



Universidad
de Navarra
Faculty of
Nursing

What is the experience of parents with Perinatal Palliative Care?

Author: Lourdes
Jiménez-Villarejo Díaz

Tutor: María Begoña
Errasti Ibarrondo



1. Introduction:

When a baby is diagnosed with a congenital anomaly that is incompatible with life, parents go through a different pregnancy experience, they are faced with two options, either terminate or continue with the pregnancy. If termination is rejected, parents receive Perinatal Palliative Care (PPC). The experience of these parents with this specific care is explored in this study.

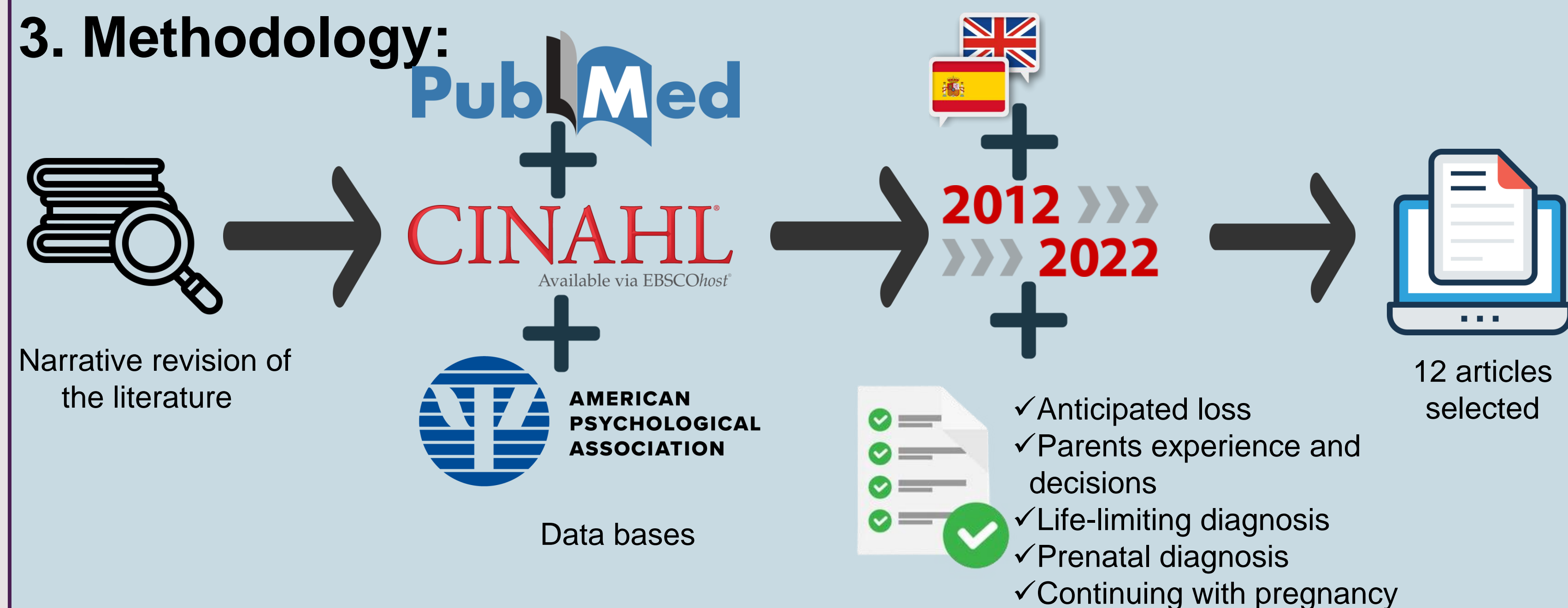


2. Aim:

The aim of this study is to explore the experience of parents that receive perinatal palliative care.



3. Methodology:



Research question: What is the experience of parents with Perinatal Palliative Care? (PS)

P	S
Parents	Perinatal Palliative Care & Experience
↓	
Synonyms	Mother Father
	Lethal Prenatal Diagnosis Perinatal Hospice
	Views Feelings

5. Conclusion:

In conclusion, parents who undergo PPC have positive outcomes despite the loss of their baby. However, PPC must be emphasized in the medical world and socially.



6. Bibliography:



4. Results:

A total of 12 papers were selected, after critical readings were carried out, the results were divided into five themes: 1) Prenatal-Diagnosis, 2) Decision-making, 3) Continuing with pregnancy, 4) Birth, 5) Bereavement.

1. Prenatal Diagnosis

When a life-limiting condition (LLC) is diagnosed in neonatal check-up, the way it is delivered by health professionals (HPs) is of outmost importance for parents, due to their emotional shock after receiving the news (1). Grief and shock are experienced by parents, as well as a sense of loss of identity since they were expecting to be parents in their parental roles (2). They withdraw themselves socially because they feel that they no longer fit the social concept of pregnancy (2).



2. Decision making

Parents are faced with two choices, abortion or to continue the pregnancy. Influential factors on the continuation of pregnancy are:

- ✓ Religion, beliefs, principles, Personal viewpoints on abortion (1).
- ✓ Wanting to spend as much time as possible with the baby and being able to see him/her. (1, 6).
- ✓ They believe that it is the best for their baby and not wanting to have regrets (3).
- ✓ The belief in the sanctity of every life and that it seemed "selfish" or "unethical" (1, 3).
- ✓ Felt like the right thing to do (3).



3. Continuation of pregnancy

In this phase, parents seek and take part in a PPC team, alongside physicians, nurses, social workers and spiritual counsellors (4). Parents who choose to continue with the pregnancy want to make the most of their limited time with the unborn child. Plans for labour, delivery, and post-death occur in this stage (3).



4. Birth

Parents choose a small, carefully chosen group of loved ones and friends to visit their child while they were in the hospital (3). Mementos and interacting with the baby is cherished by parents (4, 5, 7, 8). Lastly, parents describe the birth of their child as a joyful experience (3, 7).



5. Bereavement

Parents adapt their lives to the absence of their baby (3). Different coping mechanisms are:

- ✓ Organ donation (4).
 - ✓ Breast milk donation (4, 10).
 - ✓ Contacting with other PPC parents (7).
- Mothers' vs fathers' bereavement:
- ✓ Mothers: Longer mourning period but have less difficulty opening up (3).
 - ✓ Fathers: Pass and intense phase of grief and mourning, yet they get over it quicker (3).
- Parents develop a stronger relationship(9).

