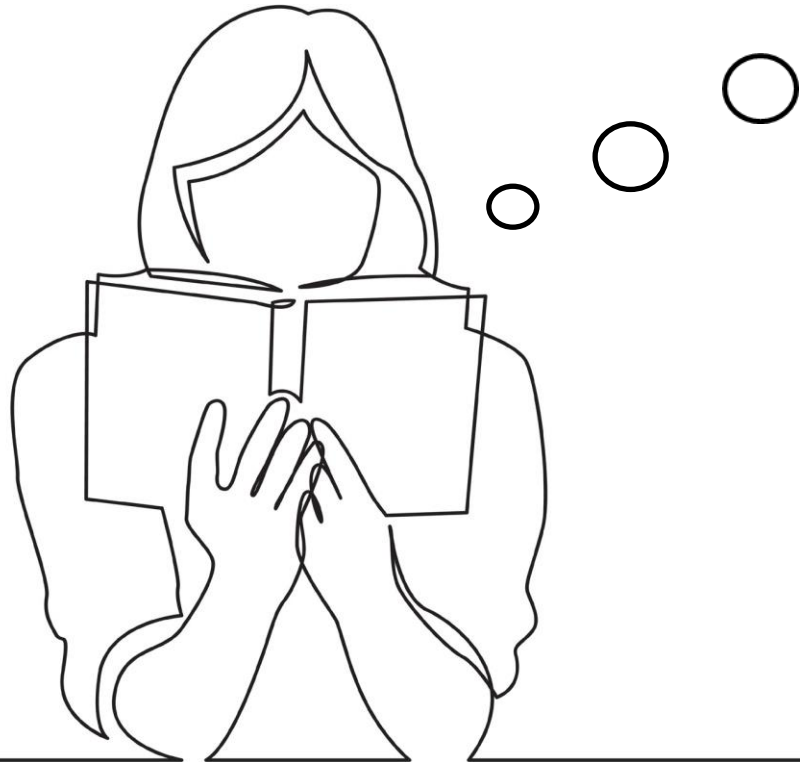




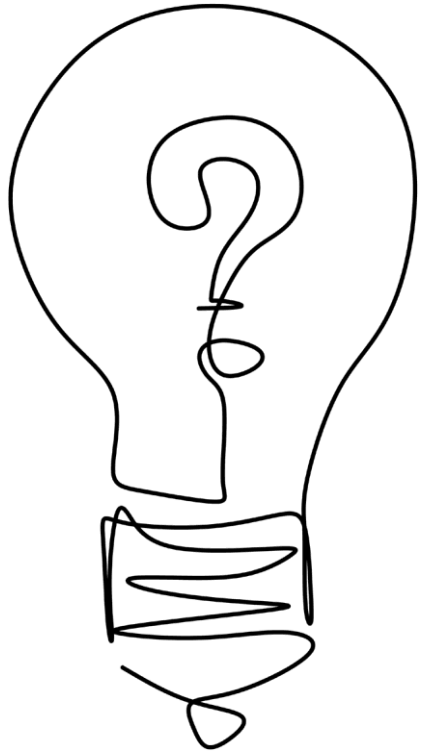
Kerstin Hein, Franziska  
Flaig, Annika Schramm,  
Gian Domenico Borasio  
and Monika Führer

**The Path Is Made by Walking—  
Mapping the Healthcare Pathways of  
Parents Continuing Pregnancy after a  
Severe Life-Limiting Fetal Diagnosis:  
A Qualitative Interview Study**

# Who should read the paper?



# What's it about?



*There has been increasing interest and a growing number of publications with recommendations for perinatal and neonatal palliative care. However, evidence supporting the existing perinatal palliative care programs is still scarce. European perinatal palliative care structures remain poorly developed.*

## Aims

- Enhance the knowledge about care experiences and needs of parents who decide to continue pregnancy despite the life-limiting condition of their unborn child
- Reconstruct pathways through existing healthcare structures from the perspective of parents.
- Identify requirements for a structured PPC program

**What did the  
researchers  
do?**

## Study design

**Method:** Qualitative Interview Study

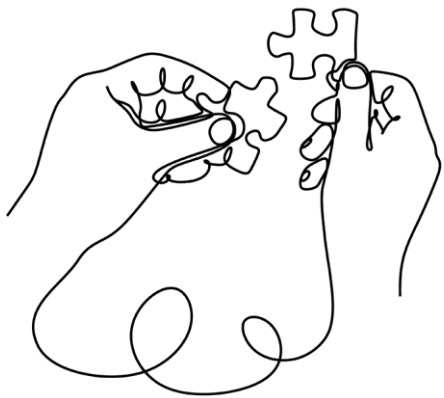
**Data collection:** Semi-structured interviews

**Sample:** Purposively selected sample of 11 bereaved mothers and 9 fathers who continued pregnancy after a life-limiting fetal diagnosis.

**Data analysis:** Coding Method of Saldaña (2016) to analyse data and compilation of templates to reconstruct care pathways.



## What did researchers find out?



## Results

- Parents experienced severe emotional distress during prenatal diagnostics due to scarce information, insensitiveness, and perceived pressure towards abortion. As a result, they overlooked referrals to psychosocial counselling, generating a care gap.
- Most parents reached the decision to continue pregnancy without professional support.
- Parents chose a trusted midwife or gynecologist as main caregiver during pregnancy.
- There were no regular referrals to palliative care. Palliative care became relevant when the child survived.
- Parents cherished farewell rituals, especially spending time with the deceased child at home.

# How can the results be used?

Hein, K.; Flaig, F.; Schramm, A.; Borasio, G.D.; Führer, M. The Path Is Made by Walking—Mapping the Healthcare Pathways of Parents Continuing Pregnancy after a Severe Life-Limiting Fetal Diagnosis: A Qualitative Interview Study. *Children* 2022, 9, 1555.

<https://doi.org/10.3390/children9101555>

## Considerations for the design of a structured perinatal palliative care program:

- It is necessary to identify already existing support services and connect them through structured pathways.
- Parents require comprehensive information, sensitivity, and a non-directive approach, especially in the context of prenatal diagnostics.
- Structured pathways are particularly important following prenatal diagnostics to prevent a care gap.
- Midwives should be engaged to ensure continuity of care.
- Early access to pediatric palliative care services is recommended.

