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Network of Learning for Pediatric Palliative Care: A Pilot Project

Capstone Scholarly Project

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Abstract

In the past ten years, pediatric palliative care has evolved. Notre Dame Pedi Pals is a new venture providing pediatric palliative care for Notre Dame Hospice. Presently in Massachusetts an infant dies daily devastating the family (Massachusetts Department of Public Health, 2013). Collaboration and coordination of care is a common concern for these families who are difficult to identify and study, so that the measure of the effects of this care is challenging. Coordination and assistance with this aspect of care is viewed positively by parents of a similar group of children suffering from major chronic, life-altering diseases (Data Resource Center for Child and Adolescent Health, 2007).

The purpose of the pilot is to study the effects of an electronic medium in facilitating collaboration among Massachusetts Pediatric Palliative Care Program professionals. Through a common, electronic "Network of Learning" platform, this Capstone Pilot promoted a learning venue with these collaborative activities: weekly discussion questions, monthly journal club, and sharing of stories. Invitations were sent to all coordinators involved in the Massachusetts Pediatric Palliative Care Network, all primary care providers, and referral specialists to this secure, free, and electronic platform with a n=6. Present collaborative communication practices using Feudtner's (2007) five points of collaborative communication were measured pre-pilot and post-pilot at Notre Dame Pedi Pals to measure the effects of the pilot participation on collaborative communication. Modified Index of Interdisciplinary Collaboration scores were tabulated pre- and post-pilot to evaluate change from pilot participation. At the conclusion of the pilot, formal evaluation occurred and was inconclusive.

Keywords: collaboration, Pediatric Palliative Care, Network of Learning

Problem Identification

Pediatric palliative care, a focus of the Institute of Medicine (IOM) during the past 15 years illustrates a care model which provides care throughout the lifespan to relieve suffering. The IOM report by Field and Behrman (2003) has used principles to illustrate pediatric palliative care, including holistic pediatric care of the child and family, respecting and involving the family as part of the team, providing effective and compassionate care for children and their families across the care continuum, mandating education of professionals and others, charging institutions and individuals in promoting excellence, and implementing research in all aspects of pediatric palliative care (p.7). Hospice care provides specific care to these children at the end of their lives. In Massachusetts, this benefit is not a provision of the Pediatric Palliative Care program as defined by the Department of Public Health (DPH).

Pediatric end-of-life care for the Worcester County population is a new focus for the practitioners at Notre Dame Hospice. The clinical skill set for quality hospice care is currently present in the staff through Joint Commission certification and certification in Hospice through the American Nurses Credentialing Center (ANCC). For the adult hospice program, there is a satisfaction rate of 90% from the families, and internal audits using Hospice and Notre Dame Hospice standards are also at 90% or greater showing excellent care of the original population (Donna Bergin, personal communication, 11/15/12). Family-focused, quality care is an integral aspect of pediatric palliative care. Plans are in place for family input regarding the quality of Notre Dame Pedi Pal care in 2013, confirming the agency's commitment to quality and measurement of the care provided.

Specific, clinical education for the staff in both pediatric and pediatric palliative care is imperative as the staff are inexperienced in caring for this population. The extremely specialized nature of pediatric palliative care practice and the small number of practitioners, limit interdisciplinary collaboration. Aware of this gap in staff education, Karyn Rizzo, the executive director with extensive experience in hospice, projected a budget of \$7000 to cover staff education programs, the marketing plan, and the development and alignment of area agencies to serve the projected 35 families for 2012-2013 (Karyn Rizzo, Personal communication, September 15,2012).

Problem Statement

Among the population of Worcester County in Massachusetts families of infants and children not receiving quality, evidence based, pediatric palliative care are at risk as indicated by inaccessible services such as waiting lists, general lack of knowledge of these services by families and providers, non-acceptance of hospice because it implies death, and lack of education of interdisciplinary providers regarding pediatric palliative care. Limited finances, time, and lack of standard protocols, jeopardize this care; collaboration challenges between agencies also result in inferior pediatric palliative care. As a new program, the need for additional guidance and staff educational deficits complicate this care. This lack, however is mediated by staff and societal commitment to provide compassionate care, effective collaboration, facilitation of community involvement and partnerships, and staff and family education. Collaboration, advocacy, end-of-life education, and therapeutic presence also moderate the causes of the child's illness as do prognostic factors, time and financial limitations, family's culture, and communal factors- all of which existed prior to this problem.

Evidence of the Problem

Notre Dame Hospice in Worcester, Massachusetts, through a Massachusetts DPH grant given in July of 2012, provides pediatric palliative care in Worcester County and is known as Notre Dame Pedi Pals. As part of the state's network of ten community agencies, the program goal is to provide coordinated family centered palliative care to these children and their families following state guidelines. Budget funding per year is \$3,500 per family with 100% of this projected figure covering salaries and respite care. Education of Notre Dame Pedi Pal staff, development of care models and practices, development of organizational structures, and team creation are all tasks in initial phase of program implementation commencing July 1, 2012. Restriction of accepted families is initially placed at 10 but in November, 2012 it was raised to 15. Careful tracking of service cost and provision of care is done by the clinical coordinator, a social worker. Four of these children on caseload are projected to die in the next six months due to their illness. Maximum number of families projected to receive this care from this grant is 18 for fiscal year 2012-2013.

The first year of life has the largest number of deaths at 28,509 at a rate of 6.8 per 1000 in 2009 (Henry J. Kaiser Family Health Foundation, 2013). According to Annie E. Casey Foundation (2013) 27 per 100,000 deaths from ages one to 19 were projected for a total of 20,016 deaths (Nelson, 2012). In 2009, infant demise in Worcester County totaled 49 of the 365 deaths for the state (Massachusetts Department of Public Health, 2013) with an additional 41 deaths from age one to age 20 (Mass CHIP: Kids Count, 2009). According to Magee and Brindisi (2012) the infant mortality rate for the city of Worcester since 2002-2008 has been eight to nine per 1000 births versus five deaths per 1000 births in Massachusetts. For minorities, these

numbers are higher with black mortality rates at 22 per 1000 births and Hispanics nearly 18 per 1000 births from 2006-2008 in Worcester, clearly a problem (Magee & Brindisi, 2012).

Families who have experienced these losses need the ongoing bereavement service that a pediatric palliative care program provides. Notre Dame Pedi Pals is designated to provide this service as part of its pediatric palliative care, in central Massachusetts.

Data is not available for those children who use palliative care in the United States and the state of Massachusetts notes that 600 children die annually many of whom did not receive palliative care (Bates, Bona & Wolfe, 2011). More comprehensive data on children with special health care needs is known and in Massachusetts the number is 350,000 (Bates, et al., 2011). As collaboration and family focused care are important in palliative care, statistical measurement of this care could be derived from those children with special health care needs who are surveyed. Many in this group of children suffer from life-limiting illnesses and would qualify for pediatric palliative care in Massachusetts. Family centered care in Massachusetts for this special population is 73.5% versus 67.4% nationwide (Data Resource Center for Child and Adolescent Health, 2007). Effective care coordination, which measures the family satisfaction with coordination and communication in Massachusetts, is 65.7% versus 68.7% nationwide, but usage of help with care coordination in Massachusetts is 27.8 % versus 20.7 % nationwide (Data Resource Center for Child and Adolescent Health, 2007). This data from a similar population of children might be true for the pediatric palliative care population in the state: effective care coordination and assistance to families seeking this coordination are needed.

Few services exist for pediatric palliative care families. Boston Children's Hospital offers pediatric palliative care as a consultant service through the Pediatric Advance Care Team (PACT

Team) and many children in Notre Dame Pedi Pal's program receive care there. With most families needing to travel over 60 miles for services, collaboration is vital in this interdisciplinary endeavor, particularly when the family prefers its child to die at home. Pediatric end-of-life care, however, is a specialty offered only by the Visiting Nurse Care Connection in Worcester County through their Maternal Child Health hospice program, as Notre Dame Pedi Pals is not certified for hospice (Tracy Larson-Benvenuto, personal communication 9/12/12). Without additional education, nurses and other professionals at Notre Dame Hospice are reluctant to care for these children. Those presently delivering this care have been surprised about the complexity of needs required to deliver quality care to these children (Tracy Larson-Benvenuto, personal communication, 9/27/12). In Worcester Country, only one social service agency provides pediatric mental health services in the home, and there is a six month wait for service- an additional family burden.

Provision of pediatric palliative care needs both a health care and public health response. Pediatric palliative care has increased in utilization since publication of two reports from the Institute of Medicine (IOM) in 1997 and 2003, dealing with end-of-life issues and with pediatric palliative care. Healthy People 2020 of the United States Department of Health and Human Services (2013), states as one of its goals: a reduction by 10% of infant, child, and adolescent mortality rates from birth through age 18. Pediatric palliative care, however, is not mentioned as a prevention strategy to support those families whose child's prognosis is grim (Nelson, 2012).

Pediatric palliative care, its principles, and goals aim to foster cohesion and appropriate provision of compassionate care. The first challenge is to accurately define the group who needs this care. Estimated nationally 500,000 children exist with life limiting illnesses (Himmelstein,

Hilden, Boldt, & Weissman, 2004; Knapp, et al., 2008). A subgroup of those children would benefit from palliative care, but the number of that subgroup is hypothetical (Nelson, 2012).

Review of the Literature

Collaboration

Collaboration is a major function of pediatric palliative care. The children and their families who receive this care often have complex chronic health conditions requiring multiple agency involvement and interdisciplinary dialogue. Pediatric palliative care is recommended to commence and to be provided during the curative treatment phase and concluding with end-of-life care (Field and Behrman, 2003). This requires significant skill and collaboration from all providers.

Partnership models show state (Carroll, et al., 2007; Hawley, 2010; Knapp, et al., 2008), metropolis (Rogers, et al., 2010) and hospital endeavors (Carroll, et al., 2007; Pelant, McCraffey, & Beckel, 2012). These partnerships expose the struggle inherent in collaboration to provide effective palliative care. Hawley (2010) illustrates a grass-roots approach; the mother portrayed uses her personal grief to propel action for change which led to a statewide policy and programs in Pennsylvania providing pediatric palliative care. Florida built a program in 2005 (Knapp, et al., 2008) which uses diagnostic codes as an initiator of referrals and uses three agencies Children's Medical System Network (CMSN), Agency for Healthcare Administration (AHCA), and area hospices who assist with referrals, finance, and provision of care. Washington, D.C., collaborative program uses an outside agency to assist with coordinating and improving services across agencies (Rogers, et al., 2010). Children's Hospital of Pennsylvania (CHOP) offers a collaborative palliative care program with outreach to five states, using

education as its chief means of facilitating collaborative change (Carroll, et al., 2007). Pelant, et al., (2012) offers pediatric palliative care service in a Midwest hospital using staff education, internal and external referrals, leadership commitment, and hospital wide system changes to accommodate this care. Absent are community based practice models of pediatric palliative care in the current literature (Nelson, 2012).

Communication is imperative in pediatric palliative care. Through case studies, Rushton (2005) illustrates the power of *being with* and *doing with* as a communication style involving deep presence. Feudtner (2007) discusses collaborative communication as being synergistic, goal focused, and accepting of complexities and uncertainties in this care process. In a small study, an education program is effective in improving difficult conversations, but not in dissipating professional anxiety regarding end-of-life care and resuscitation plans (Browning, et al., 2009). Evaluation of the routine conversation which impact collaboration and quality care is absent from the literature. E-health (Knapp, 2010) is mentioned as a vehicle of communication, however much work needs to occur before this is a viable modality of information and communication sharing. Although research is limited, parent to parent mentoring and parent to expert care providers association during pediatric palliative care are effective as illustrated by a small qualitative study by Konrad (2007). Validated measurements for this population are scarce; however, Widger and Picot (2008) have tested two: a Perinatal and a Pediatric questionnaire. The results of their initial validation show that one third of participants feel a need for better bereavement services and continued involvement from the providers who dealt with them during their loss.

Participatory Research, a collaborative research process done by Mongeau, Champagne,

and Liben (2007) illustrates the challenges encountered: formation of a trust relationship, cultural differences in the work environment, organizational hurdles, additional researcher time requirements, and the challenge of pediatric palliative care itself. Research is a recommendation of the American Academy of Pediatrics (AAP) (2002) and the IOM's Field and Behrman (2003) and collaboration as the foundation of the research is a bonus.

Coordination of Care

Coordination of care is an important aspect of collaboration. For families dealing with a terminally ill child, effective facilitation of coordinated care improves quality of life. Death is highly unpredictable as is the trajectory of the child's illness so multidisciplinary care and providers are needed to promote quality palliative care. The fragmented health care system thwarts services; there are few pediatric hospices and pediatric nursing homes. Communication issues are also concerns in promoting coordination of care. What is known in the literature is that families and children state they have better quality of life if the process is seamless (Heller & Solomon, 2005).

Reid, Haggerty and McKendry (2002) note in their systemic review that continuity of care is poorly defined. The term has various meaning across providers, disciplines, and family members, so it is difficult to measure. They also note that coordination of care requires continuity of information, personal relationships, and clinical management (Heller & Solomon, 2005; Reid, et al., 2002). Thus, for the families involved in palliative care, coordination needs to be adequately addressed in those three areas to improve the quality of life as experienced by the family. FOOTPRINTSSM of pediatric palliative care, (Toce & Collins, 2003) is an example of this type of continuity of care. Their advanced care planning teams promote attention to all these

three aspects of coordination: 1.) information continuity, 2.) clinical management, 3.) relationship building activities.

Education

The 2003 IOM report on pediatric palliative care proposed: to improve curriculum for students, to provide education for practitioners and the general population using such tools as simulation and seminars (Field & Behrman, 2003). Of note, there are no educational strategies or interventions which are evidence based. This continues to be an issue in the field, although there are programs developed through national organizations which plan to address this, such as National Hospice and Palliative Care Organization (NHPCO), End-of-Life Nursing Education Consortium (ELNEC), Center to Advance Palliative Care (CAPC) and National Network for Pediatric Palliative Care.

In a review of the present literature, the number of articles that deal with pediatric palliative care, education, and collaboration, is scant. Most of the articles mention usage of education as part of their collaboration without specificity (Hawley, 2010; Pelant, et al., 2012; Rogers, et al., 2011); one discusses the need for education for nurses noting barriers to this education (Morgan, 2009); one is an educative article on pediatric palliative care (Crozier & Hancock, 2012). None show efficacy or the educational curriculum provided and the evidence is low quality.

Internet Education and Pediatric Health Providers

Internet usage is prominent in the United States (US). According to a recent PEW study (Fox & Duggan, 2013), 81% of US adults use the Internet. In 2012, 72% of US adults use the Internet for health information; 35% use it for diagnostic inquiries; but for a serious personal

diagnosis, 70% consult personally with providers (Fox & Duggan, 2013). The World Health Organization (WHO, 2013) has launched a campaign called Positive Practice Environments which attempts to address the information needs of a world health force in various ways, some of which is through the Internet, because an un-informed workforce is detrimental to health.

In a search for the benefits of this education for providers who will be the participants of the DNP Student's project, all results are geared toward adult health needs. There are insights, however, which can be applied to those who practice with the pediatric population. Creative educational modalities such as a Virtual Grand Rounds for rural social workers (Cunningham & Vande, 2009) have video conferenced over four years providing training of 359 individuals who received orientation and education in social work with positive evaluations. E-learning has been used with positive results by the Veteran's Administration (Kobb, Lane & Stallings, 2008) for their home care orientation program for telehealth. Simulation is another popular means of educating professionals and the National League of Nursing (Hovancsek, et al., 2009) uses a community of practice to work with an international group incorporating simulation in education. Challenges for those involved, include time constraints, culture, role definitions and expectations for the project, as well as varied nursing education and practices in all countries. Collaboration is valued in this educational practice.

E-health learning includes "just in time" or Internet Point of Care Learning: a self-directed Internet education program offering clinical vignettes for Continuing Medical Education (CME), with certification maintenance using Internet modules for primary care pediatricians to guide evidence based practice (Kind, 2009). One study evaluates Taiwanese nurses' usage benefits of e-learning using an informational system success model highlighting three quality

constructs: system quality, information quality, and service quality (Chang, Chung & Hwang, 2011). While all constructs are important, information impacts usage of this system. The Internet has truly changed the health care provider's world even though assimilating vast arrays of information and judging that information can be time consuming for the busy practitioner (Higgins, Sixsmith, Barry, & Domegan, 2011).

The Centers for Disease Control (CDC) (2013) has developed an evidence based guide for e-learning programs. It provides information pertinent for implementation and evaluation processes. Learning objectives must have measurable outcomes and strategies in the education program; interactive curriculum strategies of engagement are highlighted; easy interface and navigability of the site are important; accurate, succinct content, using graphics and media is recommended; at the conclusion of the program, an assessment of the learner's comprehension is required.

Pilot Objectives

The DNP student's objectives for the pilot are as follows:

- 1.) Through participation in the network, collaboration will be better understood.
- 2.) The resources offered will improve use of community networks for the families in Pediatric Palliative Care.
- 3.) The synopsis articles will improve care and the health of these vulnerable children.
- 4.) The videos will increase one's knowledge and help one experience what some of these families are experiencing.

5.) Sharing of stories will foster hope and commitment to continue this important work to these vulnerable, often isolated families (Electronically retrieved from Pediatric Palliative Care Forum, 2013).

Project Model Theory

To provide an open, free forum, across many professional disciplines, in a state-wide geographic area, a common web-based site through PhConnect, a "Community of Practice" forum sponsored by the CDC (2013), will be the Internet entrance to this "Network of Learning". The goal and hypothesis of this learning network are that this voluntary, learning venue will foster mutual understanding of collaboration through interactive education. The Internet site require admittance from the site administrator. Following acceptance to PhConnect as a participant, entry request from the forum administrator, (the DNP student) to the free Pediatric Palliative Care Forum is required.

Wenger, Trayner, and deLatt (2011) propose a social value model in which learning is a social engagement and is composed of a "Network of Learning" and a "Community of Practice". Models include "Community of Practices" that are learning organizations that work as a community, share a passion for a common domain or interest, and organize themselves to meet the objectives of the group (Wenger, et al., 2011). A "Network of Learning" is a place where one learns, problem solves, exchanges ideas, shares multiple perspectives, and connections (Wenger, et al., 2011). The pilot adopts the Wenger model to optimize connectivity among its isolated group of experts by eliminating geographic barriers and time restraints. It is applicable to a broad based population. These social learning components foster value to the learning engagement and can be separate components or a continuum of components.

One of the elements of an electronic project model is unrestrictive invitations. The Network approach invites a wide audience and a targeted one to increase the response to learning in the Network. The invitations to the Network can be a personal connection or through a social network such as Facebook, Twitter, or Linked-In. A looser connection of the participants expands the forum. Too large a Network runs the risk of excessive "noise." The DNP student invited members only through e-mail to eliminate excessive "noise".

Dissemination of information, oversight of the project, and feedback from the participants are components of this model. While the learning space in this network may be open to a large community, the learning is often individualized and utilized as one likes with little control of where that information may go (Wenger, et al., 2011). Vigilantly monitoring the connections and maintaining ties are essential; a lack of personal commitment has a price: inertia of ideas to fruition.

As this is a continuum of learning community, building exchanges can foster a Community of Practice, in which the learning is focused, goal oriented and problem solving. There is social value to this learning, and it is cyclic: 1.) immediate value, 2.) potential value through knowledge capital, 3.) applied value such as practice change, 4.) realized value: performance improvement and 5.) value reframing and redefining success (Wenger, et al., 2011). The authors also discuss an evaluation of each of these value phrases which will be used post-project and shared with the participants in this learning network. This is a unique venture in pediatric palliative care without models in the literature.

Project Description

Aims and Goals

The pilot project goal was to offer an electronic, educational platform on pediatric palliative care, with opportunities for common learning to promote collaboration in Pediatric Palliative care. Through this common learning network, an opportunity to share experiences, expertise, and ideas was fostered through weekly discussions, monthly journal club, End-of-Life training through ELNEC, synthesized articles, confidential sharing stories, and resource pages. An objective of the response oriented activities (weekly discussions, sharing stories, and journal club) was to enhance collaboration. Because the nine Massachusetts programs involved in pediatric palliative care were throughout the state, by offering this project electronically, the distances were bridged.

Measurement

Descriptive statistics measured the number of invitees, members who subscribed to the forum, their demographic data, and their engagement in the discussion section. A qualitative survey to measure the usefulness of this electronic platform as a learning and engagement tool concluded the pilot. The pilot ran for nine weeks rather than the initially projected ten and was evaluated after the conclusion. As this is a pilot to determine usage of the "Network of Learning" site, notation of the percentage of participants from Notre Dame Pedi Pals was obtained as well as the percentage of other participants. These values were used to determine continuance of the project post-pilot. As there was a continuous invitation, each group's involvement was projected to increase by twenty-five percent. See Appendix A for pilot specific goals, objectives, and indices.

Description of the Learning Pilot

The project was a pilot program of a "Network of Learning" which was open to the public through a free portal housed in PhConnect.org, a public, confidential, free forum for communities of practice offered through the CDC. Through this site, weekly discussions were offered rather than the monthly Journal Club; a helpful resource page and synopsis of journal articles pertinent to pediatric palliative care were posted at a rate of two per week; a sharing of stories was established; and evidence based practice principles were accessible. End-of-Life training was offered through posting of ELNEC modules without Continuing Education Units (CEU's). Relevant videos and discussion questions were posted. Evaluations were then obtained from members of the group.

Pre-Launch of Pilot

Prior to the launching, voluntary surveys were sent to all participants and repeated after the nine week pilot. This self assessment included a pre-pilot qualitative survey, a survey of Modified Index of Interdisciplinary Collaboration (MIIC) and demographic survey. Please see Appendix B for content of MIIC (Oliver, Wittenberg-Lyles, & Day, 2007) and Appendix C for the pre-pilot qualitative survey and Appendix D for demographic survey. A chart review evaluating collaborative communication using the Five Points proposed by Feudtner (2007) was obtained on all the records in the Notre Dame Pedi Pals Program pre- and post-pilot which noted the present collaborative communication. Please see Appendix D for details of the Five Points and proposal of measurements. Telephone invitations and e-mail invitations were sent to all involved with Notre Dame Pedi Pals and to the professional disciplines involved with this program: nine Massachusetts Pediatric Palliative Care program directors, the Massachusetts Department of Public Health Coordinator, Massachusetts Coalition for Nurse Practitioners, the

PACT Team at Boston Children's Hospital, primary care providers, VNA Care Network Maternal Child Health Team, UMass Worcester Oncology Program, public health office in Worcester, Massachusetts, and schools involved in education of such disciplines as Child Life Specialists and Music Therapy. The pilot ran for nine weeks, and the pre and post qualitative surveys were e-mailed to all the members as noted in Appendix C, Appendix F and timeline in Table 1 in body of text.

Timeline

Table 1.

Preparatory and Pilot Timeline Activities

<u>Calendar Dates</u>	<u>Actions</u>
11/1/12 to 12/31/12	<p>Explored "Network of Learning" theory and possible electronic sites to implement a pilot project.</p> <p>Discussed project with those involved with Notre Dame Pedi Pals.</p> <p>Initiated telephone and e-mail contact to network contacts.</p> <p>Tested the platform.</p> <p>Began platform development began and included: First week's discussion question, journal club, shared story page, video Page, synopsis of articles, resource page, ELNEC program, and evidence based practice principles page.</p> <p>Set goals and objectives as noted in Appendix A.</p>
1/1/13 to 1/31/13	<p>Re-invited those involved in Pediatric Palliative Care in Massachusetts.</p> <p>Reviewed charts of Notre Dame Pedi Pal charts following Feudtner (2007) collaborative communication. Submitted findings of the review to K.Rizzo and Program coordinator.</p>

See Appendices: G and C for details.

2/1/13-2/12/13

Announced pilot initiation date.

Invited participation and membership internally through PhConnect.

Wrote learning objectives for the pilot.

2/12/13 to 4/20/13

Began Pilot Program with weekly discussion question, scheduled monthly Journal Club and queried about interest and changed to full article submission, and initiated story sharing, synthesised two articles weekly.

Noted initial numbers of group at start date and continued recruitment efforts.

Sent Initial MICC, initial qualitative survey and demographic survey sent to those in the group.

Put information on spreadsheet made for initial results but deferred posting results.

Posted weekly announcements posted to participants via the site e-mail.

Sent updates at week 3, 6, and 9 of pilot to committee and preceptor via e-mail.

Consulted with Karen Hokanson Ed.D about designing evaluation tool for CDC E-Learning Guides (2013) and Wenger, Trayner and deLatt (2011) Guide for the Network.

See Appendices B,C, D, and E for details

4/20/13 to 6/1/13

Reviewed charts at end of pilot.

Sent MIIC and post-pilot qualitative survey at conclusion of the program. See Appendices B, D, and F for details.

Developed and sent Survey Monkey to all participants evaluating educational content, suggestions for improvement, and continued participant commitment if project continued.

Sent evaluation of the project's results to the participants and also a letter of thanks for their participation on 6/1/2013

Costs and Benefits

The platform provided for this pilot was free to the public, offered a free help service with a 72 hour turn around response time, and is found in the CDC website. The Doctor of Nursing Practice (DNP) student hours were contributed volunteer hours and the participant cost of time was projected at the maximum hourly salary at Notre Dame Hospice. Table 2 described the projected costs of the pilot program in contributed hours of service.

Table 2.

Projected Cost of the pilot program

<u>Participants</u>	<u>Service Hours /week</u>	<u>Pilot Weeks</u>	<u>Cost</u>
Administrator (DNP candidate)	10	15	$\$40 \times 10 \times 15 = \$6,000$
Participants of Forum n=6	1	10	$\$40 \times 1 \times 10 \times 6 = \$2,400$
Total=7	150+60	210	$\$6,000 + \$2,400 = \$8,400$

This forum, if the results are positive could be used as continuing education or post orientation program for the Massachusetts Pediatric Palliative Care Network's nine sites. At present the state has budgeted continuing education of \$199 per person which for Notre Dame Pedi Pals program and its nine staff is \$1791 from the state. The contributed hours of time to complete this program was 15 hours with a cost of \$40.00 per hour per person for a total of

\$5400. This total minus the state contribution leaves a total of \$3609. Table 3 describes the anticipated costs for Notre Dame Pedi Pal's program and its benefit if successful.

Table 3.

Projected Continuing Costs and Benefits

<u>Weekly Time Projection</u>	<u>Hourly Cost</u>	<u>Total</u>
Administrator: 5 hours/week	\$40x5x 52= 1000 (salaried)	\$10,400
<u>Participants: 1 hour/week</u>	<u>\$40x8x52=16,640 (contributed)</u>	<u>\$16,640</u>

Net Gain due to contributed hours is \$ 6,640 compared to present expense of \$ 3,609

Evidence of Stakeholder Support

The executive director, Karyn Rizzo, of Notre Dame Hospice was fully supportive of this project as it was a method of learning which encouraged networking and aimed to improve collaboration across the Massachusetts Pediatric Palliative Care network. As a member of the Massachusetts Hospice Federation, she was equally aware that the Federation and the clinicians involved in Pediatric care desired this collaboration and education. Equally supportive was the head of the Massachusetts Department of Public Health Administrator for the project, Ms. Jennifer Bates (personal communication 12/6/2012).

Copy of this agreement is found in Appendix H.

Implementation and Monitoring

The "Network of Learning" opened on 2/12/2013 in PhConnect.org. Announcements in PhConnect.org upon initial opening of the "Network of Learning", midway point on 2/13/13, and

3/27/13 were made. Minor adjustments to the plan were incorporated: the first week's lengthy discussion question ran for two weeks as did the last discussion question. Initially designed to last ten weeks, the project was shortened to nine weeks and concluded on 4/20/2013. To procure interest in the journal club, a survey was sent to the members of the group through electronic mail, to ascertain interest in the journal club. Because of the lack of response, the club was not scheduled but weekly articles were substituted during the last four weeks. The video page was updated completely once for viewing ease. An additional page was added dealing with professionals and therapies in various disciplines such as Child Life Specialists, Music Therapy, Medical Clowning, and Pet Therapy. Videos were used to explain their services and benefits on this page.

The ELNEC program slides were shown on PhConnect.org, but not offered for CEU's as the program required a live setting so questions could be answered (Pam Malloy, personal communication, 3/25/13). Once entrants entered Pediatric Palliative Care Forum site, they received the demographic survey, MIIC, and pre-pilot qualitative survey electronically as attachments. At the conclusion of the nine week pilot, a Survey Monkey questionnaire (See Appendix I), post-pilot survey, and the MIIC were sent to all participants electronically and for those at Notre Dame Hospice: in paper format. As there were only three pre-pilot responses to MIIC and three pre-pilot surveys, results were not posted initially, another minor adaptation. The paper format was an adjustment for the Notre Dame Pedi Pal's group to test if there would be an improved response rate. The paper format yielded one MIIC response but no post survey result versus zero electronically.

Evaluation of the Pilot

Collaborative Communication Tool

As per project design all Pedi Pals charts were reviewed and evaluated using the tool developed as an adaptation of Feudtner's Collaborative Communication pre- and post-pilot. The DNP student's premise was that by participating in this pilot, collaborative communication would be affected. That cannot be stated as there was low participation by Notre Dame Pedi Pal's staff and the presence of high collaborative communication pre- and post-survey. Please see Appendix J for an example and scoring of one chart with qualitative responses for both survey time frames. Thank you notes were sent on May 13, 2013 to all participants. The complete results of the evaluation were sent on June 1, 2013 to the twelve participants, Notre Dame PediPals Coordinator, Tracy Larson-Benvenitu and Karyn Rizzo, executive director and DNP student's preceptor.

Descriptive Data

Invitations and Responses

There were few responses throughout the project. The following Table 4 shows the initial invitation data and responses and concluding invitation and data responses as of May 10, 2013.

Table 4.

Descriptive Data of Pilot Invitation and Response

<u>Survey Type</u>	<u>Initial Invitation</u>	<u>Initial Response</u>	<u>Concluding Invitation</u>	<u>Concluding Response</u>
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E-Mails	N=34	N=7	N=118	N=5
MIIC	N=12	N=3	N=12	N=3
Demographics	N=12	N=3	N/A	N/A
Pre-Pilot	N=12	N=3	N/A	N/A
Post-Pilot	N/A	N/A	N=12	N=1
Survey Monkey	N/A	N/A	N=12	N=1

Demographic Data

Demographic responses totaled four out of the twelve members in the PhConnect.Org. who had been invited via e-mail upon entrance to the pilot. All four were women and white. Two were ages 34-49 and two were 50-65. Two had master's degrees, one a Bachelor's degree, and one some college. One had no experience in Hospice. Hospice experiences for those who answered positively were three, two and less than one year respectively. Years working with children were zero, one, 12, and 30. Professional experience was three, three, 30 and 37 years respectively.

MIIC Survey

MIIC results were tabulated on the three responses submitted pre-pilot and the three responses submitted post-pilot from five individuals. The score was obtained by mean testing of the 42 questions of the survey. The mean results were Pre-pilot: 3.63 from S.D., 3.83 from DNP student, and 4.6 from D.L for the three responses received and Post-pilot: 3.8 from DNP student, 4.26 unknown respondent, and 3.93 from JB. The 0.0 numbers were used by the DNP student as placement values for descriptive statistics, as there were a total of five different individuals. The only MIIC results completed pre- and post-pilot were the DNP student's, so no conclusions or

comparisons of change in collaboration can be made for this pilot. Tests for normality using Kolmogorov-Smirnov were non-significant at $p=.138$ showing normal distribution. Post-Pilot MIIC mean was 2.39 with a standard deviation of 2.19. Tests for normality using Kolmogorov-Smirnov were non-significant at $p=.063$ showing normal distribution. A paired sample T-test was utilized to compare the member numbers at pre-pilot MIIC and post- pilot MIIC. Changes in score would have revealed increased or decreased interdisciplinary collaboration. There was no significance or no change in collaboration scores noted between pre-pilot MIIC (Mean=2.41 and Standard Deviation=2.23) and post-pilot MIIC (Mean=2.39 and Standard Deviation=2.19), $t(4) = .008$, and $p=.994$.

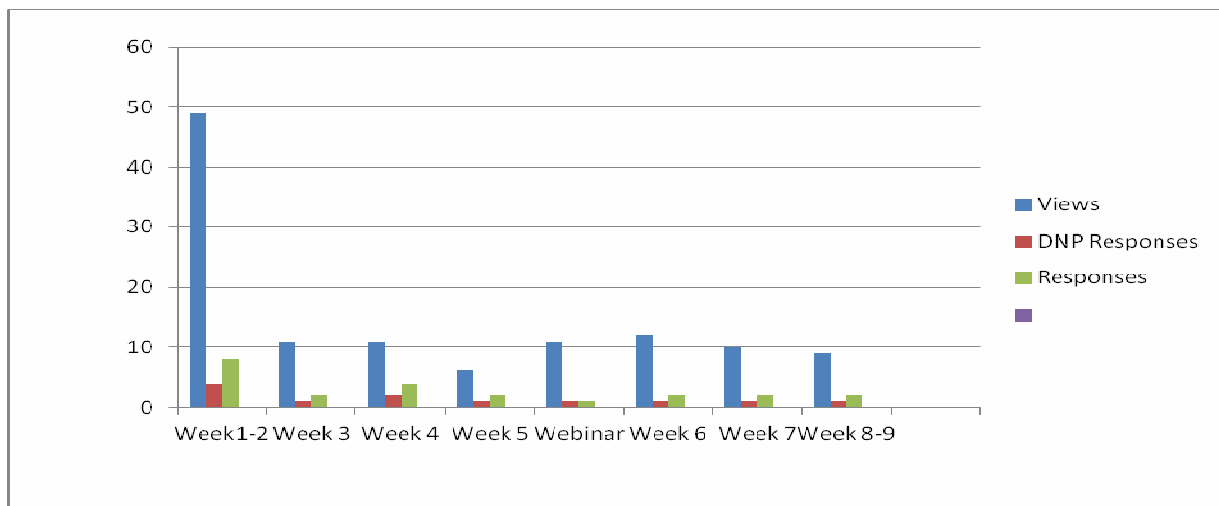
The DNP student's response was the only one received regarding the site Survey Monkey. Therefore, no measurable conclusions can be made. For those responses see Appendix I.

There was a 20% increase in the Notre Dame Pedi Pal's acceptance of the "Network of Learning" site from initial $n=4$ to $n=5$ during the pilot's launch which did not reach the goal increase of 25%. The projected outcome measurement of our partners in the Massachusetts Pediatric Network joining in this network with an increased rate of 25% was met at 100% with the addition of one individual. Other participants increased by 100 % from an initial three to six members. As there was a two step process to gain access to the network, two members of the network applied to PhConnect.org and were accepted as members, but never requested entrance to the site even with additional invitations. See Appendix A for complete data and measurement results.

Descriptive statistics to evaluate mean and standard deviation were done on pre-pilot and pilot launch numbers. Then a paired sample T-test was utilized to compare the member numbers at pre-pilot and pilot progression for significance as this would show improved interdisciplinary collaboration, a premise of the pilot. There was no significance noted between pre-pilot entrants (Mean=2.3333 and Standard Deviation =2.08167) and pilot entrants (Mean=4 and Standard Deviation=2.64575), $t(4) = -2.5$, and $p=.130$. Even if there was significance the results would need to be viewed cautiously due to the small sample response with only one person completing the measure pre- and post-pilot.

The website also noted numbers of views in the discussion area, but there was no way to determine what participant was viewing the site, so traffic to the site may have been due to the site administrator. The Webinar presented was placed in the discussion area and traffic to that webinar was noted. Responses were individualized and initiated by the participants. The data obtained graphically is in Figure 1.

Figure 1: Weekly Responses and Views in Discussion Section.



Qualitative Data

From the pre- and post-pilot surveys which were sent electronically to each individual member of the forum, the DNP student analyzed qualitative data to illustrate understandings of collaboration, factors impeding collaboration, behaviors required for collaboration, and the value of collaboration. The only post data response was from the DNP student. The pre-pilot surveys revealed the following understandings of collaboration: engagement in a mutual relationship, working together to meet a common goal, and mutual dialogue. Behavioral manifestation responses noted listening, respect, open-mindedness, engagement, and mutuality. Impediments to collaboration included disrespect, domination of the process, and close-mindedness. This data was shared with the group electronically on June 1, 2013 with the evaluation results.

E-Learning Tool's Guide

The CDC (2013) has developed an evidence based E-Learning website to assist in development and implementation of an electronic program. The analysis of content is through instructional analysis, learning objectives, interactivity, interface and navigation, and general content. The evaluation process includes formative and summative evaluation, a common educational evaluation process. Formative evaluation is a method of evaluation which evaluates the product before it is launched and then trouble-shoots the product. Summative evaluation evaluates outcomes.

Instructional Analysis

Rationale for utilizing this method and the focus of this analysis included why, when, who, content, goals, and audience responsibilities. The program had a flexible design without

mandatory responsibilities for the audience. The *why* of this format was threefold: distances of the potential audience, time frame of the project with time input control for the administrator, and the testing if an electronic vehicle would be useful and used. All these conditions were met. The *when* for the project was capstone dependent and was met. The DNP student's *goal* for the project was to provide a learning framework with information, an arena for collaboration, and educational material to improve skills. The provisional goal was met. The lack of response, however, prevented effective evaluation of the site. The *who* for this project was purposefully professional. Invitations were extended to all members of the Massachusetts Pediatric Palliative Care network through their executive directors, primary care providers of Notre Dame Pedi Pal patients, Boston Children's Hospital PACT Team, UMASS Pediatric Oncology Team, Shelly's Place staff, and the Music Therapy Department at Anna Maria College and the Child Life Specialist Program Directors at Wheelock College. Only one member outside of the five in Notre Dame Pedi Pals successfully entered and two others successfully applied to PhConnect.org and were accepted as members, but did not fulfill the next step of requesting membership to the site forum even with additional invitations. One entrance point would have facilitated some increase in membership. Content focus was provided to assist different professional audiences by the DNP student. Lack of response to the evaluation tool prevented the DNP student from knowing its efficacy.

One of the initial caveats was to possibly provide CEU's for the ELNEC program. This, however, was not possible as one must provide this training in person to facilitate answering of questions. Motivation for attendance and usage of this site was purely at one's own impetus.

Interactive presentations were not possible to do on this site, and the DNP student had no personal skill in the usage or formation of Wiki's or platform building.

If this project was to continue, finding a more interactive site would be ideal.

Contracting an Information Technologist to assist with platform development which would allow for interactive participation in real-time would improve the site. Creating an easy to use format, would increase active participation resulting in engaged and interactive learning. If an existing learning platform, such as Blackboard was available, this would be implemented. The voluntary nature of the designed pilot also did not assist with participation. Mandatory participation in the forum would be required in a future, similar project as one study (Gafni & Geri, 2010) showed this increased engagement. Providing free professional rewards, such as CEU's or similar professional credits would be used for future projects to augment audience size and participation. Although colleges were contacted, such as Anna Maria College and Wheelock College, in any future project, the DNP student would inquire about student learning project needs, invite student collaboration, and model the practice during the project.

Learning Objectives

Learning objectives were utilized following the SMART model which stands for **S**: specific, **M**: measurable, **A**: action-oriented, **R**: reasonable, and **T**: time-bound. As the responses in the pilot were limited to the discussion question section, this area was the only section which could be measured and required specific responses. Measurement of responses was discussed in the qualitative data section. Action orientation for the learning was through the discussion section, responses to the DNP student's surveys, and the Journal Club site which became inactive due to lack of response. A true evaluation of reasonableness was not possible

with such low response rates. Most interactivity on the site was passive: reading the stories, the articles, watching the videos, and accessing the pages. Real-time interaction was only possible through scheduling meetings which did not occur as planned through the journal club.

Site Evaluation

Interface and navigation was difficult on this site. There was no easy way to attach articles or other items with usage of e-mail. The site was set up to foster "Community of Practice" meetings, so my usage of this as a "Network of Learning" was a work-around. Acceptance of the site limitations therefore was necessary.

There were limitations to the site pages as well. Site content evaluation of health literacy was as follows: the font size was small, graphics were difficult to attach and use, synopsis of articles was at a level of grade 11.7 and discussion questions were at grade 9.1 from Microsoft 2007 Flesh-Kincaid Readability. Future recommendations for any pilot or project of this type would be a grade eight reading level for all content. The EBP content was partially interactive and this content or similar would be used. None of the videos on the site were available in another language which could be used by the clinicians to help families.

Sister Karen Hokanson SND, Ed.D. was invited and accepted the DNP student's request to review the educational format and content of the site. Some of Sister Hokanson's (2013) comments were as follows: "Excellent learning goals with clear outcomes....It might be good to group power points by topic and use bit.ly website to shorten the links." The second comment helped to improve the ease of viewing on the site.

Formative evaluation was attempted by improving the look of the site during the pilot as much of the content was added weekly by design. Pre-pilot, the DNP candidate tested the

program with a friend during the formation of the site in order to check ease of entrance and her opinion as to the set up. Frequent requests for comments regarding the site were initiated. There were no responses to these. Summative evaluation was done at the conclusion of the pilot. Please see Appendix I for the content and survey responses. The DNP student's answers were the only response and must therefore be viewed cautiously.

Project Model Theory Evaluation

Wenger, et al., (2011) used a social value model to evaluate networks of learning. Evaluation included these indicators judging learning and were:

- 1.) immediate value
- 2.) potential value through knowledge capital
- 3.) applied value such as practice change
- 4.) realized value: performance improvement
- 5.) value reframing and redefining success.

Wenger's immediate value was evident in initial interest in joining the site which increased by 42% over the nine week pilot. Figure 4 in this text showed views and responses visible during the pilot's course. While responses in general were limited, those who responded seemed to gain some immediate benefit. The DNP student certainly gained the immediate value of cultivating the site, adding to the site, and continuing to invite members to the site. The site's educational expert noted, "I learned a lot from the information shared" (Personal communication, Sr. Karen Hokanson SND, Ed.D., 3/15/2013).

Wenger's potential value from knowledge capital was not measurable due to low response rates for any of the surveys. There was no way to track views other than in the discussion area; utilization of the videos and other resources could not be measured. The DNP student learned that knowledge capital can be a personal goal and measures capturing this were not known or explored at the pilot initiation. Motivation to learn over time was a challenge for all.

Wenger's applied value could not be evaluated due to low response rate. The DNP student certainly became more knowledgeable regarding resources, the diseases, and the interdisciplinary teammates. Certainly the view regarding palliation throughout the care cycle was a new personal incorporation for the DNP student.

Reframing of expectations of involvement per Wenger's model was implemented at week five; stressing discussion involvement and participating in the Mito 101 course was emphasized to all members. Other than the DNP student, no one else responded to the challenge and reframing of expectations was unsuccessful. Realized value was not measurable due to limited responses.

One of the measurements which the DNP student anticipated as a reframing measurement indicator was the post-pilot survey. As there was only one responding participant from Notre Dame Pedi Pals, this could not be used. Lack of response again influenced measurable data. For this model theory, lack of response influenced four out of the five areas of measurement and the pilot was either a failure, read and not responded to, read and some behavioral changes in practice were implemented, and read and new insights regarding collaboration were gained in

one's practice. This DNP student cannot know the results.

Post-Project Plans

A goal of pilot testing this learning network was to facilitate collaboration across the Massachusetts Pediatric Palliative Care Network. Unfortunately, the limited response rate suggested that the project should not continue at this time. Only one person from the Network accessed the site and did not participate in any of the discussions. The site itself was geared toward discussions and committee meetings. The DNP student adapted its general usage to do the preliminary work of the "Network of Learning" Phase in preparation for implementing a "Community of Practice" Phase to problem solve collaboratively if that was the group wish. No group formulated in the nine weeks. In areas other than the discussion sections, there was no tally of visits. As there was only one response from the Survey Monkey, there was no means of measuring the effectiveness and usefulness of the various pages developed.

Pediatric Palliative Care is a very specialized field and the practitioners in this field are passionate about what they do. Opportunities for collegial networking is limited, particularly in the community setting. As the site is free, the DNP student plans to continue the site for another six months adding further material and continuing to invite members of PhConnect.org to join.

Post-Pilot, a thank you letter with an evaluation will be sent to all members who joined and to the three who joined PhConnect.org, but never requested membership to the site. See Appendix K for details of this letter and the evaluation contents. As there was so little traffic present in the site, its cost effectiveness was not proved and cannot be promoted for usage by the Massachusetts Department of Public Health's Pediatric Palliative Care Network. Cost for the

pilot was as follows in Table 5.

Table 5.

Updated cost of the pilot program

Participants	Weekly Service Hours	Project Length Weeks	Cost
Administrator (DNP candidate)	10	15	$\$40 \times 10 \times 15 = \$6,000$
Weekly Participants N=2	1	10	$\$40 \times 1 \times 9 \times 2 = \720
Total Weekly Participants N=3	150+18	168	$\$6,000 + \$720 = \$6,720$

Present cost per person for the state's education program for Notre Dame Pediatric Palliative care education is \$3,609 of contributed hours for education versus my pilot's cost of \$6,720. The state's current program of education was less costly.

Concluding Discussion

As a novice of this type of project, the DNP student was also an inexperienced electronic platform educator. Choosing a mentor was fortuitous. The DNP student's exposure to electronic educational learning was helpful in program formulation particularly in the area of resources and videos. No personal working knowledge of Wiki's was definitely a drawback. The CDC (2013) E-Learning Guide stated an interactive site was evidence based for learning. The DNP's student's Pediatric Palliative Care Forum could not provide this form of education. This would be an area that this DNP student would learn about for future, similar projects.

The site itself did not lend to an interactive engagement process while learning. Input and dialogue in real time, a great way to gather information and facilitate collaboration was not possible. Ease of entrance, usage, and not being on one's work-site computer system were all obstacles unable to be addressed during this project. While the DNP student certainly was facilitating discussions regarding collaboration, not modeling that behavior educationally may have been a project design failure. As Boston College provided a Master's in Nursing in Pediatric Palliative Care, through contact with the program's professor, the DNP student sought a fellow student to enhance the site and model collaboration which was not accomplished. The DNP student was the sole facilitator of the learning events. While invitations were made to respond and add to the site, being an administrator adds an inherent power dynamic, which may have influenced the responses. The influence of this inherent power dynamic would be planned for in any future project.

One surprise from this project was a request to submit a written interview to PhConnect.org about the site and my value for the site on February 23, 2013. Recently, the interview was published. See Appendix J for details of this interview. While there was a certain ease in using this site and process as a means to foster collaboration and offer a non-commuting area to learn and begin to develop relationships, collaboration would seem to benefit from some personal contact.

A drawback to this pilot was the short time frame to establish appropriate buy in to this pilot. Personal contact might have facilitated usage of this platform as a learning network. Even with the Notre Dame Pedi Pals group, committed membership was only one out of the nine on the team. As a vehicle to promote collaboration through learning, this goal was not

supported by the response rate although personal contact might have improved the responses. One study (Tutty & Klein, 2008) showed that collaboration in a face-to-face format was preferred to collaboration virtually. As a professional, volunteer network of learning, this may have been an obstacle to its usage. A compulsory requirement, which was found to improve participation in one study (Gafni & Geri, 2010) might have supported usage of this learning network but was not the design for this pilot. Although responses were limited, this pilot did advance the limited research translation in the area of "Network of Learning" and Pediatric Palliative Care.

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[int/workforcealliance/about/initiatives/ppe/en/index.html](http://www.who.int/workforcealliance/about/initiatives/ppe/en/index.html)

Appendix A.

Goals, Objectives and Outcomes

Goal	Objective	Measurable Outcomes	Pilot Outcomes
<p>1.) There will be active recruitment of those involved in pediatric palliative care in Massachusetts through this novel forum</p>	<p>Electronic invitation will be given to all participants in Notre Dame Pedi, the coordinators of all the Massachusetts Department of Public Health participants in the pediatric palliative care program, the Boston Children's Hospital Palliative Care Team, and other's with whom we have coordinated with.</p>	<p>Initial measurement of membership involvement of two group: Notre Dame Pedi Pals (Names of participants are present on site) and others.</p> <p>Twenty-five per cent increase in membership at the conclusion of the pilot for both groups.</p> <p>Descriptive statistics of invitation rate versus acceptance of invitation rate.</p>	<p>N=7 at start of pilot. N=4 for Notre Dame Pedi Pals N=0 for state pedipals participants N=3 (others)</p> <p>20% increase (N=1) in membership for Notre Dame PediPals 100% Increase (n=1) in State Pedi Pals</p> <p>Pre Pilot: 7/34 Pilot: 5/118</p>
<p>2.) There will be evidence of collaborative communication in Notre Dame Pedi Pal's records.</p>	<p>Using Collaborative Communication Five Points as a guide there will be documented collaborative communication and initial measurement will be stratified and presented to the Clinical coordinator of the program and the Executive Director.</p>	<p>100% review of the charts with analysis of findings using Feudtner's (2007) Five Points as a measurement tool will be completed pre and post-pilot project. Post Pilot evaluation of the tool used will be done by administrator and presented to Clinical Coordinator and Executive Director and updated for further usage.</p>	<p>Measurement goals met 100% pre and post pilot.</p> <p>Met with Clinical Coordinator and Executive director to discuss results on</p> <p>Tool usage to be implemented as part of QI</p>

<p>3.) There will be completed MIIC, demographic survey, and qualitative survey by participants pre and post pilot measurements will occur.</p>	<p>Baseline data of interdisciplinary collaboration and repeated after completion of program will show present and changed interdisciplinary collaboration as a result of the pilot using MIIC.</p> <p>Means will be measured per the survey pre and post pilot.</p> <p>Baseline qualitative survey on collaboration will be done pre and post-pilot</p> <p>Descriptive statistics of demographics</p>	<p>Baseline response rate for Notre Dame Pedi Pal team and all others.</p> <p>Analysis of the Means of the MICC will be done on the pre-pilot and post-pilot and results will be communicated to each participant for 100% response rate from the administrator.</p> <p>Analysis of the survey will be done by the administrator and posted to phConnect and communicated to the participants and the measured outcome is 100% of those received.</p>	<p>Total of 4 Demographic surveys, 3 MICC and 3 Qualitative surveys pre-project.</p> <p>Analysis of Means done of MICC pre and post pilot. n=2 post-pilot</p> <p>Communicated results post-pilot: 100% of both scores</p> <p>Survey analysis done pre and post pilot and results communicated for both results post-survey: 100%</p> <p>Analysis in body of paper</p>
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Appendix B.

Modified Index of Interdisciplinary Collaboration (MIIC), (Oliver, Wittenberg Lyles, & Day, 2007).

Instructions:

All responses measured on a 5-point Likert scale (1=Strongly Disagree, 2=Disagree, 3=Neither Agree or Disagree, 4=Agree, 5=Strongly Agree)

With regard to your current primary work setting/organization, please indicate the extent to which you agree or disagree with each of the following statements:

1. I utilize other professionals in different disciplines for their particular expertise.
2. I consistently give feedback to other professionals in my setting.
3. Professionals in different disciplines in my setting utilize me for a range of tasks.
4. **Teamwork with professionals from other disciplines is not important in my ability to help clients.
5. **The colleagues from other professional disciplines and I rarely communicate.
6. The colleagues from other disciplines with whom I work have a good understanding of the distinction between my role and their role(s).
7. **My colleagues from other disciplines make inappropriate referrals to me.
8. I can define those areas that are distinct in my professional role from that of professionals from other disciplines with whom I work.
9. I view part of my professional role as supporting the role of others with whom I work.
10. My colleagues from other disciplines refer to me often.
11. **Cooperative work with colleagues from other disciplines is not a part of my job description.
12. **My colleagues from other professional disciplines do not treat me as an equal.
13. My colleagues from other disciplines believe that they could not do their jobs as well without my professional discipline.
14. Distinct new programs emerge from the collective work of colleagues from different disciplines.
15. Organizational protocols reflect the existence of cooperation between professionals from different disciplines.
16. Formal procedures/mechanisms exist for facilitating dialogue between professionals from different disciplines (ie, at staffings, inservice, rounds, etc)
17. **I am not aware of situations in my agency in which a coalition, task force, or committee has developed out of interdisciplinary efforts.
18. Working with colleagues from other disciplines leads to outcomes that we could not achieve alone.

19. Creative outcomes emerge from my work with colleagues from other professions that I could not have predicted.
20. I am willing to take on tasks outside of my job description when that seems important.
21. **I am not willing to sacrifice a degree of autonomy to support cooperative problem solving.
22. I utilize formal and informal procedures for problem-solving with my colleagues from other disciplines.
23. **The professional colleagues from other disciplines with whom I work stick rigidly to their job descriptions.
24. Colleagues from other disciplines and I work together in many different ways.
25. Professionals from other disciplines with whom I work encourage family members' participation in the treatment process.
26. **My colleagues from other disciplines are not committed to working together.
27. My colleagues from other disciplines work through conflicts with me in efforts to resolve them.
28. When colleagues from different disciplines make decisions together they go through a process of examining alternatives.
29. My interactions with colleagues from other disciplines occurs in a climate where there is freedom to be different and to disagree.
30. Clients/patients/students participate in interdisciplinary planning that concerns them.
31. Colleagues from all professional disciplines take responsibility for developing treatment plans.
32. **Colleagues from all professional disciplines do not participate in implementing treatment plans.
33. Professionals from different disciplines are straightforward when sharing information with clients/patients/students.
34. My colleagues from other disciplines and I often discuss different strategies to improve our working relationships.
35. My colleagues from other professions and I talk about ways to involve other professionals in our work together.
36. **Colleagues from other disciplines do not attempt to create a positive climate in our organization.
37. I am optimistic about the ability of my colleagues from other disciplines to work with me to resolve problems.
38. I help my colleagues to address conflict with other professionals directly.
39. Colleagues from other disciplines are as likely as I am to address obstacles to our successful collaboration.
40. My colleagues from other disciplines and I talk together about our professional similarities and differences including role, competencies, and stereotypes.
41. **My colleagues from other professions and I do not evaluate our work together.
42. I discuss with professionals from other disciplines the degree to which each of us should be involved in a particular case.

** Items are inversely worded, so they need to be inverse coded.

Appendix D.**Demographic Survey****Instructions:**

Please answer this demographic survey. It will be completely confidential. I am using this information for descriptive statistics in order to study who responds to my Network of Learning Page: Pediatric Palliative Care. Please e-mail the results back.

Thank you for your participation.

Gender:

Male_____ Female____n=4____ No Response_____

Age:

18-33_____34-49__n=2____50-65__n=2____65-80_____ >80_____ No
Response_____

Education:

High School Education _____Trade School/ Professional Education post High School_____

Some College to Associate Degree__n=1____ Bachelor's Degree__n=1_____

Masters Degree or higher _n=2_____No Response_____

How many years worked in your primary profession/job_____ No Response_____

How many years in Hospice/Palliative Care _____No Response_____

How many years with children _____No Response_____

Race:

Multiracial _____Black or African American _____American Indian or Alaska Native_____

Asian _____White _n=3____Native Hawaiian or Other Pacific Islander _____No

Response_____

Appendix E.**For Chart Review for Collaborative Communication**

- "1. Establishing a common goal or set of goals that guide our collaborative efforts.*
- 2. Exhibiting mutual respect and compassion for each other.*
- 3. Developing a sufficiently complete understanding of our differing perspectives.*
- 4. Assuring maximum clarity and correctness of what we communicate to each other.*
- 5. Managing intrapersonal and interpersonal processes that affect how we send, receive, and process information." (Feudtner, 2007, p. 534).*

Chart Review for Excel Spreadsheet of Notre Dame Pedi Pal Records to Measure Collaborative Communication

Chart Reviewer: Administrator (DNP Candidate) Review: Pre-Pilot and Post- Pilot

Data of results submitted Pre-Pilot and Post-Pilot by Administrator to Karyn Rizzo and Tracy Larson-Benvenuto.

Instrument Developed

Name/Initials and Date of Birth	
Date Reviewed	
Evidence of Goal Setting	Yes/No/NA
Provider	RN,SW,MT,Massage, CLLS
As care progresses, evidence of further goal setting and collaboration	Yes/No/NA
Provider	RN,SW,MT,Massage, CLLS
Documentation of communication present	Yes/No/NA
Provider	RN,SW,MT,Massage, CLLS
Clear Documentation	Yes/No/NA
Provider	RN,SW,MT,Massage, CLLS
Any questions after reading it	Yes/No/NA
Provider	RN,SW,MT,Massage, CLLS
Managing intrapersonal and interpersonal processes that affect how we send, receive and process information	Yes/No/NA
Provider	RN,SW,MT,Massage, CLLS
Type of process	Letter, Telephone, etc
Date of Initiation of Service	
Date of discharge	

Explanation of initials: RN=registered nurse, SW=social worker, MT=Music Therapist, CLLS= Child Life Specialist

Appendix G.**Letter of Invitation to the Pilot**

Sister Margaret Nelson FNP-BC

8 Bigelow Street

Somerville, Ma. 02143

Dear

I am a student in UMass-Amherst in the Doctor of Nursing Practice Program, Public Health Nursing Leadership. I am requesting your help from you and your staff to participate in a project to promote virtual collaboration on the issues of pediatric palliative care. This project will encourage collaboration, networking, and best practices. In its initial phase, it will be a networking of learning forum and a pilot project.

The platform is contained in the PhConnect of the CDC's website <http://www.phconnect.org/group/pediatric-palliative-care-public-network-forum>. For those who are interested, please sign in and become a member. There is no fee to join. Once you have joined, an e-mail will be sent to me from the site and your personal e-mail is not shared.

This Network of Learning will have weekly discussion questions, videos, a monthly Journal Club, information about evidence-based practice, a Sharing Stories page, synopsis of articles page and useful websites. There are places to make comments and discussions can be initiated by anyone. Your participation is encouraged, but is entirely voluntary.

Thank you in advance for your assistance in this matter. I am looking forward to networking virtually.

Sincerely yours,

Sr Margaret Nelson FNP-BC, cDNP at UMASS-Amherst

Appendix H.



UNIVERSITY OF MASSACHUSETTS AMHERST
 Skinner Hall
 651 North Pleasant Street
 Amherst, MA 01003-9304

School of Nursing
 413-687-2626

Fall, 2010

To Whom It May Concern:

I am the Director of the DNP Program at the University of Massachusetts, Amherst, School of Nursing. I am writing this letter on behalf of Dr. Margaret Nelson, your student preceptor. Your student is in the final year of the DNP program, is a DNP Candidate, and is planning to complete the final requirement for the Degree, a Capstone Scholarly Project, in your facility. Your student will be designing, implementing, and evaluating the effect of translating a programmatic intervention into your practice or setting. As these projects are considered performance improvement or program evaluation projects and not research studies, the University does not require Institutional Review Board permission for this student to actualize the project as outlined by the student. I am using this letter as a "Key Stakeholder" commitment letter for the student to use in the Capstone Scholarly Project Proposal. A Graduate faculty member of the School of Nursing will, also, be working directly with your student as Chair of the Capstone Scholarly Project.

Thank you in advance for allowing this student to actualize the Capstone Project in your facility. If you have any questions, please call me at 413-687-2624 or email jdemart@nursing.umass.edu.

Key Stakeholder Signature: Karen Duggan, RN, CHRN, CNS Date: 1-4-13
 Student Signature: Scholar Date: 1-4-13

Sincerely,

Jean E. DeMartinis

Jean E. DeMartinis, PhD, FNP-BC
 Associate Professor
 Director DNP Program

Appendix I.

Survey Monkey

1. Please evaluate the discussion questions.

a.) Type of questions

- a) Always made me think
- b) Sometimes made me think
- c) They were just right
- d) Too difficult to answer

2. Number of Questions in the Discussion Page: Please respond

- a) The right amount
- b) Too many
- c) Not enough

3. Comments to improve the discussion questions

A greater variety of focus
Seemed all collaborative, team or coordination focus

4. Journal Club: Please evaluate

	yes	no
Did you read the articles?	<input checked="" type="radio"/>	<input type="radio"/>
Did you participate?	<input type="radio"/>	<input type="radio"/>
Do you find Journal Clubs useful?	<input checked="" type="radio"/>	<input type="radio"/>
Did you prefer just the posted articles to read at your convenience?	<input type="radio"/>	<input type="radio"/>

5. ELNEC Page

As this needed to be presented in person, information presented only without CEU's

	Yes	no	Partially	Not Applicable
Did you read the modules?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you find this information useful?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Were they too overwhelming?	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I changed the format were they easier to read?	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6. Evaluate the Videos. Did you watch any of them?

- yes
- no
- some

7. How many videos did you watch?

- Zero
- One to three
- Four to six
- Seven to nine

8. Colleague Services: Did you enjoy the videos and content? Please comment

Yes. I learned something about what my colleagues work focus is about

9. Comment on ways this video page could be improved

was fine

10. Please respond regarding Synopsis of Articles

	yes	no
Did you find this page helpful?	<input type="radio"/>	<input type="radio"/>
Did you read any?	<input type="radio"/>	<input type="radio"/>

11. How many synopsis articles did you read?

- Zero
- One to Four
- Five to Nine
- Greater than nine
- All

12. Please comment on Sharing Stories

	yes	no
Did you read these stories?	<input type="radio"/>	<input type="radio"/>
Did you find this page helpful?	<input type="radio"/>	<input type="radio"/>

13. Please Comment on ways to improve this Sharing Stories page

no comment

14. Please comment about the Resource Page

	yes	no
Did you like this page?	<input type="radio"/>	<input type="radio"/>

	yes	no
Did you find the resources helpful?	<input checked="" type="radio"/>	<input type="radio"/>

Did you try to comment or add a resource?	<input checked="" type="radio"/>	<input type="radio"/>
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15. Evidence-Based Practice

	yes	no
Did you find this page helpful?	<input checked="" type="radio"/>	<input type="radio"/>
Did you use it to judge the evidence?	<input type="radio"/>	<input type="radio"/>

16. Please comment on the Learning Objectives

They were simple and general in nature for the site

17. Are the Objectives being met?

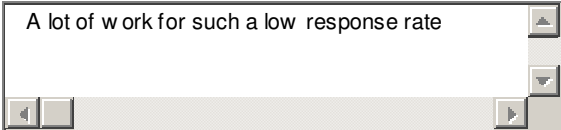
- Yes
- No
- No Comment
- I did not look at this

18. Rare Disorder Page: Please respond

	yes	no
Did you find this page helpful?	<input checked="" type="radio"/>	<input type="radio"/>
Do you think that this page needed more emphasis?	<input type="radio"/>	<input type="radio"/>

19. Please add suggestions to the entire site

A lot of work for such a low response rate



Appendix J.

For Chart Review Example for Collaborative Communication

- 1. Establishing a common goal or set of goals that guide our collaborative efforts.
- 2. Exhibiting mutual respect and compassion for each other.
- 3. Developing a sufficiently complete understanding of our differing perspectives.
- 4. Assuring maximum clarity and correctness of what we communicate to each other.
- 5. Managing intrapersonal and interpersonal processes that affect how we send, receive, and process information." (Feudtner, 2007, p. 534).

Name/Initials and Date of Birth	
Date Reviewed	
Evidence of Goal Setting	Yes/No/NA
Provider	RN,SW,MT,Massage, CLLS
As care progresses, evidence of further goal setting and collaboration	Yes/No/NA
Provider	RN,SW,MT,Massage, CLLS
Documentation of communication present	Yes/No/NA
Provider	RN,SW,MT,Massage, CLLS
Clear Documentation	Yes/No/NA
Provider	RN,SW,MT,Massage, CLLS
Any questions after reading it	Yes/No/NA
Provider	RN,SW,MT,Massage, CLLS
Managing intrapersonal and interpersonal processes that affect how we send, receive and process information	Yes/No/NA
Provider	RN,SW,MT,Massage, CLLS
Type of process	Letter, Telephone, etc
Date of Initiation of Service	
Date of discharge	

Explanation of initials: RN=registered nurse, SW=social worker, MT=Music Therapist, CLLS= Child Life Specialist

Qualitative examples of Goal setting:

Evidence of Goal Setting: "Increase eye contact, increase vocalizations, increase gross and fine motor dev and independent music play during therapy" as noted by the music therapist

"RN Visits prn per POC" by the nurse: POC=Plan of Care

"Improved quality of life in the home with implementation of plan of care services" by the Social Worker

Appendix K

Q2 2013 Featured Connection: Margaret Nelson

Every quarter, phConnect will feature a new connection from the world of public health. Interested in being a Featured Connection, know someone whose work should be profiled, or want to spotlight someone from your community?

[Nominate them here!](#)



Sister Margaret Nelson

Q: In which communities do you participate?

A: Three: [Pediatric Palliative Care Forum](#), [Health Educators and Learning Professionals](#), and [Health Literacy and Public Health](#).

Q: Why did you choose to become involved with these particular communities?

A: As a student, I learned about Communities of Practice which was a new topic for me and the theory seemed to fit about how to relate, organize and solve problems together. I have a new interest in Pediatric Palliative Care and opened the site and am offering it to the public to learn more about these children and families who require this type of care.

Q: How has becoming involved with your community positively impacted your daily work?

A: I have been a nurse for many years and in my years of practice, I have never encountered the syndromes these families are dealing with. To find resources which help others gain the knowledge to be effective care givers is wonderful.

Q: What would you say to colleagues who ask you if they should join your community?

A: Welcome. I hope the site is helpful and please feel free to e-mail me or begin a discussion.

Q: Why do you choose to participate in phConnect? (Realized benefits)

A: In this busy world, it is nice to have a place where one can collaborate electronically. What I know may benefit you and what you know may benefit me. Plus being a part of the CDC is wonderful place to have this.

Sr. Margaret Nelson FNP-BC
Doctor of Nursing Practice Student
University of Massachusetts Amherst
Public Health Leadership Program
Somerville, MA

