

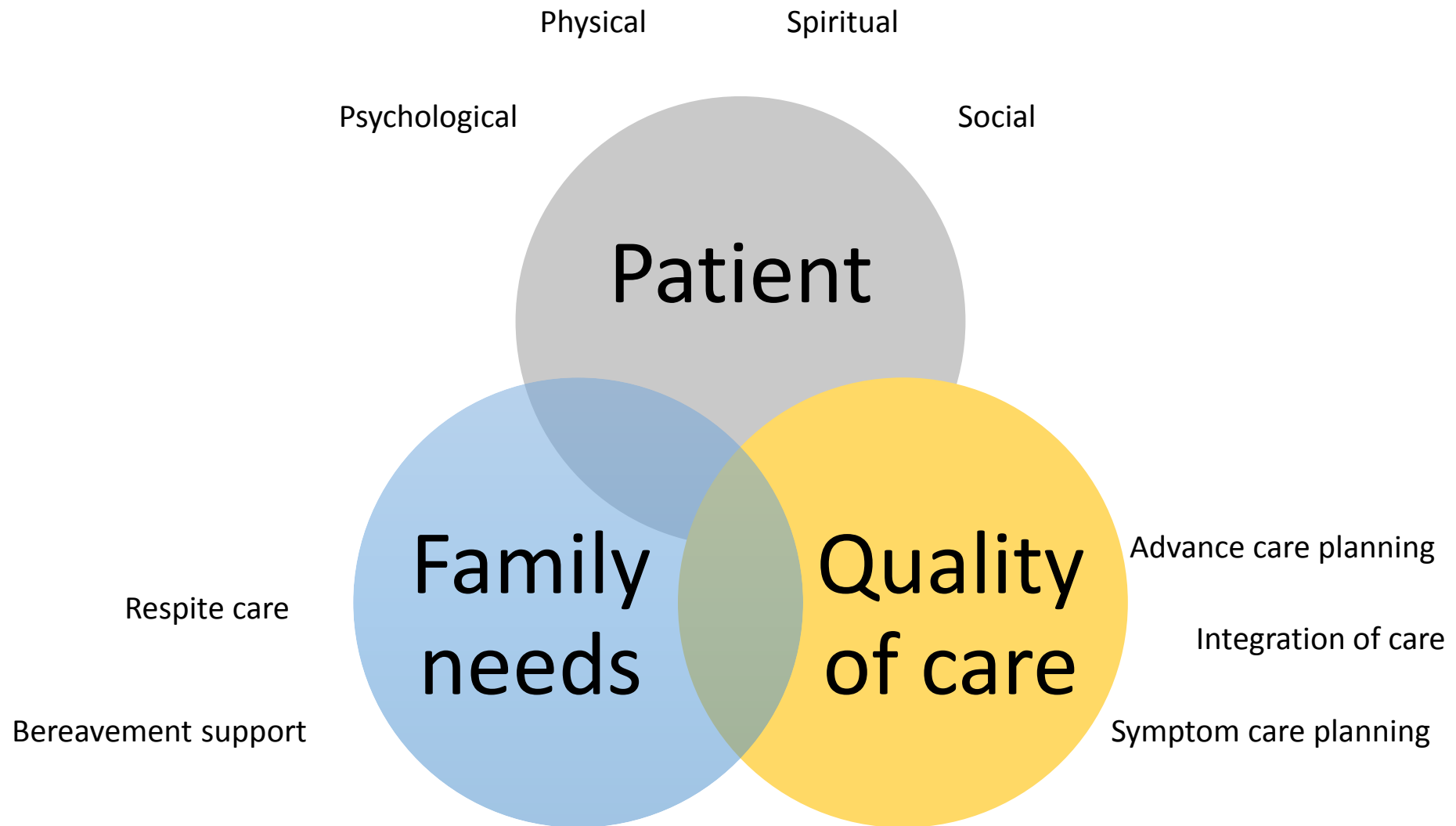
End of life care for children with heart disease

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The aim of paediatric palliative care

To help children with life-limiting and life-threatening illnesses and their families achieve a good life and a good (enough) death



Children living with life-limiting conditions

Congenital anomalies	(30.7%)
Oncology	(13.7%)
Neurology	(12%)
Haematology	(9.8%)
Respiratory	(8.8%)
Genitourinary	(6.2%)
Perinatal	(7.7%)
Metabolic	(3.8%)
Circulatory	(3.8%)
Gastrointestinal	(2.4%)
Other	(1.1%)



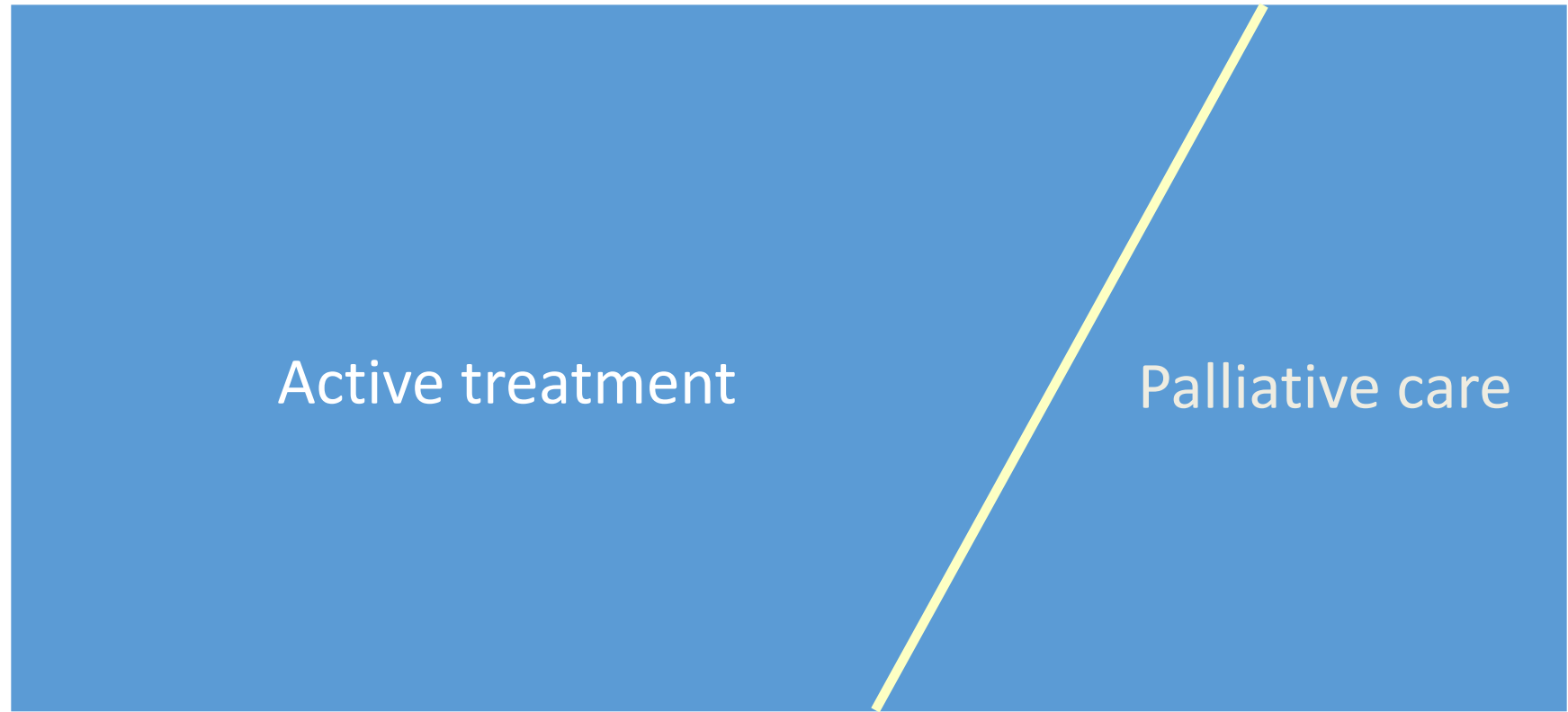
Active treatment

Palliative care

Diagnosis

Curative treatment
ceases

Death



Active treatment

Palliative care

↑
Diagnosis

↑
Death

Patterns of Care at End of Life in Children With Advanced Heart Disease

Arch Pediatr Adolesc Med. 2012;166(8):745-748.
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doi:10.1001/archpediatrics.2011.1829

Emily Morell, BA; Joanne Wolfe, MD, MPH; Mark Scheurer, MD; Ravi Thiagarajan, MD;
Caroline Morin, RN; Dorothy M. Beke, RN, MS, CPNP; Leslie Smoot, MD; Henry Cheng, MD;
Kimberlee Gauvreau, ScD; Elizabeth D. Blume, MD

- Young patients (75.7% <1 year)
- Almost all ventilated
- Half receiving ECMO/VAD support
- 55% underwent CPR during their final hospital admission
- Infants dying in intensive care environments; often at a distance from home

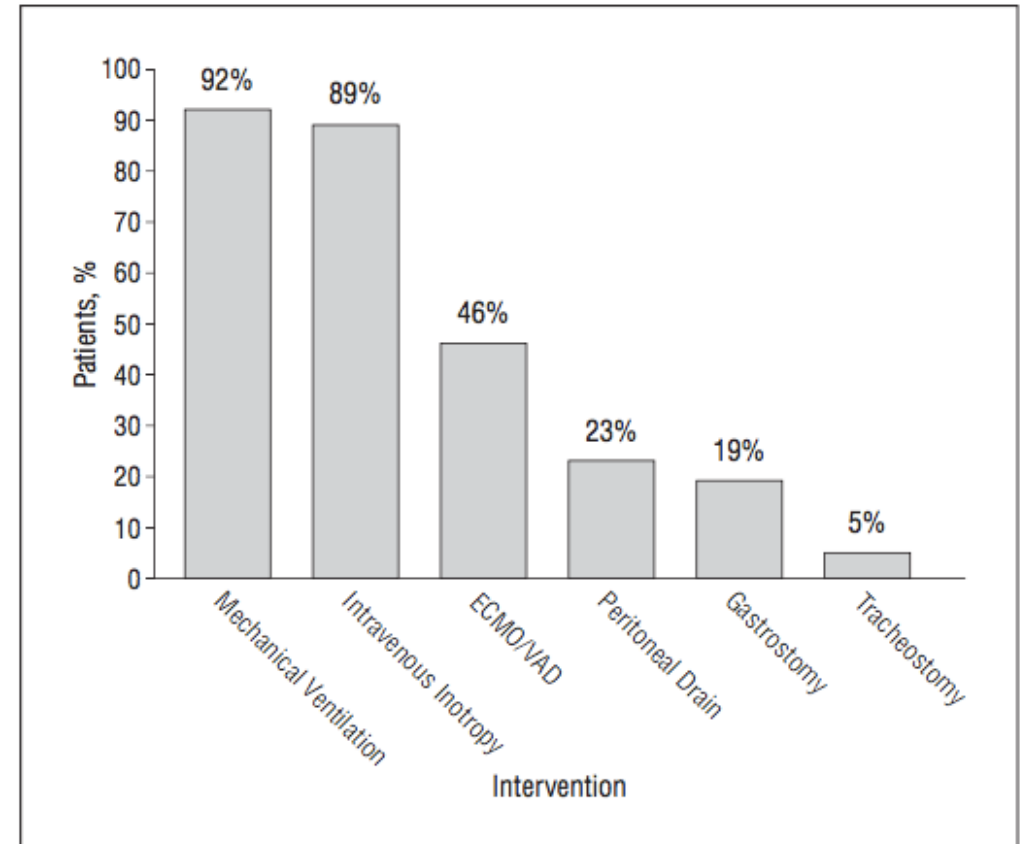


Figure 1. Interventions performed within 24 hours of death. Most patients received highly technological and invasive measures within 1 day of death. ECMO indicates extracorporeal membrane oxygenation; VAD, ventricular assist device.

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- Misperception that cardiac patients die a ‘sudden’ death so the EOL period is short. For this study cohort the mean duration of last admission was 22 days
- 69% died following withdrawal of disease directed care



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- Initial interaction between families and healthcare teams has a focus on 'fixing'
- Progressive heart failure often follows an undulating course – the point at which there is no possibility of long term survival is difficult to identify



Active treatment

Palliative care

↑
Diagnosis

↑
Death

‘Hope is an expectation of greater than zero of achieving a goal’

Robert Twycross

‘[Heart] transplant is like having a lottery ticket in your back pocket’

Consultant Cardiologist, Heart Transplant Service

Hope vs. Optimism

Optimism

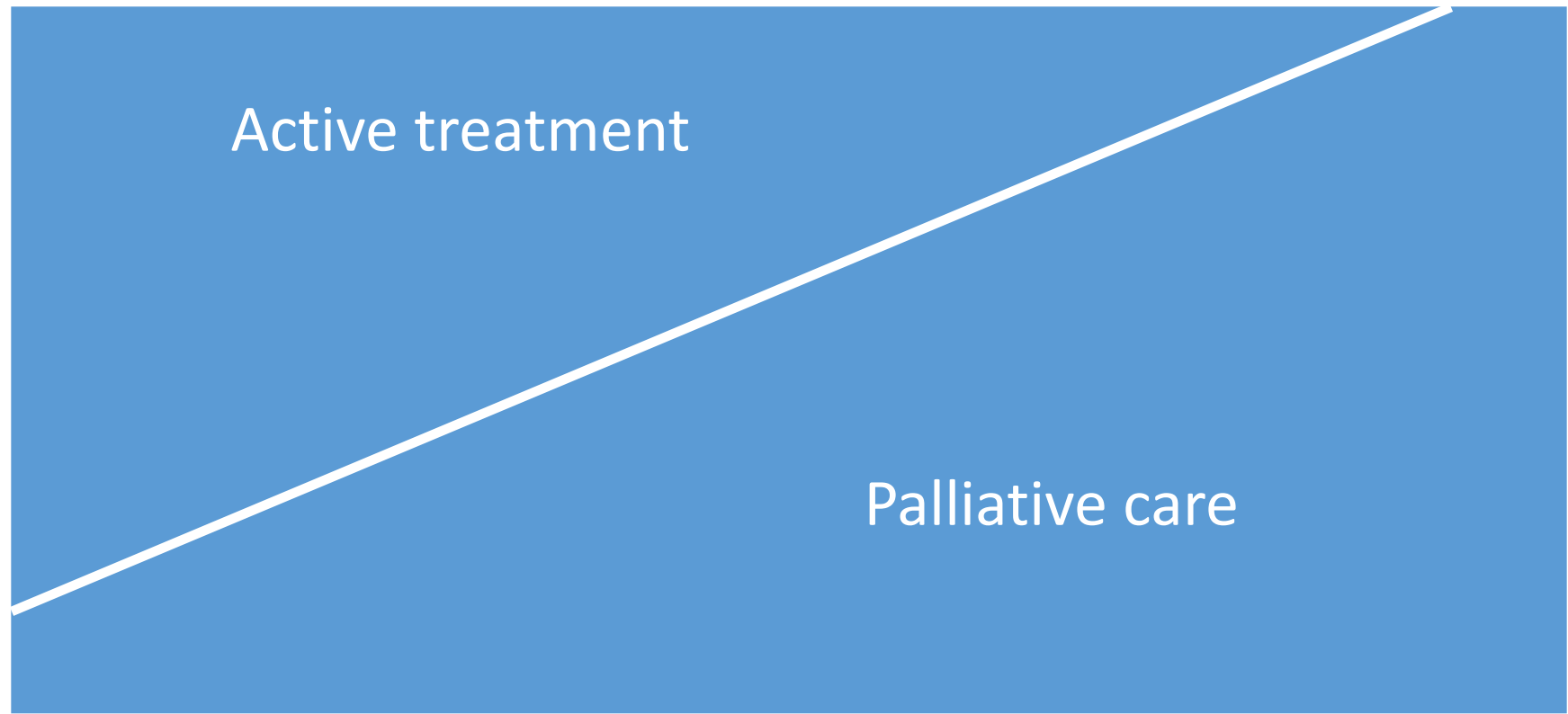
‘An individual’s confidence in achieving a good outcome’

Hope

‘Goal oriented way of thinking that encourages an individual to invest time and energy in achieving their aims’

‘Hope is not a plan’

Atul Gawande



Active treatment

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Diagnosis



Death

Parental Perspectives on Suffering and Quality of Life at End-of-Life in Children With Advanced Heart Disease: An Exploratory Study*

Elizabeth D. Blume, MD¹; Emily Morell Balkin, MD¹; Ranjit Aiyagari, MD²; Sonja Ziniel, PhD³;
Dorothy M. Beke, RN, MS, CPNP-PC/AC¹; Ravi Thiagarajan, MD¹; Laura Taylor, MD²;
Thomas Kulik, MD¹; Kenneth Pituch, MD²; Joanne Wolfe, MD⁴

- 50 bereaved parents surveyed
- Mean age of child at death – 6 months (3.6d – 20.4y)
- At EOL: 86% intubated, 46% receiving mechanical circulatory support
- 78% died following withdrawal of LST, 16% during attempted resus

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- 47% felt their child suffered ‘a great deal’ ‘a lot’ or ‘somewhat’ during the EOL period
- Perceived suffering did not vary with degree of consciousness or mode of death (following withdrawal of LST vs during resus. attempt)
- Symptoms
 - <2yr olds: breathing and feeding difficulties
 - >2yr olds: fatigue and sleep difficulties

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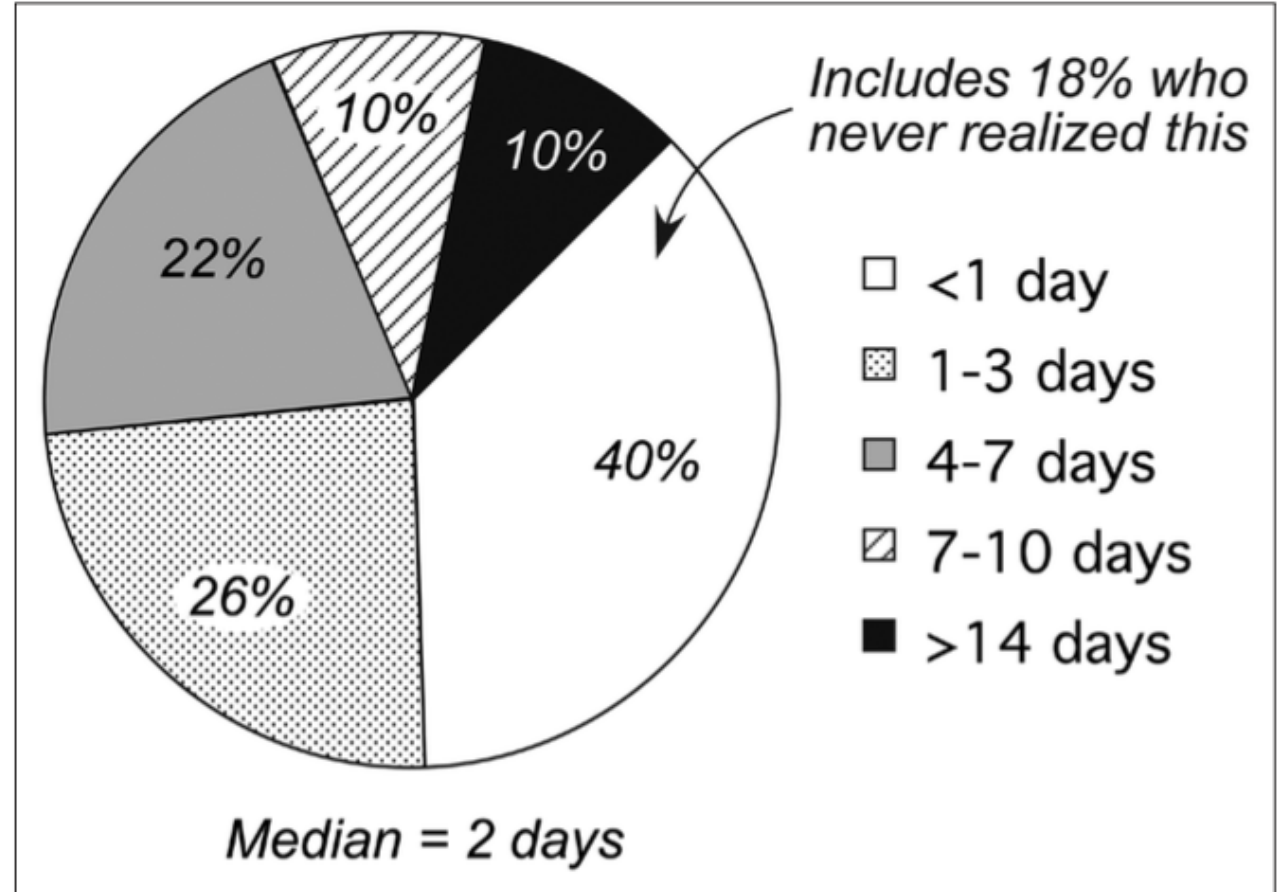


Figure 1. Time prior to death when the parent realized their child had no realistic chance for survival. Almost half of parents (47%) realized this either at time of death (never) or within 1 d prior to death.

To provide good EOL care

- Parallel plan – recognise uncertainty and support them through this
- Understand their goals and priorities
- Try to enable choice and control to optimise quality of life and experience of death
- Good symptom management



Thank you

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