FINAL PROGRESS REPORT

Title of Project:	Profiling the Needs of Dying Children
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Organizations:	The University of Washington (2000-2002) and The Children's Hospital of Philadelphia (2002-2006)
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Abstract

Purpose: To delineate through a series of studies the epidemiology of childhood life-limiting and terminal illnesses, identifying temporal trends and patterns of health service usage.

Scope: Children living with or dying from complex chronic conditions (CCCs), from birth to 25 years of age, in various settings ranging from hospitals to nationally representative population-based samples, over the past two decades.

Methods: Cohort and population-level case series designs along with survey methods.

Results: Over the past quarter century, as the number of pediatric deaths declined, a greater proportion of deaths have been due to CCCs. The site of death among children and young adults who died with underlying CCCs has shifted from the hospital toward home. Among those patients who died in hospitals, the distance from home has increased. Disparities regarding site of death and distance from home have existed across racial and ethnic groups. Hospitalization becomes much more common during the last 3 months of life, but, even during this terminal period, most dying children are residing at home.

Key Words: infant, child, adolescent, pediatric, palliative care, end-of-life care, hospital care, bereavement, chronic illness, illness trajectory, geography

Purpose

In the original proposal for the 5-year KO8 award, I wrote that “my guiding career purpose is to improve the quality of life for children with complex chronic conditions, their families, and those who care for them” and that I intended “by the end of these 5 years to direct a complex chronic conditions service at a children’s hospital, one with meaningful collaboration with parents and community providers, and with a continuously improving palliative and end-of-life care as a central component.”

The epidemiologic and health service research agenda developed in the proposal and then executed over the ensuing year of the award had three broad aims:

> **1. To quantify the epidemiology of pediatric deaths due to CCCs**, measuring the changing population-based incidence of deaths due to these conditions, making strong inferences about the changing prevalence of terminal CCCs in the pediatric population, and identifying clinical markers for periods of high risk of death as a means to aid prognostication and planning.
>
> **2. To assess the need for expanded hospital-based pediatric palliative care services** by measuring the changing incidence of deaths in hospital due to CCCs, measuring the in-hospital prevalence of terminal CCCs, and testing whether the current system of healthcare for these children provides an adequate degree of continuity of care.

3. To measure and value individual patient and family needs by developing a proactive and systematic approach to comprehensive assessment of the needs of children living with life-limiting conditions, promoting more “holistic” care of these children, and eventually evaluating the clinical utility of this approach through a randomized control trial.

The resulting research findings has provided key information regarding the populations of children living with terminal complex chronic conditions, enabling healthcare systems to redesign key concepts and service components to meet needs better and helping healthcare policymakers appropriately assess the needs of this population and track whether these needs are being met.

The research plan was guided by two main hypotheses, each of which motivated specific research aims:

Hypothesis A: Deaths attributable to complex chronic conditions (CCCs) constitute an increasing proportion of all pediatric deaths, both at a population level and more specifically among patients cared for by children’s hospitals.

1. Determine whether the prevalence of terminal congenital CCCs is rising in the national population.
2. Measure the change in prevalence of children with terminal CCCs on the wards of children’s hospitals, thereby assessing the magnitude of need for hospital-based pediatric palliative care services.

Hypothesis B: The quality of care and support for these dying children and their families often deteriorates over the last 2 years of life, with declining continuity of care and untimely referral to hospice.

3. Test whether the ‘intensity’ of medical care increases in the 30-day interval prior to the day on which death occurred compared to the preceding 23-month interval.
4. Test whether the continuity of care deteriorates in the last 2 years of life for children with CCCs.
5. Examine the timing of referral to hospice of all children.

This research sought to improve the care and health policy for children with CCCs in three ways. First, evidence of an ‘epidemiological transition’ in pediatric mortality – from mostly accidental and sudden death to deaths that occur somewhat inevitably with a longer yet unpredictable dying process – would motivate the redesign of pediatric health care services and physician training at both the regional and national level. Second, parts of this research should produce techniques to monitor health utilization data for indicators of the quality of care provided to terminally ill children. Finally, the results of these studies will ultimately inform the development and trial of a longitudinal needs assessment program for children with complex chronic conditions.

Scope

In the year 2000, when this research work commenced, pediatric palliative and end-of-life care was largely neglected, ignored, or spurned. Outside of the care of children with cancer and very premature infants, little was known about either the epidemiology of pediatric life-limiting conditions or the patterns of health service use experienced by this population. During the ensuing half-decade, pediatric palliative and end-of-life care has assumed national prominence (as evidenced by the 2003 IOM report, *When Children Die*, and the recent NPR report on Caring for Kids at the End of Life (available at the following URL: http://www.npr.org/templates/story/story.php?storyId=5630255) as well as the fundamental sanction within the profession of medicine through the recent creation of the Board of Hospice and Palliative Medicine as an American Board of Medical Specialties subspecialty.

The research agenda pursued under this award sought to inform this movement with the highest-quality data and analysis. The institutional and population-level studies have involved subjects, from birth into adulthood (but mostly 0-25 years of age), in specific hospitals or states or the entire US. Most studies focused on subjects who either had died or had a documented complex chronic condition while hospitalized.

Methods

The studies reported below have used a variety of epidemiologic and health services research methods; have been population based, hospital based, or based on national surveys; and have used death certificate data, administrative hospital discharge data, hospital chart data, or survey data.

Results

My collaborators and I have completed seven studies that address the above-mentioned specific aims as well as the broader research agenda of profiling the needs of dying children. Here, I provide abstracts of each study:

1. NATIONAL STUDY OF CHILDREN DYING IN CHILDREN'S HOSPITALS.

> BACKGROUND: End-of-life care is an important yet underdeveloped component of pediatric hospital services.
> OBJECTIVES: We sought 1) to describe the demographics of children who die in children's hospitals, 2) to describe the prevalence of complex chronic conditions (CCCs) among these cases, and 3) to test the hypotheses that cases with more CCC diagnoses experience longer periods of mechanical ventilation and of hospitalization prior to death.
> DESIGN & METHODS: We identified all deaths of patients 0 to 24 years of age that occurred in the 60 hospitals contributing discharge data to the National Association of Children's Hospitals and Related Institutions data consortium for the years 1991, 1994, and 1997. We classified ICD9-CM discharge diagnoses into nine major categories of CCCs (neuromuscular, cardiovascular, respiratory, renal,

gastrointestinal, hematological/immunological, metabolic, congenital/genetic, malignancy), as previously described. We examined the distribution of CCC status among cases and then tested the association between CCC status and the duration of mechanical ventilation and hospitalization prior to death, using Cox proportional hazards regression modeling to adjust for confounders and account for the clustering of data by hospital sites.

RESULTS: Of the 13,761 deaths identified, 42% had been admitted between 0-28 days of life; 18%, between 1-12 months; 24%, between 1-9 years; and 15%, between 10-24 years. Fifty-three percent were White, 20% were Black, and 9% were Hispanic; 38% had Medicaid listed as principal payer, 35% had Blue Cross or another insurance company, and 8% were self-pay. Based on all the discharge diagnoses recorded for each case, 39% had no CCC diagnosis, 44% had diagnoses representing one major CCC category, 13% had diagnoses representing two categories, and 4% had diagnoses representing three or more CCC categories. The median duration of hospitalization was 4 days, and the mean was 16.4 days. After adjustment for age, sex, year, receipt of mechanical ventilation, and principal payer, compared to patients with no CCC diagnoses, those with one major category had a significantly lower hazard of dying soon after admission (HR 0.60, 95% CI, 0.57-0.63), those with two categories had an even lower hazard (HR 0.54, 95% CI, 0.50-0.57), and those with three or more categories had the lowest hazard of rapid death (HR 0.51, 95% CI, 0.46-0.57). This trend of diminishing hazard of rapid death was significant across the three groups of children with one or more CCCs ($p<0.001$).

CONCLUSIONS: Children’s hospitals care for a substantial number of dying patients, who differ widely by age and medical conditions. Children who die with complex chronic conditions are more likely to experience longer periods of mechanical ventilation and hospitalization prior to death. Hospital-based palliative care services will need to care for patients with diverse conditions from infancy into young adulthood and perhaps will need special medical as well as social service techniques to serve well those children who have complex chronic conditions.

2. WHERE DO CHILDREN WITH COMPLEX CHRONIC CONDITIONS DIE? PATTERNS IN WASHINGTON STATE, 1980-1998.

BACKGROUND: Little is known about factors that influence whether children with chronic conditions die at home.

OBJECTIVES: We sought to test whether deaths due to underlying complex chronic conditions (CCCs) were increasingly occurring at home and to determine what features were associated with home deaths.

DESIGN & METHODS: Retrospective case series of all deaths occurring to children age 0-18 years in Washington state from 1980 to 1998 utilizing death certificate data, augmented with 1990 United States Census data regarding median household income by zip code in 1989.

MAIN OUTCOME MEASURES: Site of death.

RESULTS: Of the 31,455 deaths identified in infants, children, and young adults under the age of 25 years, 52% occurred in the hospital, 17.2% at home, 8.5% were in the emergency department or during transportation, 0.4% were in nursing homes, and 21.7% were at other sites.

Among children who died due to some form of CCC (excluding injury, sudden infant death syndrome, and non-CCC medical conditions), the percentage under 1 year of age who died at home rose slightly from 7.8% in 1980 to 11.6% in 1998 ($p<0.01$ for trend), whereas the percentage of older children and young adults with a CCC who died at home rose substantially from 21% in 1980 to 43% in 1998 ($p<0.01$ for trend). Children who had lived in more affluent neighborhoods were more likely to die at home ($p<0.01$ for trend). Using leukemia-related deaths as a benchmark, deaths due to congenital, genetic, neuromuscular, and metabolic conditions, and other forms of cancer were all more likely to occur at home ($p<0.01$). Significant variation in the likelihood of home death, not explained by the individual attributes of the cases, also existed across the 39 counties in Washington state ($p<0.01$).

CONCLUSIONS: Children who die with underlying complex chronic conditions increasingly do so at home. Age at death, specific condition, local area affluence, and the location of home all influence the likelihood of home death. These findings warrant further study, as they have implications for how we envision pediatric palliative care, hospice, and other supportive services for the future.

3. HOSPITAL CARE FOR CHILDREN AND YOUNG ADULTS WITH COMPLEX CHRONIC CONDITIONS IN THE LAST YEAR OF LIFE.

CONTEXT: Although consensus has emerged that pediatric palliative care should be improved, few studies have examined the health services received by children and young adults who die with complex chronic conditions (CCCs).

OBJECTIVES: To describe the hospital care received by children and young adults who die in the last year of their lives and to test whether utilization increased as the date of death drew nearer.

DESIGN AND METHODS: Retrospective case series of all deaths occurring under 25 years of age from 1990 to 1996 in Washington State. Death certificate information was linked to hospital utilization records in the year preceding death. Cases were identified as having a CCC if either the death certificate or the hospital utilization records cited a diagnosis included on a previously published list of ICD-9-CM diagnoses. Outcomes were the timing and duration of hospitalizations and the nature of hospital procedures during the year prior to death.

RESULTS: Of the 8893 individuals included in the analysis, 25% had CCCs. Among infants with CCCs, 84% were hospitalized at the time of death, and 50% had been mechanically ventilated during their terminal admission. Among the 458 CCC-neonates dying under a week of age, 92% of all days of life were spent in the hospital; among the 172 CCC neonates dying during the second to fourth weeks of life, 85% of all days of life were spent hospitalized; among the 286 CCC infants dying during the second to 12th month of life, 41% of all days of life were spent hospitalized. Among children and young adults with CCCs, 55% were hospitalized at the time of death, and 19% had been mechanically ventilated during their terminal admission. For these older patients, the median number of days spent in the hospital during the year preceding death was 18 (interquartile range, 0 to 52), yet less than a third of this group was hospitalized at any point in time until the last week of their lives. The degree to which the rate of hospital use increased as death drew near varied across categories of CCCs.

CONCLUSIONS: Infants who died spent a substantial proportion of their lives in hospitals, whereas children and adolescents who died from CCCs predominantly lived outside of the hospital during the last year of life. To serve these patients, pediatric palliative and end-of-life care will have to be provided in an integrated, coordinated manner both in hospitals and home communities.

4. THE SPIRITUAL CARE NEEDS OF HOSPITALIZED CHILDREN AND THEIR FAMILIES: A NATIONAL SURVEY OF PASTORAL CARE PROVIDERS' PERCEPTIONS.

BACKGROUND: Although most Americans view spirituality as a vital aspect of the illness experience, little is known about this domain of pediatric healthcare.
OBJECTIVES: To profile pastoral care provider's perceptions of the spiritual care needs of hospitalized children and their parents, barriers to better pastoral care, and quality of spiritual care in children's hospitals.
METHOD: A cross-sectional mail survey of pastoral care providers at children's hospitals throughout the US, with a 67% response rate from 115 institutions.
RESULTS: Respondents estimated that, among patients they visited, 34% were chronically ill and 21% were clearly dying. Half or more of patients were thought to have spiritual care needs regarding feeling fearful or anxious; coping with pain or other physical symptoms; and regarding their relationship to their parents or the relationship between their parents. Among patients' parents, 60-80% were estimated to have felt fearful or anxious; had difficulty coping with their child's pain or other symptoms; sought more medical information about their child's illness; questioned why they and their child were going through this experience; asked about the meaning or purpose of suffering; and felt guilty. Respondents agreed on three barriers to providing spiritual care: inadequate staffing of the pastoral care office; inadequate training of healthcare providers to detect patients' spiritual needs; and being called to visit with patients and families too late to provide all the care that could have been provided. Overall, respondents judged that their hospitals were providing 60% of what they deemed as ideal spiritual care.
CONCLUSION: Pastoral care providers believe that the spiritual care needs of hospitalized children and their parents are diverse and extensive. With system-level barriers cited as limiting the quality of spiritual care, considerable improvement may be possible.

5. TECHNOLOGY DEPENDENCY AMONG PATIENTS DISCHARGED FROM A CHILDREN'S HOSPITAL: A RETROSPECTIVE COHORT STUDY.

BACKGROUND: Advances in medical technology may be increasing the population of children who are technology dependent (TD). We assessed the proportion of children discharged from a children's hospital who are judged to be TD and determined the most common devices and number of prescription medications at the time of discharge.
METHODS: Chart review of 100 randomly selected patients from all services discharged from a children's hospital during the year 2000. Data were reviewed independently by four investigators who classified the cases as TD if the failure or

withdrawal of the technology would likely have adverse health consequences sufficient to require hospitalization. Only those cases in which three or four raters agreed were classified as TD.
RESULTS: Among the 100 randomly sampled patients, the median age was 7 years (range: 1 day to 24 years old), 52% were male, 86% primarily spoke English, and 54% were privately insured. The median length of stay was 3 days (range: 1 to 103 days). No diagnosis accounted for more than 5% of cases; 41% were deemed to be technology dependent, with 20% dependent upon devices, 32% dependent upon medications, and 11% dependent upon both devices and medications. Devices at the time of discharge included gastrostomy and jejeunostomy tubes (10%), central venous catheters (7%), and tracheotomies (1%). The median number of prescription medications was 2 (range: 0-13), with 12% of cases having five or more medications. Home care services were planned for 7% of cases.
CONCLUSION: Technology dependency is common among children discharged from a children's hospital.

6. DISTANCE FROM HOME TO THE HOSPITAL WHERE DEATH OCCURS: A POPULATION-BASED STUDY OF WASHINGTON STATE, 1989-2001.

CONTEXT: For patients who die in hospitals, greater distance from home can burden both the dying patients and their caregivers. Regionalization of tertiary health care services over the past decades may be increasing this distance, particularly for younger patients whose care is especially regionalized and for patients cared for at larger referral-center hospitals.
OBJECTIVE: To test the hypotheses that the distance from home to hospital is inversely related to the age of the dying patient, directly related to the size of the hospital, and has increased over time.
DESIGN: Population-based case series.
Subjects and Setting: All deaths of Washington State residents that occurred in Washington State hospitals from 1989 to 2001.
MAIN OUTCOME MEASURE: Travel driving distance between home residence and hospital were calculated using geographic information systems (GIS) techniques.
RESULTS: Children who died in hospitals were much farther from home than their adult counterparts: the mean distance was 39.1 km for neonates and 47.3 km for children aged 1-9 years, compared to 20.7 km for adults aged 60-79 years and 14.6 km for cases > 79 years of age. This substantial trend of decreasing distance with increasing age persisted even with adjustment for patient characteristics, including underlying causes of death. The disparities of distance were even greater among cases at the 90th percentile for distance (115.9 km for neonates compared to 30.7 for cases > 79 years). Hispanic, American Indian, and Native Alaskan patients who died in hospitals were farther from home than White patients, while Asian and Black patients were closer to home. Adjusting for patient characteristics, the distance from home residence to hospital increased by 1% annually.
CONCLUSIONS: The potential emotional, social, and financial burdens that greater distance between home residence and hospital imposes on dying patients and their families may be mounting as this distance increases, and are likely born disproportionately by children and certain ethnic groups. These findings have implications for the local and regional design of end-of-life supportive care services.

7. LIKELIHOOD OF HOME DEATH ASSOCIATED WITH LOCAL RATES OF HOME BIRTH: INFLUENCE OF LOCAL AREA HEALTHCARE PREFERENCES ON SITE OF DEATH.

> OBJECTIVES: We tested whether local cultural and social values regarding the use of healthcare are associated with the likelihood of home death, using variation in local rates of home births as a proxy for geographic variation in these values.
> METHODS: For each of 351,110 adult decedents in Washington State who died from 1989 through 1998, we calculated the home birth rate in each zip code during the year of death and then used multivariate regression modeling to estimate the relation between the likelihood of home death and the local rate of home births.
> RESULTS: Individuals residing in local areas with higher home birth rates had greater adjusted likelihood of dying at home (odds ratio [OR]=1.04 for each percentage point increase in home birth rate; 95% confidence interval [CI] = 1.03, 1.05). Moreover, the likelihood of dying at home increased with local wealth (OR=1.04 per $10,000; 95% CI=1.02, 1.06) but decreased with local hospital bed availability (OR=0.96 per 1000 beds; 95% CI=0.95, 0.97).
> CONCLUSIONS: The likelihood of home death is associated with local rates of home births, suggesting the influence of healthcare use preferences.

As pointed out in the conclusions of these abstracts, these studies provide information that can guide the planning of pediatric palliative care services both at the national level and at the level of individual children's hospitals. In particular, the findings from the studies point to 1) the importance, from a population-based perspective, of the needs of dying infants, because they constitute the majority of cases; 2) the importance of patients dying from diseases other than cancer, because they also constitute the majority of cases; and 3) the important but likely limited impact of hospital-based palliative care services for children dying beyond infancy, given the limited exposure that these patients have to hospitals. Each of these three motivates an enlargement of perspective from a limited clinic or hospital-oriented view to that of a population of children.

List of Publications and Products

The following publications were all supported to varying degrees by the KO8 award, either by directly supporting the research activity or though the indirect effect of improving my analytic research skills as part of the career award objectives. The bolded publications are the ones most germane to the area of pediatric palliative and end-of-life care.

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