

Palliative & End of Life Care for Children & Their Families

Christine H. Sajous, M.D.

Childhood Deaths in America

0 – 19 Yrs 29% of the U.S. population

2% of all deaths

Deaths in Children < 5 Yrs

1900 30% of all deaths

1999 1.4% of all deaths

Top Causes of Death by Age Group

	< 1 Yr	1 – 4 Yrs	5 – 14 Yrs	> 15 Yrs
	Congenital Anomalies	Accidents	Accidents	Accidents
	Prematurity	Congenital Anomalies	Malignant Neoplasms	Homicides
	SIDS	Malignant Neoplasms	Homicides	Suicides
All Causes	27,337	5,249	7,595	30,656
Rate Per 100,000	705.6	34.7	19.2	81

- Most children are healthy but many live with serious health problems

- Any given day 5,000 children are in their last 6 months of life and could benefit from hospice care
- 8,600 more could benefit from palliative care

- Less than 1% of children living with chronic life threatening illness receive palliative or end of life care

Gender Differences

- Boys of all ages have a higher death rate than girls
 - < 5 years 20% higher
 - > 5 years 130% higher

Race Differences

- At all ages, rates for African-Americans are higher than for White and Hispanic children

Where Do Children Die?

Hospital Settings	56%
Emergency Dept.	16%
Dead on Arrival	5%
Home	11%
Site Unknown	11%
Nursing Home	0.36%

Where Do Children with Cancer Die?

Hospitals	58%
Home	36%
Hospital Outpatient Settings	2.8%

Where Do Children with Complex Chronic Conditions Die?

1980	21% at Home
1998	43% at Home

- In more affluent areas, more children die at home
- Considerable regional variations exist

Implications

- Palliative and end of life care must be flexible if it is to meet the child's and family's needs

- Injuries are important contributors to deaths in childhood. They leave families in shock.

- Many important causes of death in childhood are linked to socioeconomic factors

- Hospitals, especially the NICUs and PICUs, play a particularly important role in caring for children who die both acutely or with complex chronic problems

- Parents long remember how health care professionals helped or hurt them
- Most parents report a mix of good and bad experiences

- Some parents tell stories of exemplary care
- Parents are often faced with uncertainty of their child's prognosis and treatment options

A Child's Experience with Dying Will Depend on:

- Family's circumstances, values and responses to illness
- Medical and other services that are available to meet physical, psychological & spiritual needs

Pathways of Care

- Curative
- Life prolonging
- Palliative

What Is Palliative Care?

- Palliative care seeks to prevent or reduce the symptoms caused by serious illnesses while maintaining the child's quality of life

Problems in Communication

- Physicians report anxiety about an impending death with children and their parents

- Residency programs do not do an adequate job in teaching the patient centered approach in discussion with patients & their family

Talking to Children

- Older children may want information directly from their physicians
- Communication must be adjusted to the child's developmental status

- Children are very often aware that they may not live to grow up or that they will die soon
- Family preferences and cultural values should be understood and respected

Barriers to Considering Palliative Care & Advanced Care Planning

- Parents focused on curative or life prolonging care may be reluctant to consider hospice or end of life planning
- Financial problems

Most Important for Parents

- Pain control
- Economic support
- Spiritual support

Most Important for the Children

- Pain control
- Spiritual support
- "Normal life"
 - Play time
 - School attendance
 - Looking different

Conclusion

- Medical, nursing & other health professional schools or programs should collaborate with professional societies to improve the care provided to seriously ill & injured children by creating curriculum and experiences

- More research should focus on care for infants, children, adolescents and their families, including siblings from the time of diagnosis through death and bereavement