



Perinatal Hospice:

A Compassionate, Life-Affirming Option

Part 1

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Key Points

Family Research Council set out to analyze the experiences of pregnant women who had recently received counseling and medical care through perinatal hospice.

Women who choose perinatal hospice tend to be married, white, and religious and have above-average incomes.

Women who received adverse prenatal diagnoses were frequently advised by a healthcare professional to seek an abortion.

Women were rarely advised to carry pregnancies to term, and few were given information about perinatal hospice by healthcare providers.

A high percentage of women found the perinatal hospice very helpful emotionally and very supportive in the grieving process.

The purpose of this report is to analyze the experiences of a group of pregnant women who recently received counseling and medical care through perinatal hospice. All of these women tragically received a diagnosis that their preborn child had a life-limiting condition and might die before or shortly after birth.

Specifically, this report will look at 1) the demographics of women who choose perinatal hospice, 2) the recommendations and advice given by healthcare providers after the adverse diagnosis, and 3) the experiences of pregnant women who went through perinatal hospice. Part two of this report will include testimonials from women.

This report has the ability to make a positive contribution to both public policy and individual decisions regarding adverse

This report can be read online at frc.org/PerinatalHospice

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prenatal diagnoses. Following the U.S. Supreme Court's *Dobbs v. Jackson Women's Health Organization* decision (2022), the mainstream media has covered stories involving women who sought abortions after learning that their preborn child had a life-limiting condition. Very often, the media portrays abortion as the only option in these exceptionally difficult circumstances. The compassionate, life-affirming option of perinatal hospice receives comparatively little attention. This report will inform policymakers and medical professionals that women who chose perinatal hospice very often have a positive opinion of both the counseling and treatment they received.

Methodology

In 2023, researchers at Family Research Council contacted 11 organizations that offer perinatal hospice, including Be Not Afraid, String of Pearls, Tepeyac OBGYN, Isaiah's Promise, Leaves in Time, My Child, My Gift, Lily's Gift, Jerome's Hope, Sufficient Grace, and Mariam's Blessing. These organizations agreed to distribute a voluntary survey to women who went through perinatal hospice. The survey contained questions about their demographics, prenatal diagnosis, advice from health care professionals, and experiences with perinatal hospice. Eighty-two women responded to the survey. Additionally, 56 women responded to an open-ended question about the helpful aspects of perinatal hospice, and 54 women said they would make themselves available for a brief interview describing their experience.

Demographics

Most of the women who choose perinatal hospice tend to be married, white, and religious and have above-average incomes. The average age of the women who responded to the survey was 38.

Background

Of the 82 respondents, 75 percent identified as white, while only 11 percent identified as Hispanic, and only two percent identified as African American.

Marital status

Nearly 94 percent of the women who chose perinatal hospice were married.

Income and Education

Over 25 percent of the women who chose perinatal hospice reported an annual income of over \$160,000, and over 54 percent reported an annual income of over \$100,000. Additionally, over 77 percent had a bachelor's degree, and over 30 percent possessed a graduate degree.

Religious Affiliation

Over 75 percent of women who chose perinatal hospice identified as either Catholic or Protestant. Fewer than three percent failed to state a religious affiliation. Furthermore, over 70 percent of women who chose perinatal hospice reported attending religious services once a week or more often, and 63 percent identified as “very pro-life.”

Demographics of Women Who Obtain Abortions

Numerous studies show that women who obtain abortions are disproportionately young, single, low-income, and racial minorities. As such, the demographics of women who chose perinatal hospice are

markedly different from those of women seeking abortions. Increasing awareness of perinatal hospice among younger women, low-income earners, and racial minorities would certainly be a worthwhile goal for pro-lifers.

Previous Pregnancy Experiences

Women in the survey had been pregnant an average of four times and had given birth an average of three times. This was the first pregnancy for only about 10 percent of the women in the survey. Interestingly, over 60 percent of the women had experienced a previous miscarriage, and about 46 percent had experienced a premature delivery. Less than three percent reported having a previous abortion.

Of the 66 women who reported their prenatal diagnosis, the most common diagnoses were Trisomy 18 (16 women), Anencephaly (10 women), and Trisomy 13 (six women). On average, the women received the adverse prenatal diagnosis at 19 weeks gestation. Only two of the 63 women who responded to this survey question reported receiving an adverse prenatal diagnosis at some point during the first trimester of their pregnancy. Interestingly, 10 percent of the women reported that they had previous children with adverse prenatal diagnoses.

Aftermath

Tragically, over 86 percent of the children who received adverse prenatal diagnoses died. A small but substantial percentage of the women indicated that they underwent a considerable amount of emotional hardship in the aftermath of their child's death. Eight percent indicated that they were having "a lot" of trouble accepting the death of their child, and 21 percent indicated that their grief interferes with their daily life "a lot." A larger percentage of women experienced moderate amounts of emotional hardship.

Sixty-two percent indicated that they were having “some” trouble accepting the death of their child, and 58 percent indicated that grief only “somewhat” interferes with their daily life.

A high percentage of women reported some degree of relationship stress as a result of the diagnosis. However, only a relatively small percentage reported serious relationship difficulties. Specifically, the survey indicates that approximately 88 percent of women encountered some relationship stress, but more than half the women reported no relationship difficulties. Furthermore, over 85 percent of the women surveyed indicated that they were “very confident” in their decision to carry the pregnancy to term.

Recommendations from Healthcare Professionals

Most of the women who received an adverse prenatal diagnosis were encouraged to obtain an abortion. Over 55 percent of the women received a recommendation of abortion by at least one of her doctors. Sadly, a majority of women who were advised to obtain an abortion reported that they received this advice on multiple occasions from doctors or healthcare professionals. Only 13 percent of women were encouraged by their first OBGYN to carry their pregnancy to term. Similarly, only 12 percent who sought advice from a high-risk pregnancy specialist were advised to carry their pregnancy to term. Furthermore, only 19 percent of women were given information about perinatal hospice at the time abortion was recommended, and only 25 percent said that their insurance provided access to perinatal hospice.

Experiences with Perinatal Hospice

Nearly all of the women who knew about perinatal hospice learned about it through friends, family, medical professionals, or online research. Relatively few heard about perinatal hospice through a pastor

or a priest. Overall, a high percentage of the women expressed satisfaction with the care and counseling that they received. Over 83 percent felt that perinatal hospice was very supportive emotionally. Additionally, 67 percent found that perinatal hospice services were very helpful in the grieving process. The women who obtained perinatal hospice were offered a wide range of services. A very high percentage were offered counseling (77 percent), photos or mementos of their baby (91 percent), prayer (86 percent), support groups (83 percent), a birth plan (90 percent), and a burial or funeral plan (80 percent). Substantial but smaller percentages were offered sonograms (54 percent) and memorial services (53 percent). In a high percentage of cases, women viewed these services as very helpful.

Table 1: Services Offered to Women Obtaining Counseling at Perinatal Hospice

Service	Percentage Offered	Percentage Who Found Service Very Helpful
Counseling	77%	55%
Sonograms	54%	66%
Photos or Mementos	91%	89%
Prayer	86%	76%
Support Groups	83%	44%
Birthplan	90%	73%
Burial/Funeral Plan	80%	76%
Memorial Service	53%	81%

Interestingly, many women said that the experience of receiving an adverse prenatal diagnosis and then carrying the pregnancy to term did not change their attitudes toward abortion. However, a significant minority (36 percent) said that the experience of carrying the pregnancy to term made them more “pro-life.” That said, many women indicated a better understanding of why some women would want to terminate a pregnancy after receiving an adverse perinatal diagnosis. A small percentage of survey respondents indicated that their experience had made them more supportive of legal abortion.

Conclusions

This survey of women who sought perinatal hospice care after receiving adverse prenatal diagnoses revealed some interesting and important insights. A high percentage of the women who obtained perinatal hospice care were white, married, religious, and had above-average incomes. Also, a high percentage of the time, women who received adverse prenatal diagnoses were advised to seek an abortion by a healthcare professional—in some cases, on multiple occasions. Women were advised to carry pregnancies to term only a small percentage of the time, and relatively few women in the survey were given information about perinatal hospice by healthcare providers. Finally, a high percentage of women found that the perinatal hospice was very helpful emotionally and very supportive in the grieving process.

This survey has important implications. The results indicate that many healthcare professionals either do not know about perinatal hospice or are reluctant to recommend perinatal hospice services to pregnant women who receive adverse prenatal diagnoses. Furthermore, a strong majority of the women who obtained perinatal hospice care strongly approved of the counseling, emotional support, and other services that they received. As such, increasing awareness of perinatal hospice among policymakers, healthcare professionals, and the general public is an important and worthwhile goal. It will give women who obtain adverse prenatal diagnoses more options. Furthermore, it will hopefully result in a higher percentage of these women making life-affirming choice of perinatal hospice for themselves and their preborn children.

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