



Perinatal Palliative Care: A qualitative study evaluating the perspectives of pregnancy counselors

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Abstract

Background: A prenatal diagnosis of a life-limiting disease raises complex ethical, emotional, and medical issues. Studies suggest that 40%–85% of parents decide to continue the pregnancy if given the option of Perinatal Palliative Care. However, structured Perinatal Palliative Care programs are missing in many European countries. In Germany, parents have the right to free psychosocial support from pregnancy counseling services after the prenatal diagnosis of a life-limiting disease.

Aim: We aimed to investigate whether German professional pregnancy counselors perceive the need for structured Perinatal Palliative Care and if so, how it should be conceived.

Design: This is a qualitative interview study with purposeful sampling. The interviews were analyzed with the coding method of Saldaña.

Setting/participants: A total of 10 professionals from three different pregnancy counseling services participated in the study.

Results: The main topics raised by the professionals were as follows: (1) counseling and parental support during the decision-making process; (2) fragmented or missing support infrastructure for parents; and (3) challenges, hesitations, and barriers, particularly from the different stakeholders, regarding a Perinatal Palliative Care framework. They highlighted the importance of the integration of Perinatal Palliative Care in existing structures, a multi-professional approach, continuous coordination of care and education for all healthcare providers involved.

Conclusion: A structured Perinatal Palliative Care program is considered as necessary by the pregnancy counselors. Future research should focus on (1) needs reported by concerned parents; (2) attitude and role of all healthcare providers involved; (3) strategies to include stakeholders in the development of Perinatal Palliative Care networks; and (4) outcome parameters for evaluation of Perinatal Palliative Care frameworks.

Keywords

Palliative care, perinatal care, prenatal diagnosis, qualitative research, perinatal hospice, pediatric palliative care

What is already known about the topic?

- Since prenatal diagnostics are more often applied, the number of families confronted with a severe life-limiting disease of their fetus is increasing.
- In contrast to the United States and Canada, Perinatal Palliative Care is not yet a common option for affected couples in Europe.
- Data suggest that many families decide to continue the pregnancy if Perinatal Palliative Care is offered to them.

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What this paper adds?

- This study indicates that pregnancy counseling professionals advocate for a structured Perinatal Palliative Care program.
- To avoid the risk of alienating important stakeholders, a comprehensive Perinatal Palliative Care program should be integrated in already existing structures, encompassing a multi-professional team and continuous coordination of care, as well as education of relevant healthcare providers.
- A comprehensive framework should ensure that affected couples are informed about all options, are supported during the decision-making process, and have freedom of choice and professional support regardless of their decision.

Implications for practice, theory, or policy

- The results of this study can inform the development of a Perinatal Palliative Care framework for affected families.
- The hesitations and barriers mentioned by the professionals stress the need to carefully integrate a Perinatal Palliative Care program in already existing structures, in close cooperation with all relevant stakeholders.
- Future research should focus on the attitudes and roles of other involved healthcare providers, such as midwives, obstetricians, and neonatologists.

Introduction

Prenatal diagnostics have developed rapidly. In the 1970s and 1980s, they focused on invasive prenatal testing.¹ Nowadays, with non-invasive prenatal testing, it is possible to identify fetal autosomal trisomies in maternal blood.^{1,2} Due to the increasing use of prenatal technologies, more and more couples are confronted with the diagnosis of a severe life-limiting disease of their unborn child.^{3–6}

These diagnoses raise emotionally challenging decisions for couples and clinicians concerning a possible termination of the pregnancy.^{7–9} Couples who decide to carry on with the pregnancy need to make decision about the rest of the pregnancy, delivery, and the degree of medical interventions they desire.^{10,11} Perinatal Palliative Care seeks to support these families.^{10,12} In previous studies, 40%–85% of concerned couples who were offered Perinatal Palliative Care decided to continue the pregnancy and most of them were content with their decision in retrospect.^{13–16} However, in Europe, structures for Perinatal Palliative Care and the scientific monitoring of the effects of Perinatal Palliative Care are still poorly developed.¹³

In Germany, psychosocial counseling during pregnancy is offered to families in specialized pregnancy counseling centers. These centers also provide counseling before and after prenatal diagnostics.¹⁷ Thus, professionals of pregnancy counseling services are key informants to determine the need for a structured Perinatal Palliative Care program in the German context. We conducted interviews with experienced counselors to understand their experiences and determine whether there is a need for a structured Perinatal Palliative Care program and how the framework of such a program should be conceived.

Methods**Design**

This is a descriptive qualitative study with professionals from pregnancy counseling services. The aim of the investigation

was to explore the subjective perspective of experienced participants and to generate hypotheses about the needs and requirements for a structured Perinatal Palliative Care program. The method and its reporting follow the *Consolidated criteria for reporting qualitative research (COREQ)*.¹⁸ The interview guideline and the coding list are available from the first author (F.F.). In order to maintain anonymity, the participants' informed consent does not allow us to share the complete interviews with third parties.

Sampling and recruitment

Participants were selected by purposeful sampling. Criteria for inclusion were as follows: (1) professionals of pregnancy counseling services with (2) experience in counseling cases of prenatally diagnosed life-limiting disease ("information-rich cases")¹⁹ and (3) interest in the research question.

The following factors were considered to maximize participant variation: (1) different pregnancy counseling services: (a) two general pregnancy counseling services (one denominational, one independent) and (b) one independent specialized pregnancy counseling service (pre- and post-prenatal diagnostics); (2) city versus medium-sized town/small town.

Eligible persons were identified by gatekeepers and contacted by F.F.

Data collection

The interviews followed a semi-structured interview guide according to Helfferich.²⁰ The interview guide was reviewed in a research group with methodological, clinical, and bioethical expertise and was piloted with one counselor, resulting in minor revisions. Interviews were conducted from May to October 2015 by F.F., midwife and medical student. Participants received an information letter about the study background, methods, and data protection and gave their written consent.

At the beginning of the interview, the interviewer explained the term life-limiting disease as described by Van Mechelen et al.²¹: incurable disease, progression despite therapy, significantly limited life expectancy, and potential benefit of symptom-oriented treatment focusing primarily on the quality of life.

Four main questions were asked during the interview: (1) Can you describe the counseling process of a couple who received a prenatal diagnosis of a life-limiting disease? (2) Which options do you offer in the counseling process? (3) If parents decide to continue the pregnancy, what do they need? (4) *After presenting a possible Perinatal Palliative Care structure* (see Supplemental Appendix 1): What do you think about this proposal?

Sociodemographic data were collected, and interviews took between 40 and 60 minutes. All interviews were audiotaped and transcribed verbatim. All personal information was irretrievably anonymized, and audio recordings were deleted. The study protocol and materials were approved by the ethics committee of the Munich University Hospital (no: 149-16).

Data analysis

Transcripts were analyzed by F.F. and an assistant researcher (T.S.) according to the coding method of Saldaña,²² using the software MAXQDA 12. During the first cycle, data-driven codes were generated using descriptive coding, in vivo, and evaluation coding.²² Data were analyzed independently by the two researchers. Codes were repeatedly compared, optimized, and summarized. Memos were written during the whole process. The resulting list of codes was reviewed during the second cycle and reorganized into three main categories using focused coding. Focused coding rearranges first cycle codes and develops a coherent synthesis of data in accordance with the research questions. Results were discussed with co-authors and validated in a multidisciplinary research meeting.

Results

Professionals from three different Bavarian pregnancy counseling services participated in the study. Two counseling services were part of nation-wide pregnancy counseling associations. Overall, 11 interviews were conducted with 12 participants (2 female professionals were interviewed together because of the special structure of their working place). Two interviews were excluded from the analysis: one was the pilot interview and the other was excluded due to scarce professional experience of the participant. Table 1 lists the demographic characteristics of the remaining 10 participants.

Three major issues emerged from data analysis:

Table 1. Demographic characteristics of the participants (N = 10).

Characteristics	Participants
Gender (n)	
Female	9
Male	1
Age (years)	
Mean age (SD)	49.1 (1.01)
Range	38–60
Area of working (n)	
Large town (>70,000 inhab.)	7
Medium-sized or small town (<70,000 inhab.)	3
Training (n)	
Psychotherapist	1
Social worker	9
Professional experience in pregnancy counseling (years)	
Median	19
Range	5–29
Number of cases per year with a severe prenatal diagnosis (n)	
Median	7
Range	2–350
Denomination (n)	
Catholic	6
Protestant	2
Non-denominational	1
No information	1

SD: standard deviation.

1. Emotional and professional challenge of counseling couples facing a prenatal diagnosis of life-limiting disease;
2. Fragmented or lacking support infrastructure for affected couples;
3. Challenges, hesitations, and barriers regarding a Perinatal Palliative Care framework.

Emotional and professional challenge of counseling couples facing a prenatal diagnosis of life-limiting disease

Special conditions for affected couples. Most participants perceived the counseling process of these couples as unique. After receiving the diagnosis from the gynecologist, the couples are reported to be in a state of shock. Thus, participants offered them exceptional counseling conditions like prompt access and long-term support, including bereavement counseling, sometimes until the next pregnancy.

Addressing the emotional shock after the diagnosis. Participants perceived couples as stunned and unable to adequately express their concerns. At this point, participants stressed that they offered couples patience and enough

time to empathetically listen to them and to speak openly about the situation. In the following citation, one participant reported from the perspective of a client revealing the intense feelings triggered by the situation:

I suddenly realize that my own pregnancy, the status of being in good hope, no longer exists. There are just black clouds, there is just the feeling, oh my god, perhaps I am carrying a curious being, disfigured and malformed and ill and disabled. (Interview 10, male counselor)

Confronted with the loss of their hopes for a future as a family with a healthy child, couples felt despaired and helpless. The parental shock was described as emotionally challenging by the professionals.

Describing the decision-making process. Participants observed that couples often did not really understand the meaning of the diagnosis. Thus, participants described that they intend to help couples to realize the meaning and to clarify the consequences of such a diagnosis. They mentioned the option to connect couples with other parents or support groups for the particular diagnosis.

The uncertainty of diagnosis and prognosis led to immense stress for the couples. One counselor stated:

Sometimes there are thoughts like “Will the child have a chance of survival and what will it mean if it survives with high care needs?” Some parents are more afraid of this than of the child’s death. (Interview 11, female counselor)

Participants informed parents about the options of abortion as well as continuing with the pregnancy. They stressed the importance of carefully considering all alternatives, because couples have to live with their decision for the rest of their lives:

You have to live with the fact that you made this decision. And that is easier, when you know or when you are conscious about the fact that at that moment it was right. Because it will, maybe afterwards or in a couple of years, you will always have doubts. Or you might have doubts. But if you know, I had no other choice. I went through everything. I really made my choice. It felt right. This, I think, is a relief. (Interview 11, female counselor)

Participants felt that physicians often failed to adequately inform parents about the available options and pressured them into making a quick decision leaving no time to think about all alternatives, sometimes even pushing families to abortion. One participant stated:

The problem I see is the following: When doctors communicate such a diagnosis, it seems to be as if the families get the feeling: the child is ill, we can’t have it, we need to abort it. It is communicated like that. That there is no other option because it is not possible to live like that.

Therefore this thought already resonates while the diagnosis is communicated. (Interview 7, female counselor)

As participants stressed, also family and friends seem to believe that abortion will be a quick and easy solution. Thus, couples who wanted to continue with pregnancy faced a lack of understanding.

According to participants, couples were uncertain about legal rights, including (1) what they would be allowed to decide on their child’s healthcare after birth; (2) whether healthcare providers will accept a decision against life-sustaining measures; (3) whether they will accept the wish for their baby to die in peace without suffering; (4) what will happen if the baby survives pregnancy and birth for a longer time than expected; and (5) who will support them at home in such a situation.

They stressed that parents were worried that their baby will have to suffer. This will require a special competence in symptom control. As the following quote emphasizes:

And if the decision is, I will have the child, this goes along with the uncertainty, will I find a doctor who says “We’ll leave the baby in peace, we will not do high-tech medicine. We will make sure that it doesn’t need to have pain.” Or, often it is the respiration that falls. And then there will be something to avoid them choking miserably. (Interview 4, female counselor)

Overall, participants stressed the importance of having time for the decision-making process: time to realize the diagnosis, time to get all the information needed, time to talk about all options, time to decide, time to mourn, and time to be accompanied for as long as needed. They also stated that affected mothers and fathers might have different needs, which is one reason why the experience could threaten the couples’ relationship.

Fragmented or lacking support infrastructure for affected couples

Participants described that support already exists, but it is rather fragmented and uncoordinated. They stressed that only a few of the affected couples were able to access their counseling services. The lack of coordination between healthcare providers was mainly pointed out in cities, whereas in medium-sized/small towns, adequate support infrastructure was considered as completely missing. Participants reported that some physicians were convinced that they provided enough counseling by themselves and some did not acknowledge the necessity of psychosocial and emotional support at all.

Since participants were aware of their lack of medical knowledge and insufficient information about palliative care, a multi-professional approach was seen as essential.

Participants requested specific education for all health-care providers involved.

Participants also highlighted the central role of midwives during pregnancy, delivery, and postnatal period and advocated for continuous support provided by the same midwife during the whole process as a way to better navigate these families through the delivery and afterbirth:

Of course, it would be great for a pregnant woman, for whom it is already clear that the prognosis or the findings are unfavorable, to have access to the same midwife during pregnancy, delivery and also during the follow up. I would see that as the optimal situation. (Interview 11, female counselor)

Challenges, hesitations, and barriers regarding a Perinatal Palliative Care framework

During the interviews, participants were asked their opinions about a possible framework for Perinatal Palliative Care (Supplemental Appendix 1). They mentioned specific challenges and barriers. Some of the participants were concerned that their own work might no longer be needed by these families. Participants feared their individualized support could get lost. They stressed their experiences in accompanying couples and their psychosocial expertise including grief counseling. Thus, participants would appreciate to be an active part of a framework.

Furthermore, participants expressed doubts as to whether and how physicians doing prenatal diagnostics could be involved in a Perinatal Palliative Care program, given that some physicians did not even consider it necessary to refer these couples to pregnancy counseling services. Participants also anticipated that conflicts might arise with obstetricians in hospitals regarding delivery planning, as well as with neonatologists about the planning of adequate/individualized care for the newborn. One participant mentioned that it could be difficult for some professionals to accept a parental decision to forgo life-sustaining treatment options.

Nevertheless, all participants recognized the value of implementing a framework for Perinatal Palliative Care. They suggested that it could complement the already existing resources and provide improved coordination of care for families. Participants mentioned that the offer of such a program could facilitate the decision to continue with the pregnancy, since couples would not feel like they were choosing a pathway that was completely out of the ordinary.

Some participants proposed to integrate a Perinatal Palliative Care framework in the already existing structures, in order to avoid redundancies and improve collaboration between stakeholders. As one participant stated:

Everything can run in parallel, but it would be nice to get someone else on board. Care should just be taken that not too many people are caring for the families, that it will become too much for them. It is just important to complement each other well. (Interview 2, female counselor)

Besides, participants expressed concerns about financing a framework and about the high amount of human resources necessary. Participants stressed that Perinatal Palliative Care should be attached to medical centers, so that the access would be available to as many couples as possible.

Discussion

This qualitative study provides information from the pregnancy counselors' point of view about the need for Perinatal Palliative Care and how a framework should be conceived.

Main findings

Generally, parents are informed about the life-limiting disease of their unborn child by physicians without being offered psychosocial counseling. Participants characterized couples as being shocked and traumatized by receiving the diagnosis, which is consistent with the results of previous research on this topic.²³⁻²⁶

Participants also mentioned that parents in this situation need time to recognize their new circumstance, obtain information, and reflect on available options in order to make an informed decision. These results reinforce previous findings that highlight decision-making as a multi-step process where time pressures make it more difficult for affected couples to find their own way.⁸

Participants often identified the quality of medical counseling as insufficient. Some stated that parents are missing comprehensive information about the prognosis and the different treatment options, especially the uncertainty about prognosis, which could lead to immense stress for them. Therefore, limitations of the prenatal diagnosis need to be openly communicated.²⁷ Some participants even reported that parents were not informed by physicians about the option of carrying the pregnancy to term, which was also described by Chitty and colleagues²⁸ many years ago.

Several reasons for this perceived lack of information need to be discussed. It is known that in existential crises, processing and retaining of information may be severely reduced. Barriers and hesitations around talking about life-limiting disease as well as the lack of training physicians receive in communication may be possible reasons that palliative care issues are not well discussed. Furthermore, physicians as well as family members and friends often seem to believe that abortion is the best

way of dealing with the unfavorable prognosis of the fetus.^{9,14,28–31}

In contrast, the American College of Obstetricians and Gynecologists and the American Academy of Pediatrics strongly recommended non-directive counseling respecting the principles of informed consent. The “full range of options, including fetal intervention, postnatal therapy, palliative care, or pregnancy termination, should be discussed.”³²

Prior studies have shown that couples who opt to continue with pregnancy often faced a lack of understanding and support from their families as well as from healthcare providers.^{9,14,31,33–35} Some participants reported that they had the impression that parents coped better with bereavement if they carried pregnancy to term. This is consistent with prior research showing that the experience of continuing the pregnancy can strengthen the couple as well as the surrounding family.^{16,28,36–40}

Participants stressed the importance of healthcare providers acknowledging the parents’ worries about their baby’s suffering. Therefore, parents need to be sure that everything will be done to relieve the baby’s symptoms.^{12,39} Furthermore, Walker et al.⁹ and Denney-Koelsch et al.⁴¹ stressed that parents appreciate the option to take part in the development of a care plan, and that they would like professional caregivers who accept and support their decisions and preferences.

According to our participants, it is really important that parents can trust that their wishes for the postpartum care of their child will be respected and that all measures will be taken to avoid suffering.

Qualitative studies reported that families supported by Perinatal Palliative Care described the experience as meaningful and the birth as a joyful moment.³⁹ More than 90% experienced the life of their children as positive for the children and their families¹⁴ and did not regret their decision to continue the pregnancy.⁴²

Since continuity of care could prevent parents from feeling “emotionally exhausted,”^{39,41} the participants proposed to strengthen the role of midwives. A continuous support by the same midwife was seen as crucial to integrate these special situations into standard processes of delivery and afterbirth care. As reported in other studies, continuity of care is of paramount importance to ensure an optimal access to information and professional support for parents.^{43,44}

Need for a structured Perinatal Palliative Care program

Participants hoped that a structured Perinatal Palliative Care program could link together medical and psychosocial support for affected families. Thus, they advocated for a multi-professional and interdisciplinary approach to support this goal.^{4,45–47} Different support services already

exist, but the connection appears difficult. For example, gynecologists do not need to refer parents to pregnancy counseling services and are often unaware of the option of Perinatal Palliative Care. This highlights the importance of involving all stakeholders in the development of a structured pathway and including them in implementation and evaluation.

Participants highlighted the necessity of education of all involved healthcare providers in order to enhance the competence of professionals.^{27,48–50} Special attention should be paid to the training of communication skills.^{51,52}

Participants stressed the need to recognize existing structures when developing a framework for Perinatal Palliative Care, to avoid alienating healthcare providers who are already working in this field, which is consistent with the recommendations by Hoeldtke and Calhoun.⁴

Implications of the study

A structured Perinatal Palliative Care program should be available to all couples faced with the prenatal diagnosis of a life-limiting disease of their child. The program should link the psychosocial competence of pregnancy counselors with the specific medical and nursing support of pediatric palliative care teams. Midwives are essential for the program as continuous care persons and could play an important role as gatekeepers to the program. Structured pathways for prenatal palliative care should be developed and implemented in collaboration with all care providers involved.

Limitations of the study

Pregnancy counseling services do not exist in every state, which limits generalizability. All participants worked in southern Germany. The enquiry was restricted to a particular professional group, which in itself does not provide sufficient information to develop a structured Perinatal Palliative Care program. Therefore, we plan to interview other involved healthcare providers in future studies.

Conclusion

Our results emphasize the necessity of integrating the development and implementation of a Perinatal Palliative Care framework into already existing structures. This would help to prevent alienating healthcare providers already working in this field and would ensure continuity of care. Future studies should focus on parental needs and concerns about palliative care as well as the attitudes and roles of the diverse healthcare providers involved.

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Supplemental material

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