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Pediatric Hospice:

The career potential for pediatric residents and a comparison between systems in UK and US

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Background: Hospice and palliative care have been gaining significant momentum in the American consciousness for the past ten years. However, the vast majority of the conversations and developments have been concerned with the end of life care of adults.

Objectives: This paper seeks to examine the definition and development of pediatric palliative and hospice care both in the United Kingdom and the United States. By examining both the existing models of end of life care for children as well as understanding how such models developed, it is expected that a more educated evaluation of the pros and cons of each system can be produced. Also, by delineating both the barriers to pediatric hospice and palliative care as well as the existing local resources, one can more accurately assess the potential growth of hospice and palliative care within the realm of pediatrics, and therefore also assess its career potential.

Methods: Extensive literature searches formed the base of this study. Practical experience in hospice care delivery within the Worcester community was gained by two days of home visits with hospice nurses from UMASS Memorial Hospice, Worcester MA, as well as attendance at a weekly multidisciplinary hospice meeting. Practical experience in hospice & palliative care delivery in the United Kingdom was attained through a three week rotation with the Academic Palliative Medicine Unit, University of Sheffield, Sheffield England and a one week rotation with the Specialist Paediatric Palliative Care Team, Royal Children's Hospital at Alder Hey, Liverpool England. The Sheffield rotation included multidisciplinary meetings and placements at three adult hospices as well as inpatient adult palliative care services at two hospitals and outpatient palliative care service at a third; a day-visit to Helen's House Pediatric Hospice in Oxford England was also arranged. In the Liverpool rotation, all care was pediatric, including inpatient and outpatient services, multidisciplinary meetings, two hospices and two home visits.

Results: Pediatric hospice in the UK is primarily based on a freestanding residential hospice model that offers both respite care to children with life-limiting disease as well as terminal care. In the UK, pediatric hospice care services are more widespread, with 29 freestanding hospices, 7 hospices in the planning and/or planning stages, and 5 hospice-at-home services. Conversely, although the US began to investigate pediatric-specific palliative and hospice care before the UK, it lags behind the UK in services offered. Home care services are the preferred model for pediatric hospice care in the US, but the number of programs are few and far between. In

addition, the first and only freestanding residential pediatric hospice in the US opened only in March 2004.

Similarities between the 2 countries lie in the current slow integration of pediatric palliative care into the physician community; in neither country has it become an officially recognized subspecialty. However, the future seems bleaker for American pediatricians, who have recently suffered a setback as the American Board of Internal Medicine pushes forward for official recognition of the subspecialty by the American Board of Medical Specialties; the American Board of Pediatrics is not prepared to support the same advancement and so faces to lose the possibility of certification in pediatric palliative care.

Conclusion: The resources and facilities of pediatric residential hospices are as phenomenal as the culture of care that enwraps all who enter. It is difficult not to get excited when faced with such enormous compassion and personal connection in a professional context. While every effort should be made to support such facilities, it must be recognized that there is a lack of both demand and financial stability for residential pediatric hospices. Compared to all deaths, there is a very low incidence of non-sudden pediatric death in the US. Both low incidence and poor economics have pressured the American Board of Pediatrics to not sponsor the development of the new certification exam in hospice & palliative care, effectively blocking the rightful professional development and recognition of such a specialty in pediatrics.