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Health Care Reform and Concurrent Curative Care for Terminally Ill Children: A Policy Analysis

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Abstract

Within the Patient Protection and Affordable Care Act of 2010 or health care reform, is a relatively small provision about concurrent curative care that significantly affects terminally ill children. Effective on March 23, 2010, terminally ill children, who are enrolled in a Medicaid or state Children's Health Insurance Plans (CHIP) hospice benefit, may concurrently receive curative care related to their terminal health condition. The purpose of this article was to conduct a policy analysis of the concurrent curative care legislation by examining the intended goals of the policy to improve access to care and enhance quality of end of life care for terminally ill children. In addition, the policy analysis explored the political feasibility of implementing concurrent curative care at the state-level. Based on this policy analysis, the federal policy of concurrent curative care for children would generally achieve its intended goals. However, important policy omissions focus attention on the need for further federal end of life care legislation for children. These findings have implications nurses.

Keywords

concurrent curative care; policy analysis; health care reform; end of life care; children

Tucked in the 906 pages of the health care reform document, or the Patient Protection and Affordable Care Act of 2010 (ACA), is a relatively small provision about concurrent curative care that significantly affects terminally ill children, and yet, we know very little about the impact of concurrent curative care on children and their families at end of life. Effective on March 23, 2010, terminally ill children, who are enrolled in a Medicaid or state Children's Health Insurance Plans (CHIP) hospice benefit, may receive curative care related to their terminal health condition.^{1,2} Concurrent curative care means receiving curative care to eradicate disease or normalize the underlying health condition, while simultaneously receiving hospice care for physical symptoms and psychosocial needs at end of life.³

The policy of concurrent curative care is in response to a growing consensus in the end of life community that hospice eligibility requirements are critical barriers to end of life care, especially for terminally ill children.^{4,5} Hospice eligibility requires that children have a life expectancy of approximately six months or less as certified by a hospice medical director and an attending physician or nurse practitioner. Eligibility also requires that children discontinue all life-prolonging or curative care (i.e., chemotherapy, dialysis, bone marrow transplant, antiretroviral regimens, radiation, and transplant rejection medication) upon hospice enrollment. These two eligibility rules, in particular forgoing curative care, force families to make very difficult choices between treating a child's disease or managing

quality of end of life.⁵⁻¹⁰ As a result, many families continue curative treatments and therapies and delay enrolling in hospice care,^{9,11-13} even though there is mounting evidence of the physical and psychosocial benefits of hospice care for children.¹⁴⁻¹⁹

Policy initiatives aimed at reducing these barriers have generally focused on demonstration-based policies at the state-level.^{5,18,20-21} Important examples of state initiatives are found in Florida, Massachusetts, and California.²² These states and others enacted state policies to demonstrate the feasibility and cost-effectiveness of concurrent curative care for terminally ill children.⁵ Although these states paved the way for the current federal legislation, it is the nature of a state-level policy that only terminally ill children in those states were impacted. Therefore, the intended goals of the Federal concurrent curative care policy, under health care reform, are to improve access and quality of end of life care for terminally ill children throughout the United States.

The recency of the ACA has precluded any formal analysis of the federal policy of concurrent curative care. This paper aims to fill the gap by providing one of the initial examinations of the policy as it relates to access to care, quality of end of life care, and political feasibility.²³ Understanding this policy is timely as Attorney Generals in twenty states have filed lawsuits against the federal government in order to stop implementation of the ACA, and 2010 mid-term, congressional elections are viewed as a public referendum challenging the legitimacy of the health care reform legislation.²⁴⁻²⁵ Additionally, understanding this policy is important because an estimated 20% to 40% of the 54,000 terminally ill children in the United States, those covered by Medicaid and CHIP, are affected by the concurrent curative care legislation.^{19,26-27} Therefore, the purpose of this article was to conduct a policy analysis of the pros and cons of the federal end of life policy for children. The article is divided in three main sections. First, the federal policy is discussed to provide a context for the analysis. Second, a critical analysis of the policy of concurrent curative care is conducted using relevant literature. Finally, the findings and implications for nurses are considered.

The Federal Policy

Recent federal initiatives to improve end of life care for children were introduced during the 111th Congress of 2009. In May 2009, Senators John D. Rockefeller IV (D-WV), Susan Collins (R-ME), Herb Kohl (D-WI), Ron Wyden (D-OR), and Tom Carper (D-DE) sponsored the Advanced Planning and Compassionate Care Act of 2009 (S. 1150). The next month, the House version of the bill (H.R. 2911) was sponsored by Representatives Earl Blumenauer (D-OR), Tammy Baldwin (D-WI), Sander Levin (D-MI), and William Pascrell (D-NJ). These bills had two provision relating to end of life care for children. First, hospice care became a mandated benefit under Medicare, Medicaid, and state Children's Health Insurance Programs (CHIP) for children as defined by these regulations. Second, children were permitted to receive concurrent curative care, while enrolled in the Medicare, Medicaid, and CHIP hospice benefit.¹ The Senate bill was referred to the Senate Finance Committee and the House bill was referred to the House Energy and Commerce Subcommittee, House Ways and Means Subcommittee, and House Judiciary Subcommittee.¹ Both bills never came out of committee.¹

Later during the 111th Congress, the Patient Protection and Affordable Care Act of 2010 (H.R. 3590) was introduced and sponsored by Representative Rangel (D-NY) in September 2009. This bill was amended by the Senate to include provisions of the Advanced Planning and Compassionate Care Act of 2009 such as a provision for concurrent curative care for children. Title II Role of Public Programs, Section 2302 Concurrent Care of the ACA allows terminally ill children on the Medicaid or CHIP hospice benefit to continue receiving

curative care treatments and therapies effective March 23, 2010.² The specific language of the Act is as follows:

A voluntary election to have payment made for hospice care for a child (as defined by the State) shall not constitute a waiver of any rights of the child to be provided with, or to have payment made under this title for, services that are related to the care of the child's condition for which a diagnosis of terminal illness has been made.¹

The ACA is different than the Advanced Planning and Compassion Act of 2009 in two ways. First, the ACA does not include children enrolled in the Medicare hospice benefit. Second, the ACA does not mandate that states include a hospice benefit under Medicaid or CHIP.

In addition, the ACA does not modify or amend the hospice eligibility requirement of a 6 month prognosis to live. Children receiving concurrent care under the ACA must still qualify for hospice admission. Therefore, in order to analyze whether this federal policy mandating the inclusion of concurrent curative care in Medicaid and CHIP programs for terminally ill children may accomplish its goal of improving end of life care, there are three essential criteria against which the pros and cons of the policy must be evaluated: 1.) impact on access to care, 2.) impact on quality of care, and 3.) political feasibility.

Policy Analysis

Criterion 1: Impact on Access to Care

A federal policy of concurrent curative care must improve access and utilization of end of life care for terminally ill children. It must meet the needs of children and families by mandating care that is acceptable, affordable, and available.²⁸

Pros—A policy of concurrent curative care means that families are not required to choose between curative care and hospice care. Under the current hospice eligibility rules, families make a “terrible” and unacceptable choice between curing a child’s disease and giving up hope.⁵⁻¹⁰ Physicians are instrumental in advising families on their choice. However, the variation and complexity of health conditions often make it difficult for physicians to accurately assess prognosis or disease trajectory.²⁹⁻³⁰ Physicians are generally reluctant to refer children to hospice care and instead recommend to continue curative therapies and wait until no additional treatment options are available.³¹⁻³³ In choosing to continue curative care, children forgo access to critical and necessary pediatric hospice services including 24-hour on-call nursing, respite, pain management, psychosocial support, and bereavement.⁵ Consequently, less than 10% of terminally ill children utilize hospice care.^{6,9,34-35} Children who are admitted to hospice are typically referred late in their disease trajectory and often have very short length of stays.^{19,32} Thus, by eliminating the choose between curative and hospice care, the utilization of hospice care may be acceptable to families as they continue hoping for a cure and simultaneously managing the quality of end of life for their terminally ill child.

In addition, hospice and curative care are covered and reimbursed services under Medicaid and CHIP in the new policy. In general, families incur considerable costs such as necessary travel and out-of-pocket expenses during the end of life phase of a terminal illness.³⁶ Under the current system of curative or hospice care, chemotherapy, dialysis, bone marrow transplant, antiretroviral regimens, radiation, and transplant rejection medication are not reimbursed hospice care services.³⁷ Families that wish to continue these expensive medications, supplies, and therapies during hospice care assume full responsibility for the costs. Although research has shown that child health care expenses as low as \$250 are a

financial burden, especially for low income families, the long-term financial burden for these families can be staggering.³⁸ Many experience loss of savings, home foreclosures, and medical bankruptcies.³⁹⁻⁴⁰ However, health insurance coverage such as Medicaid and CHIP has the ability to provide protection against financial burden.⁴¹⁻⁴³ Under the new policy of concurrent curative care, the cost of curative therapies during hospice care will be assumed by Medicaid and CHIP plans. This should minimize the out-of-pocket expenses of end of life care for families. Therefore, the utilization of hospice care may be more affordable to families under a policy of concurrent curative care.

Cons—In the new policy environment, terminally ill children in some states will continue to not have access to hospice care. Hospice care is an optional benefit in state Medicaid and CHIP programs.⁴⁴ Oklahoma is the only state that does not currently offer a Medicaid hospice benefit unless children are covered by the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program.^{2,45} EPSDT is federally mandated under Title XIX of the Social Security Act and requires state Medicaid programs to provide hospice services for Medicaid-eligible children under age 21.³⁰ In addition 19 states with CHIP programs separate from Medicaid (i.e., Alabama, Arizona, Colorado, Connecticut, Georgia, Kansas, Mississippi, Montana, Nevada, Pennsylvania, Texas, Utah, Vermont, Washington, West Virginia, and Wyoming) do not include a hospice benefit.⁴⁶ ACA will not provide access to hospice care for children residing in these states. In addition, the prospects of the benefit are tenuous in several states. For example, during the 2009-2010 legislative sessions, California, Iowa, Kansas, Missouri, Colorado, Texas, and South Carolina debated eliminating the hospice benefit from their Medicaid and CHIP programs.⁴⁷⁻⁵² Although the new policy allows children to access curative and hospice care, the unavailability and questionable future of the Medicaid and CHIP hospice benefit may negatively influence utilization of end of life care for terminally ill children living in certain states.

Criterion 2: Impact on Quality of Care

A federal policy of concurrent curative care must also improve quality of end of life care for terminally ill children. It must demonstrate effectiveness, patient-centeredness, timeliness, efficiency, and equity in the delivery of end of life care.⁵³

Pros—The concurrent care policy incorporates evidence-based practices in the delivery of care for terminally ill children. Many curative treatments such as stem cell transplantation can cause a great deal of suffering for children.¹³ In fact, terminally ill children experience a variety of symptoms at end of life such as fatigue, pain, dyspnea, and anxiety.^{12-13,19,35,54-57} However, symptom management is one of the hallmarks of hospice care.⁵⁸ In the case of pain management, hospice care includes an initial assessment and review of medications within 48 hours of hospice admission, written pain management plans, and pharmacological and non-pharmacological therapies for pain reduction.⁵⁹ Research indicates that hospice care is effective in managing symptoms in terminally ill children.^{14,16-19} Thus, a policy of concurrent curative and hospice care may provide effective end of life care for terminally ill children.

Additionally, the policy is respectful and responsive to child and family preferences, needs, and values. Concurrent care provides continuity of care through continued communication and bonds with the curative team while receiving hospice care. Research shows that communication between family and the health care provider about the child's health condition is a critical determinant of parent satisfaction.⁶⁰⁻⁶⁴ This includes regular, clear, and accurate information about the child's medical condition.^{18,65} For example, a recent study reported that a majority of parents were satisfied with the care provided to their terminally ill child with cancer because the primary oncologist provided appropriate and

understandable information about the child's medical condition.⁵⁵ Maintaining a relationship with the treating physician and curative team matters to families. Under the current hospice eligibility rules, the bonds of trust developed over time with physicians, nurses, and other health care professionals treating their child typically end abruptly, and care is turned over almost completely to the hospice team.¹¹ Families are often dissatisfied with this transition from curative to hospice care.⁶⁶ However, concurrent curative care allows families to avoid the transition by providing continuity of care between the curative care and hospice care teams. Therefore, a policy that is responsive to the preferences and needs of children and families for continuity of care may promote patient-centered care.

Cons—In contrast, the policy contributes to the already fragmented care provided to terminally ill children. A majority of terminally ill children receive curative care from a variety of health care providers in a variety of health care settings.³⁴ For example, care may be delivered by a primary care provider, orthopedic surgeon, pulmonologist, otolaryngologist, gastroenterologist, nutritionist, neurologist, and a variety of therapists.⁶⁷ However, the delivery of care is often poorly or not coordinated by health care professionals.³³ Instead, it is typically managed by the family who is often already stressed by the care for their child.⁶⁸ Consequently, the new concurrent care policy adds hospice care and the hospice care team of nurses, physicians, social workers, pastors, and home health aides to the care mix. And although much of this care may be offered by the same health care system, there are some important technology challenges in coordinating care within and between providers of curative and hospice care. For example, recent studies have found that only 15% of U.S. hospitals have a comprehensive electronic medical records system (i.e., present in all clinical units).⁶⁹ Additionally, as few as 13% of community-based hospice agencies have clinical data in an electronic format, and even fewer share records with other providers.⁷⁰ Accordingly, end of life care for terminally ill children may not be efficiently delivered under the policy because of the sophisticated level of care coordination required between curative and hospice care teams.

In addition, the federal policy of concurrent curative care does not reduce waits and delays in hospice admission. Terminally ill children are still required to wait for a 6 month prognosis to live before enrolling in hospice care. Although many of the health conditions affecting terminally ill children have a undefined disease trajectory that makes predicting the last 6 months of life complicated, experts in the field of pediatric end of life care suggest that integrating hospice care at diagnosis permits families the opportunity to gradually transition to the end of life period.^{30,71} This transition time allows families to learn what to expect during the disease trajectory and communicate with their child about death and dying.^{15,72} As a result of the policy omission, end of life care may not be delivered in a timely manner to children and families.

Finally, the policy does not provide concurrent care to children on private insurance or Medicare. However, a majority of terminally ill children are covered by private insurance.^{26,73} And although a relative small number of terminally ill children have Medicare coverage, these children generally have serious health conditions such as end-stage renal disease and require dialysis or have had a kidney transplant.³⁰ The exclusion of these children from concurrent curative care may significantly vary the quality of end of life care delivered to them and create disparities in outcomes based on insurance status.

Criterion 3: Political Feasibility

A federal Act mandating the inclusion of concurrent curative care in state Medicaid and CHIP policies must be politically feasible. States must be able to transition and comply with policy changes without causing undue legislative or financial burden.

Pros—States are experienced in legislating federally mandated modifications to Medicaid and CHIP programs.⁷⁴ In fact, Florida (2005), Colorado (2007), and California (2008) have recently legislated concurrent curative care into their Medicaid programs. These states passed laws allowing the state's Medicaid offices to request Centers for Medicare & Medicaid Services (CMS) waivers for concurrent curative care for terminally ill children.²² For example, the California state legislature drafted and passed the Nick Snow Children's Hospice & Palliative Care Act of 2006.⁵ Under this Act, children who are eligible for Medi-Cal, under 21 years of age, reside in a participating county (i.e., Alameda, Santa Cruz, Monterey, Santa Clara, and San Diego counties in 2009), and have an eligible medical condition such as cancer, cystic fibrosis, or heart defects may receive concurrent curative care.^{5,75} However, with the enactment of health care reform, the U.S. Department of Health and Human Services provided State Medicaid Directors with the policy language to include in their state Medicaid and CHIP plans.² Thus, amending state laws to include concurrent curative care may not be legislatively burdensome for states.

Cons—Conversely, implementing the policy at the state-level requires a commitment to planning and personnel. Experience from states that have piloted concurrent curative care suggest that planning between state agencies and providers and state-funded case management are required. As examples, a pilot concurrent curative care program in the state of Washington took several years to plan and included a case manager assigned from the state Medicaid program.¹⁸ In addition, Florida's, Partners in Care: Together for Kids, involved years of planning and necessitated the employment of a state care coordinator.²¹ Finally, the California Nick Snow Law took five years to plan and resulted in hiring a nurse liaison by California Department of Health Care Services.^{5,75} However, investing financial resources to plan and hire personnel for Medicaid and CHIP programs may be difficult for states because their current financial state of affairs.⁷⁶ In fact, 46 states reportedly face budget deficit crises.⁷⁷ Many of these suffering states are also the same states that have explored cuts to Medicaid and CHIP hospice benefits and have filed lawsuits against the federal government to stop the implementation of health care reform (i.e., Colorado, South Carolina, and Texas).^{25,47,49,77} As an interesting note, with the exception of Michigan, none of the States that sponsored the original Advance Planning and Compassionate Care Act of 2009 are involved in the lawsuit. The issues of legislative support for health care reform, fiscal crisis, and lawsuits are intertwined. As a result, implementing concurrent curative care in state Medicaid and CHIP programs may be financial burdensome for states.

Summary Analysis and Implications for Nurses

Based on this policy analysis, the federal policy of concurrent curative care for terminally ill children would partially achieve its intended goals. Table 1 uses a scorecard approach to summarize the analysis findings.²³ Based on this analysis, the policy of concurrent curative care would likely have a positive impact on access to care with the exception of availability. However, the policy would not substantially improve quality of care because it does not address issues of efficiency, timeliness, and equity. The lack of legislative burden would offset the financial burden to states in implementing this policy. The pros of each policy criteria suggest that there is a strong interaction between curative care and hospice care that would positively impact delivery of care, outcomes, and support for terminally ill children and families at end of life. However, the cons of each policy criteria focus attention on the omissions and deficits of the policy. The cons suggest that although the ACA is an important step in mandating change in end of life care for terminally ill children, there are still issues to address at the federal level. Future legislation should rectify 1.) the Medicaid and CHIP program design that hospice care is an optional benefit; 2.) the lack of electronic medical record sharing between providers; 3.) the hospice eligibility requirement of a 6 month prognosis; and 4.) the exclusion of children on Medicare and private insurance.

Notwithstanding the policy concerns, the concurrent curative care provision of health care reform holds many opportunities for nurses.⁷⁸ First, a policy that improves access should require more nurses caring for children at end of life. By applying economic principles of supply and demand, an increase in access should translate to increases in demand for hospice care and ultimately the supply of services to children and families. Currently, only 60% of pediatric oncology institutions offered hospice services, and as few as 40% of community-based hospice agencies provided care to children.⁷⁹⁻⁸⁰ In order to respond to an increase in demand for hospice services to children, hospices may need to add additional nursing resources. This may include home health or nurses who have experience with children, or hospital NICU/PICU nurses who have experience caring for medically complex children. Depending on the immediacy of demand, hospices may also have a need for temporary, contracted nurses.

Second, a policy that improves quality should require more trained and knowledgeable nurses in pediatric end of life. Hospice care is most often associated with elderly, cancer patients, and hospice nurses are generally trained and develop specialty knowledge of geriatrics.⁸¹ However, hospice care for children is different than elderly adults. The nursing care for children often involves complex and complicated physical, psychological, legal, ethical, and spiritual issues.⁸² This care requires that nurses have skills and knowledge of pediatric medication, pediatric developmental stages, the variety of pediatric diseases, pediatric equipment and supplies, policy/ regulations/ laws, and family systems.^{19,29,82-83} However, there are resources for nurses seeking additional training in end of life care for children through the Nursing Education Consortium for Pediatric Palliative Care.⁸⁴ Information on upcoming training and seminars can be found on the American Association of Colleges of Nursing website (<http://www.aacn.nche.edu/ELNEC>).

Third, nurses can advocate for this vulnerable population and their families. Nurses have a voice in their work place in establishing end of life care for children. They also have a voice with elected officials regarding the future of health care reform. In addition, professional associations also are an avenue for nurses to get involved in the issue of end of life care for children. State hospice and nurses associations, such as the California State Hospice Association and North Carolina Nurses Association, are generally politically active on issues dealing with vulnerable patient populations. Now is the time for nurses to support end of life care for terminally ill children and their families.

Finally, the policy should expand nursing inquiry into end of life care for children. As health care reform is implemented, understanding the direct effect of policy change on access and quality is important future research for nurses. In addition, there are important opportunities for nursing scholars to contribute to our understanding of the changing technological environment necessary to coordinate curative and hospice care for children at end of life.⁸⁵ In order to assess the financial impact of this policy, economic analyses are needed to explore the change in Medicaid and CHIP expenditures. The ACA should provide fertile ground for advancing nursing knowledge of end of life care for terminally ill children.

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Table 1

Policy Analysis of Federal Concurrent Curative Care for Terminally Ill Children

Policy Criteria	Pros	Cons	Analysis
Access	Acceptability	Availability	Positive
	Affordability		
Quality	Effective	Efficient	Negative
	Patient-centered	Timely	
		Equitable	
Political feasibility	Legislative burden	Financial burden	Neutral