
Challenges in the palliative care of newborns with serious malformations after home birth

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Topics

- Background
- 2 case presentations
- Pointing out the challenging questions
- Ethical issues
- Possible conclusions



Background

- Despite medical progress, there are still life limiting diseases and malformations without curative therapy diagnosed before birth
- Doctors are perhaps more confronted to the wish of parents for birth at home in a palliative care setting
- The team is facing great challenges and ethical questions in organizing this setting



Background

- It's a fact that most of the death of newborns take place in hospital
- Although more patients may wish to give birth at home



How and where children die in Switzerland



PELICAN
Paediatric End-of-Life Care Needs in Switzerland

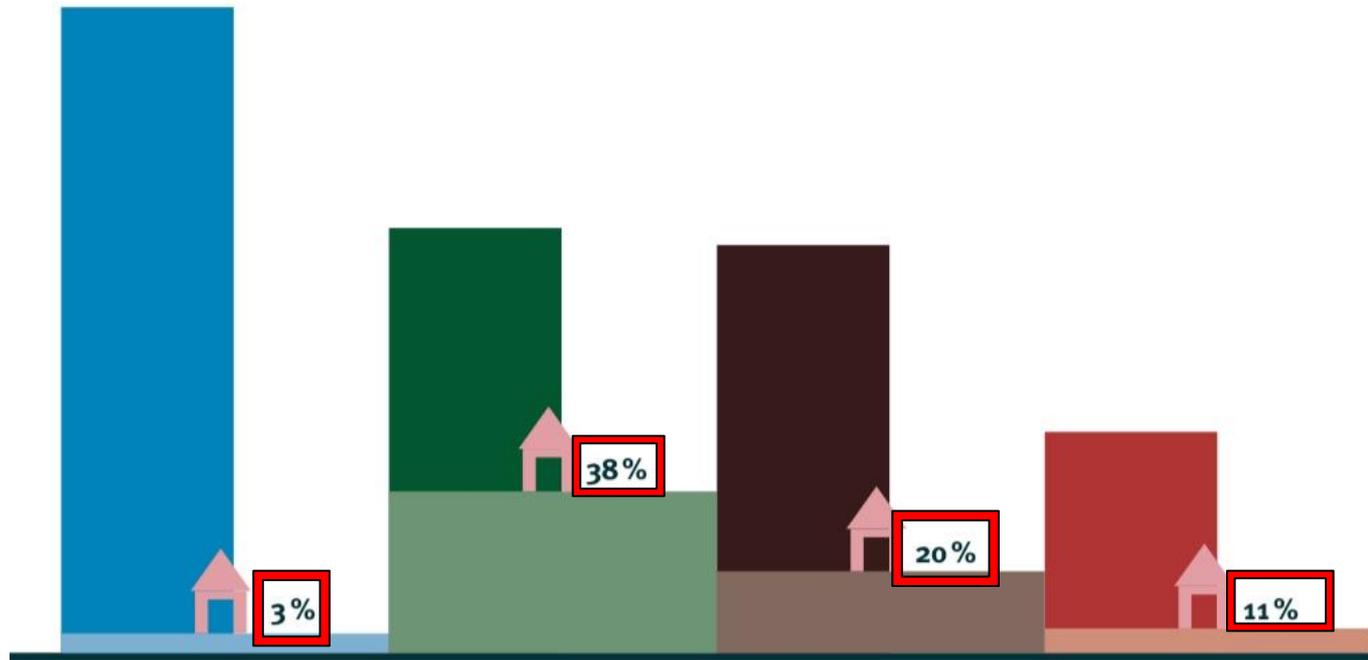
Wie Kinder in der Schweiz sterben

Schlüsselergebnisse der PELICAN-Studie

PELICAN Study 2012-2015



Distribution of pediatric mortality (149 cases)



38% newborns

25 % oncologic disease

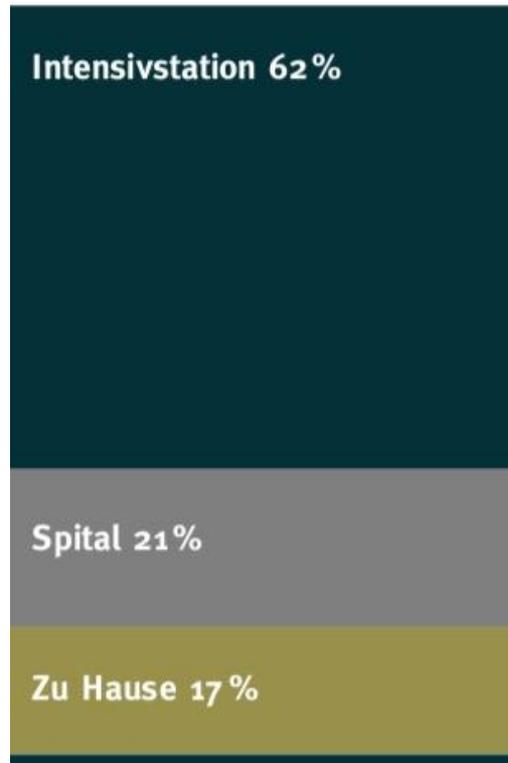
24% neurologic diseases

13% Cardiac diseases

Percentage of children dying at home



Where do children die?



Case presentation

- pregnant women in 31 weeks of gestation
- In fetal MRI lung hypoplasia, ahydramnion and renal agenesis diagnosed
- Father had renal transplantation for renal insufficiency
- Parents undetermined between keeping hope for recovery and the wish for palliative care
 - Home birth an option for the parents



Further course

Different options have been discussed:

- Birth at hospital with the option to offer medical care if reasonable
- Birth at hospital with pure palliative care; concerning the history of the father, consider renal biopsy
- Birth at home in a palliative setting
- In the meanwhile, birthing center available as well



Further Course

- Parents decided for home birth with a midwife
- A medical doctor, known to the parents, was asked for support in end of life situation and confirmation of death
- A time gap at the weekend for the continuous care by a medical doctor was difficult to cover
- Finally, the baby was born in 36 th week at home without signs of life, the midwife taking care



2. Case



- Diagnosis of trisomy 18 prenatally
- Decision of the parents to give birth at home
- Preparations were taken for the PC setting:
 - Midwife organized
 - Doctor for medical support and death confirmation
 - Palliative pediatrician involved
 - Kinderspitex for support at home
 - Advanced care planning prepared



Advanced care planning

Palliativer Betreuungsplan[©] PBP

Personalien	
Name / Vorname	(Mutter) für ungeborenes Kind
Geburtsdatum	
Zivilstand / Soziales	2 Kinder
Adresse (Strasse, Ort)	
Tel. Nr. (Festnetz/Mobil)	
E-Mail	
Erstellt	am: [] von: [] Institution: Hausarzt



Hauptdiagnosen / -anliegen		SENS
Hauptdiagnose	Trisomie 18 in utero diagnostiziert, perimembranöser VSD	
Hauptanliegen des Betroffenen	Hausgeburt und Situation so nehmen wie es sich ergibt	
Vordergründige Probleme	mögliches Versterben vom Kind postnatal	
Bemerkungen	Möglichst natürliche Geburt und Abschiednehmen zuhause; wenn das Kind überlebt begleiten.	

Entscheidungsfindung		SENS
Reanimation (kardiopulmonal) gewünscht?	<input checked="" type="checkbox"/> Nein <input type="checkbox"/> anderes:	



Further Course

- Birth at home in the 39 th week, birth weight 1800 g
- Postnatal adaptation good
- NG tube feeding started
- In the 2 week, respiratory problems
- Child passed away at home at the 18 day of life

Palliativer Betreuungsplan® PBP

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Model for Palliative care

- S**- Symptoms (Assessment)
- E**- Entscheidungsfindung (taking decisions)
- N**- Netzwerk
(Spitex, Pro Pallium, other support)
- S**- Support (advanced care and hospital discharge planning)
- E**- End of life care

Acc. To Steffen Eychmüller



Challenges in both cases

- Decision to resign medical support in an uncertain situation: „*no way back*“
- Support the uncertainty of a prenatal diagnosis
- Preparations for the continuous support at home
- Doctor of confidence needed for death confirmation
- Difficulty to organize everything for at home, manpower for care
- No investigations post mortem possible



Ethical Values

Autonomy of the parents

Dignity of the newborn



Value of a newborn with life limiting conditions



- Peter Singer refuses the value of a newborn with life limiting malformations
 - Utilitarianism
- Question of dignity and how to care



Newborn with anencephalus



Ethical values

Doing the best for child
and family

Not doing harm



Conclusion of the 2 cases

Which were the main problems ?

2 Points:

Organisational but also ethically



Which are the main challenges?

Organisation

- Building up a team
- Time constraint
- Covering day and night
- Providing medication for end of life care
- Doctor to confirm natural death

Resistance of the medical team= ethical points

- Acceptance of another model
- Willingness to take care in end of life process
- Respect the autonomy of parents for other priorities



Options and necessity to be successful

- Accepting the parents wish
- Giving clear, honest information; also mentioning uncertainty
- Palliative care teams working at home also in end of life settings

