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What Motivates Parents to Continue a Pregnancy after a Life-Limiting Fetal Diagnosis: A Qualitative Study of Parents

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Abstract

Context: Despite their painful context, the observations and recommendations of studies of perinatal professionals have shown the existence of institutional barriers to the performance of perinatal palliative care (PPC), sometimes linked to these professionals' moral judgments. This may impede their communication with parents - presentation of management options and decision-making - and the concrete performance of PPC.

Objective: This study analyzes the motives for which women or couples continue pregnancies after the diagnosis of a life-limiting fetal disorder (LLFD).

Methods: Qualitative study. Discourse analysis of internet posts written by parents on the internet forum of a parents' association. Most families underlined the importance of spending time with their baby, of getting to know them during the pregnancy and if possible after their birth. These families' priority is the opportunity to experience and fully exercise their parental responsibilities in making decisions for this unborn infant: showing a personal desire that, insofar as possible, their baby should not suffer and should be welcomed with love. Their child's lifetime, often brief, is valued as a time of meeting and of love, whether in utero or after birth; they report they attribute little importance to its duration. Avoiding a decision to end the child's life voluntarily, regardless of his or her prognosis for survival, is also decisive for many parents, even though they cannot prevent the baby's death due to the disease. A minority mention that this decision is motivated by the hope of a prognosis that will be better than expected, or that the diagnosis will not be confirmed, or a singularly better individual outcome. These cases manifested more of an opening towards a positive surprise, than a lack of confidence in the medical prediction. Religion was not mentioned as an argument for choosing PPC in our study.

Conclusion: Parental motivations to continue pregnancies diagnosed prenatally as LLFD are centered on the early bond with the unborn baby, the consideration of his or her full existence as a person, and the prevention of future regrets. These motivations do not appear to be related to religious beliefs or lack of confidence in medical diagnosis/prognosis. Parental duty and love move parents towards this decision. Perinatal professionals should acknowledge these motivations to better understand parental choice and support them.

Introduction

A life-limiting disorder is diagnosed in 3% of fetuses [1]. Studies indicate that, as we would expect, a fetal life limiting disorder (FLLD) diagnosis dramatically changes the experience

of pregnancy for expecting parents [2,3]. They live through an experience of "arrested parenthood", with fear, anxiety, sadness, and perhaps depression [2-5]. In many countries, the management of these situations is discussed with parents after multidisciplinary consultations, with distinctive orientations of care: medical

termination of pregnancy or continuation of the pregnancy with perinatal palliative care (PPC), or, more rarely with treatment to prolong life [6]. Although termination is authorized at the parents' request in several countries, including France, the option of PPC support while continuing the pregnancy has developed more recently. The proportion of parents who choose to continue these pregnancies ranges, according to a 2012 review [7], from 37% [8] to 87% [9]. In France, one retrospective study of three perinatal diagnosis centers reported a 39% increase in the number of requests for PPC over 9 years [10]. Similarly, the Agence de la Biomédecine, responsible for these centers, observed a marked increase in the continuation of these pregnancies, from 668 in 2010 to 1296 in 2015 [11].

PPC in the neonatal period presents specific characteristics that vary according to the individual situation: the duration of life is often uncertain, as is its quality [7,12]. Pregnant mothers and their partners in this situation face developmental tasks specific to each stage, from the diagnosis through after the baby's death [1]. Some recommendations for appropriate PPC management have been published [13], and some couples have described positive experiences when the PPC took place in good institutional and medical conditions [1,14].

Negative parental experiences have also been reported, including pressure from perinatal professionals to terminate the pregnancy rather than continue it in cases of prenatal diagnoses of trisomy 13 and 18 [15] or negative judgments by these professionals that leave parents feeling isolated [2,16]. These reactions by those who parents feel should be their principal support increase their difficulty and make them feel that they must struggle to be able to continue the pregnancy. These reactions by the professionals may be promoted by their personal convictions and their disinclination to deal with the complexity of managing such pregnancies and perinatal care [12,17]. Health care professionals (HCP) are often reluctant to put aside their beliefs. When they are unable to understand from their "rational" perspectives why parents make this decision, they may represent the parents' motivations for this decision as cultural and religious beliefs [18].

We hypothesize that a better understanding of parents' motivations for this choice might help change the representations of perinatal professionals and lead them to a better understanding of parental motivations and thus to an acceptance of this plan.

The objective of this study was to identify the reasons why parents reach the decision to continue a pregnancy after a prenatal diagnosis of a FLLD and to share these findings with perinatal professionals. The study also aimed to explore the specific role of religious beliefs as a motivation.

Materials and Methods

A qualitative method was used because we aimed to "study

things in their natural setting, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" [19]. We have chosen to analyze data extracted from a web-based patient-to-patient support group, which are rarely used in research. This kind of data might be considered a source of new knowledge, completing results from studies using semi-structured thematic research interviews. The advantage is to get access to patients experience without the filter of a medically-built research interviews. As a result, patients' experiences are approached in the context of peer sharing, rather than through language, concerns or assumptions related to caregivers' representations of patients' experiences. This avoids the bias of "finding only what you were looking for".

Study Population and Data Collection

The data for this study come from written messages posted by pregnant mothers and their partners on the internet support forum of SPAMA (Soins Palliatifs et Accompagnement en Maternité), a French non-profit organization created by parents for parents — and not involving HCP — to provide support for prenatal diagnoses of FLLD, lethal fetal anomalies, and/or during PPC. Messages in this forum are spontaneous, posted in French, and without disclosure of identity (first names or internet *noms de plume* are generally used). A neonatologist involved in research with bereaved parents [20] conceptualized the research together with the funding member of SPAMA. Sampling was consecutive as messages were included if they described any part of the path from discovering the anomaly to the baby's end of life or birth, mentioned the LLD diagnosis (trisomy 13 or 18, severe life threatening malformations, or growth restriction), and were written any time between 2010 and 2014.

Data Analysis

After extraction of the messages, an experienced discourse analyst, without specific personal experience with prenatal or postnatal care (N Botero, PhD), and uninvolved professionally in health care or personally in any similar situation, performed the analysis.

The philosophical perspective of the research was critical appraisal, seeking to generate change, and is congruous with the research method [21]. She first used a lexicometric tool, Lexico 3, to identify the themes addressed. Then she performed a discourse analysis to explore in depth how pregnant women and their partners reported their motivations to continue the pregnancy in this situation.

Ethics Statement

The study has been approved by the Ethics Committee of the Centre Hospitalier Intercommunal de Creteil.

This study was suggested by the founders of the SPAMA association. They had a prior approval from the administration

committee of SPAMA (5 parents, psychologist, psychiatrist, obstetricians, nurse - not involved in the research) to conduct the study on October 7th, 2014. As the study involved potentially sensitive and potentially identifying health information, some conditions have been applied: first, all the data are anonymized, and the pseudonyms changed. Second, the forum offers the possibility to post public as well as personal/private messages, and for the study, only public messages, readable by every person logging the website, are used. Third, as mentioned in the website, parents may ask the administrator to delete some (or all) of their posts whenever they want; deleted messages are not used for the study. The collection method was in accordance with the website's terms and conditions. The forum is an open source, free forum.

One of the explicit aims of SPAMA is to provide professionals with information on the parents' point of view in order to enhance their support to parents. The content of public posts allows the parents involved to contribute to improving practices for the future. The parents participating to the forum have been informed in the 2017 annual forum newsletter that a study was conducted on the basis of data extracted from the forum.

Results

Population

The study included 24 families (Table 1). The message writer was the mother in 20 cases (83%), both parents in 3 cases (12%) and a father in one (5%). Fourteen families (58%) already had other children. 24 message threads concerning 12 boys and 12 girls were analyzed (in two twin pregnancies, only one fetus was affected). Table 2 summarizes the diagnosis of the LLD as reported by the parents.

	Respondents
Age group	
<20 years (18)	1
20-30 years	10
30-40	9
Unknown	4
Manual and non-manual skilled occupations	13
Managerial and professional occupations	3
Unemployed	1
Unknown	7
Mothers' parity	
1	10
2	4
3 or more	10

Table 1: Social and demographic characteristics of the respondent parents (N=24).

Diagnosis		Number of families
Trisomy	Trisomy 18 (n=9)	12
	Trisomy 13 (n=1)	
	Trisomy 8 (n=1)	
	Trisomy, not specified (n=1)	
Cardiopathies	Left heart hypoplasia (n=2)	4
	Cardiac malformations, syndromic (n=2)	
Nephropathies	Kidney failure (n=1)	4
	Renal malformation (n=1)	
	Renal dysplasia (n=1)	
	Bilateral renal agenesis (n=1)	
Other pathologies	Fetal immobilism (n=1)	4
	Diaphragmatic hernia (n=1)	
	Severe growth restriction with placental genetic abnormality (n=1)	
	Unspecified LL malformation (n=1)	

Table 2: Fetal life limiting disorders diagnosed in the study population.

The initial announcement of the diagnosis came immediately after the first-trimester ultrasound scan for 8 families (33%) and right after the second-trimester scan for 15 (62%); 1 (5%) family did not specify the date. All the parents used the word "baby" and talked about "my baby"; no one used the word "fetus".

A physician had presented care options in 6 cases (25%) (either termination or continuation of the pregnancy): 2 during the first trimester and 4 during the second, for nephropathy (n=3), severe cardiopathy (n=1), trisomy 13 (n=1), and fetal immobilism (n=1). In six other families (25%), the parents reported that they had not been informed about a choice between termination and continued pregnancy with palliative care. They had instead spontaneously asked to continue the pregnancy, although the physician had not offered this option; this happened during the first trimester (n=3) and the second (n=3) trimester in 3 cardiopathies one nephropathy, one trisomy, and one malformation. Twelve families did not mention any choices offered by the physician.

Eighteen babies died, 8 (33%) in utero and 10 (48%) after birth with a lifespan of several minutes to 8 weeks. For one baby

with trisomy 18, outcome was not mentioned after birth. Three children (one with trisomy 8 aged 2 years old, one with a syndromic cardiopathy aged 7 years old, and one with nephropathy aged 17 days) were alive at the time the parents wrote the posts analyzed here and until their last posts.

Parental Motivations to Continue the Pregnancy

Data analysis identified the existence of 7 non-exclusive motivations, presented in Table 3. Quotations illustrating these themes are presented (M refers to mother and F to father, numbers refer to the family, and the LLD diagnosis is abbreviated by T for trisomy, CP for cardiopathy, NP for nephropathy, and O for other).

Messages concerned the decision-making process described the motivations: for 20 families, the decision to pursue the pregnancy was described as evident, intuitive: *The choice to continue this pregnancy to term seems to us to be the only possibility...* (M&F14-NP). Three other families reported the decision as complex, and preceded by serious reflection: *“We’ve gone through this painful time about the decision whether or not to end this pregnancy”* (M7-T18). The potential reasons to continue were weighed against the fear of the child’s potential suffering: *“I cannot imagine anything except taking my pregnancy to term... On the other hand, if I ever learn that my son is going to suffer enormously at his birth, that could help me to make a decision. ... Can I inflict on a child a life that’s perhaps over medicalized and besides that to have an unusual body?”* (M10-NP).

	Number mentioning this motivation (n, %)
Be able to meet, spend time with the baby	16 (66)
To experience the pregnancy as a “time of life” in its own right	15 (62)
Enable a peaceful end of life for the child	11 (46)
Go to the end of a process: “let it be”	10 (41)
Hope that the disease turns out to be less severe than expected	10 (41)
Do one’s duty as a parent	8 (33)
Protect oneself from the distress of an elective abortion	8 (33)

Table 3: Parental motivations to continue the pregnancy.

Be Able to Spend Time with the Baby

The motivation reported most often was the possibility of spending time with the baby before or after the delivery, whether or not death occurred: *“To meet my son, to tell him how much I love him. Giving up this meeting would be so painful...”* (M10-

NP); *“I want so much to meet him, to hold him to me, to tell him how much we love him...”* (M18-CP). These families counted on support by the perinatal professionals to develop a plan for the baby’s birth and end-of-life: *“Our pediatrician...is going to determine in part how we will experience our encounter with our little girl”* (M24-O). Whether the child is live- or still-born, this meeting at birth constitutes a key moment confirming their belief in the meaning of their action: *“When I held him in my arms, everything was clear; no more doubt or fear. Our choice suddenly made perfect sense”* (M&F3-T18).

To Experience the Pregnancy as A “Time of Life” in its Own Right

Announcement of the LLD led progressively to a modification in their investment in the pregnancy, now experienced as a time of life for the child, whose existence was experienced as more concrete (for example, with the choice of a first name announced to family and friends). Pregnancy was experienced as an “extra” and a time for private sharing between the parents and the baby: *“Each day is another day won, offered by life”* (M11-T18); *“As long as there’s life, there’s hope”* (M6-NP). During this period, these families expressed a desire to establish early contact with their child, through methods such as haptonomy or by mindful attention to the little details of daily life: *“Haptonomy lets me enter in contact with J and to feel her under my hand”* (M&F3-T18). *“Our baby fully shares our daily lives. The other day ...I ate a bowl [of chocolate] in secret... I said to myself that I was helping my baby do the mischief that he couldn’t do himself”* (M22-NP). The intensity of the shared feelings was underlined, rather than the life span.

Enable a Peaceful End of Life for the Child

Parents reported seeking, focusing on their baby’s well-being. They were committed to welcoming their child with serenity, in utero as at birth, whether or not death occurred: *“M is going to have a beautiful life; we will do all we can so that he is as serene and as happy as possible”* (M6-NP); *“I would like so much for the day of her birth to be a day of joy, a human day, a day of love!”* (M20-CP).

Go to the End of the Process: “Let it be”

The families expressed a desire not to impede the natural course of the child’s life and the pregnancy, so that their joint story could go forward without exterior intervention: *“A. is dead because her life was finished. She died very early in the eyes of men, but she was finished, complete, completed”* (M11-T18). A *finished life* was described here as a life experienced/lived until its *time ran out*.

Hope that the Disease Turns out to Be Less Severe than Expected

Among the 10 families mentioning this motivation, the

disorders were distributed as follows: NP = 2 (8%), CP = 2 (8%), and T = 6 (41%). This hope was a transient stage for four of them, while awaiting confirmation of the diagnosis and before accepting the reality of the disorder: *“The karyotype was indeed trisomy 18. Astonishingly, it was difficult because deep down I was hoping perhaps for a miracle”* (M5-T18); *“At the beginning, you keep hoping... but very rapidly as you go from specialist appointment to specialist appointment, the picture darkens...”* (M16-NP).

The other six families reported that once the diagnosis had been made, they had hoped nonetheless that their baby would develop more favorably than foreseen, because of the individual variability of the disease: *“I wanted to believe to the very end: perhaps if we reached a very preterm birth: might there be a tiny hope to save our little boy?”* (M&F4-O). *“I’d convinced myself that she would be one of the babies who would live the longest, perhaps several months, years, and why not, a miracle”* (M12-T18).

Do One’s Duty as a Parent

The continuation of the pregnancy included a parenting plan, by careful attention to the child’s precarious life and well-being. This helped in the construction of a self-identity as caring parents, which some considered impossible to have if they chose a termination: *“We didn’t leave her alone, either to live, or to die”* (M7-T18). This choice was part of their duty as parents and meant that they did not fail to fulfill their responsibility: *“We have done everything we could do for her... We really have the impression that we have acted as parents”* (M&F3-T18). This journey was also described positively as a source of happiness: *“We are happy to have accompanied our little M. for the entire time, as short as it was, of her time on Earth!”* (M&F14-NP).

Protect Oneself from the Distress of an Elective Abortion

Termination of the pregnancy was described as a potential source of regret and guilt feelings. It was reported as a way of accelerating the child’s death: *“We have... no guilt about his death (we could not prevent it but we did not hasten it)”* (M1-O). Five families (20%) reported that they had considered asking for a termination but had concluded that this decision would be more distressing than continuing: *“I did not have the ‘courage’ to terminate my pregnancy. It was ‘easier’ for me to accompany my baby to his natural death and to follow my heart”* (M1-O). The termination proposal was described as choosing a violent procedure to permanently and deliberately end the pregnancy and the child’s life. One mother rejected a termination out of fear of reliving a second time the distress she felt during a previous termination (M23-T18).

Mention of Religion along the Journey

No parents mentioned religious beliefs directly as a

motivation. Nonetheless, in two cases, they were presented as a background to the decision, associated with a negative moral perception of termination. For one of them, faith crystallized letting-go, to destiny: *“You have surrendered to the will of the most high, confident in Love and in prayer”* (M13).

Independently of the decision, different religious beliefs were mentioned by 17 families as cultural practices inscribing the child in the family memory after death: *“During your mass, your dear Father asked the people there not to forget you”* (M6-NP), and as a source of comfort: *“As a Catholic, I have the hope to find him again one day”* (M&F4). Six families made no mention of religion, and one reported they are non-believers.

Discussion

In the medical literature over the past decades, physicians have hypothesized that “philosophy, religion, or even doubt over the diagnosis and prognosis given by the physicians” explain why parents might decide to continue pregnancy in cases of FLLD [17]. Several studies have described the vision of care providers [12,22] and the pathway of parents who chose to continue their pregnancy despite lethal disease [23,24]. It has been suggested that in continuing the pregnancy, parents avoided a termination, were prepared for death, and had the chance to cherish their baby in utero; moreover, each of these points helped to reduce the distress of their grief. But the reasons that lead a couple or a woman to choose a plan other than a termination for a fetus with FLLD have been explored less often [1,24-26].

The strong point of this study is that these data are original as they come from an internet group in which parents were addressing other parents - without intervention of the researcher. They are therefore first-hand narratives, which are constructed and circulated without institutional mediation and not for research purposes. They thus make it possible to understand motivations disconnected from information or suggestions from professionals, providing the reasons evoked to explain rationally and/or emotionally the path towards the decision.

Parents in this study made an affirmative decision to continue the pregnancy and participate in PPC. They consequently did not ask to terminate the pregnancy. The most common motivation was to spend time, albeit brief, with the baby, some of it, if possible, after birth. This is consistent with what other authors have shown: after confirmation of the diagnosis, parents reoriented their objectives, focusing their attention on the protection of their baby in utero, to cherish and recognize and know him or her [1,26]. They sought to be protective parents trying to obtain the best possible outcome for their baby. The parents’ desire for an end as gentle as possible, without suffering, has also been shown elsewhere [26] and is similar from that of the parents who want to do what they feel is their parental duty for this baby [2].

The announcement of a diagnosis of a serious disease can be followed by the acceleration of the creation of a bond with the fetus in utero, a bond that develops earlier and more intensely during the pregnancy [27]; the action of deciding to continue the pregnancy concentrates parental capacities into an act of love that testifies to the parents' willingness to welcome the birth of this child unconditionally. This welcome thus honors the existence of the child, humanizes him or her, and affirms that "my baby is a person". In one case of an antenatal diagnosis of a lethal heart defect [28], the author interpreted this decisional act for the child as empowerment in a situation of loss of control, with the feeling of impotence to save one's baby counteracted by a creative stance.

The mothers sometimes intuitively weighed the potential consequences of this decision on their psychological well-being. In our study, some parents/mothers also stressed their need or desire to not have to cope with the consequences of a voluntary termination of pregnancy. Fear is an important argument in decision making and some mothers felt deeply and instinctively that this would precipitate them into a destructive spiral, as evoked elsewhere [29]. The fear of guilt feelings, regret, and doubts about the decision to terminate a pregnancy as well as fear of being judged by others have been reported in other circumstances as reasons women conceal terminations of pregnancy [25,30]. Inversely, accompanying one's child to a natural end of life might help parents to cope with the mourning process [31,32]. This is essentially what parents in our study formulated as "wanting to go 'to the end of a process'" or what others describe as allowing nature to take its course [25].

These different motivations most often coexist and are finally weighed against the possible suffering of the child. The reasons focused on the child (his or her well-being, lack of suffering, unconditional welcome, and recognition of his or her full existence) and those associated with the parents (feeling that they are parents, doing their parental duty, making decisions, spending time with, perhaps being able to hold their child) are related but can in some cases possibly conflict, which makes the decision more complex, especially in the presence of uncertainty.

Although a minority of the parents in our study were moved by hope that the disease might finally turn out to be less severe than expected, this was reported most often at the beginning of diagnostic processes that require confirmation in stages. This hope was reported sometimes as transient: learning the diagnosis is a process, and hope can persist for a while, until confirmation occurs, followed by recognition of the reality of the diagnosis and revisiting the goals of the pregnancy [2,26,27]. For others, nonetheless, their decision is made in a context of uncertainty. Many diseases called lethal or life-limiting have variable and unpredictable prenatal and postnatal courses, which can range from immediate neonatal death to prolonged life [23,31]. Prognosis must be confirmed postnatally:

cardiac or renal abnormalities may require serial ultrasounds and assessments before lethality can be established. For these parents, repeated ultrasounds are opportunities to see, meet, and know their baby, and bond while he or she is in utero [27].

Several parents in our study mentioned that they had themselves identified and requested PPC, although their HCPs had not mentioned this possibility. This is consistent with a study of HCPs in France reporting that nearly half of them did not inform women about the options for birth support (including PPC) [22]. An interesting result is the absence of any reports that the professionals influenced their decisions.

Of the fetuses identified with LLD, slightly more than half were liveborn, consistent with data from other studies ([9,10,31]. The uncertainty inherent in these diseases can justify dealing with them by continuing the pregnancy as in our study [22,25]. In cases of uncertainty, parents may be moved by the hope of a somewhat favorable course, which can encourage them to opt for a path enabling life, despite its uncertainty and the impossibility of planning for it. Nonetheless, our results show that uncertainty regarding the severity of the diagnosis or prognosis is not the main or the most frequent factor driving parents to continue the pregnancy. Parents did not report believing in the idea of "love conquers all". The physicians studied by Tosello, et al. considered prognostic uncertainty to be an obstacle to communication about the option of PPC [12].

Globally, despite the variations in their individual situations, the overall goal of all the parents - those with certainty and those without it - was to avoid later regrets and to feel they did the best they could for their baby. Our results are consistent with those of Coté-Arsenault, et al. [26]; they underline reasons that are not so much philosophical or religious, but rather those related to perceptions of parenthood and the child's existence, even before birth. In our study, parents did not mention religious or cultural reasons among their motivations. As these writings were spontaneous and not in response to a specific question on this subject, some parents may have chosen to retain their religious or spiritual motivations to preserve their privacy. In another context, 40% of parents reported that religious faith affected their pregnancy experience and decisions, but religiosity was not part of any pattern of characteristics associated with happiness and peace at meeting the baby, even briefly or stillborn [1,24]. Professionals may ascribe their lack of influence in the parental decision to the parents' religious motivations, but in a retrospective study in France, Tosello's team showed that only 11% of the parents mentioned religion as a motivation [10]. Religion and spirituality has been shown to play a role in some crucial decision-making in pediatrics, but this role is vague and difficult to explain [33]. The role religion and spirituality play in decision-making has been studied in other circumstances, in which researchers have shown that these factors

may influence not so much the content of the decision but how the decision is taken, and the meaning given to it.

Our study has limitations. There are relatively few cases, albeit a large number for this situation, and they all occurred in France. Moreover, this study presents the results of a limited study carried out on a corpus available online, which implies a particular digital culture: physical equipment, internet access, web research, and the desire to share one's experience with unknown people. The results may therefore not be generalizable to the entire population facing this type of situation and decision.

Globally, this study suggests that parents are facing a decision which takes time, reflection and insight in a new situation. As they need time to absorb the new situation, and to discuss it, the time of diagnosis might not be the most appropriate to talk about termination of pregnancy. It seems preferable that they have already understood this situation before reflecting on the position that would make sense for them. Moreover, this study shows the common language that can encourage a common reflection on the decision to be taken: expressions such as «what would make the most sense for you?» What would hurt you the least? Are closer to the parents' representations than « what do you want to do ».

Conclusion

In conclusion, parental motivations to continue pregnancies diagnosed prenatally as LFLD do not appear to be religious beliefs or lack of confidence in medical diagnosis/prognosis, but rather centered on the early bond with the unborn baby, the consideration of his or her full existence as a person, and the prevention of future regrets. Parental duty and love move parents towards this decision. Perinatal professionals should acknowledge these motivations to better understand parental choice and support them.

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