples... and I was speaking like this to my husband: do you see... just look at me now... at that time I needed a doctor... [she cries]... I needed a tranquilizer at that moment... [she cries]... nobody noticed."* (Mariana)

"I can't even explain it, just sadness... even a wish to die, as well... But I kept my head, if not I would have done something stupid, even, God forgive me... losing like this... I felt like wanting to die as well, together..." (Cristina).

For most of the women, the memory of the baby was expressed with the desire that it might have been alive, so it could have been breast-fed, with the image that by now the baby would have been some months old and already clever. For one of the women, the baby was remembered as the happiness experienced during the period of the pregnancy, when she already had an intuition that that would be her time for happiness, according to her testimony: *"Because... it was like this... six months of great joy [she cries]... I was so happy... [she cries]... It's as if he came to bring me great joy... [she cries]... and I made the most of everything, everything... It had been such a long time... just as I hadn't been to a playground... and we even went to a playground... [she cries]... It's as if we already knew that he wasn't going to stay... [she cries]."* (Mariana)

All the women in the study emphasized that this loss would never be replaced by another child, "the baby would never be forgotten", it was "a unique being", "very special" and "while it lived it brought great joy". *"Well, it was hard to get used to... even today I remember... it's as if it was today... Ah... I don't know, I would have liked her to be here... so I could have been caring for her... breast-feeding her... I like children a lot."* (Alzira)

The significance of the loss of the baby for the women in the study involved reflection on the event and the experience they had gone through and, for the majority of them, the loss was clothed in a multiplicity of meanings.

From the reports, we proceeded with an interpretation process based on the events that occurred. This resulted in a compilation of the meanings along three lines: loss of a part or piece of the body, attribution of the fatality to divine intervention and changes in attitude towards life, as in the following extracts:

"For me, it was part of myself that went away... I don't know, but that baby was part of me... it was part of my life. I don't know why but, I can't explain it, but... For me it was an experience, a pain... a hard experience, but one we have to go through." (Marilsa)

"It's that the baby wasn't to be mine... it had to be God's... God wanted things like that... But one He'll give me another, if He so wishes... it's never too late..." (Alzira)

"It meant a lot because I've changed a lot... I used to be very nervous with the boys, but not now. Now I think like this: I've already lost one and I'm not going to lose the others that are alive..." (Ane)

"The meaning… Don't stop living, because it's very important to live. The meaning of this loss was very deep… because we go on finding out what our mission is. Because after that pregnancy… I started demanding more from myself, like this… I think this is the lesson it left me with. You know, we have to live every minute… the minute is now… but responsibly. In the sense that tomorrow's another day and I have to be complete… so I'll be able to realize all my dreams of that minute… the ones from that time that's passed by that I planned… I can tell you that I matured with that pregnancy… I'm asking more of myself, I'm much more mature…" (Mariana)

The reports make it clear that there is a need for a social support network, to help such women overcome an experience that is gone through with such suffering. The support network that the women of the present study could count on was built on two main pillars: the family and the church. The figure of the psychologist had a presence that was very fleeting, as in the following reports:

"My relatives, my husband, I'm evangelical, they always come to pray here… My family gave me a lot of support, they said I'm still young… and there's time for me to have another one, if I look after myself… My father-in-law also gave me a lot of strength… he spoke of God a lot, he also taught us to put up with bad things. He consoled us a lot… and we're getting over it…" (Cristina)

"It was primarily my faith in God… and the pastor of my church, because he's not just a pastor, he's a friend… This pastor is the best person that could have come into my life to help me… because when I woke up in intensive care, he was already there at my side, always consoling me… in the best possible way.. without pain… without resentment, he helped me a lot. I went to the psychologist, but it was my pastor who was really my psychologist… he was the best psychologist that God could have put into my life, it was him…" (Marilsa)

Faith in divinity and religion, according to Assis[1] (1999), "brings a means of understanding and explaining the world and overcoming and enduring the day-by-day existence, bringing an association with hope (....), especially in situations of crisis, in which life appears to be under threat".

The figure of the pastor, cited by some of the women in the study, symbolizes the bridge between the terrestrial and transcendental worlds. Faith, as a pledge, consoled and comforted them.

Marilsa spoke about what a significant person who could help would be like: *"You have to look for a friendly person who can help a lot… Talking to a person like this, someone with their head on straight, helps a lot… it can even be better than the psychologist… much better… the person opens up, you say what you're feeling, you can cry, and this person's there to help you... without making you cry, you understand, helping you without your tears streaming down…"*

As a contribution to the study, by way of help for other women in similar situations, the interviewees left messages for other women to reflect on. For both the woman and the newborn to avoid suffering, some of the women in the present study suggested that women who intend to become pregnant should prepare for pregnancy by caring for their bodies. The following from Mariana explains this: *"I have something to say about everything that's happened to me… the only thing I think… that I can ask, because everyone will ask for something. But for me, what I ask is that girls prepare themselves better for pregnancy, because we need to be well... the body needs to be strong… it needs to be healthy. I know it's very difficult like this for someone… to know how to prepare for pregnancy… but I think it's necessary… because the baby suffers a lot… when we aren't ready for this pregnancy… because I feel I wasn't… because… I was so swollen… so swollen… my face became round, my eyes disappeared… I think it's a lot of good luck... that I'm here today… so I think that this preparation for pregnancy is fundamental…"*

In addition to the care for the body, some of the women in the study gave spiritual advice for other women, for them to be with God and have faith at this difficult moment of facing up to the death of the newborn. They called on other women to seek comfort in God in their moment of despair. One of the women in the study had a message for the doctors, for them to listen to the complaints of signs and symptoms that the women themselves describe, because it is the women who are experiencing and feeling the problems in their day-to-day lives and therefore they are the ones in a better position to detect them.

At the end of the interview, each of these women was asked what they were thinking of doing from now on, and what their plans were. Their replies were expressed with a view to the future, whether in relation to work, future pregnancy, resumption of studies or a desire to get married. The point these responses had in common was an emphasis on future prospects and "moving on", accompanied by a manifest intention to help other people in similar situations, because they felt prepared for this.

"What am I doing today? I'm preparing more classes, I'm taking part in more courses, because the country is you. There's no point in throwing everything onto the government's shoulders. I think we should be more active, the day has 24 hours, we don't even use 5 hours, if you look at it… time is valuable… I think we have to value this time more. For you to have an idea, I know this so well, because I had six months of pregnancy that were a very good experience… really very good… and as if I had guessed that the baby wouldn't stay. So you always have to live… never stop… but responsibly." (Mariana)

"That's it, to get better every day… Now, at this moment, what I really need is to work, because I sell flowers and I couldn't even sell flowers, because when I went out in the street, everyone was asking… and the belly and the baby… well, that shocked me even more, so I stopped… I was shut up inside the house… the neighbors came to visit me… there are some that try to get you up… For the last month I've been a normal person… I've been calm without taking tranquilizers, my tranquilizer is Jesus… he's the best tranquilizer… Now I se myself as a normal person… if anyone needs me, I'm here to help and move on." (Marilsa)

"I'm studying to see if I can get a qualification in something, sort out my life, no, I'm moving on… I'm first of all thinking of getting this infection treated and then marrying [she already had a boyfriend]… to get married so that it won't happen that I get pregnant and nobody wants to shoulder this [she cries]… " (Antonia)

"To bring up the boys and… I don't know… get a job, work, because I'm unemployed… work to help my mother… these things… It's not that a live child makes a difference from a dead one, I think… you carry it in the belly for nine months for it to then… be born dead… I think that if it had been born alive, I'd be bringing it up in the same way I've brought up the others… But now it's happened… I just pray every night and ask that it may rest in peace... a little angel… it didn't see anything… it didn't even get to breast-feed from me, nothing… I won't forget it, no… " (Ane)

"Ah, I intend to get pregnant in the year 2000… if God so wishes… But the next one will go OK… if God so wishes." (Alzira)

In the light of this, it can be seen that the women have now shifted the focus of their problems from the loss of the baby, which until then had been the center of their preoccupations, to a view of the future projected from the present. Thus, through their experience of fetal loss, they have been able to find out many things about themselves that had until then been unknown, concealed and muted.

According to Souza[17] (1998), "the definition and explanation of an illness [problem] is an interpretative act involving reflection and distancing, when the subject goes back over his experiences to interpret them, when he is no longer within the flow of experiences, which, seen in retrospect, appear to be full of meaning". (p.151)

In attempting to summarize the comprehension of the significance of losing the baby through the interviewees' words, it can be recognized that: *"It was an experience… a pain… a hard experience that came to shake me and made me think of disappearing from the world. It signified the loss of a piece, a part of me, but my baby will never be forgotten, because it was unique, special and it brought happiness. It also made me reflect, with changes in my attitude to life, in the sense of finding or rediscovering a mother's love and bringing maturation within my identity as a woman, showing the importance of valuing life, living for now, this minute, and responsibly. For me, it's only God Himself who can give an explanation, but at the same time, He was the one who comforted me most and made me see that we are nothing in comparison with the universe and it was only like this that He made me comprehend that the loss of my baby, instead of meaning nothing, meant everything."*

Experience, as employed here, is in the sense conferred by Benjamin, for whom "experience is not what takes place and is registered outside of the subject, but rather what occurs with/within the subject and therefore modifies, transforms and alters his identity" (Sousa[16] 1998, p.262).

The lesson from Benjamin[3] (1994) is that "the experience that is gone through is passed from person to person by the anonymous narrators of oral histories and, from such narrative, the experience is clarified with a practical sense that can constitute a teaching, a practical suggestion or a guideline for life" (p.198-200).

But furthermore, "the advice is sewn into the live substance of existence and has a name: wisdom" (p.200).

CONCLUSIONS

The present qualitative study has allowed us to obtain a closer comprehension of the significance of the fetal loss experienced by some women, taking into consideration all the dimensions of the human being.

It was possible to glean information for understanding such women's sociocultural realities from the different circumstances that they reported and their relationships with the healthcare services, religious institutions and other people. This showed how all these relationships occurred and were felt by such women when faced with their problem.

There needs to be a change in general concepts in the mission to attend to such women. The attendance provided by the healthcare services needs to be humanized. The need for multiprofessional follow-up of healthcare service users who suffered fetal loss was very evident. The importance of a support network for women who have gone through this problem was also shown.

Fetal loss is a rupture or crisis in the lives of these women. It implies a need for them to reconstruct their identities on a new basis that will enable them to take a leap forward in the quality of their lives and give them the wisdom for them to counsel other women so that these others may avoid going through similar processes.

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