

CHAPTER

BARRIERS TO REFERRING PATIENTS FOR PERINATAL PALLIATIVE CARE

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At the international level, perinatal palliative care constitutes a new clinical practice where challenges such as prognostic uncertainty exist, and infant survival and quality of life may be unknown. Identifying factors that can affect the way clinicians address these important ethical and clinical tensions is necessary. We explored the perceptions and professional practices of clinicians who work with parents who wish to continue a pregnancy diagnosed with a life-limiting fetal condition (LLFC) despite the uncertainty corresponding to the postnatal condition of a newborn.

Our research examined three perspectives: (a) a regionally based qualitative study of the perceptions, opinions, and professional practices of clinicians when an LLFC was present; (b) a national-level investigation of initiatives taken in perinatal care based on perceptions and professional practices; and (c) the ethical approach to the medical care as inspired by LLFCs and professional practices in perinatal medicine.

Current barriers to perinatal palliative care in France include lack of clear terminology, clinician's emotional discomfort, lack of clinician training, and lack of referrals. The vast majority of professionals (92.5%) supported considering the practice of palliative care as a regular option to propose antenatally. Our work reveals the clear need for training perinatal professionals in perinatal palliative care and for the standardization of practices in this field.

CASE STUDY

A 45-year-old, 24-week gravida 5, para 4 came to the Multidisciplinary Center of Prenatal Diagnostics (MDCPD) for a pediatric consultation. A second-trimester morphological ultrasound examination had revealed a multiple malformation syndrome with an incurable complex of cardiopathy, intrauterine growth restriction, and brain abnormalities. The patient understood the likelihood of a chromosomal anomaly as well as a limited life expectancy for the infant. The couple refused any genetic investigation and wished to continue the pregnancy, explicitly requesting that the infant receive pediatric palliative care.

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CASE STUDY (continued)

Two meetings occurred between the pediatrician and the patient to discuss the treatment options, the purpose of each paraclinical examination, the uncertainty of the infant's life expectancy, pain management, feeding options, family logistics for their large family, their geographical distance from the MDCPD, and their parenting wishes. The patient had a vaginal term delivery in the MDCPD maternity ward. Neonatal adaptation was deemed "correct" despite the presence of a heart murmur, hypotonia, hypotrophy, and facial dysmorphism with microretrognathia. As prearranged, the family's religious observations were conducted in the delivery room. The infant experienced cyanosis associated with desaturations and bradycardias and experienced rapid recoveries from each episode. Suction-swallowing disorders prevented any feeding autonomy, and an umbilical venous catheter for parenteral nutrition was immediately followed by continuous enteral feeding.

Numerous interviews between the healthcare team and the parents included prognoses for the infant's life expectancy, the family's request for hospitalization, and genetic diagnostics testing by the medical team. Although the referring physician understood the irrelevance of these tests from the parents' perspective, an attempt was made to explain how the siblings and their future offspring might benefit from these test results. The parents authorized a karyotype but did not wish to know the test's outcome. They agreed, however, to have the results accessible to those siblings who asked for them.

After 15 days of supervised care and feeding, the family requested that the infant be discharged and permitted to go home. The medical team expressed concerns over the consequences of a hospital discharge given the infant's limited life expectancy and the prospect of a home death.

Case Questions

1. How do clinicians receive and accept unexpected parenting requests given the place of parental autonomy in the care relationship?
2. How do clinicians apply the ethical principles of beneficence and nonmaleficence when clinical cases include uncertainties and doubt?
3. What are some of the challenges caregivers may experience as the patient's death approaches?

OBJECTIVES

This chapter addresses the following objectives:

- Outline results from a qualitative focus group addressing professionals' perceptions of what constitutes a lethal fetal pathology and emotional reaction to such diagnoses

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OBJECTIVES

- Present results from a French national-level investigation exploring clinicians' perceptions and professional practices
- List clinician-reported criteria in which palliative care should be available and clinician-reported barriers
- Explain the psychosocial approach to lethal fetal abnormalities using the perinatal professional's palliative approach
- Discuss recent developments and ethical considerations surrounding perinatal palliative care in France

BACKGROUND

Severe congenital malformations are one of the leading causes of childhood morbidity and mortality. Despite advances in perinatal medicine, some prenatal diagnoses preclude postnatal survival. From as early as the first trimester, perinatal professionals may be required to announce some unforeseen or bad news to the future parents.¹ The emotional charge is then exacerbated. In the event of a serious, incurable, or lethal diagnosis, the parents face uncertainty and many difficult decisions, including the option of termination of pregnancy (TOP). Whatever decisions are made, they all affect the unborn child, the family, and the parents themselves.² Parents have two choices: either continue the pregnancy and provide adequate care for the newborn while avoiding unrealistic requests or medical TOP. For most parents, these are two unbearable choices. Interrupting life or confronting the disease and opting for palliative care are not simple alternatives. Some parents decide to continue with the pregnancy.³ Not all fetal abnormalities are life-threatening at the time of birth, so perinatal palliative care (PPC) supports the infant during a sometimes limited lifespan and differs from TOP. It is not a question of choosing between two treatments to treat a disease, but rather of choosing between two different treatment plans with different time frames. The palliative care approach is an open-ended and uncertain pathway, whereas TOP ends a pregnancy but may involve psychological sequelae.

PPC, so named in English language scientific literature, is a new international specialty focusing on fetal and neonatal healthcare and prepares parents and providers for the continuity of postnatal care.⁴ Palliative care begins at the time of a complex and potentially life-limiting fetal diagnosis and continues into the postpartum period.⁵ This new area of clinical practice poses decision-making challenges for parents, as well as potential ethical dilemmas to be addressed by parents and clinicians.⁶

Within the context of a LLFC, and as a direct result of information exchanged between clinicians and parents, obtaining parental permission or consent (legal and

proper care obligation) raises questions. How much decision-making liberty do the parents have? How can healthcare professionals offer a meaningful response when, despite the presence of a lethal pathology and postnatal uncertainties, parents request that the pregnancy continue? PPC decision-making practices are fueled by various dilemmas, and several of these challenges are addressed in this chapter.

PERINATAL PROFESSIONALS' PERCEPTIONS OF LETHAL FETAL CONDITIONS

In France, the Voluntary Interruption of Pregnancy Act of 1975 (the “Veil Law”) allows a woman to request a termination of her pregnancy if the fetus is diagnosed with a *high probability of a grave, incurable pathology*. Yet, 1296 women in France eligible for termination opted to continue their pregnancy in 2015—100% more than in 2011. In 79% of these cases, the pregnancy resulted in a live birth.⁷

The very term *lethal fetal pathology* (LFP) is debatable, and the term *life-limiting fetal conditions* (pathology limiting postnatal survival) seems more appropriate.⁸ Postnatal life span with an LFP is unpredictable, and the list of inevitable and rapidly fatal diseases is open to discussion.⁹ Unfortunately, the ability to have an ideal prognosis to manage care is not currently within our reach.¹⁰ A recent report from Dominic Wilkinson in the United Kingdom recalls that pathologies commonly referred to as *lethal*¹¹ could have a prolonged survival.⁹ The most striking example among these cases is trisomy 18, which now has a life span reported up to 50 years.¹²

In order to clarify the meaning of the term *LFP*, we conducted a qualitative study based on exploratory interviews with professionals from two multidisciplinary prenatal diagnosis centers in France.¹³ Our interviews focused on the professionals' definition of an LFP, their perspectives, associated difficulties that arose from such definitions, and the context of professional practices in LFP situations. Most of the professionals defined LFP with the following components: limited survival time, level of the condition's severity, and whether the fetus was viewed as noncurable or nonviable. Some professionals stated that a death in utero or at birth was to be the criterion for an LFP, whereas others viewed a pathology for which medical intervention was impossible (e.g., complex heart disease) as the criterion. These defining criteria question what actually constitutes “lethality.”

For some clinicians, LFP was also defined as a particular emotional experience: a situation that “tortures us” (gynecologist), which “often breaks our heart” (neonatologist), or which makes us want to “take up arms” (gynecologist). The LFP was considered from the perspective of the definition, the resulting difficulties, and within the situational context of professional practices. The focus group analyses showed the complexity of the issues and the difficulty in defining them. The practices mentioned are marked by the consideration of multiple issues (professional, informational, human, ethical, etc.) and questions the need and merit of a multidisciplinary approach.^{4,14,15}

NATIONAL-LEVEL INVESTIGATION EXPLORING CLINICIANS' PERCEPTIONS AND PROFESSIONAL PRACTICES

As a follow-up to our pilot study, our second study's objectives were to establish a national inventory within the MDCPD's LFP practices of perinatal professionals in France: (a) to identify the criteria in which palliative care should be available when a potentially antenatal, lethal pathology is diagnosed; and (b) to identify the barriers to the acceptance of palliative care. We performed a quantitative national-level survey of 214 perinatal professionals practicing at the MDCPD.¹⁶

General Findings

More than a quarter of those surveyed believed that over 20% of fetal pathologies seen at the MDCPD could correspond to an LFP diagnosis. This reply was more often stated by pediatric professionals rather than gynecologists, testifying to a lack of clear terminology or definition of LFP. Professional practices concerning these LFP were heterogeneous: trisomy 18, major or syndromic diaphragmatic hernia, anencephaly, major hydrocephalus, and bilateral renal agenesis.¹⁶ The majority of professionals considered neonatal palliative care necessary to accompany parents anticipating their infant's death and that a birth plan in palliative care can be considered as an alternative to TOP.

Criteria in which Palliative Care should be Available

Professionals reported that respect and support for the parental choices was the most important factor in the decision-making process. The item examining autonomy, "respect parents' freedom of choice," garnered support from more than half of the professionals (56.6%, $n = 120$). The item examining newborn presumed quality of life was also an important factor (97.1%, $n = 204$), despite the infant's anticipated shortened lifespan. Additionally, diagnostic certainty for some infants affected decision making (98.1%, $n = 207$) and influenced the delivery of palliative care information antenatally.

Barriers to Palliative Care

Differences Among Specialists

Our study revealed differences in professional perspectives between pediatric and obstetric specialists concerning certain clinical, legal, and ethical aspects of the prenatal diagnosis of a "lethal" pathology (Table 7.1). There were varied perceptions of palliative care between obstetrical physicians and neonatologists regarding its definition as "an active and continuous care practiced by an interdisciplinary team in an institution or at home, focused on relieving pain, soothing mental suffering, safeguarding dignity, and supporting persons implicated in the infants' lives."

TABLE 7.1 Definitions and Perceptions of LFA Reported by Perinatal Professionals

	n (%)		p-VALUE
	MFMs	FCPs	
Diagnosis and prognosis of LFA			
Difficulty in diagnosing LFA	73 (73.7)	94 (85.5)	0.035
Prognostic uncertainty of LFA	29 (29.0)	37 (33.9)	0.442
Neonatal palliative care is care intended to provide end-of-life support for patients	90 (90.9)	72 (64.9)	<0.001
Provision of palliative care to a neonate is fundamentally analogous to that provided to other patients	59 (59.6)	47 (42.3)	0.013
PPC can be considered as an alternative to TOP	86 (87.8)	80 (71.4)	0.004

FCPs, fetal care pediatric specialists; LFA, lethal fetal abnormality; MFMs, maternal–fetal medicine specialists; TOP, termination of pregnancy.

Source: Modified from Tosello B, Dany L, Bétrémieux P, et al. Barriers in referring neonatal patients to perinatal palliative care: a French multicenter survey. *PLoS ONE*. 2015;10:e0126861. doi:10.1371/journal.pone.0126861

Lack of Training

Fewer than half of the professionals received any practical training (more common among FCPs 59.6% vs 34.4%; $p < .001$), and fewer than a quarter received any theoretical training. The medical teams' coherence, their training, and their multidisciplinary are essential tools to deliver the most appropriate information and to minimize the ethical and emotional difficulties that inevitably emerge in these situations. Training perinatal professionals on palliative care will lead to making qualified teams for this approach: caring for any doubt with a high level of confidence and respect, a good level of communication, and with a capability to reconfigure roles in the face of the unexpected.

Complexity in Defining Terminology

In our studies, both the qualitative and quantitative aspects of the surveys showed the complexity and difficulty in defining LFP. Complexities are characterized by multiple issues, including professional, informational, human, and ethical. These challenges set the foundation for a multidisciplinary approach.

Medical Interventions and the Patient's Psychosocial Influences

Inclusion of palliative care in perinatal medicine must be considered in the context of these findings and current medical frameworks. From a medical perspective, severe pathologies involve an action. TOP, for example, is one action. In an intensive care setting, curative treatments are an example of action-oriented interventions. In

palliative care, actions involve intentional strategies to maximize infant comfort and parental bonding. However, the nature and meaning of these varied actions are partly defined outside of the medical setting, in contexts where psychosocial influences lead to expectations and norms. The potential development of providing PPC should have us reflect on these pre-existing frameworks along with an ongoing deference to both ethics and personal suffering. It is necessary to explore the decision-making process that operates in this context. We need to look not only at future parents, but also at the clinicians who intersect with parents because the decision depends on how uncertainty can be approached by both sides.¹⁷ Joining together the professional experiences and practices along with the bio-psychosocial processes, which can give meaning, could prove useful for advancing reflections on LFP, their management, and possible options.

A PSYCHOSOCIAL APPROACH TO LETHAL FETAL ABNORMALITIES USING THE PERINATAL PROFESSIONALS' PALLIATIVE APPROACH¹⁶

Although three-quarters of French perinatal professionals had difficulties defining LFP,¹⁶ there was a shared collegial knowledge regarding the uncertainty and ethical issues posed by fetal pathologies. We tried to determine the perinatal professionals' perspective concerning the role of social representations of LFP and of perinatal palliative approaches in the management of this uncertainty.¹⁸ The free association method provided access to these representation fields.¹⁹ We asked subjects to spontaneously say words or expressions ($n = 3$ in our study) from the key phrases "lethal fetal pathology" and "perinatal palliative care." From this, the main analysis that followed was the "similarity analysis," thus making it possible to explore the generated graph from a relation between two elements of a set. This enabled us to highlight the structure underlying the internal organization of these elements.¹⁸

The similarity analysis for "lethal fetal pathology" (Figure 7.1) had three distinct groups.

The first group was organized around the expressions for TOP, which contained an emotional dimension of parents and palliative care. The second group consisted of support and information-related elements, and the third group included a group of diseases. Death was the connecting word between the group "termination of pregnancy" and the group of diseases. The similarity analysis for "perinatal palliative care" (Figure 7.2) showed two distinct groups with a large group organized around the notion of support.

The words related to this group had a strong link with respect to common values (dignity, benevolence, humanity), with palliative practices, and death or mourning. This group was strongly associated with the second group, which related to both pain and parents. Figures 7.1 and 7.2 reflect the difficulties inherent in diagnosing with precision as well as prognostic uncertainties. If the fetal diagnosis is closely related to the definition

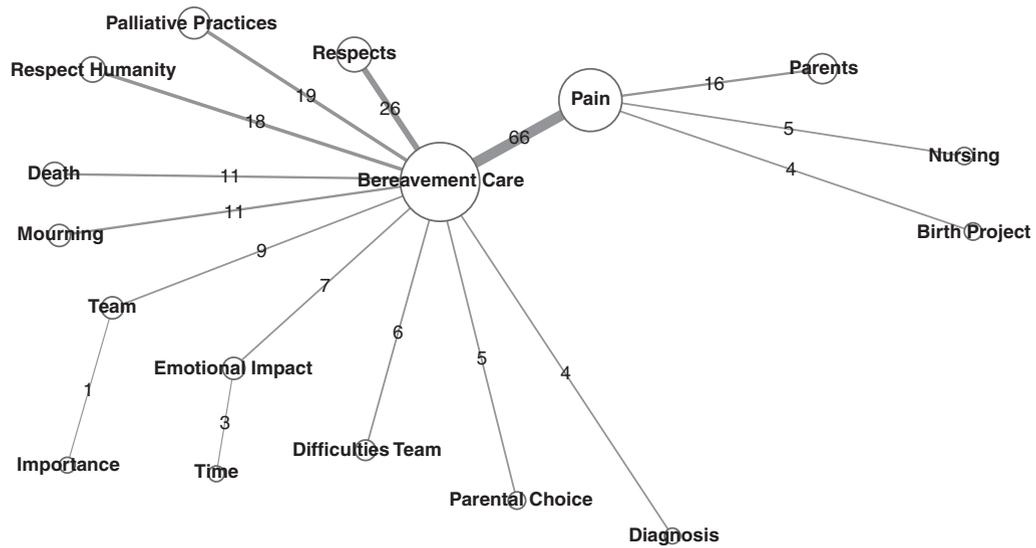


FIGURE 7.1 Similarity analysis of the thematic categories for PPC.

PPC, perinatal palliative care.

Source: From Tosello B, Dany L, Bétrémieux P, et al. Barriers in referring neonatal patients to perinatal palliative care: a French multicenter survey. *PLoS ONE*. 2015;10:e0126861. doi:10.1371/journal.pone.0126861

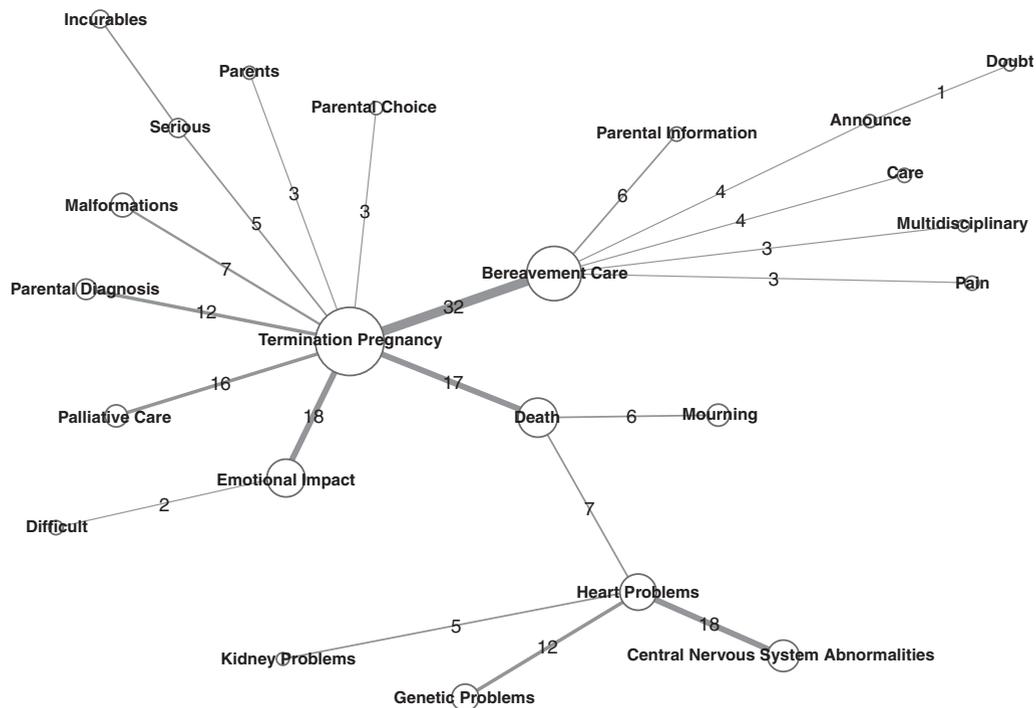


FIGURE 7.2 Similarity analysis of the thematic categories for LFA.

LFA, lethal fetal abnormalities.

Source: From Tosello B, Dany L, Bétrémieux P, et al. Barriers in referring neonatal patients to perinatal palliative care: a French multicenter survey. *PLoS ONE*. 2015;10:e0126861. doi:10.1371/journal.pone.0126861

of LFP, according to the French context, TOP can be considered as a “standard under the pressure of uncertainty.”¹³

RECENT DEVELOPMENTS

Recently, the French Society of Neonatology Ethics’ Committee convened to discuss adoption of a more probabilistic approach, especially since Wilkinson’s same article gives survival probabilities. The Committee will distinguish the serious and incurable pathologies strongly associated with limited life expectancy (bilateral renal agenesis, double diaphragmatic hernia, thanatophoric dwarfism, trisomies 13 or 18 with serious malformations) and those serious and incurable pathologies associated with prolonged life (number of inoperable heart diseases and conditions, congenital renal diseases, as well as certain neurological pathologies). In France, a median postnatal survival of 24 hours is reported for severe fetal diseases²⁰ and thus those previously mentioned fetal pathologies (trisomy 18, major diaphragmatic hernia or syndromic, anencephaly, major hydrocephaly, bilateral renal agenesis) are heterogeneous.²⁰

The representation of PPC program appears to follow a conceptual evolution.²¹ A palliative approach supports parents during the pregnancy journey to relieve the emotional trauma parents experience beginning in the antenatal period and providing anticipatory guidance to parents for the remainder of the pregnancy, birth, and postnatal period. Palliative care also addresses any potential comfort needs for the infant. This approach is similar to the one that the adult palliative care professionals have in France.²² Implementing an active and effective PPC program requires some degree of family-centered and cultural standardization,^{21,22} which questions the place of perceptions and their implications.¹⁶ The role of these perceptions and of their implications needs to be examined. Such an approach would test the technical, scientific, practical, social skills, and knowledge, as well give professionals a means to update their skills and evaluate its future applications.

An Ethical Approach to PPC

This collection of behaviors, conduct, and representations by perinatal professionals can provide an important starting point for normative ethical reflection.^{13,16} Indeed, since the fetus is said to be “ill,” it becomes a patient in its own right.²³ The respect of this principle toward the fetal patient rests in balance, always assessed according to the interest, respect, and autonomy of the pregnant woman. Nevertheless, these are all *prima facie* obligations, and none is more important than another. The pregnant woman is torn between protecting her unborn baby and her limited autonomy. Therein lies our professional challenge and responsibility to inform women within a perinatal ethical model.²⁴

There are great uncertainties within the defined perinatal scope, and caregivers and parents are confronted with exceptional situations. How do they integrate these uncertainties in making care decisions? How do both parents and professional caretakers

collaboratively distinguish, share, and assume the risks to develop care strategies? These strategies, while not pretending to erase the uncertainty, can help manage the doubts of the healthcare overseers and de facto improve the care of patients (the woman or the couple and the newborn).

Thus, to guarantee parents the freedom to make choices that, whatever they may be, will considerably affect their future, the medical team must take into account several factors: the tensions between the information's inherent objectivity and the subjectivity of the couple; the relationship to time; the sense of vulnerability based on other's viewpoints; and a multidisciplinary approach and support.²⁵

It is for this reason that a shared decision may be the most effective way to rationalize the participation of lay people so as to guarantee that the pregnant woman and her companion select the best of all the difficult options while respecting their initial wishes. This process involves a trade-off between the risks and benefits of each option and the individual's preferences/expectations of the potential consequences. Although discussion does not guarantee the certainty of any resultant decisions, it does ensure that the decision is rigorously made by analyzing and confronting all the arguments and by seeking informed and reasonable solutions. Will we be able to justify why the woman chooses one option over another, a choice that will have been fully tested and, therefore, taken in good conscience and legitimized by the way it was reached?

Clinical Implications

- Antenatal anticipatory guidance is described as detailing the various prenatal and birth scenarios as well as explaining those outcomes to the patient.
- Introducing the professionals and their services to the family seems to be a factor of reassurance and trust,²⁶ and this multidisciplinary approach helps define the child's care.
- The palliative culture training of perinatal professionals: the teams must be attentive to any misgivings by any of their members along with a high level of confidence, respect, a good level of communication, and a capacity to reconfigure roles in the face of the unexpected. That is to say, to modify the usual hierarchical order so as to appropriately adapt to the situation at hand.²⁵
- It is important to avoid being too directive with procedures or protocols because this risks thwarting reflections and openness to the singularity of each situation. Proposing a reflexive and collaborative approach from the outset generates an adapted decision-making process.

CONCLUSION

Ninety-two percent of surveyed French perinatal professionals support the idea of informing their patient about possible PPC in the case of an LFP.¹⁶ The frame of reflection regarding perinatal palliative training, such as exists in England, is essential in France.^{27,28} A French framework could address the lack of knowledge about PPC and help to build a

multidisciplinary care program. A specific PPC program is actually based on an existing specific plan detailing the values and purposes of the palliative approach. It would recognize the patients' and families' needs and provide a multidisciplinary team trained in PPC and in an adequate unit.²⁹ Contributing elements to enhance a PPC program would be:

- a. training to increase the professionals' skills in broaching and disseminating palliative culture information;
- b. inclusion of parents regarding the plan of care and potential range of outcomes for their infant;
- c. family communications and medical file documentation during each step of the process;
- d. respect for consistent pre- and postnatal intentions;
- e. collaboration with an obstetrical team in planning the birth and palliative care (place of birth, place of fetal monitoring, mode of delivery, etc.);
- f. preparations for postnatal care (confirmation of palliative care, gradual transition to palliative care if necessary, management of comfort care, place of hospitalization, complementary explorations, etc.);
- g. substantiating parental wishes and needs (or the family in the broad sense), in collaboration with needed and appropriate structures (mobile teams of palliative care, regional resource team in pediatric palliative care, volunteers, associations, etc.); and
- h. guidance and support for perinatal mourning by trained teams.

From this reflection, the prenatal care and pregnancy experience could be described as detailing the various prenatal and birth scenarios and the variety of options to deal with these realities. In fact, providing the family with the resources and options available to them seems to be a key component of reassurance and trust.

We have detailed the multidisciplines and their various participants and we believe it is important to develop a team approach to palliative perinatal professional training for this difficult passage of uncertainty for all those involved. Nevertheless, being overly directive in conveying procedural protocol and rationales in order to compartmentalize decisions needs to be avoided; rather, a collaborative approach leading to a decision-making process must be adapted. Integration of the perinatal professionals' perspectives and biopsychosocial practices on managing serious and incurable fetal diseases can advance the possible options for management within this context.

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