Journal of
Community & Public Health Nursing

Ramsey and Matt, J Comm Pub Health Nurs 2016, 2:4
DOI: 10.4172/2471-9846.1000144

Research Article

OMICS International

Policy Review and Recommendations: Palliative Care for Pediatric Patients in the United States of America

Richard John Mooradian Ramsey* **and Susan B Matt**

College of Nursing, Seattle University, 614 20th Avenue, Seattle, WA 98122, USA

***Corresponding author:** Richard John Mooradian Ramsey, J.D., M.S.N., R.N.,College of Nursing, Seattle University, 614 20th Avenue, Seattle, WA 98122, United States, Tel: 206-910-4580; E-mail: Rich@nurserich.com

Received date: October 14, 2016; **Accepted date:** November 21, 2016; **Published date:** November 28, 2016

Abstract

This research analysis focuses on palliative care approaches common within the United States and aims to show strengths, weaknesses, areas for improvement and research gaps to be closed by future studies. Ultimately, the end goal is to build a feasible, appropriate and actionable government policy proposal to ensure that all chronically ill Americans, in particular infants, children, and adolescents, receive the best care possible. This research involves briefly analyzing and assessing, using value theory and meta-ethical considerations, the unique palliative care systems in the United Kingdom, Canada and Belgium. The onion research paradigm and techniques provide the framework for this study. The research strongly suggests that the American palliative care system in general, and pediatric palliative care system in particular, are woefully lacking and in need of significant changes and improvements. Recommendations include: moving from a particular category consideration to a holistic approach that involves integrating many disciplines and family members into the treatment plans of adults and children alike; providing more robust and palliative-specific training programs; increasing funding for palliative care research, options, programs, education, and organizations; placing a stronger emphasis on networking with community spiritual, emotional, medical, and human resources; establishing units specifically designed to treat infants, children, and adolescents and catering to their and their families' needs; and creating campaigns to ensure that all Americans are familiar with palliative care options.

Keywords: Palliative care; Hospice; Pediatric; Young adult; Adolescent; United States; Europe

Introduction

Many countries, including the United States, have experienced an increase in the number of chronically ill patients, including infants, children, and adolescents. This places a new strain on health care systems and requires unique approaches to delivering care that promotes patient wellness. Recently, the United Nations Convention highlighted its concerns regarding the rights of chronically ill people and required all member states to adopt effective and efficient programs to meet the unique and oftentimes challenging needs of this specific segment of the population [1]. Unfortunately, developing a suitable palliative care system to meet the needs of all patients is cumbersome, costly, and exhausting; nonetheless, it is a task that each nation must complete [2]. This paper explores palliative care systems in the United States (U.S.) and other countries to identify strengths, weaknesses, areas for improvement, and research gaps to be closed by future studies.

Purpose

The purpose of this project is to call attention to the deficiencies in the palliative care approaches in the U.S. compared to those in other developed countries, with the goal of proposing recommendations to improve the palliative care system in the U.S. in general, and palliative pediatric system in particular.

This research analysis focuses on palliative care approaches common within the United States and aims to show strengths, weaknesses, areas for improvement, and research gaps to be closed by future studies. Ultimately, the end goal is to build a feasible, appropriate, and actionable recommended policy proposal to ensure that all chronically ill American pediatric patients receive the best care possible. This research involves analyzing and assessing, using value theory and meta-ethical considerations, unique palliative care systems in the United Kingdom, Canada and Belgium. Subsequently, the American palliative care system will be detailed to describe its current status and internal problems. Finally, a list of recommendations to improve the palliative care system in the U.S. in general, and palliative pediatric system in particular, as well as future areas for research, will be provided.

Methodology

The study employs the onion research paradigm. This method was deemed the most appropriate because it encompasses all of the research objectives, and is considered both a valid and reliable way of obtaining information and drawing appropriate conclusions [3]. The onion research paradigm incorporates philosophies such as epistemology, ontology, and axiology. Epistemology focuses on the concept of knowing, and provides evidence regarding how the lack of palliative services for children with chronic and/or life-limiting illnesses equates to child maltreatment [4]. The characteristics, processes, and principles that guide the quest for knowledge are essential elements of the epistemological technique [5]. Ontology is the philosophical approach based on realism and candidly analyzes positive and negative assessments and reviews [5]. Therefore, the research will truthfully assess benefits and shortcomings of the palliative care program in the U.S. Finally, the axiological technique

Citation: Ramsey RJM, Matt SB (2016) Policy Review and Recommendations: Palliative Care for Pediatric Patients in the United States of America. J Comm Pub Health Nurs 2: 144. doi:10.4172/2471-9846.1000144

highlights the overall worth of research findings, while taking into consideration value theory (taking into consideration what humans value and why from a psychological, sociological and economic context) and meta-ethical considerations, in which the meaning of moral judgments are explored and supported [3].

The Concept of and Need for Palliative Care

Defining palliative care

Prior to delving into the issues surrounding palliative care in the United States in general and palliative care amongst American infants, children, and adolescents in particular, it is pertinent to establish a working definition of palliative care. In their research, Smith et al. [6] determined that oftentimes palliative care is erroneously used as a synonym for hospice care when, in fact, they are related but distinct concepts. While hospice care involves providing quality holistic care for a person solely at the end of their life, "palliative care is patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering, [that] addresses physical, intellectual, emotional, social, and spiritual needs throughout the continuum of illness" [7]. Palliative care, unlike hospice care, begins at the point of diagnosis, and its delivery continues throughout the entire course of the illness.

The World Health Organization (WHO) defines palliative care for children and outlines the aims and ambitions of such care. Palliative care for children "is the active total care of the child's body, mind, and spirit, and also involves giving support to the family." It starts when a child receives a serious, often life-limiting medical diagnosis, and its continuation is not based on whether or not a child receives curative treatment for their disease [8]. Physicians and healthcare providers are tasked with evaluating and alleviating a child's physical, social and psychological distress.

Palliative care is complex and involves a coordinated program of care involving many professionals amongst multiple disciplines [9]. In the early stages of illness, patients often receive therapies designed to prolong life and relieve pain and suffering. A team of palliative care specialists assesses the patient and designs an appropriate plan based on the individual needs and illnesses of the patient. Importantly, when developing these individual treatment plans, the team of professionals takes into consideration a wide range of factors, to include the physical, mental, emotional, and spiritual health and wellbeing of the patient, the patient's wants and desires concerning their treatment, and the possible negative and positive implications that could result from utilizing certain treatments and procedures [9]. Palliative care integrates psychological and spiritual nurturing with more traditional forms of medicine and pain prevention to aid patients and their families in their journeys along the trajectory of the specific diagnosed condition including, in certain cases, moving towards coming to terms with the impending death of the patient [9]. Palliative care accomplishes this in all instances by aiming to allow the patient and family to work towards developing a positive perspective of the health condition with the hope that they will then be capable of better enjoying their lives while living with the diagnosis. To this end, palliative care programs connect this population with essential services such as: (1) pain and symptom management, (2) social services, counseling, and bereavement services, (3) complementary therapies, (4) case management, and (5) respite services [10].

Assessing the need for pediatric palliative care within the United States

There are 560,000 children across America currently living with serious chronic and/or life-limiting illnesses, and every day in the United States over 5,000 children with chronic conditions are within the last six months of their lives [11]. In 2013, over 42,000 children died in this country [11]. A report by the Institute of Medicine concluded that "children with fatal conditions and their families fail to receive competent, compassionate and consistent care to meet their physical, emotional and spiritual needs" [10].

Children and young adults with palliative care needs are unique compared to the adult population. Pediatric patients vary in age, and their complex medical conditions are best monitored by pediatric specialists [12]. The care team is presented with the unique challenge of providing care that is developmentally appropriate to these patients [12]. Providers must consider trajectories of illness, effectiveness of pain and symptom management interventions, funding mechanisms, research paradigms, education initiatives, communication strategies, ethical concerns, and a shortage of healthcare staff with palliative care expertise [12].

Parents and families who are caring for a child with life-limiting conditions (LLCs) face great challenges. Typically, seriously ill patients require the care of a team of physicians, therapists, specialists, social workers, and spiritual leaders; whereas, the patients' families are themselves in need of medical, spiritual, and emotional counseling to understand their loved one's illness and process the emotions they themselves are experiencing [13]. Chronic illness puts tremendous financial, emotional, physical and spiritual stress on patients and family members alike [13]. When acting as their child's primary caregiver, there can be intravenous medications and fluids to administer, therapies to perform, tests to run, and appointments to keep [14]. Many families are also challenged as they often experience a reduction of income; some parents have difficulty maintaining employment [15]. Holistic approaches for chronic illness such as palliative care programs are needed in modern day society to deal with the increased number of people who are living longer while suffering from terminal illnesses.

Healthy People 2020, a 10 year national objective initiative put forth by the United States Office of Disease Prevention and Health Promotion (ODPHP) strives to: identify nationwide health improvement priorities; increase public awareness and understanding of the determinants of health, disease and disability and the opportunities for progress; provide measurable objectives and goals that are applicable at the national, state, and local levels; engage multiple sectors to take actions to strengthen policies and improve practices that are driven by the best available evidence and knowledge; and identify critical research, evaluation, and data collection needs [16]. Currently, Healthy People 2020 does not specifically address pediatric palliative care, and the ODPHP is currently developing these goals for its 2030 initiative. Expansion of services for the pediatric community in need of palliative care now and submitting proposals aimed at improving the delivery of pediatric palliative care, will result in the achievement of many of the health initiative's goals.

According to the National Association for Children's Hospitals, 1.3 million children in the United States could benefit from hospice or palliative care services [17]. However, there are significant challenges to meeting this identified need. Despite the widespread use of palliative care services by adult Americans, engaging the public in a discussion regarding palliative care, and especially towards the end of life, for anyone, let alone for children, is a difficult task. “The death of a child is not accepted in our culture. Parents feel the need to make every attempt to preserve their child’s life, often at great personal sacrifice and frequently involving severe threats to the integrity of the family itself” [18]. Our nation’s reluctance to address the needs of pediatric patients who are faced with serious life-limiting illnesses and/or death has prevented the specialty from maturing, and much work needs to be done to train a proficient workforce of care providers capable of meeting this population’s needs.

A global call to action

The United Nations Convention on the Rights of the Child highlighted the concerns regarding the rights of adolescents and patients with chronic diseases, and, therefore, it became a mandate for the member states to enact laws that ensure the protection of this vulnerable population.

The [UN] Human Rights Committee, the European Court of Human Rights and the InterAmerican Court of Human Rights, have [all] recognized the need for States to provide special measures or heightened “due diligence” to protect the personal liberty and security of every child...Children experience pain and suffering differently to adults owing to their physical and emotional development and their specific needs...The threshold at which treatment or punishment may be classified as torture or ill-treatment is therefore lower in the case of children, [and] the failure to ensure access to controlled medications for pain and suffering threatens fundamental rights to health and to protection against cruel, inhuman and degrading treatment [19].

The call by the United Nations hinted at the need for an efficient system created based on a succinct analysis of the internal structures within individual nations along with other global considerations [1]. The conventional mechanisms were to create support for a political environment that will promote the adoption of adequate palliative care policy measures in all nations to ensure the protection of the right and interests of children, patients, and their families. However, the development of a suitable system for palliative care involves the contribution of stakeholders of each nation-state coupled with global support. At their weakest, patients depend on their caregivers to offer proper guidance, meet needs, and provide necessary support until they reach their death. Some of their experiences are beyond the boundaries of their caregivers, and this void can be filled by policies tailored to guarantee care and treatment. But, as most countries fail to have a robust and coherent policy to help ensure access to quality palliative care, the maltreatment of such patients is a common phenomenon [19]. Therefore, the need to create systems meant to mitigate the risks and problems associated with caring for vulnerable young persons with chronic and/or life-limiting illnesses is necessary [2].

Palliative Care in United Kingdom

Beginning in 2003, the government of the United Kingdom adopted the Every Child Matters Policy, which was aimed at increasing medical, physical, and emotional support offered to children by the state [20]. This newly implemented plan classified children according to their specific level of pediatric needs. In general, children were first put into one of two groups: those who simply needed access to universal healthcare services and those who required special care and attention according to their individual needs [21]. This was the first step towards ensuring that children received palliative care for chronic illnesses. Three years later, the government of the United Kingdom updated its policy framework to incorporate a stronger emphasis on palliative care in an effort to find ethically sound and physically appropriate means of providing palliative care to children [22].

In 2012, the Poverty and Social Justice Policy was signed into law by the government. One of its main objectives was to establish an effective prevention-based strategy for patients with terminal illness and their families [23]. The plan entailed subsidizing costs incurred by low-income families with terminally ill members. Funds were allocated to ensure that the parents of terminally ill children had the means to provide for their children’s needs, such as education, medicine, and shelter, as well as supplementary income to help sustain the family as they rearranged their lives (and sometimes were forced to quit their jobs) to care for their chronically ill child [23].

The United Kingdom has a well-established palliative care system that is adequately funded, and focuses primarily on treating patients holistically, emphasizing the need to consider each patient as a unique entity in need of personalized care [24]. There is no “cookie-cutter” approach to palliative care; instead, each patient is assessed individually and plans are developed to meet individual and familial needs. Moreover, ample laws and provisions are in place to ensure that all patients receive the care needed to maximize their quality of life. For instance, younger patients have access to pediatric experts who specialize in caring for terminally ill infants, children, and adolescents [24]. In turn, young patients and their families receive a higher quality of care in the United Kingdom as a result of these government policies.

In general, the United Kingdom’s palliative care system is effective for three overarching reasons. First, it is well funded and well supported by government agencies, and provides a legal guarantee that all people, regardless of socio-economic status, have access to care. Second, it addresses the needs of whole families and does not simply limit its scope to the patient. Finally, it differentiates between the needs of adults and children and has special provisions for minors and their parents.

Palliative Care in Belgium

Brussels, Belgium opened its first palliative care unit in 1985 [25]. That same year, Belgium recognized the formation of its first palliative care home team that was specifically designed to meet with patients in their homes and care for their individual spiritual, physical, emotional, and psychological needs [25]. Palliative care continued to grow from 1985 to 1990, and in this time period the nation saw the creation of many palliative care hospital units and home teams, especially in its larger cities [25].

These initiatives were met with a great deal of success and were attractive options for chronically ill patients [26]. In 1991, the country officially announced that it would increase its investment in palliative care medical experiments and research [25]. By 1993, the Belgian government had already begun to prepare structures for palliative care to be implemented throughout the nation [27]. Four years later, the government officially installed a regional network of federally funded palliative care units [27]. This new system consisted of 25 regional networks and many different medical, spiritual, and mental health professionals who worked together to provide patients with the best care possible [27]. By 1998, Belgium had, in addition to the regional network of hospital-based palliative care units, 28 separate teams designated to provide care to patients in their homes. The next year, the country increased its investment in palliative care and installed mobile palliative care support teams in each of its hospitals [27].

In 2002, the Belgian government passed a law to ensure that palliative and related care was guaranteed to each and every citizen. The law stipulates the rights of each and every patient as follows [27]:

- Good, quality medical services;
- Free choice of medical providers and caregivers;
- Right to refuse treatment and information;
- Informed consent for all medical interventions;
- A copy of all medical records;
- Patient confidentiality; and
- Access to a palliative care liaison at each hospital location.

Importantly, palliative care in Belgium, since its inception, has targeted all age groups and specialized care has been provided for infants, children, and adolescents. Pediatric specialists work with palliative care teams to assess the mental, spiritual, and physical well-being of minors and to ensure that their unique and individual needs are met. Moreover, a significant amount of support is awarded to families of chronically ill children [27]. Most recently, in November 2015, Belgium hosted the first Conference on Perinatal Palliative Care [26]. Its main contributors came from one of Belgium's two pediatric palliative care education programs. The conference's chief objective was to "offer various points of reflection from neonatologists, nurses, psychologists and ethicists in order to build a framework of care which make[s] sense for both families and caregivers" [26].

In 2015, Belgium formed its first Pediatric Palliative Care Group specifically designed to work exclusively with children. As previously stated, Belgium has offered palliative care to all individuals, regardless of age, since its inception; however, this special care team, comprised of pediatric experts, is regarded as a significant step towards providing better quality palliative care to children [26].

Belgium has earned its highly esteemed reputation in palliative care delivery for four overarching reasons: (1) it has been around for a significant amount of time and, therefore, has had time to work out problems and shortcomings and make necessary changes; (2) it is well-funded and supported by the Belgian government; (3) the Belgian people welcome palliative care initiatives and view them as a vital part of care for themselves and their loved ones; and (4) Belgium's program has one of the best pediatric palliative care systems comprised of special teams designated to deal exclusively with the needs of infants, children, and adolescents. Moreover, it is currently in the process of formulating its own perinatal care team to provide care for preterm and newborn babies. As a result of its focus since its inception on providing well-funded, quality palliative care for young people that was supported by the government and its people, Belgium's pediatric palliative care system is a model that must be emulated.

Palliative Care in Canada

In Canada, the government primarily funds palliative care [28]. "[Palliative] care is an increasingly important need in [the Canadian] health care system with the potential to affect all Canadians" [28]. In addition to caring for the physical, emotional, and spiritual needs of Canadian patients, palliative care is designed to meet the therapeutic needs of patients, offer options and opportunities to develop the patient's social, recreational, and life skills, and strengthen family dynamics by reducing stress and improving the quality of life of both the caregiver and patient [28]. To help facilitate these goals and objectives, palliative care is broken down into three broad divisions: in-home respite care; facility-based services; and day services [29].

In-home respite care allows patients to stay in the comfort of their own homes while receiving care for their condition(s). Trained professionals come to the patient's house and provide them with the care and support needed to manage their illnesses [29]. Although this option is quite costly, the Canadian government has successfully procured the funds necessary to sustain it. A particular care center is assigned to each patient, which is responsible for coordinating all care and delivering in-home services catered to individual needs and care wants [29].

Facility-based services are mostly located within hospitals and other medical centers and are designed to allow the patient to stay in a safe environment surrounded by trained professionals and medical personnel [28]. Patients receive a wide range of services to meet their needs. Generally, patients only enter these facilities when their conditions have deteriorated significantly, and not many people spend a long period of time in them. These units provide social and spiritual support, as well as traditional care and treatments.

Finally, the Canadian government also networks with other agencies and organizations to provide holistic care and day services to all patients. For instance, existing programs assist in building long-term, fruitful relationships with the caregivers and the families of the child [30]. Parent respite cooperatives also help families coordinate care and engage with experts and other families who are in the same or a similar predicament. This provides an expanded support network for families and patients. Other services, such as buddy programs, volunteer-based initiatives, summer camps, and group daycares, are incorporated into Canada's pediatric palliative care plan to ensure that all children receive the care and attention they need and deserve [28].

Canada has special palliative care programs designed to meet the needs of children. The Respite Care for Children was started to help children with chronic illnesses and their families receive the spiritual, physical, and emotional care needed. According to the Canadian Healthcare Association [28], the following care and treatment programs are designed specifically to care for children's unique needs:

- Matching Brokerage Programs: Designed to help facilitate long term, lasting relationships between the family and the caregivers; care is provided in the home of the patient, respite worker or volunteer;
- Patient Respite Cooperatives: Organizations created by families with the aid of a professional liaison to offer respite care exchange programs; families can utilize these resources to obtain emotional support and exchange direct care (such as other members taking care of sick children while their parents are away);
- Volunteer Families and Buddy Programs: These programs match families and patients with similar disabilities or ailments with one another or match a child with an older mentor to provide them with guidance and support;
- Summer Camps and Group Day Care: Programs designed to offer recreational and medical support while providing children with the opportunity to experience social, emotional, and physical growth and development;
- Group Respite Facilities: Medical facilities specifically designed to only offer respite care to younger patients;
- Community Residences and Residential Treatment Facilities: Medical facilities designed to care for a wide range of patients to include respite pediatric patients; and

- Pediatric Nursing Homes: Created to offer long term care to children with fairly severe and chronic medical needs.

Canada has one of the strongest palliative care programs in the world, and its pediatric care program is, arguably, the best in the world [28]. The main reason for its success is its wide range of programs, services, and options specifically designed for children and their families. Importantly, many of these programs and initiatives are volunteer-based and cost relatively little compared to traditional medical treatment. Canada's focus on grassroots, community-based support and care groups and networks allow parents and patients to deal with chronic medical issues easier, thanks to the extensive care options [28].

The United States Scenario

The 2015 Palliative Care Report Card, a report by the Center to Advance Palliative Care and National Palliative Care Research Center that details variations in access to palliative care within the United States, shows a continued increase in the number of hospital palliative care teams in the U.S. [31]. For instance, in 2008, only 53 percent of U.S. hospitals with fifty or more beds reported palliative care teams; today, this number is closer to 67 percent [31]. Moreover, the number of U.S. states with Grade A palliative care teams (defined as 80 percent or more of the state's hospitals having a palliative care team) increased significantly, from 3 percent in 2008 to 17 percent [31]. For the very first time, in 2015, no U.S. state received a Grade F (defined as 20 percent or less of the state's hospitals having a palliative care team) [31]. These were all viewed as significant improvements to palliative care offerings in the United States. However, the U.S. still fell woefully behind most other developed Western nations' palliative care program ratings, and received an overall Grade B. Unfortunately, one-third of all U.S. states received a Grade C or D [31].

It was not until 2013 that the American Academy of Pediatrics released a policy statement on palliative care/hospice care (PP/HC). The statement listed six overarching components and commitments of PP/HC [32]:

- Provide a patient centered and family integrated approach to care;
- Respect the autonomy of patients and partnering with patients and their family members;
- Offer care that is readily accessible, high quality, and equitable across socio-economic groups;
- Provide high quality care across lifespan and age spectrum that is integrated into the total continuum of care;
- Ensure that all healthcare workers are able to provide rudimentary palliative care and are capable of consulting PP/HC specialists in a timely fashion; and
- Improve care through constant research and quality improvement efforts.

Pediatric palliative care within the United States started in the 1980s at two locations – Cleveland Clinic and the Medical College of Wisconsin [33]. These early initiatives were hospital-based and pediatric patients received all of their care and support within a hospital setting. Currently, pediatric palliative care units have increased significantly and total around 1,400, with bed-space available for approximately 300 patients [34].

Over the past several years, American hospitals have significantly increased palliative care options for seriously and chronically ill children; however, little is actually known about the number and appropriateness of U.S.-based pediatric palliative care (PPC) programs [35]. Of 162 children's hospitals surveyed, less than 70 percent offered pediatric palliative care treatment programs. The research findings of significant note include: (1) the rate of new program creation peaked in 2008, with 12 new programs created that year, and 10 new programs in 2011; (2) most programs offer only inpatient services, and most only during the workweek; (3) the number of consults per year varied substantially across programs, and was positively associated with hospital bed size and number of funded staff members; and, (4) PPC programs report a high level of dependence on hospital funding [35].

A more holistic approach to pediatric palliative care, which included meeting the needs of both children and their families, started as a volunteer-based initiative, similar to ones in Canada. These volunteer-based, grassroots organizations and groups were very successful and grew significantly over the years [34]. Today, these volunteer-based organizations are considered to be the most utilized palliative care options available for children and their families [35].

Shortcomings in United States Palliative Care

Despite the increased need for palliative care within the United States, "even experienced physicians often struggle when initiating complex, emotionally laden discussions about palliative care with seriously ill patients and their families" [36]. Palliative care is extremely difficult because it often focuses primarily on controlling pain and helping terminally ill patients and their families to come to grips with death. Pain and emotional care is individual-specific and no "one size fits all" approach exists. Instead, professionals have to be able to carefully assess individual situations and develop plans that work best for each patient. Assessing and controlling pain and promoting emotional health is problematic with even fully aware and mentally sound adults. The task is even more difficult with infants, children, and cognitively impaired individuals suffering from mental illness, dementia, and other similar conditions that affect judgment and mental capacity [37].

Economic concerns pose challenges as well. Many people lack the health coverage and economic resources to afford long term, care, such as hospice care. The costs of taking care of a family member with a terminal illness are high, and many families lack the financial means to properly care for their terminal loved ones [38].

Results

Oftentimes, this results in palliative care taking place under unsafe circumstances [39]. Most experts note that protection policies and state-sponsored services are imperative to ensure that chronically ill patients, to include infants, children, and adolescents, receive the care they need and are not subject to sub-standard treatments and care.

Research suggests that within the U.S. there is a lack of public awareness regarding palliative care options [36]. Moreover, there are negative stigmas and stereotypes that still persist associated with chronic illnesses and palliative care [36]. Unfortunately, the current level of research available to physicians and trained professionals within the U.S. is lacking. In the estimation of most medical experts, U.S.-based palliative care research is insufficient to establish a valid and reliable basis for policy establishment [36].

The Palliative Care Report Card suggests several major weaknesses and deficiencies in the United States palliative care program. The most significant are as follows [31]:

- Hospital palliative care units are understaffed and overstretched. They are unable to properly care for the large number of patients who could benefit from palliative care services. To date, about 3.4 percent of hospital admissions receive palliative care treatment; however, an estimated 8 percent need it. About 1.8 million Americans admitted to the hospital each year do not receive the palliative care treatment they need.
- The quality and availability of palliative care within U.S. hospitals varies significantly by region and state. Per the Palliative Care Report Card, "In the South Central U.S., no state gained an A or B grade and less than one-third of hospitals in Arkansas, Mississippi and Alabama reported a palliative care team. The South Central region is most in need of improvement" [31]. On the other hand, the same report indicated that all hospitals in Vermont and New Hampshire have palliative care programs. Moreover, Montana, Nevada and Utah all had palliative care rates of over 85 percent;
- For-profit hospitals, regardless of their location or size, are less likely to provide palliative care services to patients than their nonprofit peers. Only 23 percent of for-profit hospitals in the U.S. provide palliative care services; however, 78 percent of nonprofit hospital and 59 percent of public hospitals provide palliative care services; and
- American families with children who are in need of palliative care have few options and opportunities available. Many families experience a reduction in income, and some parents, especially mothers, have difficulty maintaining employment. The families of such pediatric patients are subjected to additional duties and responsibilities because the U.S. government does not have appropriate systems in place to care for these families' needs.

In order for the U.S. to build consistent quality pediatric palliative programs, many obstacles must be addressed. The U.S. must create evidence-based palliative care training programs to ensure a highly trained workforce can provide quality care to patients and families. It must also create incentives for for-profit hospitals to provide palliative care services to the population it serves. Finally, regardless of economic status, all patients and families in need of palliative care must have access to it.

Recommendations and Future Research

Leaders in the U.S. must make radical changes to its palliative care system if they hope to build a more comprehensive system of care to offer an appropriate level of care to all citizens in need. The U.S. must move away from a particular category consideration to a holistic approach that involves integrating many disciplines and family members into the treatment plans of adults and children alike [33]. The U.S. must recognize that when an individual is plagued with a chronic health issue, their families are impacted as well. Palliative care programs should always be individually tailored and administered at a regional or local level to help patients and their families address their specific and unique needs. The United Kingdom's, Belgium's, and Canada's highly functional and lauded palliative care programs serve as exemplary guides to help the U.S. establish its own palliative and pediatric care programs that are effective and appropriate.

Based on the effectiveness of Belgium's, the United Kingdom's, and Canada's palliative care programs, and identifying the shortcomings of the corresponding U.S. programs, the research justifies the following recommendations:

- A national framework must be developed around which local policy development can by constructed.
- The United States must ensure that palliative care is localized and designed to meet patients and their families' unique needs;
- Significantly more funding needs to be dedicated to palliative care (to include pediatric palliative care) research, options, programs, education, and organizations;
- More robust and palliative-specific training programs must be established to ensure that all medical professionals are not only aware of palliative care options, but can provide patients with the right resources to get the care they need and deserve;
- Questions pertaining to palliative care should be added to already existing licensing and certifying exams for all medical professionals;
- More health care providers need to understand palliative care and focus on palliative care research;
- Textbooks and other clinical guidelines need to be published on palliative care;
- Palliative care workers and experts need to determine what content must be included in healthcare educational and residency programs;
- A holistic and integrated approach must be developed that includes networking with community spiritual, emotional, physical, and human resources, led by community public health nurses;
- Special units specifically designed to provide care to infants, children, and adolescents and meet the unique needs of their families must be established;
- Liaisons and coordinators must be prepared to help patients connect with health professionals, support groups, religious leaders, telephone hotlines, and other resources to include printed materials and appropriate online references; and
- Public awareness campaigns must be established to ensure that all Americans are familiar with palliative care options, as well as the unique challenges and obstacles pediatric palliative care patients and their families face; and
- The government must subsidize all palliative care through expansion of services provided by the ACA, to ensure that financial obstacles do not stand in the way of people receiving care.

The Advanced Practice Public Health Nurse as Change Agent

Who will lead the charge and bring about these systematic changes in our palliative care is an important question to be asked. Advanced practice public health nurses (PHN) are perfectly situated to shape the policies necessary to adequately care for these patients and their families holistically. The PHN's work involves promoting and protecting the health of populations through the intersection of public health practice and nursing science [40]. The PHN engages individuals and communities in partnerships to address the determinants of health through a collaborative approach [40]. These advanced practice nurses utilize their unique skill set gained through their graduate education in public health nursing along with their professional experiences to seek solutions to the problems communities identify as most burdensome [40]. These nurses are compelled by an ethical obligation to assist vulnerable populations, and they are entrenched within the communities they serve. They have built knowledge of and trusting relationships with both individuals and stakeholders throughout their communities. This in turn enables PHNs to effectively provide care where it is needed, from giving basic comfort measures to individuals, to disseminating education about the disease process throughout a community, to working with stakeholders at all levels and advocating for and helping to create systemic policy changes aimed at sustainably improving the public health [40]. It is a natural extension of their profession to task PHNs to advocate for those who have weakened voices within societal power structures such as youth, specifically those in need of palliative care, and to work within well-known existing systemic structures to create change. Assigning these nurses with the challenging task of leading the efforts to build a cohesive and coherent national pediatric palliative care policy throughout the U.S. is a perfect way to begin this most critical mission of a great nation.

Conclusion

The U.S. pediatric palliative care programs are woefully lacking and behind most of the rest of the developed Western world. However, by dedicating the time, energy, and resources to augmenting, expanding, and improving its palliative care options and opportunities, the United States can meet the demands set forth by the United Nations concerning palliative care. A special focus should be placed on ensuring that all medical professionals receive some level of palliative care education. In addition, it is crucial that more funding be made available for research and development. It is pivotal that well-funded teams are designed to meet the challenges of pediatric palliative care patients and their families' needs, desires, and expectations. Fortunately, Belgium, the United Kingdom, and Canada already have excellent pediatric palliative care systems in place. It would behoove the U.S., therefore, to model its future initiatives on these successful examples.

As the wealthiest nation in world history, the U.S. is capable of building policies and programming to support one of its most vulnerable populations. In a nation whose political leaders often tout their Judeo-Christian values as a reason for building, funding and implementing bold new policies and programming, the United States and its leaders must embrace its moral obligation that is in line with these professed virtues to ensure that all of its young citizens in need have access to quality palliative care. Public health nurses are standing by to lead the charge and create the change they seek for the communities they serve.

References

1. Gitterman A, Germain CB (2008) The life model of social work practice: Advances in theory and practice. New York: Columbia University Press, pp: 611.
2. Cardwell M, Flanagan C (2003) Psychology A2: The complete companion. Oxford: Oxford University Press, pp: 338.
3. Gomm R (2008) Social research methodology: A critical introduction. Hampshire: Palgrave Macmillan.
4. Kothari CR (2009) Research methodology: Methods and techniques (2nd edn). New Delhi: New Age International (P) Ltd.
5. Kumar R (1999) Research methodology: A step-by-step guide for beginners. Thousand Oaks, CA: SAGE Publications.
6. Smith TJ, Temin S, Alesi ER, Abernethy AP, Balboni TA, et al. (2012) American society of clinical oncology provisional clinical opinion: The integration of palliative care into standard oncology care. J Clin Oncol 30: 880-887.
7. National Consensus Project for Quality Palliative Care (2016) Palliative Care.
8. WHO (2016) WHO definition of palliative care.
9. Hallenbeck JL (2003) Palliative care perspectives. New York: Oxford University Press.
10. Bona K, Bates J, Wolfe J (2011) Massachusetts' pediatric palliative care network: Successful implementation of a novel state-funded pediatric palliative care program. J Palliat Med 14:1217-1223.
11. National Hospice and Palliative Care Organization (2015) NHPCO's facts and figures: Hospice care in America 2015 Edition.
12. Friebert S (2015) NHPCO facts and figures: Pediatric palliative and hospice care in America. Alexandria, VA: National Hospice and Palliative Care Organization.
13. Cook A (2011) Home based volunteers-bridging the gap between respite visits. BMJ Supportive & Palliative Care 1: 201–201.
14. Carter KB, Mandrell BN (2013) Development of a respite care program for caregivers of pediatric oncology patients and their siblings. J Pediatr Oncol Nurs 30: 109-114.
15. Mongeau S, Carignan P, Champagne M, Laurendeau M, Liben S (2004) Beyond respite and activities...a message of solidarity: Evaluation of the In-Home Respite Program Phase II.
16. (2015) Healthy People 2020.
17. Armstrong-Dailey A, Zarbock SF (2009) Hospice care for children. Oxford: Oxford University Press.
18. Levetown M (1997) Pediatric hospice care: Not the care of small adults. Home Health Care Manag Pract 9: 36-42.
19. Open Societies Foundation (2016) Public health fact sheet: Children's palliative care and human rights.
20. GOV.UK (2003) Every child matters.
21. Smyth D (2011) Politics and palliative care: The United Kingdom. International Journal of Palliative Nursing, 17: 49–49.
22. United Kingdom Palliative Care Funding Review Team (2011) Funding the right care and support for everyone: Creating a fair and transparent funding system. J Pain Palliat Care Pharmacother 25: 362-364.
23. Department of Work and Pensions (2012) Social justice: Transforming lives.
24. Orlik C (1993) Survey of family based respite care schemes in the UK: First survey, January 1991. United Kingdom: Norah Fry Research Centre.
25. Abarshi E, Echteld MA, Van den Block L, Donker G, Bossuyt N, et al. (2011) Use of palliative care services and general practitioner visits at the end of life in The Netherlands and Belgium. J Pain Symptom Manage 41: 436-448.
26. International Children's Palliative Care Network (2015) Belgium to hold its first ever perinatal palliative care conference.
27. Belgian Health Care Knowledge Centre (2016) Organisation of palliative care in Belgium. Belgian Health Care Knowledge Centre.
28. Canadian Healthcare Association (2012) Respite Care in Canada.
29. Stajduhar KI, Lindsey E, McGuinness L (2002) A qualitative evaluation of an HIV/AIDS respite care service in Victoria, Canada. Eval Health Prof 25: 321-344.
30. Kuziemsky CE, Lau F (2008) A comparative analysis of computer based hospice palliative care datasets in Canada. BMC Palliat Care 7: 6.
31. Center to Advance Palliative Care (2016) Palliative care report card.
32. American Academy of Pediatrics (2016) American Academy of Pediatrics-Section on Hospice and Palliative Medicine.
33. Tepper LM, Toner JA (1993) Respite care: Programs, problems and solutions. Philadelphia: Charles Press Pubs (PA).
34. Morrison RS (2013) Models of palliative care delivery in the United States. Curr Opin Support Palliat Care 7: 201-206.
35. Feudtner C, Womer J, Augustin R, Remke S, Wolfe J, et al. (2013) Pediatric palliative care programs in children's hospitals: A cross-sectional national survey. Pediatrics 132: 1063-1070.
36. Lo B, Quill T, Tulsky J (1999) Discussing palliative care with patients. ACP-ASIM End-of-Life Care Consensus Panel. American College of Physicians-American Society of Internal Medicine. Ann Intern Med 130: 744-749.

37. Mary NS, Jayita Deodhar M (2015) Respite model of palliative care for advanced cancer in India: Development and evaluation of effectiveness. Journal of Palliative Care & Medicine 5: 1-4.
38. Wolkowski A (2011) Does respite care address the needs of palliative care service users and carers? An exploration of their perspectives and experience of respite care. BMJ Supportive & Palliative Care 1: 216–216.
39. Twycross RG (2002) Introducing palliative care (4th edn) Oxford: Radcliffe Medical Press.
40. Swider SM, Krothe J, Reyes D, Cravetz M (2013) The Quad Council practice competencies for public health nursing. Public Health Nurs 30: 519-536.